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INTEGRATED WORKING AND OUTCOMES FOR
DISABLED CHILDREN AND THEIR FAMILIES: A
SERVICE USER PERSPECTIVE

ANNE-MARIE CARNEY
2009

A dissertation submitted in partial fulfilment of the requirements of the University of
Chester for the degree of Master of Business Administration 2009

"Clients are the real deal of change not models"

Duncan, B (2008)

"Partnering with clients to monitor outcomes formally engages the most potent factor of change"

Duncan, B (2008)

"Us feeling part of it has improved outcomes as we're all working on the same things…"

Research participant (2009)

Acknowledgements

Thanks to the following, without whom this piece of research would not have been undertaken or completed.

To my parents, both of whom died during this period of study, but whose inspiration and belief in me has always enabled me to both continue and complete.

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Finally and most importantly to all the participants in the research without whom it wouldn't have happened. This work is dedicated to them, their generosity and their resilience.

Abstract

There has been considerable discussion in the last decade about the integration of Children's Services and the development of outcomes frameworks to evaluate their effectiveness. However, whilst these drivers have shaped a whole 'generation' of service development, scant attention has been paid to the evidence base as to any cause and effect relationship between the two or to any service-user perspective. It is from this standpoint of 'barrenness' that the research question emerged.

This study outlines the gap in the existing knowledge base as to whether integrating services does in fact impact on outcomes specifically for the parents/carers of disabled children from a service user perspective.

The interpretive methodology adopted is that of a grounded theory approach, moving the reader towards emerging 'new' theory. To accomplish the task the author presents her individual paradigm and explores the extant literature to inform her findings. The methods implemented are described in detail and findings which initially 'tell the story' of experiences of integrated services, and identification of outcomes, reposition the reader within an integrated framework where both basic needs and more aspirational outcomes can be addressed.

Current gaps in integrated services are highlighted and implications for both further research and future service provision are offered in conclusion.

Declaration

This work is original and has not been submitted previously for any academic purpose. All secondary sources are acknowledged.

Signed:

      A.M.Carney

Date: 4th June 2009

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1. Introduction

1.1 Background to the Research

This research project is motivated by a genuine interest in the impact of the government driver towards 'Integrated Working in Children's Services' and its' relationship to improvement of outcomes for children and families.

The researcher is a manager of a multi-agency Children's Service for disabled children (0-5) and their families. Her current role involves the operational management of a city-wide specialist service comprising many cross-agency disciplines, for example, Community Paediatricians, Teachers, Psychologists, Speech and Language Therapists, Social Workers, Key workers, Outreach Workers, Health Visitors, Administrators. The strategic work of the role is focused on driving the Integrated Working agenda forward and on the implementation of the transformational whole systems change needed to ensure a coordinated response to need.

The organisation has been in existence for five years and the author of this dissertation has been leading and managing the change involved in bringing the integrated approach together since its' inception.

Previous experience and background prior to choosing this research area cuts across the statutory, voluntary and private sector and encompasses public sector management both in England and abroad (Social Services in Spain).

The above 25 years work experience with children and families in varied contexts, alongside academic reading and study provide the backdrop to the relevant experience brought to this piece of research.

1.2 Research Question
Title

> "Integrated working and outcomes for disabled children and their families– a service user perspective"

Objectives of the investigation:

- To critically analyse contemporary thinking on multi-agency working and the integration of children's services

- To identify and assess the benefits of outcomes based theories and practice

- To investigate the relationship between integrated working and outcomes for disabled children and their families from a service user perspective

- To draw conclusions from the above objectives in relation to the aim of the study

1.3   Justification for the Research

- An identified gap in the current knowledge base in relation to the links between integrated working and improved outcomes for disabled children and their families.

- An identified gap in all the outcome frameworks (Looked After Children framework, Core Assessment of Need framework, Every Child Matters Framework) re: disabled children

1.4   Methodology

Research philosophy

The research philosophy for this paper will clearly not be positivist, as the data collected will be qualitative and collated by a "feelings" researcher, Saunders, Lewis and Thornhill. (2007 p.103), presented in narrative form rather than presented as statistical data. As Saunders et al (2007) state, there is a position which would suggest that the researcher forms part of the data collection process. The methodology chosen, for its' appropriateness to the subject area and to the cohort to be interviewed is interpretivist.

The complex world of multi- agency, integrated Children's Services and the debate surrounding the measurement of outcomes and impact on children and families lends itself to an approach which encapsulates complexity. Within the interpretivist epistemology the need for an empathetic response on the part of the researcher, entering into the world of the research subjects, is both necessary, and allowed, therefore enhancing the likelihood of quality data emanating from the research. Grounded theory

with its' roots in symbolic interactionism and the writings of Charles Cooley (1864-1929) and George Herbert Mead (1863-1931) will form the conceptual framework whereby the researcher will *"enter the worlds of those under study to observe the actors' environment and the interactions and interpretations that occur"* Goulding (1998 p.866). Knowledge and extant theory will be used to inform the findings of the inquiry.

The ontological stance of the author will be one of subjectivism both whilst exploring issues of organisational culture to bring about an integrated Children's Service, and whilst exploring the research subjects' view of improved outcomes. Although the pragmatist (Saunders et. al 2007 p.110) within the author will allow for the research proposed to remould and adapt in its choice of methods if early signs indicate that this would be more helpful in answering the research question. As a researcher the author acknowledges that she has an axiological or value based position in wanting to enquire into this subject area, based on many years of attempting to understand what aspects of support and or intervention really do make a difference to children and families. The awareness of this value base will be fundamental to aiding balance and to scrutiny during the analysis of emerging theory emanating from the research (Varey 2006).

Research Approaches

The approach adopted for the purpose of this study will be inductive as the researcher will be collecting data and developing theory linked to the data collected as opposed to deductive where the researcher would be developing her theory or hypotheses and then designing the methods to test the theories. Inductive reasoning will generate ideas and hypotheses from the data and the strength of the methods used will ensure a *"closeness to the truth"* (Greenhalgh, 2001 p.169) a validity which should begin to give some insight into a service user's perspective of integration linked to outcomes.

Research Methods

The study in question will be exploratory, moving towards an in-depth understanding of stakeholder's experience of integrated services and their impact on outcomes for the child and family. To this end, one to one semi-structured interviews and stakeholder groups will result in the case study material being collected, collated and presented in a narrative form.

Philosophical room will be made to present quantitative data, if this emerges as helpful to the findings, a possible mixed method approach (Bryman & Bell 2007). The obvious limitations of this approach will be the lack of generalisation possible and as the cohort will be small, the lack of it being representative. Yin (1994) cited in Saunders et.al (2007) points out that statistical generalisation cannot be made from case study research methods but one may be able to make theoretical generalisations.

In contrast to quantitative research which would be likely to use statistical sampling (random sampling), this qualitative research will use 'theoretical sampling' deliberately seeking out *"individuals or groups who fit the bill in order to explore the research question in depth rather than convenience sampling"* Greenhalgh (2001 p.171). Data analysis will be systematic using a grounded theory approach (Glaser & Strauss 1967, Glaser, 1992, Glaser, 1998) of constant comparison of one interview with another. Note taking and memoing (Walker & Myrick 2006 p.550) will aid the identification of core themes and a core category. The theory will be emergent and informed at every stage by the data. The statements made by all can be compared and deeper analysis undertaken as themes evolve.

As part of the research design, triangulation will be enabled in two ways, firstly by *'informant verification'* Saunders et al (2007 p.292), in other words by the researcher presenting her written accounts to those taking part in the research for them to verify the content and secondly from existing research in this area. The qualitative research methods discussed above allow for and even encourage the modification of the research question in the light of findings along the way. As Greenhalgh (2001 p.169) states *"this is known as the iterative approach and it shows a commendable sensitivity to the richness and variability of the subject matter"*. It is outside of the scope of this study to use more than one researcher to analyse the data independently which offers a process of improving validity.

1.5   Outline of the Chapters

In the following chapter, a critical review of the literature will be undertaken with the aim of analysing and summarising the contemporary knowledge base, both with regard to integrated working and to outcomes for disabled children and their families. In Chapter 3 a detailed description and explanation of the methodology and methods will be offered. Chapter 4 will explore in depth the research findings in relation to parent/carer real or desired outcomes and in Chapter 5 conclusions will be drawn with regard to the

relationship between integrated working and outcomes. Recommendations both for future research and implications for future action planning for the organisation in question will also be made in Chapter 5.

1.6   Definitions

Throughout this study the following definitions of recurrent terminology will be adhered to. The terms described below are potentially rife with a multitude of interpretations and therefore worthy of the clarification of their usage in the context of this research and in the light of the literature review (Chapter 2)

Integration: can be seen as a variety of managerial or operational changes to systems to bring together inputs, organisations, management and delivery of particular service functions. Integration aims to improve the service in relation to efficiency and quality (Adapted from Health article www.highbeam.com/doc/191-126387413)

Integrated Working: is where everyone supporting children, young people and their families works together effectively to put the child and their family at the centre, meet their needs and improve their lives (adapted from Children's Workforce Development Council, 2006)

Outcome: A condition of well being for children, adults, families or communities (adapted from Friedman 2005)

Indicator: A measure which helps quantify the achievement of an outcome (adapted from Friedman 2005)

Disability: is the loss or limitation of opportunity for people with impairments or long term medical conditions to take a full part in the life of the community on an equal level with others due to physical, organisational and attitudinal barriers.

1.7   Summary

This introduction has hopefully served as an appetiser for what is to be presented in the following chapters. A contextualisation of the research and the gap in the knowledge base which this work will attempt to go someway towards addressing has been offered. In the next chapter, a critical review of the literature will be undertaken with the aim of analysing and summarising the contemporary knowledge base, both with regard to integrated working and to outcomes for disabled children and their families.

2 Literature Review

2.1 Introduction

This literature review will give an overview of the relevant government policy drivers, statutory duties, studies, systematic reviews and related good quality research with regards to integrated working, with specific reference to improving outcomes for disabled children and their families. An attempt will be made to contextualise the research question within the body of knowledge available at the time of writing.

During the exploration of the literature and available knowledge base on the above subject area, a gap in the research was identified, that of the service user perspective in relation to outcomes for disabled children. This gap in knowledge forms the main driver of this study and it will be explored below in a more in-depth analysis of the literature.

Briggs and Garner (2006), in a systematic review assessing integration strategies and effects on outcomes, conclude that there are few good quality studies around which evidence that integration improves outcomes. They cite five studies of 'reasonable quality' where there is no clear evidence that integrating primary health care services improves the delivery of health services or people's health status in middle or low-income countries. They also argue that there may be unintended outcomes such as health workers becoming overloaded or deskilled or that integration strategies may increase the cost of service provision. One of the striking lessons learnt in this systematic review process was that all the studies included and excluded in their review, focused on the provider side, without any consideration of the service user views on integration and improvement of outcomes.

In contrast, Statham (2004) in her overview of best evidence of effective services to support children in special circumstances concluded that there is a lack of well designed evaluations of the effectiveness of services for certain cohorts of children (children at risk of offending, teenage parents, children whose parents have drug, alcohol or mental health problems, children living with domestic violence and children who have been abused). However, she does highlight some 'promising' approaches to supporting children whose outcomes are lower than their peers. It could be argued that some of the lessons from Statham's overview could be extended to services for disabled children. The approaches reported as supportive were: a holistic multi-agency approach, the

importance of links between children's and adult services and the value of providing children with intensive, targeted support within universal services as and when needed.

Statham (2004) alongside Briggs & Garner (2006) stresses the need for better outcome measures to strengthen the existing evidence base in the literature and for more robust research to be undertaken, as most studies have been small-scale, lack comparison and have weak outcome measures. Sloper (2004) also supports this view stating that there is much more evidence on the process of multi-agency integrated working than on the outcomes.

One model of integrated working where evidence on outcomes for children and families has been reviewed favourably is in the area of multi-agency key working for disabled children. Liabo (2001) reports positive outcomes such as improved quality of life, better relationships with services, better and quicker access to services and reduced levels of stress. Greco et al (2005) whilst exploring multi-agency partnership models in key worker services for disabled children found that factors relating to improved outcomes included the management of the service, the definition and understanding of the key worker service and the provision of training and supervision for key workers. In 2006 the same authors produced further useful findings from the views of staff involved in key worker services. However none of the above studies report on service users' views of outcomes which shall form the heart of this piece of research.

Search strategy

A wide range of databases and sources have been accessed to identify relevant materials published in the last decade.

- Department of Health (DOH), Department for Education and Skills (DfES), Department for Schools, Children and Families (DSCF), Office of the Deputy Prime Minister, Cabinet Office and the Department for Work and Pensions

- The Cochrane Library, Medline, SCIE, ASSIA, Web of Knowledge, ZETOC

- E-Books via the British Library and IBIS

Search terms used for the purposes of this literature review have included: 'multi-agency', 'integrated', 'transdisciplinary', 'disabled child*', 'joint working', 'outcomes child*', 'outcomes families', 'outcomes based accountability'.

2.2 Main Themes and applicability to research question

Integration

"Integration occurs when separate acts are joined together into one larger performance" Johnson & Yawkey (1988 p.100)

During the past decade and following legal inquiries such as that of Victoria Climbie (Laming 2003, 2009) and the more recent case of Baby P (2008) the key policy driver across Government Departments has been to highlight the need for multi-agency integrated working (e.g. Department of Health 1997, 1999, 2001, 2004, 2006; Cabinet Office 1998, 2005; Department for Work and Pensions 2006; Department for Education and Skills 2003a, 2003b, 2005, 2006 & 2007; Department for Children, Schools and Families 2008; HM Treasury and DfES 2007).

The legal context and framework established to promote integrated working is evident in The Health Act (1999) which encourages the use of 'flexibilities', that is, pooled budgets, lead commissioning and integrated provision to ensure that barriers to effective working together are minimised.

Other statutory duties in place to specifically ensure the inclusion of disabled children and young people in society and to enforce the need for multi-agency cooperation are;

- the Childcare Act (2006) which requires that local authorities make arrangements for childcare to be provided in an integrated manner

- the Children Act (2004) where Section 10 creates a statutory framework for local cooperation, in order to improve the well-being of children in the area, imposing a duty on the local authority to cooperate with relevant partners and;

- the Disability Discrimination Acts (1995 & 2005) which include provisions relating to, employment, goods and services to the general public, education and the duty on all public authorities to promote disability equality.

The need for integrated, child and family-centred services for disabled children and their families forms a common thread throughout all recent government policy drivers e.g. Every Child Matters: Change for Children (DfES 2004), the Early Support Programme (DfES 2006), the National Service Framework: Disabled Children and Young People and those with Complex Health Needs (DH, 2004) and Aiming High for Disabled Children (DfES, 2007).

The rationale for multi-agency working has been espoused vociferously over the past decade. In 1998, Payne put forward an argument for multi-agency working stating the there was a real need for a holistic approach to social problems as the evidence of the connections was overwhelming. Citing this as a basic rationale has meant that it is unsurprising that much of the literature relating to multi-agency working promotes its benefits. Benefits of multi-agency working reported by Atkinson, Wilkin, Stott, Doherty and Kindel (2002) were as follows: for organisations; it can offer a broader perspective, better understanding of the issues and increased understanding and improved interactions with other agencies. For individuals within organisations working collaboratively across agencies can provide a positive experience overall, however could lead to augmented workload or demands. Machell, 1999 (as cited by Atkinson et al. 2002) refers to complexity theory and the benefits of multi-agency working as a creator of climates of uncertainty, diversity and instability and that this in turn enhances creative problem solving.

However, Delaney (1994) offers a critique of other potential reasons as to why agencies may choose to collaborate and cites Whetten as far back as 1982, giving increased efficiency when faced with potential dwindling resources or the decreasing of client frustration when using services as reasons for multi-agency collaboration. The government over the past decade has, as enthusiastically as the research, embraced the 'joining-up of services' (integration) for children and families as being the 'right' direction towards transformation and improvement of outcomes.

This 'integration' can take many forms, including involving bringing together different kinds of expertise, for example creating teams of primary and secondary health care workers alongside social care staff. Integration can mean co-location of staff or employment of staff in a single organisation. It can also take the shape of pulling resources together close to and around the service user to enable better care coordination and support. However, throughout this literature review it will be

repeatedly evident that gaps exist in the evidence about integration and improved outcomes and that previous work, for example, by Fulop, Mowlen and Edwards (2005) needs building on. Fulop et al (2005) contribute to the evidence base of integration in health care and offer a typology of integration where the importance of governance and structure is equally matched by the importance of process and cultural changes.

Figure 1: Typology of healthcare integration
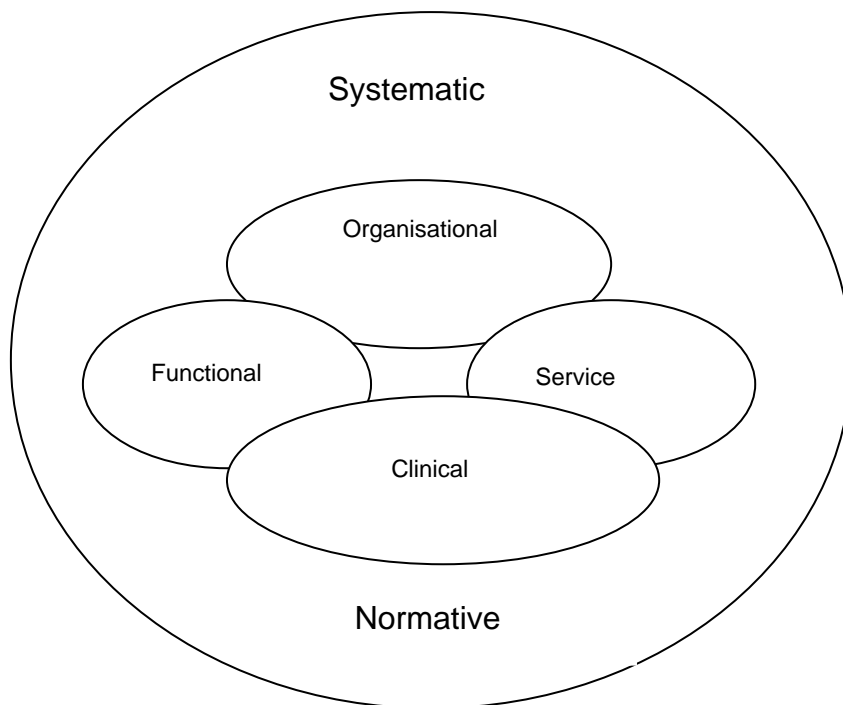
Source: Fulop et al. (2005), adapted from Contandriopoulos et al. (2001)

There is a wealth of research from the experience of integrating services in the USA where, for example, in relation to health care, people may have many more options in terms of insurers and providers depending of course on their economic status. Therefore, the extent to which this research is applicable to the UK is arguable. Ramsay and Fulop (2008) cite Enthoven and Tollen (2004) who report advantages to systems in the USA that integrate payer and provider. Burns and Pauly (2002) in contrast cite various examples of failed attempts at integration arguing that Enthoven and Tollen's research was targeted at an analysis of contexts where the conditions prior to integration were optimum, multi-disciplinary teams were already in existence, well established health plans were in place and there had been many years of developing organisational cultures.

Johri, Beland and Bergman (2003) when presenting case studies of older people's care in the USA, UK, Italy and Canada conclude that integration reduces costs and admissions, provides more appropriate care and improves quality of life for service users and carers. They highlight key success factors as being integrating case management into multi-disciplinary teams; the presence of a single point of entry; financial factors, for example, providers sharing financial responsibility with commissioners. They also highlight the key role of case managers as the primary link between agencies.

Ham (2005) when looking at the main impact of UK based pilots based on the USA Kaiser model (a model of multi-disciplinary care reaching 8.7 million people in the USA) found that effective IT systems were central to the pilots' progress. Other improvements reported mainly by senior officers involved in the pilots were improved leadership capacity, partnerships and identification of need. However, Ramsay and Fulop (2008 p.3) argue that these findings are not based on suitable measures. Evans (2003) is critical of the research undertaken by Ham, Sutch and Shaw (2003) stating that in particular Ham did not declare a competing interest in the paper as he was at the time Strategy Director in the DoH running Kaiser pilots in 7 Primary Trusts across the UK. Evans maintains that Ham et al's conclusions (2003) as of those of Feacham, Sekhri and White (2002), that Kaiser achieves better acute bed utilisation through integration of care, is presented as a fact with no hard evidence to substantiate it.

 An analysis by Boaden et al (2006) of another pilot programme in the UK, Evercare, delivering care to people over 65 via the creation of a specific coordinating role (Advanced Practice Nurses), reported changes in the way people worked, development of project management skills, increased contact with high-risk patients and nurse reported improvements in appropriate treatment. No significant impact on admissions or mortality was reported and the low number of pilots participating in the study gives little significance to the findings.

Care trusts were introduced in the NHS Plan (DH, 2000) in order to enable local coordinated health and social care delivery, based on the principles of pooled budgets, lead commissioning and integrated provision. Glasby and Peck (2005) report staff concerns related to integration centring on; its evidence base, the narrowness of its definition in that it does not include the voluntary sector and the fear that social care would become dominated by health targets. On a more optimistic note the same authors

report Care Trusts as enhancing flexibility and accessibility in spite of being hard work to establish. Nonetheless, clarity of effectiveness in relation to cost and impact on health outcomes are yet to be reported.

The need for integrated working is also highlighted throughout the academic literature in the form of systematic reviews, studies, and other research papers. Clarke (2006) undertook a full literature review on preventing the social exclusion of disabled children and states that the research on multi-agency working highlights as above, that this is the golden thread, but *"that barriers exist in terms of systems, perspectives and resistance to joint working"* (p.iii). Clarke's findings also suggest that a common theme through the literature is that definitions of disability can also prove to be a barrier, so therefore it may be pertinent at this stage of the literature review to exemplify definitions of the terminology surrounding disability and for the author to position both herself and the reader within this semantic maze. For Clarke (2006) 'disabled children' is used to describe all children who *"face disabling barriers to social inclusion"* (p.1). This is in contrast to the medical model or definition of disability which describes children in relation to their impairment or pathology, whether that be physical, sensorial, learning or cognitive and which often omits the children who may be experiencing mental or emotional distress. Tassoni (2003) is explicit in her definitions of terms in the context of the controversial fact that definitions can cause stereotypes and therefore many professionals and parents dislike them. On the other hand she argues that policy makers have always needed definitions as funding is always linked to criteria based on a definition.

Linked to the disparity of definitions of 'disabled' and 'disability', the resultant data available and population estimates of disabled children vary and cannot be absolutely accurate either at a national or local level. Whilst reviewing the evidence it is important to be aware of the heterogeneity of this group and of the vast disparity in any reporting of or definition of disability. The latest Aiming High for Disabled Children (2007) although acknowledging that there is a lack of longitudinal data at a national level reports there currently being 570,000 disabled children and young people in the UK of whom 100,000 have complex care needs. The above debate in the literature about definitions and good quality up-to-date information and statistics is essential to the provision of services in the public sector to those in need:

*"Collection and appropriate use of such information facilitates the operation of mutually aware, child-centred services working together to ensure the best possible **outcomes** for children, and especially those with additional needs"*
Aiming High for Disabled Children 2007 p. 28

Outcomes based theories and practice

The impact on and improvement of outcomes for children, young people and families accessing multi-agency/integrated services, as stated earlier in this paper still remains in 2009 a reason for further inquiry. The improvement of outcomes and the development of integrated services for children, young people and their families can be identified as the golden thread running through all recent policy initiatives. The government's ECM (2003, 2004) outcomes framework, focusing on the five key outcomes of be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic well being is now central to all policy for children. Similarly, the National Service Framework (NSF 2004) emphasises the need to work together to improve outcomes. So what about disabled children in this 'consistent' policy framework?

Two of the key policy documents, the NSF Standard 8 (2004) and the Strategy Unit report (2005) set out long term and detailed recommendations specifically linked to the improvement of outcomes for disabled children and their families. The specificity required when discussing outcomes for disabled children must be underlined here as Beresford, Rubiee and Sloper (2007) illustrate, how can we 'measure' progress in relation to "expected normative development" (p. 2) as in the ECM outcomes framework. The ECM outcomes alongside the Looked After Children and the Framework for the Assessment of Children in Need (Department of Health, 2001) focus rightly on outcomes for children, but are not inclusive of outcomes for parents. Beresford et al. (2007) having identified this as a gap in the frameworks undertook interviews with disabled children and their parents towards defining desired outcomes both for the children and for the parents in their own lives. They used descriptors of 'fundamental outcomes' as being healthy and staying safe and 'higher level outcomes' as being enjoying and achieving, making a positive contribution and economic well being. This research concluded that although some of the desired outcomes of disabled children and their families are similar to those of non-disabled children, such as having friends and independent interests, the level to which these outcomes are met differs.

The authors recommend that a widening of the definition of outcomes needs to take place to truly include disabled children and their families. They particularly highlight communication as something basic which is missing from the ECM framework and which disabled children without appropriate means of communication or access to communication aids are unable to have other doors opened to them which enable them to socialise and be active.

When exploring with parents their desired outcomes, the above authors cite seven themed areas which parents linked to the emergence of improved outcomes in their lives; personal identity, physical and emotional well being, feeling skilled and informed, the balance between caring and parenting, maintaining family life, positive adjustment of siblings, practical and financial resources and experiences as service users .

 In 2002, Atkinson et al. undertook a three phase study investigating thirty multi-agency initiatives, interviewing 139 participants and doing detailed case study analysis. Their findings in relation to impact and outcomes were all linked to impact for organisations and groups and individuals within those organisations. They describe a wide range of benefits as having been identified by professionals **for** children and families. There is no identification of benefit directly reported **by** children and families. Similarly Dowling, Powell and Glendinning (2004), found that research into partnerships had centred almost entirely on process issues, while much less emphasis had been given to outcomes. They strongly asserted that this knowledge gap needed to be filled 'urgently'. Similarly, in 2007, Atkinson and Maxwell, in their illustration of a paradigm shift in a Children's Partnership from collecting data on activity to managing information on a multi-agency outcomes performance measurement basis, nevertheless does not address the service user perspective on this process.

Outcomes cited by the Department of Health for their Integrated Care Pilot Programme are:

National outcomes:

- A compelling addition to the evidence base about what improvements in quality and outcomes can be achieved through integration, through an evaluation of the whole programme

- An appetite and process for sharing and implementing improvements widely across health and social care and beyond

Suggested local desired outcomes are:

- Improved quality of care, health, equity and economy, at a faster rate than in comparable populations

- Improved patient and user satisfaction, reported outcomes and quality of life

- Improved partnerships in care provision

- Better use of scarce resources and more effective and economic delivery systems

- Improved relationships, governance, risk management and innovation in specific delivery systems (DOHp.5)

The current national indicator for Children's Trusts to report on in relation to evidence of improved outcomes is National Indicator 54 which will assess parents' general experience of services for disabled children (aged 0-19) and the extent to which services for disabled children are delivered according to the 'core offer' standards of Aiming High for Disabled Children, information and transparency, integrated assessment, participation and feedback mechanisms and complaints.

Contextualising the emphasis on outcomes, the Queen's Nursing Institute (2008), recognise that in a climate of commissioning and increased competitiveness to provide services, the evaluation of outcomes is increasingly essential in the public sector.

## 2.3. Parent Disciplines/fields

The constraints of this work mean that it cannot attempt to cover the breadth of developmental and social psychology, sociology, anthropology, organisational theory, management theory and philosophy that potentially converge on the subject matter. Nevertheless, in order to gain a full understanding of the research question it is important to acknowledge the influence and importance of the historical roots of the related disciplines. Goulding (1999) cites methodologies such as *ethnography, semiotics and phenomenology"* p.5 as being central to the discussion surrounding qualitative paradigms in social research. The influence of psychology and sociology

cannot be underestimated in this inquiry as the researcher aims to construct what the participants see as their social reality with relation to the influencing factors which impact on outcomes for themselves and their children. Grounded theory although originally rooted in the work of sociologists has now increasingly entered the research frame in a variety of disciplines, management now being one. Goulding (1999) conveys that grounded theory (Glaser & Strauss, 1967) has *"largely been excluded from the discourse on interpretive and postmodern methodologies"* p.5. She suggests that this may be due to the two distinct approaches brought to grounded theory by its original authors and the evolution of what some authors see as positivist practices or the language of positivism such as, open coding, axial coding, verification procedures. Strauss and Corbin (1998) cited by Walker and Myrick, (2006 p.558) state however that *"Analysis is the interplay between researchers and data. It is both science and art"* and conclude that it could be claimed that consequently Strauss brings the science and Glaser the art.

2.4. Conceptual Model

In order to frame the methodology and methods used to explore this research question the author developed a conceptual model to aid understanding and give depth to the process,

Figure 2: How a Grounded Theory approach may assist in arriving at 'new' theory
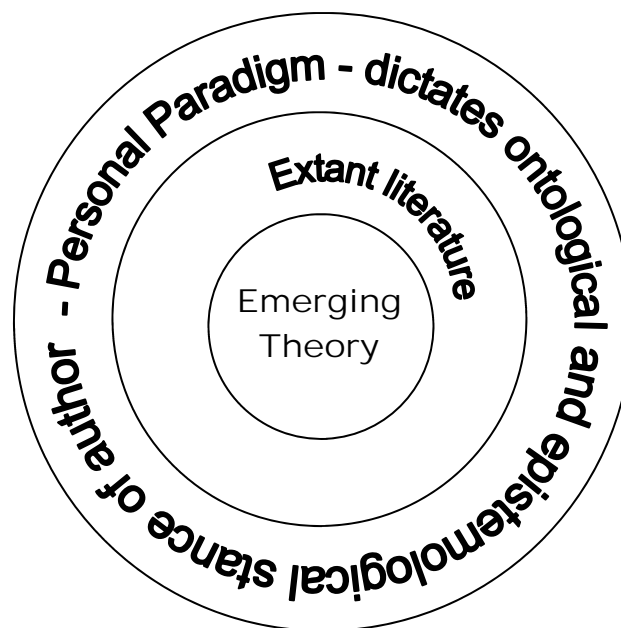
The above conceptual model provides the springboard for what is an emergent journey from which a model addressing the research question will hopefully emerge.

2.5 Summary

Prior to the discussion of methodology in the following chapter, as can be seen from the above critical evaluation of the literature it would appear that the 'hard' evidence linking integration to improvement of outcomes remains limited and worthy of more research given the pressing drivers around integration in the current Children's Services climate. This study will have at its heart the service user perspective on integration in Children's Services for disabled children and their families and its relationship to outcomes, as it is evident from the literature review that this remains a critical gap in the body of knowledge currently available.

3. Methodology

3.1 Introduction

In this chapter a detailed description will be presented of the qualitative methodology chosen to explore and answer the research question. A more in-depth description of grounded theory will be offered as the chosen route to the analysis of the findings. A brief discussion of research philosophy and principles will be presented in order to contextualise the choice of methodology as being most appropriate for this piece of research. The justification for choice of methodology will be made explicit and will be clearly linked to the literature review (Chapter 2). Limitations of the chosen methodology and rejected methodological stances will be examined. A 'thick' description of the methods adopted will be given to facilitate any future research in this area. Finally, the ethical issues which arose during the research process will be discussed.

3.2 Methodological considerations

A qualitative researcher, according to Greenhalgh (2001), studies things in their natural setting, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them. They use a holistic perspective which preserves the complexities of human behaviour. Qualitative research begins with an intention to explore a particular area, collects 'data' (i.e. observations, interviews), and generates ideas and hypotheses from these data largely through what is known as inductive reasoning. The asset of the quantitative approach lies in its reliability i.e. the same measurements should yield the same results time after time. The strength of the qualitative research lies in its validity (closeness to the truth) i.e. good qualitative research should touch the core of what is going on not just skim the surface. The validity of qualitative methods is greatly improved by the use of more than one method in combination, a process known as triangulation, and by more than one researcher analysing the data independently. The methods of qualitative research allow for and even encourage the modification of the research question in the light of findings along the way. This is known as the iterative approach (Greenhalgh 2001).

With regard to sampling, quantitative research uses statistical sampling (random sampling) and qualitative research uses theoretical sampling (deliberately seeking out individuals or groups who fit the bill in order to explore the research question in depth

rather than convenience sampling Saunders, Lewis and Thornhill, 2007). It is important that the researcher's perspective is declared. Methods will be described in detail below. The data analysis will be undertaken in a systematic way. One way of doing this according to Greenhalgh, (2001) is content analysis, the drawing up a list of coded categories and cutting and pasting each segment of transcribed data into one of these categories. The statements made by all can be compared and more sophisticated comparisons made e.g. did people who made statement A also tend to make statement B. This inquiry will take Greenhalgh's ideas further and adopt a grounded theory approach to the analysis of the data.

The term grounded theory, according to Fisher (2007) was first used by Glaser and Strauss in 1967. The two theorists over the years went on to, not exactly form opposing opinions, but to adopt different stances on the nature and process of grounded theory. By 1990, Strauss alongside Corbin was beginning to formulate stages and procedures that they advocated should be followed by anyone undertaking grounded research. Glaser, by comparison, consistently held the view that both the emergent theory and the research topic itself must evolve from the research material. Glaser's approach is described by Fisher (2007 p.123) as being "*a looser style of interpretation that allowed the material to speak for itself*". By using, as stated above, an iterative approach the 'theory' for this research will be drawn out of the rich data gathered from the interviews and stakeholder events. The researcher will be taking a stance somewhere in the middle of these two positions as the research topic was defined prior to the material being gathered. However, the flexibility to allow the theory to emerge from the data has been adhered to. Some aspects of a structured approach have also been adopted in this research process as search strategies as outlined in Chapter 2 were used, defining terms and concepts. A more 'purist' grounded theory approach would have been preferred by the researcher. However, due to time constraints and the nature of undertaking an MBA and other 'life' demands, an eclectic approach had to be taken with regard to the methodological considerations rather than a slavish adherence to a 'Glaserist' style. A consequent limitation therefore has been the possibility of having missed something in the search process. Had the researcher had years to undertake the project she may have been able to elicit new and different insights to those outlined in the findings.

3.2.1 Justification for the selected paradigm and methodology

The generation of theory from data was chosen, using a grounded theoretical approach, as there was a clear gap in the evidence relating to linkages between integration and outcomes for disabled children and their families, therefore highlighting the need for the initiation and creation of 'new' theory. Contrary to the common belief that existing theory should at best be avoided, if not completely ignored, when adopting a grounded theoretical approach, Goulding (1999) highlights that the use of extant theory is discussed by Glaser (1978) as being important to the researcher, so as to heighten awareness of emerging concepts and theory. Therefore, the researcher in this inquiry has constantly reflected back to the literature (see Chapter 2) in an attempt to contextualise the emerging data from this inquiry.

As a means of adopting and maintaining a critical 'eye' throughout, a radical critique approach (Moss Kanter 1992, Pollert 1996, Alvesson & Wilmott 1996) was explored as one means to understanding the alleged link between integration and improvement of outcomes. This exploration was undertaken in an attempt to challenge assumptions about government drivers being evidence based and as a method of critical reflection to enhance understanding and depth of analysis. A brief summary of the thinking is given below in the form of critical questions being formed

- Is the joining up of services directly linked to improvement of outcomes for children and families?

- Are government drivers likely to be based on PESTLE factors, not only on improvement of outcomes? Could it also be that integration causes downsizing, more generic lower paid workers doing work of higher paid specialists?

- Whilst the joining up services for workers can make the work more interesting (closer exposure to other disciplines etc.) could it also be disempowering? (other workers being tasked with what was 'my' specialism).

- making services more accountable to service users – this is seen as ethically valid however on other hand could the whole 'choice'/'commissioning' agenda be seen to be linked to cuts and privatisation of the public sector – creating a 'market place' economy with what was historically delivered centrally by the public sector

- Could the interviewing of parents/carers who may believe that multi-agency working is definitely improving things for their family be part of a 'false consciousness'?

Although helpful in framing a critically analytical approach to the study, the above critique will not influence the study, as Glaser 1998 p.116 states *"The problem will emerge... It is about time the researchers study the problem that exists for the participants in the area, not what is supposed to exist. "*

3.2.2 Rejected Methods

Quantitative methodology was rejected for the purposes of this study due to its' overall deductive nature as no clear hypotheses is being tested here. Probability sampling is best suited to survey-based research not case study strategies. As this study is inductive the experimental approach to research strategy has not been utilised. Robson's case study approach (2002) cited in Saunders et al. (2007 p.139) as

> *"a strategy for doing research which involves an empirical investigation of a particular contemporary phenomenon within its real life context using multiple sources of evidence"*

was initially considered as being 'fit for purpose' for this study. On reflection the author opted for grounded theory based on the opportunity the approach offers to develop and build new theory.

Parent questionnaires were considered as a means of being one of the "fastest ways of gathering large amounts of data from members of the public" Parahoo (1993), cited by Pritchard & Howard (2008 p.37). In spite of this advantage it was felt that the importance of searching for rich, potentially 'new' data was more suitably matched to undertaking grounded research with in-depth interviews with a small number of participants.

'Stepwise replication' Polit & Hungler (1997) or the ability to have more than one researcher independently examining data sources through which data can be compared was unfeasible for this study due to time constraints and the individual nature of the research design. Similarly a full inquiry audit was beyond the scope of this study but would, in future more extensive studies, be recommendable as a tool to enhance confidence and credibility with regard to the validity of the data. Equally, it has been impossible to undertake longitudinal research in relation to outcomes for the

participants involved and their children but again this would be recommended within the scope of future studies.

3.3   Research Design

The sampling method used was within the non-probability sampling techniques, as in order to meet the objectives of the study, the researcher needed to undertake an in-depth study focusing on a small group of participants. Patton (2002) cited by Saunders et al. (2007) states that the validity gained from the study will have more to do with the data collection and analysis than necessarily with the sample size. The sampling method used was purposive, that is, an open invitation to a stakeholder event as the researcher could predict that families attending would be motivated to share experiences and therefore more likely to wish to participate in the research and be particularly information rich. From that moment the sampling method became self-selective as families consensually opted into the study to participate in individual interviews or to continue to attend monthly stakeholder events.

Table 1: *Profile of participants interviewed*

| Family	Parents/Carers Participating	Children in family	Age range of disabled children
Family A	Mother Father	Two disabled children One older sibling	Under 5
Family B	Mother	One disabled child One older sibling	Under 5
Family C	Father	One disabled child Two siblings	Over 5
Family D	Mother	One disabled child One sibling	Over 5
Family E	Mother Father	One disabled child Two siblings	Under 5
Family F	Mother	One disabled child	Under 5

The range of need in the children of the families interviewed is very varied, children with social communication difficulties and diagnoses of autism and children with physical, medical and complex learning difficulties. Some of the families have experienced clear diagnoses of need from birth, others later in the child's early life. At least two of the children have what are termed to be 'rare syndromes/conditions'. All of the families have had contact with a great range of health, social care and educational professionals over the first years of their children's lives. The two children over five, via theoretical sampling were included in the interviewing process to ensure some comparable material was accessed in relation to families' experiences and outcomes prior to the existence of a one front door more 'integrated service'.

Triangulation was used to ensure that there was an increased likelihood of valid findings. Denzin (1989) cited by Polit and Hungler, (1997) identified four types of triangulation;

1. Data source triangulation: the use of multiple data sources in a study

2. Investigator triangulation: The uses of multiple individuals to collect, analyse, and/or interpret a single set of data

3. Theory triangulation: the use of multiple perspectives to interpret a single set of data

4. Method triangulation: the use of multiple methods to address a research problem.

As stated by Jack & Raturi (2006 p.345), the purpose of triangulation is to *"obtain confirmation of findings through convergence of different perspectives. The point at which the perspectives converge is seen to be reality"*. As illustrated by Figure 3 below triangulation for this study was achieved by the constant interrelationship between 1:1 interviews, stakeholder events and the literature accessed.

Figure 3:
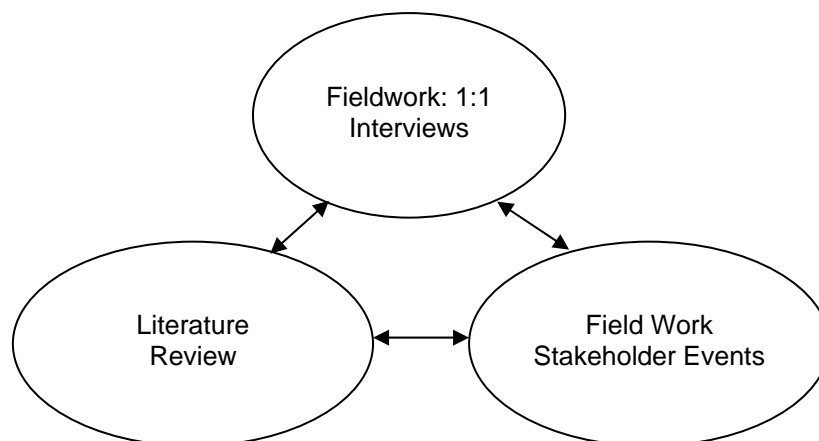
Adapted from Jack & Raturi (2006)

Lincoln and Guba (1985) recommend ways to provide an external check on the inquiry process, firstly, peer debriefing sessions to review and explore various aspects of the research and secondly, 'member checks' or 'informant verification' (Saunders et al. 1997). This study as part of its design has incorporated both of these 'checking' processes as an integral part of design and process. Regular peer debriefing sessions were held throughout the process where the researcher was exposed to searching questions from others and where she could explore avenues to pursue in the emerging findings. Stakeholder events contributed data and formed part of a search for "disconfirming evidence" (Polit and Hungler, 1997 p. 306). By holding a series of open invitation stakeholder events (3 in total with an average of 12 parents at each) for parents/carers of disabled children throughout the life of the inquiry, the researcher hoped to enhance the data set by systematically searching for data that would challenge emerging data from the interviews. The inclusion of the stakeholder events helped to continuously refine emerging theory.

By being very clear from the beginning of the study about the axiological stance and previous experience of the inquirer, 'researcher credibility' as defined by Patton (1990) was achieved. Dependability and confirmability were enhanced by the regular use of an MBA learning support group of peers facilitated by a tutor to examine the objectivity and neutrality of the data set.

The researcher has attempted to inform the transferability and external validity of the study by providing 'thick description' or a detailed description of the context, process and content of the inquiry. Contextual similarity for future researchers could be judged by the extent to which this study has attempted to provide sufficient information to inform that comparison.

3.4. Research Procedures

The methods process began with an initial open invitation stakeholder event to former parent/carers (children over 5) and current parent/carers (children 0-5). At this event information was verbally given about the research topic, written information sheets were distributed as were consent forms and a letter inviting participation (See Appendices A-C). The open ended themes for the interview questions were tested with a group of professionals who are also parents of disabled children. The interviews were

organised in the venue of the family's choice and time of choice. Four families chose interviews in their own homes and two in the researcher's place of work as they were familiar with the building. All interviews took place during the day apart from one which needed to take place in the evening in order for both parents to be involved in the process. Interviews were undertaken during February and early March 2009. The interviews were initiated in an open-ended way and although specific questions/themes were offered to all participants, free-flow discussion was encouraged to increase the likelihood of data coming from the informant's experience. Interview themes are attached as Appendix D.

Monthly stakeholder events were held over a period of three months (January to March 2009) where on average 12 parent/carers attended each. Part of each of these sessions was used to explore the research inquiry as to what, if any correlation there is between improved outcomes as service users and the integration of services.

Five of the six interviews were with mothers of the children participating, of which two had the father of the child present also, and one of the interviews was with the father only. The full age range of the disabled children of the families participating was 0-7, as two of the participants had previously experienced the support of the multi-agency service and their children had now moved out of that service age range constraint. The children and young people have a variety of often complex and inter-related medical and social care needs; they access a range of services from community paediatrics, neurological, genetic and cardiology medical consultants to speech and language therapy, sleep and eating clinics, mainstream schools, assessment nurseries and special schools.

Constant comparison was at the heart of the analysis of the findings, comparing interview to interview, stakeholder event to stakeholder event and interviews with stakeholder events. Theory began to emerge and then the comparison became comparing theory to data. Both during and after each interview and stakeholder event notes were made and categories were identified. Links between categories began to emerge and a core category (high frequency and well connected to other categories) began to emerge as central. When 'saturation' point was reached, memoing and sorting formed the final part of the process leading to the findings described in detail in Chapter 4. Glaser (1998) suggests two main criteria for judging the adequacy of the emerging

theory: one that it fits the situation, and two that it works, that is, that it helps the people in the situation to make sense of their experience and to manage the situation better.

3.5.   Ethical Considerations

One of the key ethical considerations when embarking on this research was to ensure that no harm or intrusion of privacy would be evoked. Given the potential for sensitivity in the nature of the inquiry, great care was taken with regard to being explicit about the right not to take participate in the research. At interview stage even where signed consent had been obtained, the right not to take part was offered and explained. The option of not answering specific questions was offered, as was the right not to talk about the past if it was felt to be distressing. All the families answered all questions and used their own discretion as to how detailed they were with their responses. The researcher attempted to collect the data accurately and fully, avoiding as Saunders et al (2007) warns *"exercising subjective selectivity in what you record"* p.187. As the researcher was known to the participants in her role as manager of the service they had or do access, it was very important to clarify the specific role she was in as researcher to ensure that in the interviews appropriate boundaries were set and adhered to in relation to the content.

During the analysis of data the ethical considerations have been, ensuring that the researcher maintained objectivity in arriving at the relevant and main concerns for the participants, not what **was** supposed to exist in the area of outcomes and integration, but what **is** really there. It is hoped that by doing this, the relevance of the study is enhanced as Glaser (1998) argues *"relevance comes only in the perspective of the subjects"* p.117. Being honest about the data is paramount in this study through verification and modifying by constant comparison.

3.6.   Summary

A possible limitation with this methodology has been that Glaser (1998) recommends approximately a year for the completion of a grounded theory dissertation – this study was time constrained to eight months from conception to completion. The upside of using this theoretical framework was that the methodology delimits the project through methods such as 'saturation' and 'sorting' and therefore enables the researcher to move on in the process. The researcher had a 'complete' methodological package to follow and could pace it to suit needs. The process of collecting, coding and analysing data ran

parallel with the process of categorising, memoing, sorting and then finally writing, facilitating the researcher to stay productive. In the following section the author will begin to explore the emergent theory informed by the rich data derived from the processes described in this chapter.

4. Findings

4.1 Introduction

Findings will be presented as a description of the collection and interpretation of the data demonstrating how, why and from where, early concepts and categories were derived Goulding, (1999). Secondly, there will be a search for theoretical meaning. It is in Chapter 5 that the author will re-evaluate the extant literature presented in Chapter 2 in order to establish linkages and where possible extend the thinking to 'new' areas. Again in Chapter 5 conclusions will be drawn linking the main findings to the specific lines of inquiry outlined in the research question.

4.2 Application of methodology

As asserted by Goulding 1998 in her exploration of qualitative, interpretive research in marketing, *"it is no understatement to say the researcher's life would be much easier, if less intellectually challenging, if each methodological philosophy was clear cut and defined..."* p.862. In the application of the methodology chosen, the researcher undertaking this study has at all times had to be aware of the use of dual or even multiple methods, such as, combining elements of grounded theory with triangulation and thick description. Wallendorf and Brucks 1993 cited by Goulding 1998 highlight how this can be problematic given the implicit expectation that pluralism should demand high standards of excellence in all the research methods used.

What most sets grounded theory apart from other research theory is its emphasis on theory as being explicitly emergent. This study has attempted to stay faithful to this approach by aspiring to understand the research aim and questions and to trust that the theory would be implicit in the data. The rigour has been in the continuing search for new evidence which may have disproved the emerging theory. Glaser, 1998, suggests two criteria for judging the adequacy of the developing theory; one, that it fits the situation and two that it works, that is, that it helps the people in the situation to make sense of their experience and to manage the situation better. It is hoped that this study will add to the knowledge base locally and therefore satisfy the latter function.

Goulding (1998) argues that although grounded theory could be said to resemble phenomenology in certain aspects, there exists some underlying variation. These

distinctions she argues focus on the sources of the data and the use of the extant theory base. In phenomenological studies the views of the participants *are considered the only valid source of data"* p.51. As will be illustrated below by using grounded theory these emergent findings have directed and redirected the author to the literature as knowledge and theory has been used to triangulate the findings.

Through the use of open coding (Fisher, 2007), substantive coding, theoretical coding (Glaser, 1998) and constant comparison (Glaser 1998) and drawing on memos created after every interview and stakeholder group, conceptual theoretical analysis became an ongoing process throughout the study's life (Polit & Hungler,1997). The distinction made by Dey, 1993 cited in Saunders et al 2007, between the analysis of qualitative and quantitative data is that *"while number depends on meaning, it is not always the case that meaning is dependent on numbers"* p. 472. Any meaning attached to numbers is only evident in the 'thin' abstraction graph found below (Figure 4) which will begin to give the reader a flavour of 'high frequency' categories emanating from the interviews and stakeholder events. A self-cautionary reminder was made at this 'coding' stage by the researcher to ensure that evidence was not to be substantiated by 'numbers' only.

With regard to the process of beginning to analyse findings, the grounded theory methodology used was found to be extremely advantageous as coding and memoing throughout the process has provided a progressive analysis of data *"fostering trust in one's own creativity and preconscious processing"* (Glaser 1998 p.147). By coding and memoing quickly and constantly comparing after each interview/stakeholder group, the researcher was able to begin to delimit the amount of codes generated, identify when a category was reaching saturation point (see graph and text 4.3.) and begin to generate theory. It is the main concerns of the participants categorised under the eight substantive headings below (4.3) which will form the thread for further theory generation and inform the conclusions outlined in Chapter 5. It is the interaction between the substantive and theoretical codes which *"characterizes grounded theory and an analytical inductive research methodology"* (Glaser, 1998 p.164).

4.3. Findings from research question

It is both timely and appropriate at this stage to remind the reader of the research aim and objectives prior to presenting the findings related to the question. The aim of this work has been to enquire into the area of integrated working and outcomes for disabled children and their families from a service user perspective. Clear objectives were established as a means of informing the methodological approach to the study. By means of:

- critically analysing contemporary thinking on multi-agency working and the integration of children's services and

- identifying and assessing the benefits of outcomes based theories and practice

it was hoped that the inquiry would add to the gap in the knowledge base by investigating the relationship between integrated working and outcomes for disabled children and their families from a service user perspective. This section will present the rich data gleaned from the interviews and focus groups held with parents/carers of disabled children and Chapter 5 will draw conclusions from the above objectives in relation to the aim of the study.

The eight categories emerging from the process as being the principal concerns for participants will be explored below. Figure 4 offers a visual 'thin' analysis allowing the reader to see high frequency categories beginning to emerge from the data offering little at this stage to the materialization of theoretical concepts nevertheless serving as a descriptive analysis of some early findings. The presentation of findings in this form could be seen as "labelling and logical elaboration resulting in 'conceptual description' rather than 'conceptual theory' (Jones and Noble 2007 p.87). Nevertheless the defence rests on this description being simply one part of the process in the journey towards emerging theory.

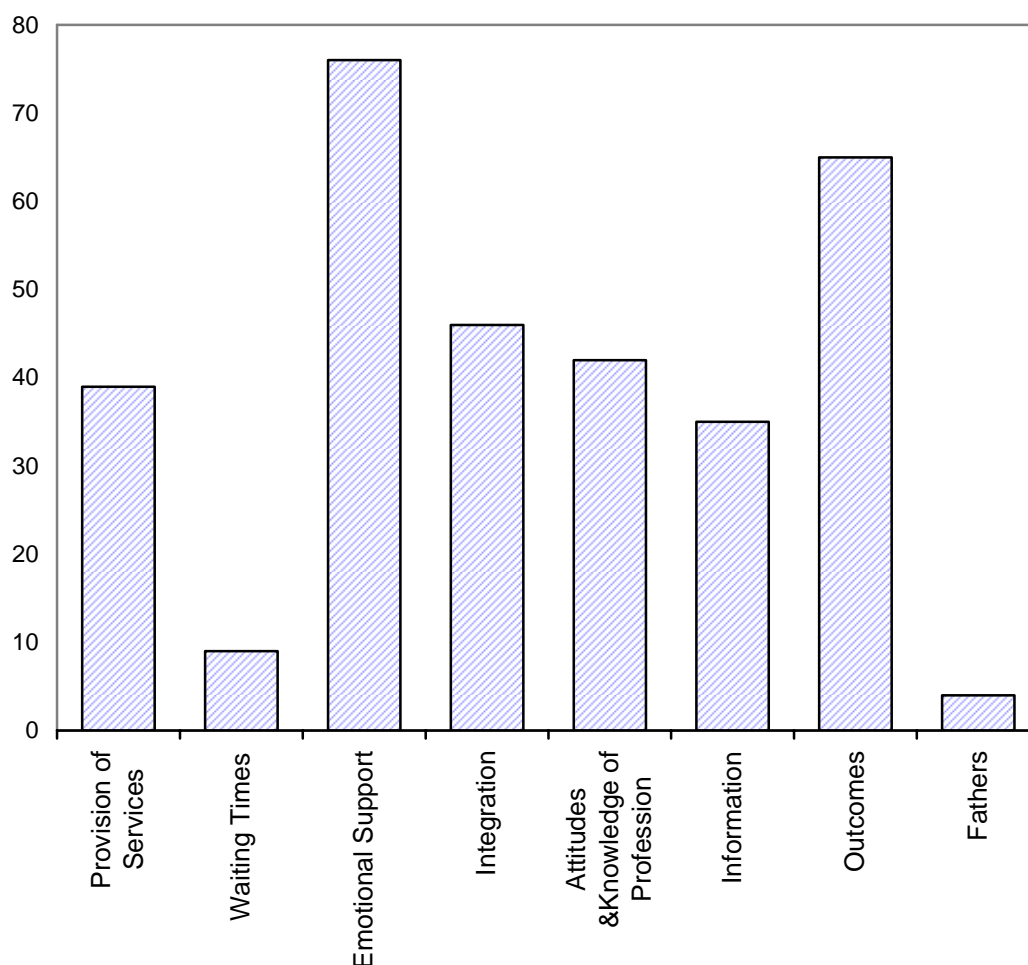**Figure 4: Principal emerging themes for participants**

Figure 4 begins to describe the 'story' of what is important **to** and **for** parents of disabled children participating in this study. It graphically illustrates the emphasis placed by parents on eight recurring themes each reaching 'saturation' point in both the interviews and the stakeholder events. A more detailed analysis of the 'story' behind Figure 4 is offered below.

 Provision of services: This category encapsulates the amount, type and experience that parents had of single services (for example, health visiting, community nursing, GP's, physiotherapists, acute sector consultants, occupational therapists) prior to coming into contact with a coordinating, integrated service provision.

> *"We had already been accessing physiotherapy- the hospital was the only place we were in contact with for the first three years. Loads of appointments 'hell but normality'… we were always fighting and chasing people."*

"We were with the birth hospital for two years and then got referred to the Community Paediatrician"

"The first service I found out about was my Health Visitor. I talked to her about my child not settling, not sleeping"

Waiting times: This category captures the data in relation to how responsive and/or accessible services were to the family.

"There was a nine month wait between the Health Visitor coming and someone else coming to visit us at home. The waiting period made me angry. When I thought there was a possibility of support I felt excited, then I was disappointed by the gap, the wait. "

"Post five years old there was a breakdown in communication re: a further diagnosis, over a nine month period we tried three routes, school, community paediatrician and specialist team and went round and round in circles, it was a very anxious one or two years."

Emotional support: This category as illustrated by the graph above was high frequency and will be discussed further below in core category analysis and as part of Chapter 5.

"What was helpful was having someone to talk to"

"I was left on my own for hours after having been asked to leave the delivery room, no one was telling me what was happening. It was frightening for my partner also without me. I wanted to be treated like a human being, but felt like the medics controlled all the information."

"I felt really isolated, was totally on my own – deeply isolated…Having information eventually about the grieving process helped, that what we were feeling was normal. That was such a relief."

"The emotional support, feeling like there is someone to lean on…I think I would have crumbled if I hadn't had these services to lean on. Life was too

stressful, going out as a family was embarrassing, or I used to get angry with other people in the street for not understanding."

Attitudes and knowledge base of professionals: This category emerged as participants began to identify attitudinal factors in relation to their contact with front line professionals delivering services.

"The difficult thing has been the different ethos of school professionals"

"In a particular part of the hospital I believe they are not tuned into children with special needs"

"The breaking the news part was a complete disaster"

"The helpful aspects of the medics care was the knowledge factor, the openness, likeable and the attitude of 'together we'll work through this'."

"The workers attitudes were open-minded, listening to me, flexible…"

"The workers didn't have the knowledge and experience of disability, so as parents it didn't feel safe leaving our child there so we just stayed at home. Staff weren't approachable – didn't have the understanding"

"I went to the GP who was off with me and treated me like an over anxious mother. I still felt there was something wrong and went to the hospital where the doctor was patronising and rude, not prepared to listen to me."

Information: Being easily able to access information or for professionals to share information transpired as another important category to the parents taking part in the research.

"The other difficult thing has been trying to convince professionals to share information – please share information so we don't have to repeat it – share between all the doctors. How can a worker do their job without all the information?"

"Access to information shouldn't depend on individuals – services should have more leaflets/marketing/bright stand out profiles…"

"All the lost hours in hospital why can't they have packs of information made up for parents or internet access to recommended medical sites, why can the medics know what sites to access and not let us know."

Outcomes: This category illustrated both the positive and negative outcomes for parent/carers and for the disabled child and their siblings.

"In general these were not very good experiences or good times; we felt we had no life"

"We have been given back some time to ourselves, life has become less cluttered"

"We didn't feel alone, the kids made friends through the siblings support group, we didn't have to repeat our 'story', it made the kids happier, made home life happier all round"

"I'm not alone. My experience is appreciated to improve services…believing that what I say is valuable…the main difference has been in my confidence."

"I believe there would be many more separated families if pressure wasn't lessened… more mums would be having a breakdown and more dads doing a runner and more children may be harmed or exposed to family violence and disabled children are much more vulnerable in this respect…support going in quicker prevents these things from happening"

Fathers: This was a 'surprise' category for the researcher given the depth of analysis shared by the participants into the specificity of the issues for fathers.

"I think an important issue is how the dads react when all this is going on. My partner was private, didn't really want people to be involved"
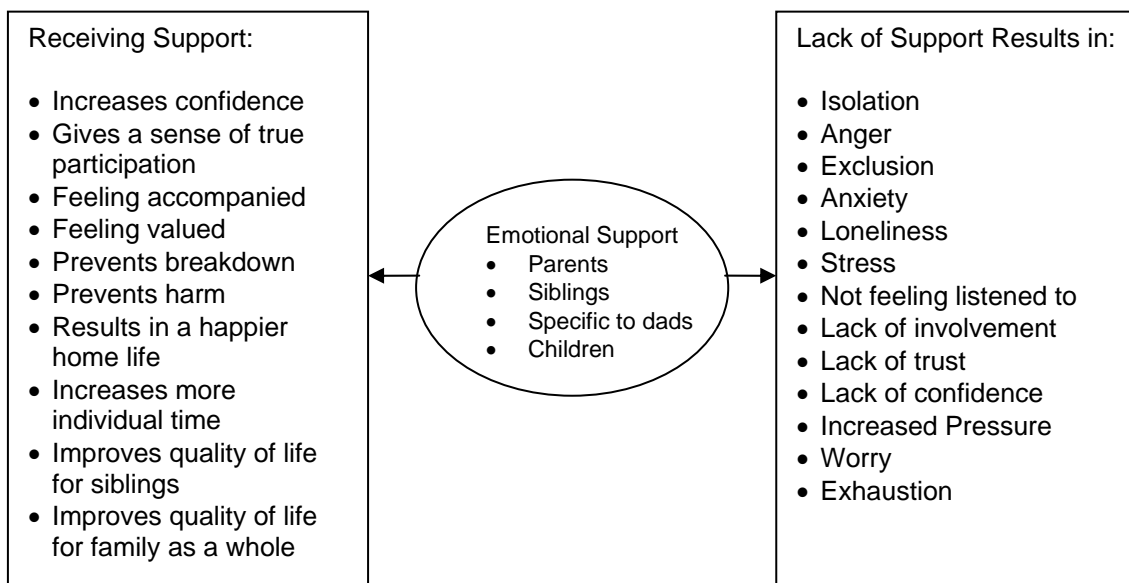
"Life crashed at diagnosis but the 'male thing' about not breaking down kicked in and I felt like I had to support everyone, partner, other children, grandparents. I'm still waiting to have my breakdown."

"On an anecdotal note your emotions are all over the place. Support for dads is starting to come through but in the meantime I'm still waiting for the breakdown."

"Where are the men? I'm not saying they're not doing anything I am just wondering where they are?"

Following the above process of substantive coding, theoretical coding was beginning to emerge and a core category of emotional support allowed further analysis to be undertaken (Figure 5 below).

Figure 5:

Receiving Support:		Lack of Support Results in:
• Increases confidence • Gives a sense of true participation • Feeling accompanied • Feeling valued • Prevents breakdown • Prevents harm • Results in a happier home life • Increases more individual time • Improves quality of life for siblings • Improves quality of life for family as a whole	Emotional Support • Parents • Siblings • Specific to dads • Children	• Isolation • Anger • Exclusion • Anxiety • Loneliness • Stress • Not feeling listened to • Lack of involvement • Lack of trust • Lack of confidence • Increased Pressure • Worry • Exhaustion

Given that emotional support emerged as so vital to service users, could it be said to be the basis from which all other improved outcomes emanate (see Chapter 5)?

The conceptual shape began to take form linking integration to outcomes as further theoretical analysis took place responding to the research aim. A number of guiding/unequivocal connections between integration and outcomes began to emerge from the service user perspective. It is at this stage that the research is moving towards

the response needed to begin to inform the gap in the knowledge base (see Table 2 below).

Table 2: Integration and Outcomes

Integration and improved outcome for Family/Parents/Siblings/Disabled Child	Evidence from this research
4.3. (i) Coordination (Family)	*"Prior to contact with integrated service we were always chasing things or people"* *"The key worker coordinating all the services and helping me realise I was also an expert in my child's life gave me the confidence to carry on"*
4.3. (ii) Participation (Parents)	*"Asking us for input, what we think helps us feel involved"*
4.3. (iii) Ordinary 'quality' family life (Parents)	*"Gave us time back to ourselves as a family"* *"Happier home, share problems, able to be an ordinary household"* *"You can just be a family"*
4.3. (iv) Support for Siblings (Siblings/Parents)	*"Quality of life for our older child has increased as they can now understand the disability"* *"The support for my disabled child's sibling makes me as a parent so much happier to know she is having a good time"*
4.3. (v) Inclusion (Disabled child)	*"Our child is now included in mainstream school in the local community"* *"Being able to access my disabled children to mainstream education has brought them on and having a linking up of services really helped that process"* *"Staff being clear about medical needs – the joint work between health and education"*
4.3. (vi) Improved outcomes for disabled child (Disabled child)	*"Improved outcomes for my child have been joint planning between nursery, school and home meant better progress on targets."* *"Speech and Language (SLT) and staff at school and home all doing PECS improved communication"* *"Us feeling part of it improves outcomes for child as we are all working on the same things – the Physio, SLT, Occupational therapist (OT), Specialist teacher, school and home"*
4.3. (vii) Increased Emotional Support (Parent)	*"Having one point of contact to lean on means I don't feel as lonely"* *"I have more time to myself now"* *"Worry less knowing things are coordinated so my quality of sleep has improved, not worrying all the time about what I need to be organising"*

4.4 Summary

In this chapter findings and evidence has been presented to illustrate the 'voice' of the service user in the debate about improved outcomes and integration. There are clearly positive indicators from service users as to what is making a difference to their lives and there are clearly some gaps. It is the further analysis of these which will be pursued in Chapter 5.

5. Conclusions and Implications

5.1 Introduction

The intention of this chapter is to make some contribution to the body of knowledge by summarising what was known prior to this study (the body of knowledge already available) and what we now know after a detailed analysis of findings has been undertaken. In Chapter 2, a gap in the knowledge base was uncovered, that of a lack of evidence illustrating the link between the integration of services and improved outcomes for disabled children from a service user perspective. Chapters 3 and 4 aimed to describe the process of discovery alongside the participants of this study. This chapter serves to draw conclusions from the research and indicate the implications for future service provision for disabled children and their families and for future research.

5.2 Critical evaluation of adopted methodology

In relation to critically evaluating the adopted grounded theory methodology, Glaser 1998, dedicates a whole chapter to the discourse surrounding the potential for 'forcing' data into categories as a possible criticism and risk attributed to adopting a grounded research approach. Skodol-Wilson & Ambler-Hutchinson, 1996 refer to 'premature closing' as a possible criticism of some grounded theory studies, signifying leaving the field too early or under-analysing data and not moving beyond description of the data. The same authors cite 'methodological transgression' as a concern, referring to, for example, phenomenological research being presented as grounded theory. Goulding, 1998 points us to the random rules which have emerged from other authors, citing in particular Riley, 1996, who stated that a sample of 12 must be the minimum for any grounded theory study. The author of this particular study has attempted to stay faithful to the concept of saturation and rich analysis of the data as a marker for leaving the field. It could of course be argued that having remained in the field longer may have shaped more theory, however it became evident that both the interviews and stakeholder events were generating similar themes and after six interviews and three stakeholder events no new themes were emerging so a decision was taken to leave the field.

A key critical question to pose of the findings and conclusions is in relation to their credibility. Lincoln & Guba (1985) cited by Fisher (2007 p.296) suggest a credibility

test based on, range of research techniques used, triangulation methods adopted, constant questioning of interpretations against data, keeping research material archived and checking interpretations with the participants. For the purposes of this research, triangulation was achieved by constant comparisons being made between data emanating from individual interviews, stakeholder groups and the literature. The memoing and coding provided the constant process of questioning of interpretations against data. All research material has been archived and informant verification was used to check interpretations of interviews.

In relation to internal validity the critical question is whether the conclusions drawn in this chapter justify any claims of cause and effect. Campbell and Stanley (1963) cited by Polit and Hungler (1997 p.182) coined the term internal validity as making reference to the extent to which, the *"independent variable is influencing the dependent variable"*. In 'experiments' it is easier to control unrelated variables through the use of control groups and randomization therefore providing the potential for a high degree of internal validity. Polit et.al (1997) in a nursing/medical research framework, discuss four threats to internal validity, history (events which take place at the same time as the study), selection, maturation (processes happening for subjects of research during the study as a result of time passing), and mortality (the loss of subjects during the study).Of these four a discussion with regard to selection would seem to be the most relevant to this study. Caution should be taken in interpreting the data as participants self-selected into this study so it could be argued that they were a) highly motivated to take part b) already engaged with services to some degree and c) unlikely to represent the views of more 'hard to hear' groups of parents/carers.

 External validity, or 'transferability' Lincoln & Guba (1985) cited by Fisher (2007) refers to the generalizability of the research findings to other settings and samples. In relation to this study it could be argued that the same research undertaken in a different country or culture may result in distinct conclusions and that it would be helpful to replicate the study in different settings with new subjects. Nevertheless the external validity is supported by Table 4. below in a comparison made in relation to transferability with the extant literature.

The use of questionnaires in this study could have reached many more parents; however, as Pritchard and Howard (2008) state, the use of questionnaires would not

have provided the detailed information gained from a small number of participants. Nevertheless it is important to acknowledge that further sources of data such as questionnaires may have enhanced the findings.

Winter (2001) offers a series of notions to support the researcher improve the validity of their findings. The use of 'reflexive critique' throughout this study has enabled the researcher to accept that the findings may be tinted by personal values and assumptions. Winter's concept of 'collaborative resources' has been used to validate findings as the issues have been examined by stakeholders *"involving them as resources in understanding the research questions"* (Fisher 2007 p.300). Furthermore, the 'plurality of structure' idea posed by Winter (2001) is useful in recognising that had different groups of stakeholders participated in this study, for example, managers of services, professionals or the children and young people themselves, different conclusions may have been reached.

With the above critical evaluation of the methodology in mind, conclusions about the research aim and objectives will be discussed below, acknowledging that the reader may need to pay attention to competing explanations for reported conclusions. The author has indeed had to place a critical eye at all times on her interpretation of results and the drawing of conclusions from them.

5.3 Conclusions about research aim and objectives

The aim of this work has been to enquire into the area of integrated working and outcomes for disabled children and their families from a service user perspective. Clear objectives were established as a means of informing the methodological approach to the study, by means of:

1. critically analysing contemporary thinking on multi-agency working and the integration of children's services and

2. identifying and assessing the benefits of outcomes based theories and practice

The missing pieces of the jigsaw for the author in the pursuit of knowledge, both in the course of the time in the field and also during the examination of the literature were two fold:

i)   Where was the evidence connecting the success factors, establishing that there is a direct correlation between integration of services and improvement of outcomes?

ii)   Where was the voice of the service user?

It may be timely to recap with the reader the definitions of the above terms for the purpose of this study:

- Integration – a variety of managerial or operational changes to systems to bring together inputs, organisations, management and delivery of particular service functions. Integration aims to improve the service in relation to efficiency and quality.

- Outcomes – a condition of well being for children, adults, families or communities

- Service user – for the purpose of this study parents/carers of disabled children, disabled children and young people, siblings of the disabled child

In Table 3 below, some key success factors of both integration and outcomes are highlighted in what was an extensive use of the extant knowledge base accessed throughout the emerging data analysis process (Chapter 4):

Table 3: **Summary of the extant literature (see Chapter 2)**

Key success factors – Integration	Key success factors - Outcomes
• Integration of case management into multi-disciplinary teams *(Johri, Beland & Bergman, 2003)*	• Providing targeted support in universal services *(Statham, 2004)*
• Providers sharing financial responsibility with commissioners *(Johri, Beland & Bergman, 2003; Enthoven & Tollen, 2004)*	• Management of the service *(Liabo, 2001;Greco,2005;*
• Key role of case managers as the primary link between agencies *(Greco et al, 2005;Boaden et al., 2006)*	• Provision of training and supervision for key workers *(Greco, 2005, 2006)*
• High functional IT systems *(Ham,2005)*	• **Physical and emotional well being for parents** *(Beresford, Rubiee and Sloper, 2007)*
• Improved leadership capacity *(Ham, 2005;Ham, Sutch & Shaw, 2003)*	• **Parent/Carers feeling skilled and informed** *(Beresford, Rubiee and Sloper, 2007)*
• Improved identification of need *(Ham, 2005;Ham, Sutch & Shaw, 2003)*	• **Balance between caring and parenting** *(Beresford, Rubiee and Sloper, 2007)*
• Improved partnerships *(Ham, 2005;Ham, Sutch & Shaw,2003; Atkinson,Wilkin,Stott, Doherty and Kindel, 2002)*	• **Maintaining family life** *(Beresford, Rubiee and Sloper, 2007)*
• Importance of links between adult and children's services *(Statham,2004)*	• **Positive adjustment of siblings** *(Beresford, Rubiee and Sloper, 2007)*

The gap is hopefully as evident to the reader as it is to the researcher, that of the existing evidence base convincing us that there is in fact a direct correlation between the two columns in the table; Integration and Outcomes. The most relevant literature informing this inquiry, as seen above, is that of Beresford et.al (2007) where the service user perspective was indeed present. The remainder of the literature cited in Table 3 above and in Chapter 2, focuses on systems, structures and processes of integration and outcomes from a strategic, organisational or professionals' perspective. While helpful in contextualising the research question, this literature does not offer the richness of qualitative data needed to answer the core aim, which is that of the service users' perspective.

The research by Beresford et. al (2007) identifies the desired outcomes for parents of disabled children however makes no link to integration as a factor. The eight areas identified by the parents involved in Beresford's research are indicated in the table below and aligned where appropriate with the findings of this research:

Table 4: Commonality of desired outcomes for parents

Beresford et al. (2007)	Alignments with this research
→ personal identity	→ emotional support **4.3.(vii)**
→ physical and emotional well being	→ increased emotional support **4.3.(vii)**
→ feeling skilled and informed	→ participation **4.3.(ii)**
→ the balance between caring and parenting	→ ordinary quality of family life **4.3.(iii)**
→ maintaining family life	→ ordinary quality of family life **4.3.(iii)**
→ positive adjustment of siblings	→ support for siblings **4.3.(iv)**
→ practical and financial resources	→ coordination **4.3.(i)**
→ experiences as a service user	→ coordination and partnership **4.3.(i)**

As can be seen above there are clear alignments and transferability of the reported desired outcomes for parents. The variation between the extant literature and this particular study is:

- the link identified by the participants in this study between desired outcomes and contact with a coordinating, integrated service (illustrated by Figure 5 below & Table 2. Chapter 4).

Figure 5:
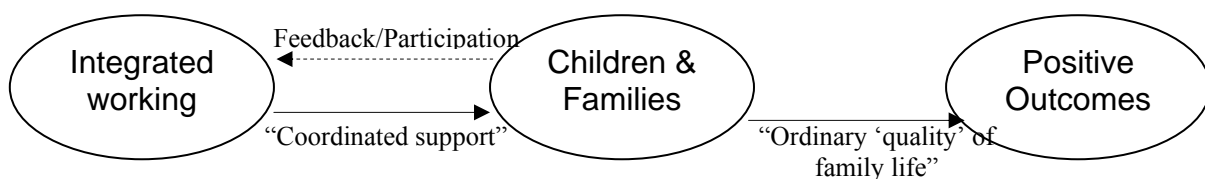
Families in this study who had received services both prior to and during there being a coordinating 'integrated' service in existence were able to articulate this link clearly and how it had impacted on outcomes for their family. They reported that the coordinating aspect of being in contact with an Integrated Service ensured that they were able to:

i) experience being a full participant in the process and

ii) move from their basic needs being met to more aspirational outcomes being achieved for their family as a whole.

Parents highlighted the importance of this experience not being a 'one-off' contact with services but as a continual participatory process where feedback is positively encouraged and welcomed by the integrated service.

In contrast to Beresford et al (2007) who found that parents struggled to understand the concept of outcomes, in this study, by framing the concept of outcomes as 'what positive differences have you experienced?', the participants appeared to have no difficulty being very specific and naming concrete outcomes (Chapter 4, Table 2, 4.3(i)-(vii)). A clear lead is given by contributors to this research as to a model for service design which would ensure that the 'golden thread' (Clarke, 2006) between integration and outcomes is realized (Figure 7 below).

Figure 7: Improving outcomes for disabled children and their families**: AN INTEGRATED MODEL**
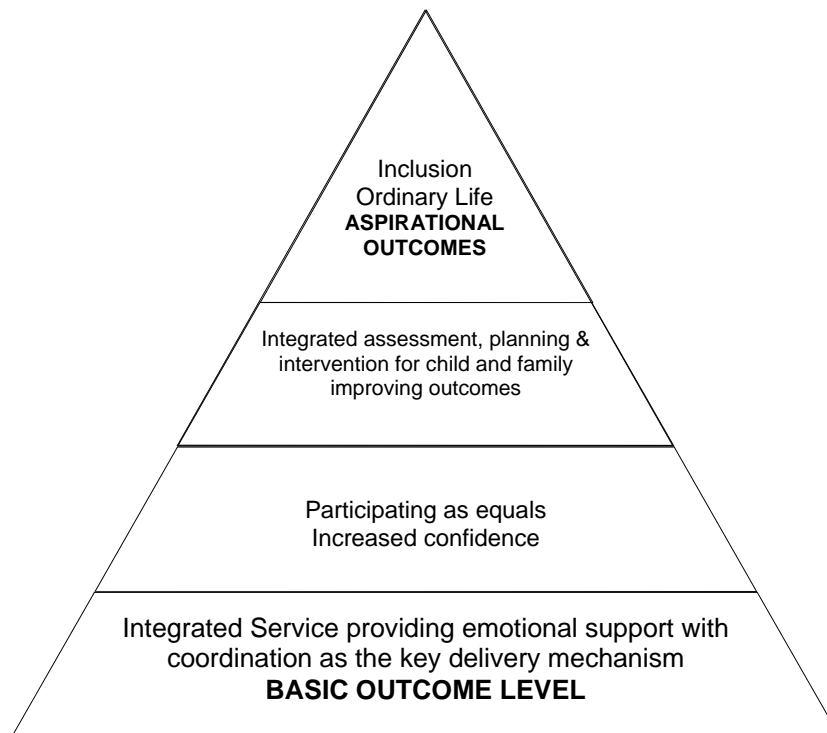
The basis for service design would be a one front door integrated service, offering emotional support and coordination as its main delivery mechanism (meeting **BASIC OUTCOMES**). This in turn serves as the foundation for a successive journey towards achieving more **ASPIRATIONAL** outcomes. As parents become active participants in their child's journey, their confidence increases enabling them to be part of all the integrated assessment, planning and intervention processes along the way leading to a sense of living an 'ordinary life' in an 'ordinary household'.

The Audit Commission (2008) asks a fundamental question of local Children's Services 'Are we there Yet?' This research would suggest not, and the gaps highlighted by the participants, which could inform both future research and recommendations for local integrated commissioning priorities are explored below.

The gaps stressed by parents which continue to weaken the link between integration and improved outcomes are:

- The need for **improvement in the integration of children's and adult services**. Parents expressed anxiety as to what would happen when their children reached the 'transition' into adult life and knew anecdotally from other parents that services were not yet streamlined and they were likely to experience fragmentation.

  > *"I would be integrating children and adult services, not putting children into age boxes"*

- **Workforce attitudinal issues.** Participants had experienced a wide range of attitudes from professionals, from exemplary to insulting, resulting in either feeling comforted and reassured to feeling anger and impotence (see 4.3). The Children's Workforce Development Council (2008) framework for 'One Children's Workforce' describes this area as 'behaviours focused on positive outcomes for children and young people'. The shared understanding of these 'behaviours' will be paramount to ensuring that disabled children and their families encounter knowledgeable, empathetic, respectful attitudes irrespective of which professional group they are in contact with.

  > *"The doctor was patronising and rude, not prepared to listen to me…not tuned into children with special needs."*
  >
  > *"I would say one of the main difficulties has been in relation to the attitudes of some of the Children's workforce"*

- **The inclusion of relevant indicators for disabled children in existing outcomes** frameworks and the addition of **outcomes for parents**. The ECM outcomes framework (2003, 2004), now central policy for all children, alongside all other government drivers highlighted in the literature review (Chapter 2) provides the context within which agencies have a duty to work towards integrated working. These policy developments also highlight the need to focus on outcomes for disabled children. However, translating the relevance of these outcomes for disabled children can at times prove challenging as they are based on 'normative' development. Progress, achievement and making a positive contribution for a child with a degenerative condition or life limiting illness will look very different to a child developing 'typically'. Beresford et al (2007 p.38) point to the importance of incorporating outcomes for parents also, "as the well

being of children is inextricably linked to parental well being therefore directing resources to supporting parents is a legitimate way of helping children to achieve positive outcomes".

> *"They have a play specialist/nurse for the child, but no emotional support for the parents"*

- **Consistency of what is on offer from pre-birth throughout the age range.**
  Parents are currently experiencing a one front door approach to service design for their children 0-5 and are voicing the need for this to continue in a stream lined manner throughout the age range.

  > *"What has been difficult has been the five plus –I would love the 0-5 service to carry on until my child is 19 – now that would be integration"*

- **A specific focus on fathers needed.**
  One gap highlighted by this research, which future planning in respect of integration may need to focus on is that of targeted support for fathers.

  > *"I think an important issue is how the dads react when all this is going on. My partner is private and didn't really want people to be involved. He's now on board with everything"*

- **The need for ongoing service user (parents/carers, children and young people and siblings) participation** as being fundamental to influencing the strategic direction of organisations. In the absence of this the risk is of replicating service led agendas both at national and local level rather than needs led service development as the 'brave new world' of commissioning and expanding the market comes into play.

  > *"I feel really welcome and an equal partner in everything"*
  >
  > *"My experience is appreciated to improve services, being invited to come and do talks comes from believing that what I have to say is valuable."*

In conclusion, Parents/Carers consider the priority outcomes for them being, the basic offer of emotional support right from the beginning, from an empathetic member of the Children's Workforce, delivered within an Integrated framework wherein all the relevant professionals share information and work together with parents as equal partners. Parents participating in this study see this as the foundation for achieving other

desired outcomes such as their child progressing developmentally, feeling included in society and being able to live an 'ordinary', 'happy' family life. They are able to clearly articulate the areas in which these outcomes are being achieved or worked towards, as they are equally able to identify the gaps and challenges presented by integrated working and its' impact on these outcomes. Parents voiced welcoming every opportunity to participate equally, both in the direct integration of support and interventions for their disabled child and to contributing to ongoing service design. As committed as we are as professionals to shifting the journey from *"segregated to integrated and from fragmented to reformed"* (Children's Workforce Development framework 2008), whilst integration remains narrowly defined as structural/organisational change, failing to recognise the importance of **integrating the very people who use these services into its makeup**, this research would suggest that we remain in danger of omitting the direct link needed with outcomes highlighted in these research findings.

The development and roll out of personalisation (Glendinning et al. 2009) may go some way to addressing a more individualistic system of support enabling different outcomes in different families to be defined and addressed in a much more person-centred, family-centred way. The findings of this research would support the current emphasis on flexibility of service provision and the importance of attitudinal change empowering parents and children/young people to be equal participants in the integration of their support and in the identification of relevant outcomes for their family.

5.4 Limitations of study

The results of this study should be interpreted with caution and with 'transferability' in mind (Lincoln & Guba, 1985, Kennedy, Regehr, Ross Baker & Lingard, 2009). It is important to acknowledge that this data was collected in an urban area with small numbers of families of disabled children up to the age of 7. The fact that the reported themes were common across the range of participants and across the parents who had previously participated in Beresford et. als. study (2007 cited 5.3) would support a level of transferability of the analysis. Nevertheless, it remains to be tested whether the issue of credibility will be relevant across different geographical, demographic and cultural contexts. The validity of the results both internal and external should also be approached with prudence, that is, in relation to their proven cause and effect

relationship and to their generalization. Nonetheless it is important that the reader makes this judgement for themselves.

As stated by Jack & Raturi (2006 p.345), the purpose of the triangulation used has been to *"obtain confirmation of findings through convergence of different perspectives. The point at which the perspectives converge is seen to be reality"*. This study has attempted to reflect the reality of the different perspectives and offers the point at which they converge as both 'new' theory and as a guide for future research (see 5.5). The purposive followed by self-selection sampling used in this study does not claim in any way to be statistically representative of the total population of parents/carers of disabled children. The sampling method was chosen for the need to have information-rich data in order to answer the research aim and objectives (Patton, 2002).

The possible limitations of the interpretive methodology adopted in this study are well documented in critiques of Grounded Theory (Jones and Noble, 2007; Goulding 1999; Walker and Myrick, 2006). Jones and Noble (2007) argue that as a methodology used in management research that it has become far too 'pliant' and *"is in danger of losing its relevance"* p.85. However to those readers who do not need absolute certainties or *"neatly defined categories and objectively measured explanations"* (Goulding 1999 p.869) the reality of the participants in this research will, I am sure, be interpreted as their 'truth' and 'their' contribution to the ever evolving knowledge base.

5.5 Opportunities for further research

Given the research findings and the analysis detailed above, further research is recommended in the following areas following the findings of this study. A probability sampling approach reaching a wider population may be helpful to test the findings further. Research with a longitudinal remit about long-term outcomes would add depth and breadth to the ongoing development of an evidence base in relation to the link between integration of services and improved outcomes. Specific targeted research with fathers or other parent (in same sex couples) of disabled children is needed as is a detailed study with black and minority ethnic families.

5.6 Closing comment

The evidence from this research with regard to the value of seeking the service user perspective has proved humbling to the researcher. The capacity and clarity by which the participants were able to enter into the complexity of seeking to understand what integration and outcomes signifies for them as families was immense and this study has sought to present their voice.

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Appendices

Appendix A:

Dear Parent/Carer,

Please read the attached participant information sheet at your leisure and decide if you would like to take part in this piece of local research.

If you decide that you would like to take part, please sign the attached consent form and return in the stamped addressed envelope provided. I will then contact you by phone or letter to arrange a convenient date to meet.

If you decide not to take part that's absolutely fine and you can just get rid of this letter and information.

Thanks for taking the time to read this information and I look forward to either meeting up with you as part of this research project or as part of my work.

Best wishes for the New Year,

Anne-Marie Carney
(Final year student University of Chester MBA)

Appendix B

Participant Information Sheet

Research Title: "Integrated working and outcomes for disabled children and their families – a service user perspective"

Purpose of the research

The researcher Anne-Marie Carney is undertaking this research project as part of the final year of a Masters in Business Administration (MBA) with the University of Chester. It is a requirement of the course to complete a piece of primary research and the researcher has chosen the above area of study. Lots of people have studied multi-agency working and how it impacts on staff, and processes of organisations but not many people have asked the 'customers' of services what difference it has made to their lives or the lives of their families.

Who is being asked to participate?

Parents and carers of young disabled children.

How will the research be done?

The research will be done in two main ways, firstly meeting with parents/carers individually and secondly inviting them to take part in a stakeholder group. If you agree to meet with the researcher individually that will be for an hour maximum and will be at your convenience. If you agree to take part in the group discussion that will be for two hours maximum and again will be at the most convenient time and place for the group of parents/carers in question. Both the interviews and group discussions will take place between January and April of this year.

Important information for you if you decide to take part

Taking part in this research is absolutely voluntary and you will of course have the right to decline to answer any questions and/or to withdraw from the research at any time. You will have the right to request not to be recorded if a voice recorder is used and if your responses are recorded in written form you will have the right to check and verify that it is a fair record of what you said in the interview/discussion. All your data and responses will be handled both anonymously and confidentially throughout the research process.

Data

Data collected will be analysed by Anne-Marie Carney (the researcher) only and will be securely stored by her until September 2009 and then safely destroyed. A summary of the research findings will be disseminated to all participants who will also have access to the full research dissertation if desired.

Contact details of researcher

If you have any queries about this information or comments please feel free to contact:

Name: Anne-Marie Carney

Address: (offered)

Telephone: (offered)

E-mail: (offered)

Appendix C

Consent Form

Title of research

"Integrated working and outcomes for disabled children and their families – a service user perspective"

Name and position of researcher

Anne-Marie Carney, final year student, University of Chester (MBA)

Please initial box

I confirm that I have read and understood the
information sheet for the above study and have
had the opportunity to ask questions

I understand that my participation is voluntary
and that I am free to withdraw at any time without
giving a reason

I am aware that my confidentiality will be maintained
throughout the research process

I agree to take part in the above study

Name of Participant   **Date**   **Signature**

Name of researcher   **Date**   **Signature**

Anne-Marie Carney

Appendix D

MBA BUM716
Chester University

Open ended themes for interviews and exploration in stakeholder groups

Integrated working and outcomes for disabled children and their families – a service user perspective

1) How did you first find out about services?

2) What experience of public services did you have prior to being in touch with a multi-agency service

3) Describe what you thought would be on offer/who/how etc.

4) Describe what has been on offer?
    - describe a good experience
    - describe areas that have been problematic/difficult

5) What difference has it made – please be specific and tell me if you can about the detail

6) The research says that there isn't much clear evidence yet of joining services together making a difference for families – what do you think?

7) What is it, if anything, about services/professionals working together that makes a difference to
    - you
    - your child/children
    - your family

8) If you were in charge what would you be doing differently for disabled children and their families?

9) The government has developed a series of outcomes (things they think should happen for children) – what things have improved (outcomes) for your child during your time with a 'joined up' service?