Disabled Children and Young People who are Looked After:

A Literature Review.

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Introduction

In the UK, the traditional practice of routinely placing disabled children in institutional care, segregated from community life, and separated from family life, has ended. The majority of disabled children and young people now live with their birth families, many of who draw on the support of health and social services when required.

However, it is still the case that the numbers of disabled children who are looked after away from home for some or all of the time exceeds that of their non-disabled peers. Furthermore, disabled children who successfully achieve permanence in substitute families falls short of the rates recorded for non-disabled children. This is despite major social change and comparable moves in research and policy agendas which mean that disabled children are no longer considered ‘unadoptable’ and that the underpinning philosophy of permanency is considered to be applicable to all looked after children.

Despite these concerns, and with the exception of a few important local studies, there remains a noticeable lack of research knowledge regarding the numbers, characteristics and experiences of this vulnerable group of children looked after by social services.

It is against this background that OFMDFM have funded a research team, based at Queens’ University Belfast, to examine the population of disabled children in care in Northern Ireland, profiling their numbers, characteristics and experiences.

Overall Research Objectives

- To examine the characteristics of disabled children young people living in public care.
- To identify the key factors that lead to disabled children and young people becoming looked after.

- To examine the organisational arrangements and procedures within Trusts impacting on services for disabled children and young people who are looked after.

- To investigate the experiences of disabled children and young people who are looked after, including placement stability, services accessed and extent of family contact.

- To examine how the particular needs of disabled children and young people are met, or could be met, within public care and in a multi-agency context.

- To identify any examples of best practice in meeting the needs of disabled children and young people who are looked after.

- To establish baseline data on the population of disabled children living in care to inform further research into their post-care pathways and outcomes in young adult life.

The Literature Review

This first executive summary is solely concerned with reporting the findings emerging from an extensive review of literature that has focused on existing empirical and theoretical published work relating to disabled children and young people who are looked after.

The literature review has sought to address the following questions:

- What are the characteristics of disabled children and young people who are looked after?

- What are the key factors and pathways that lead to children becoming looked after?

- What are the needs of these children and their families and how they can be best met?

- What are the views and experiences of looked after, disabled children and their families?

- Are there any trends or differences (e.g. across impairment type, age, placement type, jurisdiction) in the international literature?

- What are the boundaries between being a looked after child and the extensive use of short break services; are their factors / characteristics particular to this group?

Definitional Terms

The literature review, in both the search of relevant databases and the report of the findings, has operationalized the following definitional terms.

- **A child or young person is looked after** if s/he is in public care due to a court order or is being provided with accommodation voluntarily for more than 24 hours (Children (Northern Ireland) Order 1995).

- These children and young people can be accommodated in group homes, foster care, kinship care, residential schools and/or hospital facilities. Adopted children, subject of an adoption order, are not included in this definition as, once adopted, they cease to be looked after and all parental duties and responsibilities are conferred on the adoptive parent.

- Additionally, in Northern Ireland, children and young people who are accommodated in a short break service for a period of more than 24 hours are also currently defined as looked after. No single short break placement should exceed four weeks and the total time spent by a child in short breaks should not exceed 90 days in one year.

- Some children may be close to this number of days and may, therefore, be affected by some of the issues faced by looked after children and young people and their families by contrast with those who use short breaks for relatively fewer days. Therefore, efforts have been made to include literature on this discrete group of disabled children and young people who use short breaks for lengthy periods of time if they are identifiable.

- **Disability** is clearly defined in the most recent UN Convention on the Rights of Persons with Disabilities (United Nations, 2006:4): “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various

> barriers may hinder their full and effective participation in society on an equal basis with others." This definition is in accordance with Section 75 of the Northern Ireland Act (1998) and the principles of the social model of disability by recognising both the experience of impairment and the impact of disabling barriers in society on equality of opportunity.

This review, therefore, includes literature on looked after children who are described as having cognitive, physical or sensory disability and/or mental health related needs or diagnoses. The review search strategy will also include terms for more common specific conditions that may not fall under broad generic headings (for example, autism).

Whilst these definitions form the boundaries of the present review, it is important to point out that many of the papers included in this review have a narrower focus. They either report on a particular impairment group (for example, intellectually disabled children and young people) or respond to research questions about a specific aspect of being looked after (such as, placement type or questions of prevalence).

Methods

A full report of the methods used in this review is provided in Appendix 1 of the full report. In total 58 empirical and theoretical papers were included in the review and a further 72 provided contextual background.

Findings

The findings are organised into seven main sections, which constitute the key themes drawn from this body of literature.

The Prevalence of Disability in the Looked After Child Population

Disabled children are reported to be over-represented in the looked after child population. However, in different jurisdictions and service contexts various definitions are applied. This results in a lack of clarity and subsequent variation regarding who is included in a definition of disability. For example, some include children who solely present with emotional and behaviour challenges under the heading of disability, which may inflate numbers.

Difficulties in establishing prevalence are compounded by the existence of multiple databases (across health, education and social care) which lack a common interface using individual child tracking options. Despite these definitional challenges, it is apparent that disabled children form a significant portion of the looked after child population.

Although there is a lack of research knowledge that is disability type specific in its focus, that which does exist indicates that there is a higher prevalence of males compared to females and that in terms of impairment type, intellectual disabilities are more commonly represented. Furthermore, the numbers of children with on going mental health difficulties are consistently reported as extremely high in the looked after child population. Trajectories of causality are unknown, therefore, it is unclear whether vulnerability to mental health difficulties is precipitated by experiences prior to becoming looked after, or whether the experience of being a looked after child engenders mental health difficulties.

Pathways to Disabled Children Becoming Looked After

As with the general child population, typically a series of complex and interwoven factors lead to disabled children and young people becoming looked after. From these it is difficult to extrapolate single factors, which may combine around family stress, the capacity of families to meet the care needs of their disabled child, neglect or abuse and in some instances parental illness, which may lead to the child becoming looked after, either through the provision of short breaks or domiciliary support, or in an out-of-home placement. The literature reports that disabled children are much more likely to be voluntarily accommodated rather than subject to a care order.

The research also indicates that disabled children experience a heightened vulnerability to abuse and a higher incidence of abuse is reported amongst this population. These factors lead to concerns that child protection procedures may not be sufficiently responsive to the needs of disabled looked after children and indeed that disabled looked after children may be treated differently to their non-disabled peers due to their voluntarily accommodated status rather than being subject to a care order.

There is also evidence in the literature that insufficient family support combined with (and contributing to) parental stress related to caring for disabled children who have multiple and/or complex needs contributes to families reaching a decision to seek an out-of-home placement for their child.

Placement Options for Disabled Looked After Children

An equivalent range of placement options available to the general child looked after population is open to disabled children who are looked after. However, disabled children are more likely to live in congregate settings than non-disabled children and are less likely to be fostered.

In relation to fostering, the literature reports on the feasibility of successful fostering arrangements for disabled children, which are enhanced through structured preparations and on going support.

Kinship care is an increasingly popular option for out-of-home placement for looked after children and is reported to engender potentially improved outcomes for children. However, the present authors were unable to report on kinship care in relation to disabled children having not identified any studies with this focus.

Short break placements are a popular option for disabled children and young people and their families. These placements constitute time spent away from parental care either in a domiciliary arrangement, where children are looked after in their own home and receive family support services in the home, or a residential setting. The literature suggests that the availability of short break provision is insufficient to meet the demand for such services.

Families prefer small-scale, family type short break settings rather than larger congregate or hospital facilities. However, choice is often limited to what is available. Factors such as family socio-economic status are shown to influence the type of short break used by families, with those from more affluent backgrounds accessing smaller family units and those economically challenged more likely to have their child placed in hospital facilities.

It is important to note a change of purpose in short break provision, with an emphasis now on benefits for both the disabled child and their parents, rather than simply providing respite for parents from the demands of their caring role. This is an important development in acknowledging the child’s needs as well as that of their parents.

Permanence for Disabled Looked After Children

Stability in the place where children live and the people with whom they reside is thought to enhance outcomes for looked after children. Stability can be achieved through the return of the child to their birth family after a period of being looked after, or by placement in a permanent substitute family through adoption or in some instances long term fostering.

Amongst disabled children there is a reported reduced likelihood that they will return to their birth family, and for those who do this is more likely to happen after a longer period of being looked after. Moreover, disabled children are less likely to be adopted than their non-disabled peers and are more likely to achieve permanence with foster parents. However, the latter arrangement is imbued with a sense of instability because of the lack of formal parental status accorded to foster parents, and additionally since the fostering arrangement may end when the child reaches the age of 18.

Despite the legal insecurities associated with long term foster care, the literature shows that disabled children can thrive in fostering environments, whilst also emphasising the importance of maintaining the relationship with the looked after young person’s birth family, where appropriate.

Outcomes for Disabled Looked After Children

The literature indicates that broadly, looked after children experience negative trajectories in relation to health and educational outcomes. However, there is limited empirical research in relation to the outcomes of disabled children who are looked after.

Existing work suggests that educational as well as behavioural and emotional outcomes are likely to have a more negative trajectory for disabled looked after children than the already poor outcomes experienced by looked after children generally. However, as the available research is specific to a particular residential facility and regional location, wider generalisations are not possible. The lack of outcome focused research is an important gap in the evidence in relation to disabled looked after children.

Disabled Young People Leaving Care

There is limited extant research literature on the experiences of disabled care leavers. There is a body of literature, which reports on poor outcomes for both care leavers and disabled young people generally in their transitions to adult life.

It is known that there is a high incidence of mental health difficulties amongst care leavers, however whether this is attributable to pre-existing emotional needs (prior to admission to care or as a result of becoming a looked after child) or to the new challenges of leaving care and moving towards adult life is unclear.

Investigation of the emotional and mental health needs of disabled care leavers is not clearly addressed in the existing literature and represents an important gap in knowledge. Moreover, we know little about how the experiences of disabled care leavers compare to that of non-disabled care leavers, and the views of disabled care leavers themselves are almost absent from the literature.

Disabled Looked After Children's Perspectives

A combination of changes in policy and practice contexts, as well as methodological developments have encouraged the inclusion of disabled children and young people in research. However, the views of looked after disabled children and young people are not routinely sought in relation to matters that affect them. Nevertheless, it is clear that research evidence can be enhanced through the inclusion of the perspectives of disabled children and young people who can provide unique insight into their experiences and their perceived needs.

It is apparent in evidence gathered in the present review, that engagement with disabled looked after children is more common in relation to those who have mental health needs although children with a range of impairments have been included in a small number of previous studies. It is also clear that younger children are less likely to be consulted than older children and young people.

Challenges of consulting with disabled children and young people have prompted substantial methodological and practice developments. Additionally, there is a strong lobby from disabled young people and their advocates towards meaningful inclusion of the voice of disabled children and young people in matters that affect them.

Conclusion

The existing evidence base has provided some insight into matters of interest to the review, but has also highlighted areas that require the attention of future research.

The literature reports on difficulties in establishing the prevalence of disability in the looked after child population. Accurate, clear definitions of disability and agreement across jurisdictions and across services may enable more rigorous empirical investigation of the profile of this population.

Whilst it is difficult to estimate the prevalence of disabled looked after children, there are some indicators as to the population characteristics. A high proportion of the looked after child population is reported to experience mental health difficulties. In addition, it is reported that more disabled boys than girls are looked after, and that they tend to enter care at an older age than their non-disabled peers.

In terms of impairment type, those with intellectual disabilities form a greater proportion of the population than other types of impairment. There is no research evidence, which specifically discusses children or young people with physical or sensory impairments, although they are included in studies that take a generic disability focus.

With regard to disabled children becoming looked after, they are likely to experience the same range of pre-care experiences leading to decisions to them becoming looked after as their non-disabled peers. However, the literature highlights two apparently contradictory factors: firstly, disabled children are at greater risk of neglect, abuse and violence than non-disabled children; and secondly, that looked after disabled children are much more likely to be voluntarily accommodated than subject to a care order.

In term of the needs of looked after disabled children their families, families require increased practical and emotional family support. Sufficient short breaks, both within the home and in a residential service may, it is contended, enable families to continue to provide the main stay of care for their disabled child at home, and dissipate the need for longer-term out-of-home care to be sought.

Additionally, there are indications in the literature that child outcomes require attention in relation to education as well as their emotional well-being. There is a high incidence of mental health difficulties in this population and a clear need for further support and intervention for these vulnerable young people.

With regard to the views of disabled children and young people, the research highlights that whilst birth or substitute parents were respondents in research, there were limited examples of research incorporating the voice of disabled children or young people.

Implications for Further Research

The review of literature has highlighted particular gaps in knowledge and identified the following priority areas for further empirical research:

- Prevalence studies of disabled children and young people within the looked after population based on clear and agreed definitions.

- Clinical investigations of causality regarding looked after children and young people with mental health needs to enable the continued development of useful service responses.

- Exploratory studies to assess whether disabled children are being treated differently to non-disabled children within the child protection system and in relation to their entry into care.

- Investigation into the types of family support that enable families to provide ongoing care for their disabled child and prevent admission to public care.

- Examination of pathways and outcomes for disabled, looked after children including physical and emotional health and education.

- Examination of disabled care leavers' needs, experiences, pathways and outcomes with particular attention to variations across impairment categories and type and number of placements.

- Participatory studies incorporating the views and perspectives of disabled children and young people who are looked after.

Implications for Policy Development

The findings of the literature review also identify key issues of relevance to policy. Given the lack of research in some core areas, the following are tentative themes that could inform future policy development:

- The development of agreed definitions of disability across differing service sectors and the development of an integrated database or shared interfaces between databases with the option for individual child tracking. Combined with quality assured recording, an integrated database would enable adequate population-based and outcomes-focused planning both in relation to current and prospective service need.

- The development of additional practical and emotional support for families, including increased short break provision, to support parents of children ‘on the edge’ of care to maintain their children within the family home rather than seek a permanent out-of-home placement.

- The development of foster care policy to extend and improve the range of legal options available to foster carers to strengthen their legal responsibility in respect of the disabled children they look after.

- The development of policy guidance on person-centred transition planning for disabled care leavers with clearly defined professional roles and multi-agency responsibilities from child through to adult services is essential to ensure the varied and often complex transition needs of disabled care leavers are met.

- The development of policy, practice and training regarding the inclusion of disabled children and young people who are looked after in consultation on matters which affect them. In order to avoid tokenistic participation, such inclusion should lead to clear outcomes that inform the continued development of policy and practice initiatives.

Introduction

Historically, the lives of disabled children have been characterised by segregation, separation from family life and institutionalisation. Oswin (1973, 1984) drew attention to the impoverished experiences of disabled children and young people placed in long-stay institutions, away from their families, often from a very young age. Through the prism of modern day expectations of care provision, that available in the institutions, where many disabled children remained throughout their adult lives, was very poor. More recently there has been a vast change in both in policy and practice with the introduction of community care, the development of the social model of disability and rights-based legislation (Shakespeare & Watson, 1998). A belief that disabled children who cannot remain with their birth families for a variety of reasons have the right to family life has flourished since the mid-1980's and is now strongly established (Burns, 2009). Children who were previously thought to be 'unadoptable' are now routinely included in the 'permanency agenda', which is the foundational narrative for the care of all children who can no longer live with their family of origin (Baker, 2007).

Social and demographic changes during the 1970's and 80's and some seminal research studies had a recognised impact on the lives of disabled children who could not remain with their birth families (Baker, 2007). Until about 25 years ago the idea that disabled children could be placed with a permanent substitute family was unheard of with many being labelled as unfit for adoption (Robinson & Stalker, 1999). Demographic changes brought about by the legalisation of abortion in Great Britain, a decrease in the numbers of women of child bearing age, greater acceptance of single parenthood and a growth in the use of effective contraception, meant that there were fewer babies freed for adoption and, as Philips (1998) noted, demand outgrew supply. At the same time, research published by Rowe & Lambert (1973) reported that there were thousands of children adrift in the care system who had little prospect of returning to their birth families or achieving permanency elsewhere. Innovative and specialist projects demonstrated that children with severe impairments could successfully live in permanent substitute families (Argent, 1984; Sawbridge, 1975), whilst Macaskill's (1985) important study reported on the progress made by intellectually disabled children when placed in a substitute family setting. However, barriers to the placement of disabled children with foster or adoptive families remained, not least through what is described by Robinson & Stalker (1999) as negative professional attitudes towards disabled children; quoting Macaskill they state: *"Professionals labeled handicapped children as different to normal children and tended to set them apart from* *others by emphasizing their weaknesses, difficulties and abnormalities" [sic]. (1985:95).*

In recent decades, there has been major progress in the research agenda and unprecedented developments in UK policy relating to disabled children. Whilst it is not within the remit of this literature review to discuss the policy context in detail, there are key milestones which are notable. Global treaties designed to protect the rights of children (UNCRC, 1989) and disabled people (UNCRPD, 2006) detailed minimum standards, goals and expectations of signatory governments in their responsibilities to disabled children and adults. A raft of Northern Irish and UK wide policy developments have also driven forward aspirations for disabled children and impacted on the practice expectations and responsibilities. In the Northern Irish policy landscape, items relating to disabled children are subsumed within the broad remit of general child or disability policy such as, the ten year strategy for children and young people (OFMDFM, 2006) and the Bamford Review (DHSSPSNI, 2006a, b). Key Departmental policy drivers such as Care matters (2007) and Families Matter (2009) and the recent *Transforming Your Care report* (2011) all impact on issues relevant to disabled children who are looked after, however, the range of issues affecting this disadvantaged group are not addressed in a single overarching policy document. Nevertheless, we see a move in policy which reflects the altered social agenda and the growing recognition of the complex, interwoven and previously overlooked needs of disabled looked after children.

A recent World Health Organisation Report (Emerson et al., 2012) identified priorities for action and research related to intellectually disabled people, many of which resonate with issues relevant to this review of literature on disabled children who are looked after. For example, Emerson et al. (2012) highlight concerns regarding the vulnerability to abuse, neglect and violence experienced by intellectually disabled children and the potential for such negative experiences in childhood to impact on adult development. The authors recommend that services and interventions should be delivered on the basis of assessed need, contending that bespoke support promotes better outcomes. Preventive health care directed at both the mental and physical health needs of this population is also emphasised to address persistent health inequalities amongst intellectually disabled people (Emerson & Hatton, 2007b). This is particularly relevant to disabled children who are looked after as they are likely to experience additional vulnerability to poor health. As outcomes are improved for individuals who grow up in community rather than institutional settings, the authors argue that every effort should be made for intellectually disabled children to grow up in a family environment, if not with their birth family then a substitute foster or adoptive family.

In the UK the majority of disabled children and young people will now grow up with their families at home, however, there are a substantial number who will be looked after out of their home all or some of the time. This review aims to report on the research literature that addresses the range of issues affecting this vulnerable group of children and young people. The review is based on a review of 58 empirical and theoretical papers on this multi-faceted topic and a further 72 papers which provided contextual background.

The review covers the following areas: numbers of disabled children and young people who are looked after and the challenges of measuring prevalence in this heterogeneous group; their characteristics; pathways to disabled children and young people becoming looked after; placement types and permanency; issues faced by disabled young people on leaving care; and the perspectives of parents and disabled children and young people. Literature relating to international perspectives is incorporated, where available, throughout these thematic sections. In so doing the review aims to answer the questions posed below. The review ends with an overall discussion bringing together the key themes from the literature identified. A detailed description of the methods used in the review is available in Appendix 1 and a summary of the empirical papers reviewed is provided in evidence tables in Appendix 2.

1.1 Aims of the Review

The overarching aim of this review is to map existing empirical and theoretical published work focused on disabled children and young people who are looked after.

A number of key questions are of particular relevance:

1) What are the characteristics of disabled children and young people who are looked after?
2) What are the key factors and pathways that lead to children becoming looked after?
3) What does the literature tell us about the needs of these children and their families and how they can be best met?

4) What does the literature tell us about the views and experiences of looked after, disabled children and their families?
5) Are there any trends or differences (e.g. across impairment type/severity, age, placement type, culture, jurisdiction) in the international literature?
6) What are the boundaries between being a looked after child and the extensive (e.g. 28 days+) use of short break services; are their factors / characteristics particular to this group?

1.2 Defining the Parameters of the Review

This section outlines the key concepts and terminology that underpin both the search of the relevant literature and the report of the subsequent findings.

A child or young person is looked after if s/he is in public care due to a court order or is being provided with accommodation voluntarily for more than 24 hours. These children and young people are/can be accommodated in group homes, foster care, kinship care, residential schools and/or hospital facilities. Adopted children, subject of an adoption order, are not included in this definition as, once adopted, they cease to be looked after and all parental duties and responsibilities are conferred on the adoptive parent.

Additionally, in Northern Ireland children and young people who are accommodated in a short break facility/host family for a period of more than 24 hours are also currently defined as looked after (although there are plans for a policy change on this issue). No single short break placement should exceed four weeks and the total time spent by a child in short breaks should not exceed 90 days in one year. Some children may be close to this number of days and may therefore be affected by some of the issues faced by looked after children and young people and their families by contrast with those who use short breaks for relatively fewer days. Therefore, efforts will be made to include literature on this discrete group who use short breaks for 28+ days if they are identifiable.

Disability is clearly defined in the most recent UN Convention on the Rights of Persons with Disabilities (United Nations, 2006:4): "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." This definition is in accordance with Section 75 of the Northern Ireland Act (1998) and the principles of the social model of disability by recognising both the experience of impairment and the impact of disabling barriers in society on equality of opportunity.

This review, therefore, includes literature on looked after children who are described as having cognitive, physical or sensory disability and/or mental health related needs or diagnoses. As well as generic terminology the review search strategy will include terms to cover the more common specific conditions that may fall under broad generic headings (for example, autism).

Whilst these definitions form the boundaries of the present review, it is important to point out that many of the papers included in this review have a narrower focus. They either report on a particular grouping of disability (for example, intellectually disabled children and young people) or respond to research questions about a particular aspect of being looked after such as placement type, or questions of prevalence.

A full report of the methods used in this review is provided in Appendix 1.

2. The Prevalence of Disability in the Looked After Population

Key messages

- Disabled children are reported to be over-represented in the looked after population.

- There is a very high reported prevalence of children and young people with mental health difficulties in the looked after population.

- Significant challenges exist to accurately establishing prevalence figures because of the variations in definitions of disability and differing service contexts across different jurisdictions.

- Typically there will be higher prevalence of males compared to females. In terms of disability type, typically those with intellectual disabilities are more commonly represented than other disabilities.

- It is important to establish a clear picture of the characteristics of disabled looked after young people, for instance numbers with autism, with physical disabilities, or those who are technologically dependent, so as to respond in terms of current and future service provision.

The definition of disability used in the present study (described above) is not generally reflected in the research literature. Firstly, looked after children with mental health difficulties are typically not described as disabled. Therefore prevalence figures for children with mental health difficulties will be described in a separate sub section below. Secondly, the research literature relating to prevalence of disability commonly aggregates impairment types, therefore those with physical, sensory and intellectual impairments as well as discrete diagnosis such as autism of Down's syndrome are counted together. This means that discrete prevalence figures according to impairment type are difficult to access. However, some studies do offer a description of the characteristics of looked after disabled children and these will be reported below to show relative figures where they are available. There are, of course, instances of co-morbidity of mental health difficulty and impairments and this is reported where available.

Research evidence and statistics about children in care indicate that disabled children and young people are over-represented in the child protection and public care system (Gordon et al., 2000; Braddock et al., 2001; Read & Harrison, 2002; Trout et al., 2009; Stalker & McArthur, 2010; Lightfoot et al., 2011). Whole population statistics show that approximately 6% of the population of children under 16 years in Northern Ireland are disabled (NISRA, 2007: 16), however, figures produced by the Department of Health, Social Services and Public Safety state that 14% of the children and young people in public care in Northern Ireland are disabled (DHSSPSNI, 2012:1).

In 2010, of the looked after children of school age, 24% had a statement of Special Educational Need (SEN) compared with 4% of the general school population in Northern Ireland (DHSSPSNI, 2012:10). A higher proportion of boys (16%) than girls (12%) were disabled and most SEN statements related to learning or severe learning disability (55%) and behavioural problems (13%) (DHSSPSNI, 2012:11). Statistical data also revealed that 19% of care leavers aged 19 are disabled; of these, over two thirds (71%) were learning disabled (DHSSPSNI, 2011: 6). This over-representation of disabled children and young people is also evidenced across the UK and in other countries (Sullivan & Knutson, 2000; Gordon et al., 2000). For example, in a UK study by Schofield et al. (2007) it was found that of children who had been looked after for 4 years or more, 34% of the sample were disabled or had an on-going health condition.

Whilst the literature is clear and consistent on the point that disabled children and young people are over-represented in the looked after population, there is wide variation in the numbers cited (Baker 2007). McConkey et al. (2012) report that whilst 4.62/1000 non-disabled children were looked after within the Republic of Ireland in 2008, 51.86/1000 intellectually disabled children and young people were looked after in the same jurisdiction in 2009. Similarly, Cousins (2006:6) in the Good Practice Guide *'Every Child is Special: Placing Disabled Children for Permanence'* states that:

- disabled children are nine times more likely to become looked after than non-disabled children;
- about a quarter of all looked after children are disabled;

- approximately 40% of children waiting for a new permanent family have an impairment or some form of special need; and
- intellectually disabled children are a group least likely to find permanent families.

These findings are also reflected in the English guidance regarding the '*Assessing Children and Families in Need*' (DoH, 2000) where Marchant and Jones (2000:75) indicate that disabled children are more likely to be in contact with social services and the subject of multiple assessments because they: are over-represented in groups already facing social disadvantage (who are more likely to have contact with social services); are more likely to have experiences that trigger assessment (including experiences of abuse, exclusion, social exclusion); and have other associated needs (for example, in the area of education).

2.1 Difficulties in Estimating the Prevalence of Disabled Looked After Children

Gordon et al. (2000) highlight the variation in the reported number of disabled looked after children and they suggest that this is due to uncertainty about definitions and measurements of disability. The authors state that this leads to a potential inflation of numbers as children with 'behavioural' difficulties are at times included in the definition of disability. Burns (2009) go on to highlight the particular problems with definitions in that some studies include children and young people who solely have emotional and behavioural problems under the definition of disability and some include children with 'special educational needs' whilst others do not. It is uncommon for children who solely have mental health difficulties to be counted in the disabled looked after population, however, those with intellectual, sensory or physical impairments or indeed discrete diagnosis such as autism could have a co-morbid mental health diagnosis.

The varying interpretations of disability present challenges in data synthesis as studies use differing points of departure. The exact numbers of disabled looked after children are, therefore, difficult to capture with the conflation of definitions and lack of available data (DfES, 2004). The lack of accurate data on the population of disabled looked after children detrimentally impacts on the development of services and placements to effectively meet the needs of disabled children and young people. Several authors have called for an improvement in available statistics on the population of disabled looked after children to enable more effective service planning (Baker, 2011; Burns, 2009).

2.2 Characteristics of Disabled Looked After Children

McConkey et al. (2004a) report on a study of the characteristics of a group of 108 disabled children with an average age of 15 years (range 0-20) who were looked after (defined as spending 90+ days away from home in a one year period), in one geographical area of Northern Ireland. Data were gathered via a structured interview with the each of the young people's key workers (identified by the Trust manager) and a standard pro-forma was completed to ensure consistency in data collected. Of the sample group, 59% (n=64) were male and 41% (n=44) were female, showing an over-representation of males who would typically make up approximately 51% of the general child population. The proportion of males was higher in the younger age group (1-14) at 64%, dropping to 56% in the 15-20 year age group. In terms of the disability, 51% (n=55) were reported as having severe intellectual disabilities and 29% (n=31) had profound multiple disabilities; 10% (n=11) had mild or moderate intellectual disabilities and a further 10% (n=11) had physical disabilities. In addition almost half of the 108 young people were recorded as having challenging behaviour, and a third experiencing severe communication difficulties, one-fifth of the sample was reported to have autism or autistic spectrum disorder. Fifteen of the young people were reported to be technologically dependent and three were described as requiring a highly supervised environment because of their behaviour, although information as to whether this was linked to mental health challenges is not available.

Describing the characteristics of disabled looked after children is valuable as it can be used to inform current service provision for these young people, as well as projected future provision for disabled children who live some or all of the time away from their birth families, and further the provision of services for these young people in their transition to adult services. However, there is little evidence that this type of information is routinely collected. Empirical studies do collect particular characteristics of their sample population, although this is commonly to address specific research questions rather than as an end in itself. Nonetheless, characteristics of disabled looked after children can to some extent be extrapolated from these studies. For instance a recurring feature of this population is that boys make up a greater proportion of the disabled looked after population than girls, disabled children tend to be older than non-disabled looked after children and amongst those who are disabled there is a higher proportion of intellectually disabled children and children with complex care needs (e.g. Nankervis et al., 2011a; Trout el al., 2009; Taggart et al., 2007; Rosenberg & Robinson, 2004; Laan et al., 2001; Avery, 2000). However, there is little information about impairment type or the presence of multiple impairments.

2.3 Prevalence of Mental Health Difficulties for Looked After Children

The literature on mental health prevalence rates for children and young people who are looked after is extensive, spans the age range of children and focuses on assessed mental health need on admission to care, their mental health needs when living in care and their needs when leaving care.

In terms of children coming into/at the point of entry into care, a study by Sempik et al. (2008:230) focusing on young children identified high levels of emotional and behavioural disturbance compared with the population as a whole. These findings have been confirmed through a more recent study by Hillen et al. (2012) that found pre-school children looked after to be a high-risk group for mental health and developmental disorders.

In relation to children and young people already looked after, Meltzer et al. have carried out the most well known UK surveys of mental health need (2000; 2003; 2004; 2004a). For example, Meltzer et al. (2004) carried out a UK national prevalence study of looked after children. Data were gathered by interview with foster parents, carers and residential care workers and used the ICD-10 classification, a standard manual classifying tool for mental illness and behavioural disorders (WHO, 2001). The sample included 1039 young people aged between 11-17 years, who resided in a range of looked after settings in 134 English local authorities. Findings reported 45% of these children to have a mental disorder with 37% demonstrating clinically significant conduct disorders, 12 % with emotional anxiety or depression and a further 7% scored to be hyperactive. An earlier study of prevalence of mental health disorders amongst a sample of 10,500 children and young people living in private households produced a rate of 8% (Meltzer et al., 2000).

The studies by Meltzer et al. were conducted in the UK and similar large-scale prevalence figures are not available for Northern Ireland, however, three papers respond to questions of prevalence in the Northern Irish context. Teggart & Menary (2005) investigated the rates of mental health difficulties among 110 looked after children in one geographical area. The study used a cohort design and collected data through questionnaires completed by carers and teachers of young people aged 4-16 years. Intellectually disabled young people were excluded from the overall sample, as they were the responsibility of disability services rather than CAMHS, and this brought the sample size to 64 young people. The Strengths and Difficulties Questionnaire[1] (SDQ) was used to assess mental health need. Teggart & Menary (2005) report that more than 60% of the 4-11 age group were assessed as potentially having a diagnosable psychiatric disorder, in the older age group the likelihood of a diagnosable disorder was higher with almost 2/3 of the sample group. The authors report on limitations of the study being based on a small sample size in a relatively small geographical area. The findings are strengthened however, by their resonance with larger scale studies reported above.

Cousins et al. (2010) again reporting on empirical work conducted in Northern Ireland and on a purposive sample of 165 young people aged 10-15 years living in residential and foster care, found that 89 (53.9%) of young people scored in the ‘abnormal’ range of the SDQ, and a further 27 (16.4%) were found to score in the ‘borderline’ range of this instrument. This would indicate that over 2/3 of the total sample of young people in this study were found to be susceptible to mental health difficulties. Interviews with social workers also carried out as part of this study found that they considered 92% of young people to be in good overall health, which they stated was as good as or better than other young people their age. It is surmised that the reasons for these ambiguous findings are rooted in expectations that young people who are looked after will demonstrate high-risk behaviour which may not be read as indicative of mental health difficulties.

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[1] The SDQ is a commonly used standardised measure consisting of 25 items, which refer to emotional problems, conduct problems, hyperactivity/inattention, peer relationships and pro-social behaviour. Scores can be classified into ‘normal’, ‘borderline’ and ‘abnormal’. Goodman et al. (2000) state that 10% of a typical population would rate as abnormal, 10% as borderline and 80% as normal.

The final study that reports on prevalence in the Northern Irish context is published by Taggart et al. (2007). Again the SDQ was used to estimate mental health difficulties in this population and findings reported are based on a sample of 35 intellectually disabled young people who were looked after at the time of the study compared with 125 non-disabled looked after young people. Participants were aged between 10-15 years, amongst those reported as having an intellectual disability 21 resided in residential care, 13 in foster care and 3 in a kinship care arrangement. Results from the standardised measure (SDQ) were that 77% of intellectually disabled young people were found to score within the abnormal/borderline ranges compared with 49% of their non-disabled peers; it is notable that the score reported for non-disabled children is in itself is a very high figure. It is well established that intellectually disabled people are more vulnerable to developing mental ill health than people in the general population (Emerson, 2003, 2005; Dekker et al., 2002), and this higher potential prevalence in intellectually disabled young people who are looked after indicates a need for greater awareness of the vulnerability of this multiply disadvantaged group.

The exceptionally high rates of mental health difficulties amongst looked after children reported by Meltzer, and mirrored in the Northern Ireland context, are also evident in the international literature. International studies report a similar high prevalence, which are close to clinic-referred populations (Golding, 2012; Tarren-Sweeney, 2008). For example, in Denmark, 20% of looked after children are reported to have a psychiatric diagnosis and up to 48% rate as ‘abnormal’ on the Strengths and Difficulties Questionnaire (SDQ) (Egelund & Lausten, 2009). Similarly, Milburn et al.’s (2008) Australian study reported that mental health problems are four times as likely in the looked after child population than in the general population. In addition, mental health prevalence studies of the looked after population in the US have identified rates of up to 20% with higher rates reported where developmental delay is also present (Pecora et al., 2009).

3. Pathways to Disabled Children Becoming Looked After

Key messages

- Factors that lead to a disabled child becoming looked after are complex, inter-woven and difficult to extrapolate.
- Factors include family stress, abuse or neglect, parental illness.
- The literature states that disabled looked after children are more likely to be voluntarily accommodated than subject to a care order.
- However, it is reported that disabled children experience a heightened vulnerability to abuse and that there is a high incidence of abuse experienced by this population.
- There is a concern that child protection procedures may not be sufficiently responsive to the needs of disabled looked after children and indeed that disabled children may be treated differently to non-disabled looked after children due to their voluntarily accommodated status rather than subject to a care order.
- Insufficient 'in-home' support combined with parental stress related to caring for children with multiple and complex needs may lead families to make a decision to seek an out-of-home placement for their child.

Like other looked after children, disabled children and young people enter the public care system for a variety of reasons (Baker, 2007). Contributory factors are complex, interrelated and difficult to extrapolate. A combination of the type of impairment, family background, lack of support from within the extended family and community, lack of access to services and social structural issues including vulnerability to abuse, poverty, isolation, exclusion are all likely to have an effect. In this review, evidence on each of these or the combination of these factors is reviewed.

McConkey et al. (2004a) highlighted a range of family issues that impacted on the pathways to being looked after in their sample of 108 disabled children. These included: parents being stressed and not coping (33%); children being neglected or suspected abuse (18%); that the child was living with a single parent (15%); parental physical illness (14%) or mental illness

(12%); and finally evidence of parental drug/alcohol abuse (8%). Eight of the parents in this sample were reported to be intellectually disabled, which may have been judged as a factor in their ability to parent their disabled child.

While the factors outlined above are common to all children and young people who are looked after, McConkey et al. (2004a) did also draw attention to the fact that a Care Order was in place for only 8/108 of the families (8%), reflecting the low numbers subject to legal orders rather than accommodated under voluntary arrangement. This finding is supported by Cousins (2006) who states that a far greater percentage of disabled children who are looked after are done so through a voluntary arrangements rather than in respect of legal care orders. This raises questions as to the particular factors that lead to out-of-home placement of disabled children, specifically the factors that influence decisions for children and young people to be voluntarily accommodated.

Family characteristics, family stress and challenges in caring for a disabled a child are reported as factors directly linking to parental decisions to seek an out-of-home placement for their son/daughter (e.g. Llewellyn et al., 1999; Benedrix et al., 2007; Nankervis et al., 2011). Morris (1997), reporting on secondary analysis of data collected by the Office of Population Censuses and Surveys (Bone & Meltzer, 1989), stated that the more significant the impairment, the more likely a child would be voluntarily accommodated. This arrangement is a likely reaction to parental need for support with the care of their child, coupled with a lack of in home supports. Additionally, the stresses of caring are reported to be more prevalent when children reach their teenage years and when they present with challenging or disruptive behaviour (Llewellyn et al., 1999).

Llewellyn et al. (1999) conducted an in-depth qualitative study with 167 families living in urban and rural settings in Australia, each with a disabled child aged 0-6 years with high support needs. The study sought to identify factors that influence families to care for their children at home or to seek out-of-home care. This study sought to challenge the notion that family stresses precipitated by the challenges of caring for a disabled child are necessarily the factors leading to out-of-home placement decisions. Rather this study drew on an eco-cultural theory that suggests that the central adaptive challenge for all families is to construct a sustainable, meaningful and congruent family routine (Gallimore et al., 1993). This approach challenges the notion that the disabled child is necessarily a burden on families and brings a more inclusive focus and optimistic idea that through adaptations and support these children can be viewed as a positively within family life.

Findings from Llewellyn et al. (2009:226) reveal that a strong value base underpinned parental decisions to keep their disabled child in the home environment. The child was described as a ‘blessing’ by these families and they regarded having their child at home as an opportunity rather than a barrier to being part of their community. They also talked about responsibility and their duty to care for their own child. Conversely, parents who were considering placing their child out of the home, or who had already taken this decision, reported that the strain on family life was too great to maintain the child at home. Siblings were said to be under pressure to take on too much responsibility and parents reported concerns that they might suffer negative reactions socially associated with the stigma of having a disabled brother or sister.

Families whose children were living in residential care reported that this decision had been necessary for family survival. All parents who took part were concerned that the quality of care in the out of home placement would be sufficient to meet the needs of their child. However, for those families whose children were already living in residential care, the facilities and opportunities were reported to be of high quality and some parents considered their child to be thriving in the out-of –home environment. Whilst this study provides a useful insight into the thoughts and experiences of parents who had decided to place their child with high care needs in a residential setting, it is limited by the small sample size (n=6/167) of parents recruited to the group who had placed their children in care and the fact that the data collected from these parents was retrospective. Moreover, parents may feel a need to construct a positive narrative around decisions that may be judged harshly by others. Nevertheless, it does provide a more ecological perspective on decision-making and challenges the negative focus on the disabled child as eternally a burden too great for families to bear.

It is clear from the literature that families with a disabled child are also more likely to face external stresses, which may impact on their ability to continue to care. For instance, there is strong evidence that disabled children are more likely than non-disabled children to grow up in chronic, long-term poverty (Emerson et al., 2010: Blackburn et al., 2010; Emerson & Hatton, 2007; Gordon et al., 2000). Read et al. (2012) report that taking all groups in the UK together, the equivalised income for a household with a disabled child is likely to be 13% lower than those with non-disabled children. This situation is often further exacerbated in families where there is a lone parent, in families from black and ethnic minority communities and where there is a disabled child and disabled parent living in the same household (Blackburn et al., 2010 in Read et al., 2012).

The significantly reduced financial circumstances are associated with the high costs of living with disability and the limits placed on adults in the household in taking up paid employment outside the home because of their caring responsibilities. The combination of living with social deprivation, often in inadequate housing (Beresford& Oldman, 2002) and the social stigma imposed on disabled children and young people can result in active exclusion from society (Akrami et al., 2005; O'Toole & McConkey, 1995) and may impact on families' ability to cope with the care needs of their disabled child. Philips (2000) highlights the potential for family illness or the demands of parenting other children in the family as additional potential stressors for families of disabled children.

However, not all disabled children who live away from home are voluntarily accommodated, a significant proportion are subject to a legal care order imposed because of suspected or substantiated abuse or neglect, and which imparts to the local authority sole or shared responsibility of the care for the child. Cousins (2009) in her commentary on pathways to care states that, whilst a significant proportion of children and young people who are looked after are disabled, impairment is the core reason for becoming looked after in only 4% of cases. This raises questions about how the reason for entry to care is recorded as it would be unlikely that 'disability' per se would be the sole rationale for being cared for outside the family home, and is more likely to be related to family issues such as their ability to cope with the child's care needs as discussed by McConkey (2004a).

That these children are vulnerable to abuse[2] is widely reported in the research literature (Morris, 1999; Sullivan & Knutson, 2000; Paul & Cawson, 2002; Lightfoot et al., 2011; Stalker & McArthur, 2012). Dependency on others for personal care, challenges in communication, lack of opportunity to alert others, and for those in residential care the high turnover of care staff, are identified as factors rendering disabled children at greater risk of abuse (Westcott, 1993; Morris, 1999; Paul & Cawson, 2002). There is limited consensus on the prevalence of abuse amongst disabled children and this again rests with challenges in the use of consistent definitions of disability in order to gain an accurate picture (Paul & Cawson, 2002).

Nevertheless, there is some reliable evidence, which indicates a high prevalence of abuse amongst disabled children and young people. For example, a US study carried out by Sullivan and Knutson (2000) reported on a total sample of 50,278 children and young people in one state. They found that disabled children and young people were 3.4 times more likely that their non-disabled peers to experience abuse. A further US study carried out by Romney et al. (2006) also report a high association between disability and abuse stating that 47% of a sample of 277 children removed from their home by court order following substantiated maltreatment (abuse) were found to be disabled. Whilst there are no studies of comparable size in the UK, there have been some small-scale studies with specific populations; however, these can be limited by unrepresentative or small samples (Stalker & McArthur, 2012). For example, Balogh et al. (2001) reported that 49% of a sample of children and young people in psychiatric unit had been sexually abused. However, this was drawn from a total sample of only 43 patients. Similarly, Morris (1999) reported that in one English local authority disabled children made up 2% of the population but had a 10% representation on the child protection register. A recently published systematic review and meta-analysis conducted by Jones et al. (2012) highlights the worrying high levels of vulnerability amongst disabled children to experiencing violence by comparison with their non-disabled peers. Whilst research evidence is indicative of significant levels of exposure to

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[2] Child Abuse as defined by the NSPCC refers to 'behaviour that causes significant harm to a child. It also includes when someone knowingly fails to prevent serious harm to a child' Abuse includes neglect or physical, emotional or sexual abuse'. http://www.nspcc.org.uk/Inform/cpsu/helpandadvice/organisations/defining/definingchildabuse_wda60692.html accessed: October 2012.

violence, the authors also call for more robust evidence to respond to gaps in existing knowledge.

As noted above, disabled children are more likely to be placed in out-of-home placements as a consequence of a voluntary arrangement than as a result of a legal care order. Morris (1999) states that abuse amongst disabled children and young people is often not recognised or recorded by professionals. She argues that situations that would raise child protection concerns for a non-disabled child were not viewed in the same light for disabled children. Cooke & Standon (2002) in their survey of 73 Area Child Protection Committees in the UK compared outcomes for disabled and non-disabled children. They reported that disabled children were less likely than non-disabled children to be placed on the child protection register or to have protection plans, and that there was significantly less intervention. Morris (1999) notes that partnership working with parents is perhaps more developed with parents of disabled children, and that ironically this is sometimes associated with failure to focus on the child's needs. Whether children are accommodated under a voluntary arrangement in an out-of-home placement as an alternative to initiating child protection processes and placement under a Care Order is a challenging question that arises from the literature (Morris 1999).

3.1 Unmet Family Support Needs and Relinquishment of Care

In an Australian study, Nankervis et al. (2011b) highlight the use of short break services as an emergency placement option in the case of the relinquishment of care. A relatively rare occurrence, the relinquishment of care, happens when parents do not return to collect their son or daughter from a short break stay on the basis that they can no longer cope with the demands of caring for their child[3]. Nankervis et al. (2011b) reviewed the case files of 32 families who had relinquished the care of their intellectually disabled son or daughter in a defined 12-month period. Staff members (n=17) who worked with these families were also interviewed.

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[3] Studies that describe the 'relinquishment' of care emanate from Australia and may reflect policy and service provision there. The same phenomenon is reported in other countries however it is described and contextualised differently.

The authors report that families of children and young people with very high support needs combined with challenging behaviour (for example, aggressive or self-injurious) were more likely to relinquish their care to professional services. Another factor was the age of young people as care needs became more difficult to deliver as children grew physically. Factors within the family also increased the likelihood that care would be relinquished, for example stress, exhaustion and depression in the primary carer, often the mother, as well as concerns over the impact on siblings. Stress on relationships between couples was also identified as a factor with family breakdown being a major contributor to relinquishment. Families also reported a lack of informal support networks and feelings of social isolation. Concerns regarding inadequate provision of services or the wrong kind of services for families also increased challenges to their ongoing care responsibilities. In addition, this study identified predictive factors to the relinquishment of care, namely escalating use of short breaks or requests for increased services and families repeatedly stating that they were unable to cope.

The study is limited as it was conducted in one geographical area of south Australia and relies on the responses of a relatively small sample size. Data were collected from third party informants, staff interviews and case notes. The sensitivity of the work heightened by the recency of relinquishment meant that researchers felt they could not interview parents directly. Indeed this seems to have been endorsed by some parents who were reported to have made themselves uncontactable. Nevertheless, this study does provide insight into the complex challenges faced by families striving to continue to care for their child at home and also highlights steps that could be taken to predict and potentially avoid emergency admissions of young people to public care through the relinquishment of care by their families.

The findings of this study are supported by a literature review also carried out by Nankervis et al. (2000a), which extrapolates from the literature on short breaks and relinquishment in relation to other client groups (due to the dearth of literature specifically focused on disabled children and young people and relinquishment of care). Findings from this review indicate that factors that lead to relinquishment are children’s challenging behaviours, poor coping skills and lack of support, dire financial concerns and carer distress. Short breaks may be a means of maintaining young people at home however the challenges facing carers require that services adopt a whole family approach to support. Nankervis et al. (2011a) highlight the limited attention this topic has received in research and recommend that further work is undertaken in this area so as to expand the knowledge base and identify strategies to more effectively support families.

A growing issue present in the literature and most prominently in relation to intellectually disabled children and young people, challenging behaviours and high support needs, is a tension between the application of principles of equality and inclusion for disabled children and young people in relation to remaining within the family home and the pressure reported by families that this places on their quality of life. Brown et al. (2011) report on a qualitative UK based study using individual interviews and focus groups with 17 parents of disabled children who attended a residential school. This study sought to investigate perceptions of family functioning when their child lived at home and after they began to attend the school. The study also investigated parents' perceptions of their child's behaviour before and after attending the school.

Although based on a small sample, Brown et al.'s (2011) study provides a graphic picture of the challenges faced by parents in caring for their child in the home, which included loss of sleep, the need for constant supervision and coping with challenging behaviours described as destructive, hyperactive and aggressive. The impact on family life was reported as restrictive, having a negative impact on siblings and on the family including, fatigue, loss of social lives, no personal time, low self-esteem, guilt and unemployment. The study reports an altered picture following the child's admission to the residential school. Parents both in individual interviews and focus groups variously reported that their children appeared to be calmer and happier, has improved coping ability, reduced unpredictability, reduced aggression, improved social and communication skills and an improved pattern of sleeping and eating.

In terms of family life there were also reported benefits; the family was more relaxed, relations within the family had improved, there was a positive effect on siblings, confidence grew as the marriage improved and individuals enjoyed improved sleep. Parents stated that time spent with their disabled child was now much more enjoyable and rewarding. These findings are controversial as they challenge the ideas about inclusion and right to family life for disabled children and young people. However, although these findings are based on a small sample and the study was conducted in relation to only one residential facility, they do mirror findings reported by Nankervis (2011b) as well as Benderix et al. (2007). In the former study, following the relinquishment of care, as described above, families were reported, after an initial sense of guilt, to experience 'a dramatic improvement in their quality of life' (2011:430). Families reported improved sleep patterns, feeling more relaxed and in control of their lives, improvements in marital relationships and time to spend with other children in their household. This study does not give any substantive information on outcomes for the relinquished children, more than to say that some of the young people's case files indicated that 'their quality of life had improved' (p.403).

Benderix et al. (2007) discuss an evaluation, undertaken in Sweden, of a small group home for intellectually disabled young people and young people with autism. An unusual feature of this study is that it was commissioned by a group of parents of 5 children, 10-11 years of age, who established the home as a facility for their own children. These families felt compelled to act since repeated attempts to secure adequate home based support services from the municipality had failed. Phenomenological interviews were conducted with each of the couples on two occasions: (1) several months before the child moved to the group home; and (2) two years after the child became resident in the group home. In the first set of interviews, the five families variously reported feelings of sorrow and grief, exhaustion, social isolation, inability to regulate their disaled child challenging behaviours and a negative impact on other children in the household. Follow-up interviews found parents feeling ambigious. Whilst they felt a sense of relief as the responsibility for the day to day care of their child was no longer theirs, they also expressed a sense of guilt at having placed their child outside of the family home. Feelings about the group home were divided. Some parents were satisfied and thought their child had improved and appeared to be happy, whilst others expressed dissatisfaction and were concerned that their child was reluctant to return to school after a visit to the family home; these latter families also felt that their child's behaviour had deteriorated. In spite of the concerns of some parents, overall participants were said to be more hopeful for their child's future than they had been at the outset of the study.

The results of this and other studies reviewed in this section should be treated tentatively. They rely on fairly small sample sizes and the discrete experiences of parents in particular situations and locations. The papers emphasise the importance of investing in adequate, and in some cases intensive, supports for families of disabled children to enable families to maintain their caring role alongside a good quality of family life for all family members. It is very clear from these reviewed papers that without sufficient in home or short break supports; some families may struggle to maintain the commitment of caring for a child or young person with severe or multiple impairments, at home.

4. Placement Options for Disabled Looked After Children

Key messages

- Disabled children live in the same range of out-of home settings as non-disabled children however; they are more likely to live in group home settings than non-disabled children and are less likely to be fostered.
- Structured preparatory and ongoing support can enhance the success of foster placements for disabled children.
- Kinship care is used with increased frequency as an out-of-home placement for looked after children; however, amongst the literature on this area the authors found no studies of kinship care with particular relevance to disabled children and young people.
- The demand for short breaks outstrips availability. Therefore whilst families state a preference for small-scale family type settings, the choice is often between what is available or no service. Short-breaks can also be provided through domiciliary support to children who are mainly looked after in their family home.
- Short breaks are not simply viewed as respite for parents; they are also welcomed if they are considered beneficial to the child.

Disabled children who are looked after voluntarily or on legal orders are likely to be accommodated in a range of settings. Some of these are similar to those used by non-disabled children such as foster care, kinship care or congregate residential settings, whilst others are more commonly used by disabled children for instance residential schools or short break services. McConkey et al. (2004a) described the range of placement settings used by the sample of 108 disabled, looked after children in one geographical area of Northern Ireland: 25 of the children were in foster care; 1 child was in a long-term family placement; and 34 were living in a residential facility including children’s homes, residential schools or hospital. Children placed in foster care were more likely to be in a younger age group <14 years, whereas older children (15-20 years) tended to live in a congregate residential setting.

Type of impairment was also found to have an impact on type of placement; for example children with autistic spectrum disorders who lived away from their family home were more likely to live in residential settings (38%) than foster care (14%), whilst physically disabled children were more likely to live with foster carers (45%) in comparison to residential settings (27%). Of the 15 children who were technologically dependent because of a health condition (and included in this study because of their use of short breaks), 80% lived most of the time at home. Only one (7%) lived with a foster family and two (14%) in a residential setting. This section will go on to review the literature relating to the various placement options for looked after children and with particular reference to disabled children and young people.

4.1 Foster Care

Foster care provides a popular alternative family setting for children and young people who cannot at remain with their birth families. Foster care may be an emergency or short-term option, it may be used for shared care, where a child lives part of the week with their family of origin and the remainder with a linked foster carer, or foster parents could provide a longer-term home. As with the challenges in obtaining accurate numbers of disabled children who are looked after, it is also difficult to find accurate figures on the numbers of disabled children who live in foster care. However, Burns (2009) states that disabled children are less likely to live in foster placements: 21 % of disabled children as opposed to 31% of non-disabled, looked after children.

Research evidence suggests that disabled children can have successful experiences in foster care. Laan et al. (2001) conducted a study of the placement outcomes for 78 disabled children (42 boys and 36 girls) placed with foster families. Of these children 62% were recorded as having an intellectual impairment, 15% were described as having a developmental delay and 37% were physically disabled or had a long-term illness. All of the children were described as having challenging behaviour.

This study was carried out in The Netherlands where an extensive selection and matching programme is undertaken before children are placed with foster families. Systematised individual plans are drawn up with foster parents and reviewed on a six monthly basis.

Support is provided to foster placements by an intensive and specialised counselling programme with input from educational psychologists and psychotherapists forming part of a multi-disciplinary support team. This study assessed placement outcomes in respect of this intensive support programme. Findings demonstrated successful placements in 74% of cases, success being measured in terms of placement stability, with participants spending more than 2 years with their foster family. 79% of foster parents judged the programme to be positive. This study relies on a relatively small sample size and no attempt was made to assess the views of the young people themselves as to their perceptions of their placement. However, this study does highlight the benefits of rigorous and on-going support to foster families of disabled children. This support programme could be further tested as a model for good practice in this field as well as a programme, which may potentially encourage more foster families to consider providing a home to a disabled child.

There are significant challenges to locating foster families who are willing to welcome a disabled child into their homes. There are considerable supposed barriers to fostering a disabled child including difficulties relating to coping with challenging behaviour, feeling incompetent and limited support from the care system (Roach & Orsmond, 1999). However, there are also reported benefits including: learning about the lives of disabled children, seeing their strengths, and being part of their successes (Andersson, 2001; Goetting & Goetting, 1993).

Brown & Rodger's (2009) UK study investigated the problems identified by foster carers themselves to see if they matched those reported in the literature. This study used a concept mapping approach with a six stage mixed methods strategy, to generate a synthesised list of respondent generated concepts in answer to the central research question, namely ' What are the problems you face in fostering a disabled child?' Problems reported largely matched those present in the literature, namely challenges associated with obtaining specialised professional service, the financial strain due to the increased costs of caring for a disabled child, difficulties in finding time for themselves as well as managing multiple roles and challenges related to dealing with the health care system. In addition, this group identified problems related to the lack of informal supports in their own communities, concerns about social stigma directed at their foster child and issues relating to the experiences of disabled foster parents, a matter which has received little attention.

The study by Laan et al. (2001) discussed above emphasises the benefits of support structures for foster carers. Brown et al.'s (2005) qualitative study of 44 foster carers in Canada further investigated what services or supports would be beneficial to foster parents. The major factors reported included: (1) professional supports (such as, more responsive social work support; (2) more information particularly in relation to a child's medical needs; (3) educational supports and opportunities for disabled children; (4) informal supports in the community and peer support groups; (5) financial support; (6) further training and information about impairment and disability; and (7) therapeutic inputs in the form of play, music, or speech therapies.

There is some evidence that training for foster carers leads to better placement outcomes for children and young people. For example Everson-Hock et al.'s (2011) systematic review of studies on outcomes for foster carers following a training intervention found three studies which reported a benefit of training (Dozier et al., 2006; Chamberlain et al., 2008; Sprang et al., 2008) and three which reported no benefit but no detrimental outcome (Minnis, 2001; Pithouse et al., 2002; MacDonald & Turner, 2005). Beneficial outcomes were reported where training had taken place over longer periods (10-16 weeks) and where carers were fostering children in the young age range. None of these studies focused specifically on carers of disabled children however, the lessons may well be transferrable to that group, particularly in respect of requests for training reported amongst foster carers of disabled children.

4.2 Kinship Care

Kinship care has long been an informal resource for families providing varying levels of support to children and families in need. However, O'Brien (2012) reports that this option is being used increasingly as a formal resource for looked after children. Outcomes for children placed with kin are generally reported to be positive in relation to identity formation, stability, health, behavioural and emotional outcomes as well as placement stability and the maintenance of sibling groups (Winokaur et al., 2009; Cuddeback, 2004; Hunt, 2003; O'Brien, 2002).

There is some concern about the extended lengths of time that children and young people spend in kinship care arrangements before being placed in permanent substitute families or returning home. Moreover, professionals have raised concerns as to how they position themselves in relation to families, to conduct home studies or to license relative carers (O'Brien, 2012). Throughout the literature focused on kinship care there is a noted lack of attention to the voices of children and young people both in terms of how they are included in assessment of placement with kin and in terms of their experiences of kinship care (Messing, 2006; O'Brien, 2009).

There is a fairly extensive literature base focusing on kinship care however this is not attentive to disabled children and young people placed with relatives. This gap in the research evidence is a potential area for further investigation. For instance are the reported largely positive outcomes for children and young people in kinship care found amongst disabled children; and does impairment or disability impact on relative's willingness or perceived ability to provide kinship care for disabled children?

4.3 Residential School

Although there has been a shift towards social inclusion in government policy, there remain a number of residential schools across the UK in which disabled children and young people live and receive their education. The literature highlights a number of issues in relation to the protection and promotion of welfare in residential schools. Morris et al. (2002) undertook an audit of policy and practice in 21 education and social service authorities in England. In relation to looked after procedures, the authors reported on inconsistencies and lack of clarity as to whether to treat children attending residential schools as 'looked after' and therefore avail of the protections afforded to looked after children under current regulations (such as, six monthly reviews of placement). They noted that, despite clear legal criteria on the grounds by which a child is considered to be looked after, many children living away from home in residential schools were only considered to be looked after if they are resident at schools outside of term time[4].

Morris et al. (2002) also raise questions as to the experiences of children placed on residential schools in the UK. For example, are children and families given the necessary assistance to maintain contact with each other, given that schools are often located some distance from the child's home community? And are there opportunities for them to remain a part of their local community? These concerns are reflected in a mixed methods study undertaken in the UK by McGill et al. (2005). Reporting on findings from in-depth interviews with a sample of 14 parents, the authors report that whilst parents were largely content with the quality of care and education their children received, they were concerned about the considerable distance that the school was located from the family home. This distance impeded frequent visits to their child. Additionally parents in this study expressed concerns about the future care needs of their child who had lost contact within the local community and the services available in their home locality.

There is also considerable concern that children's voices are reported as often absent from the decision making process to place them in a residential school (Morris et al. 2000). In some instances the placement of a child was reported as having been made primarily in response to the needs of parents and siblings. There are also reported instances where a placement in a residential school was made because of concerns over child welfare. Morris et al. (2002) call for increased clarity in relation to the position of these children and argue that the status of 'accommodated' or 'looked after' would enable disabled children and young people in residential schools to avail of the requirements associated with this status which may go some way to protecting their rights.

4.4 Residential Care

Historically, residential care for disabled children and young people meant large long-stay institutions where standards of care and future planning would not bear scrutiny from a present day perspective (Oswin, 1978; 1984). Currently residential settings for disabled

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[4] The authors are aware that there is only one residential school in Northern Ireland; however there are early indications that some local children are placed in out-of-area residential school settings in the UK.

children and young people may vary from being a specialist residential unit to a hospital or residential school, a group home or, for a minority, a secure unit (Burns, 2009). Congregate settings (larger scale residential homes) are increasingly less popular both with parents and within the policy agenda; however they may be the only available option for families who cannot continue to care for their disabled child at home, (Nankervis, 2011a; Brown, 2011; Benedrix, 2007). Even though residential care homes are regarded as a less popular placement option, Baker (2007) does report that they can provide a permanency option for young people placed in and remaining in residential care over a prolonged period.

There is a substantial gap in our knowledge of the experiences of disabled children and young people in group residential care and further work is required to establish ways to challenge negative trajectories and encourage improved outcomes for this population. Residential services are also well used as short breaks for disabled children and young people and their families where the child lives at home most or all of the time. The literature in this area is discussed in detail below.

4.5 Short Breaks

Children and young people who live at home with their families may also use short break services which means spending variable periods of time away from the family home in a residential facility, with a foster family or a matched family in a shared care arrangement. In some instances, though less commonly, children with high dependency needs because of a health condition may be placed in hospital facilities as a short break option. Families may also be able to use short breaks during the day when a worker will come into the family home and assume the care needs of their son/daughter for a period of time, freeing the parent to attend to other tasks or to have some time to themselves.

The demand for short breaks for disabled children is high and their availability is unlikely to meet requirements (Beresford, 1995; Cotterill et al., 1997), therefore choices may be limited with families forced to take what is available or risk having no short break service at all (Treneman et al., 1997). Nevertheless, it is not only the availability of short breaks that is important to parents, but the quality of these breaks that are provided (McConkey et al., 2004b). Robinson et al. (2001) presents a synthesis of findings from two UK studies concerned with disabled children who have complex health needs and require substantial medical input in their daily care routine, typically delivered by their parents.

In the first study data were collected from records in four English hospices in relation to 358 short-term care admissions. It was reported that 20% of the conditions recorded were likely to lead to the death of the child, 28% of the children were reported as likely to survive and 52% reported as children who 'may survive' (p.68). From these latter two groups a sample of 39 families (of 40 children) was identified. This group formed the sample for the second study, which used a qualitative approach and conducted semi-structured interviews with families whose children ranged in age between 1-19 years. All of these children received nutrition through tube feeding and had high medical support needs; the most common diagnosis was cerebral palsy (n=16). Interviews were also conducted with medical professionals in both studies.

Robinson et al. (2001) report on what they found to be a poorly developed approach to the care of disabled children and complex health needs, a lack of clarity over who is responsible for these children between social and health care agencies and disputes about who will pay for various services. They state that due to the shortage of short break provision, there is an overuse of segregated services, with limited instances of children being cared for in domestic settings except through family link services. The latter arrangement that is favoured by families is reported to be so poorly resourced it fails to attract sufficient carers to the role.

There is an ever-growing pressure on existing services for this group of children with complex health care needs resulting in increased pressure placed on families to provide intensive ongoing care at home with limited support or respite. The generalisability of the findings of these studies are limited since they rely on data collected in one service (study 1) or on a relatively small sample size which is not necessarily representative of all service users (study 2). Nevertheless, when these findings are viewed in relation to other work focused on short breaks for disabled children and young people, they gather increased salience.

McConkey & Adams (2000) conducted a study focused on the experiences of the use of short breaks in Northern Ireland. This study was undertaken in two stages; firstly a profile of the total population of families who received short break services in one Health and Social Care Trust area was completed by gathering information on a standard proforma completed by the family's social worker. Secondly, interviews were conducted with 76 families (informants were mothers for 92% of cases and both parents for the remainder) of a disabled child in this Trust area. A total of 476 families were recorded as users of short breaks in the preceding 12-month period, this represents 32% of the total population of families with a disabled child in the Trust area and reveals a lack of capacity in service availability as 9/10 parents interviewed stated their desire to avail of the short break service. Social workers also estimated that, amongst those already receiving a service, 70% would benefit from an increased level of provision.

The majority of children accommodated in short breaks were intellectually disabled (97%) with a small minority having a physical (2%) or sensory (1%) impairment. Many of the young people had high dependency needs with more than half requiring constant supervision because of challenging behaviours and more than 2/3 receiving regular medication. Families reported a preference for non-hospital based services, however the type of provision they received was found to be linked to the family income level, with those on lower incomes more likely to use hospital or institutional type facilities, and more affluent families accessing family breaks.

Notably, and in common with Robinson et al. (2001), parents indicated that short breaks were not viewed as solely meeting their needs for time off from the responsibilities of caring for their son or daughter, but that they should also be beneficial to the child themselves. The preference for leisure based breaks rather than those in institutional facilities bears this out. McConkey and Adams (2000) themselves identify that their study would have been enhanced by the representation of young people's views as well as that of their parents and social workers.

McConkey et al. (2004b) conducted a separate study on the views of 108 families whose children had used short breaks in the previous 12 months, it is not clear whether this was in the same area as the (2000) study described above or whether it involved the some of the same families. The children in this group were described as having severe intellectual, multiple and sensory impairments. Their views were not sought as it was reported that given the nature of their impairments it was not possible to include them as informants. This two- stage study began with open-ended interviews with parents, followed by a consultation seminar attended by parents/carers and various service professionals to further explore identified themes from parent interviews. In the second stage of the study, 59 parents of children and young people who had availed of residential short breaks in the previous 12 months used the items generated in the first phase to rate the service they received.

The aim of the study was to identify the features of short-break residential services that families value. These could then be used to inform the commissioning and evaluation of services in future. Findings confirm those reported in previous studies with parents reporting that short breaks should meet two functions: firstly, to give parents a break from their caring responsibilities; and secondly, that children should benefit from the experience. This second outcome of using short breaks places a requirement on services to undertake more than a 'minding' function and to extend their provision to include a varied recreational programme, which has clear implications for staffing costs and access to transport. Parents preferred services which were small, homely, child-centred environments with high standards of care.

The reported benefits of short breaks are summarised by Nankervis et al. (2011a) and include: (1) parents having a greater sense of control; (2) improved family functioning; (3) reduced carer distress and depression; (4) parents feeling refreshed after having time to rest and recoup their energy; (5) an increased sense of 'normal' life; (6) more time to spend with other family members; and (6) the chance for social outings (Damani et al., 2004; Chou et al., 2008). Indeed, McConkey et al. (2004), conclude that one of the key contributions of short breaks is that they may enable parents to continue caring for their son/daughter at home rather than seeking an out-of-home placement. Further investment in short break provision to extend the service available for families in need and, in particular, those on the ‘edge of care’ may prove both cost effective in the longer term as well as supporting the life chances of disabled children and young people at this critical stage in their development.

McConkey et al. (2011) investigated a specialist model of short break and intensive outreach support for families and disabled young people presenting with severely challenging behaviour (up to 19 years old) delivered by a national voluntary organisation in three city locations (Edinburgh, Glasgow and Cardiff). The service model included overnight accommodation for between two to seven days, staff support for young people to participate in community activities and training for families on how to manage challenging behaviours. Between 2008-2010, 123 families had accessed the service; 37 had received both kinds of support, 63 overnight accommodation only and 23 community support only. An evaluation of the service followed four stages; (1) a documentary analysis of information about the service; (2) interviews with service managers in each of the locations; (3) focus groups with key stakeholders; and (4) consultation on a draft report sent to all participants and revised at a subsequent meeting with them.

The model of service delivery is reported to be useful and effective for families in managing the care of their son or daughter and severe challenging behaviours within the home. The analysis demonstrates a role for specialist short break provision where there is identified need to be included in the network of service supports available to families. Such support may enable to families to continue to care for their child at home most of the time and offset crisis situations that may lead to longer term out of home placement. It may also enable children and young people who present challenging behaviour to avail of the opportunity to engage with short break services, thus opening the potential for both children and their families to experience the reported benefits.

This paper presents strong evidence in support of the intervention, which is triangulated through a variety of sources. However, the findings would have been further strengthened with the inclusion of the views of young people who use the service which may differ considerably from the opinions of their parents/carers and service providers.

5. Permanence for Disabled Looked After Children

Key messages

- Placement stability through return to the birth family or placement in a permanent substitute family is thought to enhance outcomes for looked after children.
- Disabled children are less likely to return to their birth families and if they do return home it is often after a long period being looked after.
- Disabled children are less likely to be adopted than non-disabled children.
- Disabled children are more likely to achieve permanence with foster parents, however this is tempered by the expectation that this placement ends at the age of 18 and that the foster parent has no formalised parental role.
- Disabled children can thrive in supported foster environments.
- Where appropriate, maintaining a relationship with the birth family is important.

Outcomes for children and young people who cannot continue to live with their birth families are thought to be enhanced through the stability and security enabled through life in a permanent substitute family (Baker, 2007; Schofield et al., 2007; Fudge Schormans et al., 2006). Whilst the idea that finding permanent placements in family settings for looked after children is underpinned by both UK policy and research (DfES, 2003; Schofield, 2007; Sinclair et al., 2005), in practice finding stable placements where children can grow and mature towards adult life remains a major challenge (Lowe et al., 2002; Sinclair et al., 2004). This is a challenge for children in the general population however these challenges are substantially greater for disabled children (Baker, 2007). It is widely agreed that disabled children can be successfully integrated into and included in the lives of a permanent substitute family (Fudge Shormans et al., 2006) however, there is evidence that looked after disabled children are more likely to be placed in residential care (Baker, 2007).

Reporting on data extrapolated from a wider study of the placements and experiences of looked after children (Sinclair et al., 2005); Baker (2007) reports on a sub-sample of 135 disabled children (23% of the total sample of 596 foster children). The aim of Baker's (2007) work was to test the hypothesis that disabled children and young people experience a ‘reverse ladder of permanency’; that is are less likely to be adopted, are likely to go home less often and to remain in care for longer periods of time. Data were collected at three time points; at entry to care, and subsequently one, and then three years later. The broader study used a mixed methods approach; however, Baker (2007) reports on statistical data drawn from postal questionnaires completed by social workers, foster cares and current carers of disabled children in the study.

Findings from the study indicate a more complex picture than a straightforward negative relationship to permanence for disabled looked after children and young people. Three main findings were reported. Firstly, intellectually disabled children were less like to be adopted than other disabled children. Moreover, amongst those disabled children who were adopted, this was more likely to happen at an older age in comparison to non-disabled children. Secondly, disabled children were less likely to return home and for those who did return to their birth family this was likely to happen at an older age in comparison to non-disabled children. Finally, disabled children were more likely to achieve permanence with their foster carer than non-disabled children; however this was tempered by the fact that there was an implied expectation that children would move on when they reached adult life (18 years) and that the foster parent did not have a clearly defined parental role.

In the US study, Fudge Schormans et al. (2006) examined factors which improve quality of life for looked after children and young people described as having developmental disabilities. This study reported on qualitative data collected from 10 substitute parents (foster parents, adoptive parents and kinship carers) of 31 developmentally disabled children. Participants were self-selecting, recruited from a convenience-based sample of individuals who responded to newspaper advertisements and subsequent snowballing using word-of-mouth. Data were collected using individual, in-depth interviews, which were audio, recorded. Open questions such as ‘What are the things that make life good for your child?’ were posed and prompts were given to seek clarification or elicit examples from participants. Reported themes included: (1) the importance of the provision of a family environment and the important role of the parent within that; (2) that children should be fully included within the substitute family so they really experience feeling being part of family life and being a valued and important member; (3) that efforts should be made to maintain contact with the child's birth family and the importance of this relationship recognised; (4) there should be more provision of effective services for disabled children; (5) substitute parents need better training about developmental disabilities; (6) financial support should be sufficient to match the child's needs; and (7) a team approach to meeting the needs of looked after disabled children helps to promote access to relevant professionals support for carers parenting and caring for disabled children.

These findings are limited by the small sample size and the method of self-selection recruitment and, therefore, may have included people who were already pre-disposed to the aims of the research. However, they do reinforce some of what is known about the benefits of finding permanent families for looked after children with or without impairments. As Jones Harden (2004) stated 'positive, consistent care giving has the potential to compensate for factors that have had a deleterious impact on children' (cited in Fudge Schormans et al., 2006: 33).

Baker (2007) recommends that placement outcomes for disabled children are systematically monitored to establish the number, type and duration of placements in stable family and residential settings, including those which are deemed unsuitable for disabled looked after children and disabled care leavers. This may help to identify barriers to achieving permanent out-of–home placements for disabled children and young people and will perhaps provide insight into how such barriers might be overcome.

6. Outcomes for Disabled Looked After Children

Key messages

- Looked after children experience negative trajectories in relation to their health and educational outcomes.
- There is limited empirical research to support this in relation to disabled looked after children; this is an important gap in research knowledge that needs to be addressed.
- Pre-care and post-care experiences may both engender social and emotional difficulties which in turn may lead to the development of mental health difficulties.

Looked after children are reported to experience poorer physical health outcomes, higher rates of learning and language difficulties and inferior educational outcomes compared to other children (Crawford et al., 2006) The difficulties and challenges in the home environment which have necessitated, in one way or another, a move into care are likely to be heightened for disabled children by the upheaval of the move and subsequent placement, with a change of school, home environment and familiar community, as well as new rules and expectations of carers. Cumulatively these additional stressors are likely to lead to negative short term and possibly longer-term behavioural, mental health and educational outcomes (Frensch & Cameron, 2002; Zeitlin, 2006).

There is little focus in research as to outcomes for children accommodated in congregate settings. Researchers in this area have tended to focus on alternative types of out-of-home placement, for instance foster care or kinship care. One exception is the US study conducted by Trout et al. (2009). The aim of this work was to determine demographic, behavioural, mental health and educational outcomes for a group of disabled young people accommodated in a large-scale congregate residential setting. Data were collected from 123 young people (50 girls and 73 boys) who entered the facility in a one-year period. Of this total, 36 had been formally identified in their school environment as disabled. A proforma was used to collect demographic data and standardised measures were used to assess behaviour, mental health status and academic performance. Data were collected via parent report and self report (child) at two time points: firstly at entry to the facility (demographic data, placement history and physical and mental health status); and secondly, at the end of the first week of the child's stay (mental health status and academic level).

Findings reported similarities across demographic domains and a comparable elevated level of behavioural challenges and mental illness across both disabled and non-disabled groups. On closer scrutiny of these results it was apparent that the disabled group had significantly higher levels of social and attention problems. However, both groups demonstrated heightened levels of externalising behaviours such as rule breaking and aggression. Academic outcomes for the disabled group were found to be significantly lower than the non-disabled group, both in relation to basic skills (reading and writing) and in respect of subject based studies. Given the profile of significant academic, functional and behavioural challenges for this group, the risk of negative outcomes was thought to be heightened (Trout et al. 2009).

6.1 Educational Outcomes

The findings reported by Trout et al. (2009) also reflect the poor trajectories in educational outcomes reported amongst looked after, non-disabled children and young people. Winter (2006) brings together research in this area citing a range of literature which has sought to examine pre-care factors that may determine higher levels of educational and health need (Polnay & Ward, 2000; Winter & Connolly, 2005). Winter (2006) also highlighted the poor educational and health outcomes for looked after non-disabled children, even when pre-care environmental factors are controlled for (e.g. Hill & Watkins, 2003).

In the Northern Irish context, departmental statistics on educational outcomes show that looked after children experience higher rates of special educational need (SEN) (24%) as well as higher rates of suspensions and exclusions together with more days absent from school (DHSSPSNI, 2010a). Of the 24% categorised as having SEN, almost half of them (48%) were reported to have a learning or severe learning disability and 12% were reported to have behavioural problems (DHSSPSNI, 2010a). Data published in the same source reports more details on educational outcomes for looked after children; however, this data excludes those with a severe learning disability. Overall, this data demonstrates that levels of attainment for looked after children are poor in comparison with the whole school population and that levels of attainment deteriorate further as the children move through school grades (DHSSPSNI, 2010a). However, it is important to note that there are reported year on year improvements in levels of attainment amongst looked after children in relation to both English and Mathematics at Key Stages 1 and 2 of the Revised Curriculum (DHSSPSNI, 2010b; DENI, 2010).

Whilst this statistical data indicates poor educational outcomes for looked after children, there is a need to disaggregate the population of disabled looked after children and to assess relative outcomes in relation to their discrete peer group. The need for rigorous empirical research focusing on a range of outcomes for disabled looked after children including education and further encompassing indicators of health and well being, is a priority area for future research with this group.

6.2 Social and Emotional Outcomes

The literature clearly shows that many children and young people who live apart from their birth families in the public care system are vulnerable to developing emotional difficulties and mental ill health. These vulnerabilities are reported to emerge from an interaction between these children's pre and post care experiences. Studies identify the interaction of problems which precipitated entry to care with the experience of being looked after as resulting in a complex interaction of past and present experiences (Golding, 2010; DeJong, 2010; McAuley & Davis, 2009; Tarren-Sweeney, 2008; Richardson & Lelliott, 2003), including pre-natal vulnerabilities potentially created through maternal stress (Bergman et al., 2007) and maternal substance abuse (Schuetze at al., 2009).

Children and young people may have been admitted to care as a result of suspected or substantiated abuse, neglect, family breakdown, parental illness, socio-economic disadvantage and abandonment (Richardson & Lelliott, 2003). Exposure to psychological trauma and emotional deprivation may obviate against the development of a secure attachment style. Looked after children may also have experienced disorganised home lives, and a significant level of neglect of their health needs combined with low behavioural expectations (Golding, 2010; De Jong, 2010). These experiences, Tarren-Sweeney (2008) points out, can detrimentally impact on opportunities for critical developmental experiences for these children.

6.3 Mental Health Outcomes

The experience of becoming a looked after child is reported to compound pre-care risks and potentially increase vulnerability to developing mental ill health. Frequent changes of placement, feelings of loss engendered by separation from birth family, loss of contact with the community; challenges in adjusting to new care arrangements and lack of advocacy can all be factors in increasing vulnerability to developing mental health difficulties (Golding, 2010; Tarren-Sweeney, 2008; Morris et al., 2002). It is reported that children in residential care are more likely to development mental ill health than those residing with foster carers (McNicholls et al., 2011; McAuley & Davis, 2009). Other factors that are reported to increase vulnerability include being an older age on entering care and being intellectually disabled (Tarren-Sweeney, 2008).

McNicholls et al. (2011) highlights the inter-relationship between placement disruption and greater levels of mental health problems, as it is not clear whether mental health problems are a contributing factor in placement disruption or an outcome of multiple placements. Younger age at entry into care if the child is placed in a family setting is reported to be a protective factor, however this is not the case if a young child is placed in a residential setting, where risks are then elevated (Tarren-Sweeney, 2008).

Whilst the scale of the vulnerability of looked after children and young people to mental health difficulties is well reported in the literature, significant emphasis is also given to the complexity and a-typicality of the presentation of symptoms amongst this group (DeJong, 2010; Tarren-Sweeney, 2008). Reasons for this are highlighted by Glaser (2000) who points out that children who become looked after are subject to a particular kind of adversity, it relates directly to their primary caregiver experience, happens at a formative time in their development and is likely to have important neuro-biological consequences.

Given their exceptional vulnerability it is suggested that pre-emptive population based assessment of mental health status at time of entry to care should be carried out (DeJong, 2010; Tarren-Sweeney, 2008). Cousins et al. (2010) suggest that there are potential opportunities to develop the therapeutic potential of being looked after through the early identification of children with particular vulnerabilities. Moreover, these authors call for a specialism to be recognised in the diagnosis and therapeutic treatment of children and young people in this population.

Given the complexity of pre-disposing factors, the age at which children are exposed to risks and the ongoing challenges of coping with the experience of being looked after, particularly those in congregate settings or unstable placements, it is suggested that a particular knowledge and skills base is required to adequately address the needs of these children (Golding, 2010; DeJong, 2010; Tarren-Sweeney, 2008). Golding (2010) highlights the benefits of multi-agency approaches to address the emotional wellbeing of looked after children and young people. Attending to these issues in the present offers the opportunity to avert on-going problems into the adult lives grown from these disadvantaged childhoods.

7. Disabled Young People Leaving Care

Key messages

- There is limited extant research literature on the experiences of disabled care leavers.
- Much is known about poorer outcomes for care leavers and disabled young people in general but more knowledge on the pathways of disabled care leavers is required.
- The relationship between the high incidence of mental health difficulties among care leavers and pre-existing emotional/behavioural difficulties and the new challenges of transitioning from public care into adult life is unclear.
- Further research is required on the comparable transitional experiences of disabled and non-disabled care leavers.
- There is a dearth of research on the views and experiences of disabled care leavers.

Disabled care leavers are a particular high-risk group who have been largely ignored in extant research literature nationally and internationally (Geenen et al., 2007; Stein and Munro, 2008). This gap in knowledge is surprising given the persistent evidence from available statistical data that disabled young people are over-represented in the leaving care population in Northern Ireland. Whilst only six per cent of the population of children under 16 years in Northern Ireland are disabled (NISRA, 2007: 16), the last Regional Leaving Care Population Census data (DHSSPSNI, 2009:19) found that 14% of the projected population of care leavers (aged 11-16 years) were disabled. This census reported that staff had concerns about the mental health needs of 27% of care leavers and 24% of care leavers had been referred to or accessed mental health services (DHSSPSNI, 2009: 16). Staff also recorded that 11% of care leavers had self-harmed in the previous 12 months (DHSSPSNI, 2009: 17). More recent Departmental statistics on disabled care leavers aged 16-18 years in 2009/10 support these findings, revealing that just over 13% of care leavers were disabled and the majority of these were learning disabled (79%) (DHSSPSNI, 2011: 8). Similarly, a local study in one Health and Social Care Trust found that up to 60% of young people living in public care within the Trust had diagnosable mental health disorders (Teggart and Menary, 2005). The co-morbidity of various impairments is also increasingly prevalent, with intellectually disabled children and adolescents being 3-4 times more likely to also experience mental health disorders (DHSSPSNI, 2006a; Slevin et al., 2011). Based on the available statistics, it is reasonable to conclude that a disproportionate number of care leavers are disabled (DHSSPSNI, 2009). The same statistical trends are also identifiable in national (Broad, 1999; Ford et al. 2007; Mooney et al., 2009) and international care leaving literature (Berlin et al., 2011; Cashmore and Paxman, 2007; Goldblatt et al., 2010; Katz et al., 2011; Stein and Dumaret, 2011; Vinnerljung et al., 2006).

7.1 Transitions and Outcomes for Disabled Care Leavers

Poorer outcomes in adult life for care leavers (Jackson and McParlin, 2006; Stein, 2008; Stein and Dumaret, 2011) and the general population of disabled young people in transition are very well documented (Beresford, 2004; DHSSPSNI, 2006b; Grigal et al., 2011; Unwin et al., 2008; Vostanis, 2005; Ward et al., 2003), including fewer opportunities for employment, further education, personal relationships and social inclusion. Several general studies on the health and wellbeing of care leavers have also helped to identify some of the key predictors of poor mental health including, entering care at an older age, being intellectually disabled, instability in placements or adverse events (Akister et al., 2010; Dixon, 2008; Tarren-Sweeney, 2008). However, further research into the impact of pre-care and in-care experiences of disabled children and young people is required. As Pecora et al. (2009) propose, careful screening on entry to and during care is needed in a prospective study to understand the incidence, duration and severity of mental health problems and other impairments.

As disabled young people leave care and move into their young adult lives, little is known about their unique experiences during the transition from child to adult services or the potential multiple disadvantage they may experience on the grounds of both disability and care leaver status (Rabiee et al., 2001; Silberman et al., 2009). Indeed, a recent NICE review identified the experiences of disabled care leavers as a particular gap in the literature and a pertinent issue for service improvement (Everson-Hock et al., 2009:51). As there is very limited research on the lives of disabled care leavers, the extent to which their transitional experiences differs from those for non-disabled care leavers or the general population of disabled young people making the transition from child to adult life also remains unknown.

Aside from the prevalence studies cited above, only four studies have specifically examined the needs and experiences of disabled care leavers (Broad, 2005; Mullan and Fitzsimons, 2006; NFCA, 2000; Rabiee et al., 2001). Locally, Mullan and Fitzsimons' (2006) CASPAR project on the mental health of looked after children and care leavers in Northern Ireland identified key practice issues including the need to: prioritise the participation of young people in service planning and delivery; have a clear, accessible and coordinated structure of mental health services for care leavers; and integrate risk reducing and resilience enhancing activities in care pathway planning to improve outcomes for care leavers.

In the UK, Broad (2005) found minimal improvement in mental health and disability support services for care leavers since the introduction of leaving care legislation and high levels of dissatisfaction with service provision. Similarly, the National Foster Care Association's (2000) project on six case studies of intellectually disabled care leavers highlighted: fears of losing protection and support; inadequate resourcing of adult services; inappropriate timing of transitional processes; restricted choices in young adult life; and, limited planning for further education or employment. Rabiee et al.'s (2001) study in one local authority area in England is notable as the first study that sought to specifically examine the experiences of disabled care leavers. This research found that disabled care leavers encounter unique challenges as they move into young adult life, have many unmet needs during the transition process and negotiate complex service systems. Transitions were often unplanned and abrupt; services were often unable to meet the support needs of young disabled people; and opportunities in young adult life were restricted by limited housing and employment options.

These previous studies are helpful but are small scale and have a varied focus on disabled care leavers' experiences. For example, Rabiee et al.'s (2001) study gave limited consideration to mental health needs and was restricted to one local authority area in England. As the absence of information about what happens to disabled young people when they move out of public care into their young adult lives remains a major gap in knowledge, very little is known about: i) the impact of the over-representation of disabled young people in the care leaving population on demand for after care and adult services; ii) the impact of impairment and disability on care leaving experiences; iii) the effectiveness of leaving care services and planning processes for meeting the needs of this population; iv) types of support that lead to the most successful outcomes for these care leavers as the progress into their young adult lives; and v) the views of disabled young people and their carers as the make the transition into adult placements and services. Further research involving disabled care leavers would help to redress this notable gap in the literature on care leavers.

However, it is clear from the available literature that disabled care leavers are at a particularly high level of risk of poorer outcomes in adult life across a range of domains including education, health, employment, social inclusion and independent living (Akister et al., 2010; Ford et al., 2007; Mooney et al., 2009; O'Connell et al., 2009; Richardson and Lelliott, 2003; Stein, 2008). This group of care leavers is, therefore, very likely to require access to adult services when they make the transition from public care and may have specialist support needs (Stein and Dumaret, 2011; OFMDFM, 2008). Indeed, Wade & Munro (2008: 219-220) emphasise: 'There is a need for focused work on particular groups of care leavers, such as those with mental health problems, disabilities or other more complex needs, whose particular experiences and service needs have been insufficiently researched.'

8. Disabled Looked After Children's Perspectives

Key messages

- Disabled children and young people's views and perspectives are not routinely sought in relation to matters that affect them.
- Research evidence is enhanced by including the views and perspectives of disabled looked after children and young people who provide unique insight into their needs and experiences.
- Engagement with disabled looked after children is more common where the children and young people have mental health needs although children with a range of impairments have been included in a small number of previous studies.
- Younger disabled looked after children are less likely to be consulted than older children and young people.

Several authors of the work cited in this review of literature have themselves noted that excluding the voices of disabled children and young people is a limitation of their research (McConkey et al., 2000). Blower & Carlisle (1994) highlighted the absence of children's views and perspectives from research pertaining to them. They highlighted an emphasis on the views of parents and professionals with children's interests being represented by proxy thought the prism of adult perspectives. Over the past two decades there have been significant steps taken to redress the need to include the views of disabled children in research about matters that affect them; and this is reflected in a wide methodological and empirical literature (Kelly et al., 2000; Kelly, 2007; MacArthur et al., 2007; Morris et al., 2002). However, this inclusion is not routine (Aubrey & Dahl 2006) and is not attentive to all research arenas or in relation to service evaluations (Cavet and Sloper 2004). Within research relating to disabled children who are looked after, the relative absence of their voices is notable. There are, however, some exceptions that this review will now discuss.

Papers focused on the views and perspectives of looked after children and young people with mental health difficulties are more numerous in comparison to research with children and young people with other impairment types, although there are some examples of consultation with these children (e.g. Abbott et al., 2002; Kelly et al., 2000, Mullan et al., 2012). In their pilot study focused on the family support needs of intellectually disabled children, Kelly et al. (2000) interviewed three children in younger and older age groups and with differing communication styles; one who used speech, one who had limited speech and gestures, and one who had no speech and used Makaton signs. The researchers report that children were able to share their views and experiences of family support and short break services and enjoyed the opportunity to share their perspectives.

It was apparent that these children were not often asked for their views but they did have individual perspectives on matters that affected them that contrasted with the adult opinions. For example, although adult interviewees had expressed some concerns about a particular short break service, the young participants gave positive responses to their experience of spending time at this facility. Although this is a very small sample based on pilot work and, as the authors acknowledge, the findings can only be viewed as exploratory rather than representative, this paper does support the value of consulting with intellectually disabled children and young people, including those using non-verbal methods of communication.

Abbott et al.'s (2002) study investigating the placement of disabled children and young people in residential schools in England involved interviews with 14 young people who attended a residential school about their experiences. These interviews formed part of 32 case studies where parents and professionals were also interviewed. The authors report that 18 of the young people from the case study sample were unable to take part in interviews; therefore, information was gathered by proxy in these cases. Children were interviewed about a range of issues: the decision to go to a boarding school; their feelings about being away from home; their education; their friendships; bullying; their annual review; and contact with their families. Most of the young people in the study had been attending the residential school from a fairly young age; 24 of the 32 had been aged 11 or younger when they first attended the school.

The children commented on the range of issues the researchers raised, however, they revealed that this level of consultation was rare, and that they do not often have the opportunity to contribute to important milestones such as, their annual review. Children’s feelings about attending the residential school were mixed, for instance some missed their families and others preferred the school environment to their home environment. Others stated that the residential school was able to offer more than their previous school such as, access to therapies. Including children in this research provides important insight into young people’s experiences, which has implications for service development.

Investigating the experiences of looked after young people with mental health difficulties, Mullan et al. (2012) report a qualitative element of their study involving in-depth interviews with 51 looked after young people aged from 12 years to 18+ in Northern Ireland. The project was assisted by a Young Person’s Advisory Group who it was reported played a vital role in ensuring that the voice of looked after young people remained at the centre of the project.

A number of key themes were identified in this project: firstly, young people reported a sense of disorientation as to why they were placed in care and why they remained there. These concerns were compounded by a lack of understanding of the system and a sense that their attempts to adjust to the care environment were having a negative impact on their mental health. Secondly, it seemed to young people that the care system was itself confused as to how to meet their needs, and thirdly, simply responding to young people’s behaviour is not helpful. There was an emphasis on the need for professionals to regard some behaviours as unsurprising and to avoid a simple fix-all answer to the different challenges faced by looked after children experiencing mental health difficulties.

Stanley (2007) also reports on qualitative work, which sought to elicit the views and experiences of looked after young people concerning their mental health needs. The work was carried out in two local authorities in England and included 14 young people aged between 12-18 years who each took part in one of four focus groups. Even for a study of this design this is a relatively small sample size, and this is further underlined by the fact that the study took place in two separate geographical areas, with presumably differing service provision, although this is not reported. Stanley (2007) also reported that young people perceived a discontinuity and disruption within the looked after system which they regarded as harmful to mental wellbeing. Young people also perceived matters such as self-harm to be an explicable response to distressing experiences. Young people attached value to counsellors or carers who themselves had experienced the looked after system as minors, a finding which Stanley suggests could inform staff and service planning initiatives.

In their Scottish study, Blower et al. (2004) interviewed 48 looked after young people to examine the need for mental health services for children and young people in care. Subsequent in-depth interviews were carried out with four young people who were described as having significant mental health difficulties. Blower (2004) report how they were impressed by how the young people in their study were able to describe developmentally appropriate, highly discriminating ways of obtaining emotional support. Whilst many of the young people interviewed described good strategies for coping with stress and demonstrated their ability to make use of available support networks, the authors concluded that there was a significant number who required further support with their mental health. They concluded that '... a majority of children and young people looked after by our local authority suffer from chronic and disabling mental health problems despite early recognition of their difficulties, attempts at solutions and supportive care settings' [2004:117].

The findings of the studies discussed above echo those of Davis and Wright (2008) in their review of the literature pertaining to looked after-children's views of mental health services. These authors note that young people are able to provide balanced views and to reflect on important aspects of services. They recommend that young people's opinions should be routinely collected in respect of service development and evaluation as well as in research. They also highlight an important issue, which is evident in the other papers discussed here, namely, the voices of younger, primary age children remain very sparsely represented in the research literature.

The value of consulting with children and young people about their experiences is underlined in the papers discussed. Within the mental health field, Stanley (2007) notes that consulting with young people enables a ‘lens shift’ whereby young people seem less challenging and more a group whose frustrations and demands reflect shortcomings in the looked after system. Winter (2006) highlights the extent to which research relating to looked after children’s health needs has tended to portray them as passive participants responding to an agenda set by adults. However, as Stanley (2007) and Mullan et al. (2012) point out, giving young people a say enables the empowerment of vulnerable young people who perhaps are more used to exclusionary or disempowering interactions.

9. Discussion

This literature review has addressed a broad range of issues relating to disabled looked after children and, in doing so, has highlighted the complex, overlapping and multi-faceted factors which impact on research in this area and on the provision of services aimed at promoting positive outcomes for this heterogeneous group and their families. The literature is as diverse as the population and in many instances there is very limited evidence relating to particular topics. For example, where there is a relatively substantial body of work on mental health outcomes for looked after children, there is relatively little evidence as to physical health, social or educational outcomes for disabled looked after children.

We found no papers which specifically focused on physically disabled children primarily or on children with sensory impairments, although both of these may have been included in diagnosis of children with multiple and complex impairments who were discussed in the literature. Children with developmental and intellectual impairments feature most commonly in the literature that broadly refers to 'disabled children', however there is less attention to children and young people with autism.

Moreover, it is also common for disabled children to be disaggregated from the general population of looked after children and only rarely do they feature in the broader looked after literature, which is substantial, and if so generally only by fleeting mention. Further gaps in the research evidence will be highlighted later in this section, however first we will turn a discussion of the key themes drawn from this review.

9.1 Discussing Prevalence

The question of prevalence of disability amongst the looked after population is one that is addressed by a number of authors. It is widely reported that disabled children and young people are over-represented in the looked after population however, the challenges and difficulties in calculating clear and accurate prevalence figures for the numbers of disabled looked after children, which are comparable across different jurisdictions, are also reported.

The principal difficulty relates to the lack of agreed definitions of disability used by different researchers and practitioners in various jurisdictions. Some include children with mental health difficulties in their count, others do not, some include children who solely have emotional and behavioural problems whilst others suggest that this inflates the numbers of looked after disabled children (Gordon, 2000). Moreover, in the UK the differing rules regarding the use of short breaks means that in some jurisdictions children who spend more than 24 hours in out of home care are counted within the looked after statistics, whilst in other areas the length of stay is extended before disabled children become categorised as looked after. There are no national prevalence datasets on disabled looked after children with each jurisdiction having its own definitional constructs and data collection systems. However, this problem is not restricted to the UK; problems in accurately describing prevalence are also noted internationally. Nevertheless, that disabled children are over-represented appears to be unchallenged.

The high prevalence of mental health difficulties among the population of looked after children is well established in the research literature, including large-scale studies (Meltzer, 2004). These findings are mirrored in smaller scale studies reporting on the high rates of mental ill health in the looked after population. That children are exposed to circumstances in their pre-care lives which may precipitate vulnerability to mental ill health is reported, however, it is also acknowledged that the experience of being a looked after child may also precipitate or compound such vulnerability.

Separation from birth parents, perhaps a change of school and community, the need to adjust to new living arrangements, possibly insecure placements and multiple moves, combined with a lack of a single trusted figure, are all factors which may raise the potential for the development of mental ill health. There is limited research evidence on the mental health status or need amongst children and young people with other types of impairment. Taggart et al.'s (2007) work on looked after children with both mental ill health and intellectual impairments is one exception.

The question of prevalence, both in overall terms and in relation to particular impairment types is important as it sets the scene for service planning both in terms of current provision as well as in relation to future service need. This resonates particularly in relation to those on the ‘edge of care’ and in relation to enabling sufficient in home support to be provided so as to maintain children and young people in their family home.

9.2 Reasons for Disabled Children Becoming Looked After

Consideration of contrasting points made in the literature raises particular questions about disabled children's pathway to becoming looked after. In the first instance, the literature indicates that most disabled looked after children are voluntarily accommodated. Given the strong evidence of raised vulnerability and high incidence of abuse against disabled children, combined with the majority of children being reported as voluntarily accommodated, Morris (1999) questions whether disabled children are always subject to child protection processes where there are concerns of neglect of abuse, or are protected through safe removal in a voluntary arrangement with parents. Specifically, Morris asks whether disabled children are being treated differently to non-disabled children in child protection and looked after systems.

9.3 Permanency and Stability

Seeking permanence and stability in placement, either through returning to the birth family or with a substitute family is the guiding policy for all looked after children. However, the literature reports that it is less likely for disabled children to be able to return home, if they do it is likely to be at an older age and after a longer period of being looked after. Disabled children are also less likely to be fostered and those who are will commonly be in a younger age group. The literature also states that with preparation and support, disabled children can be successfully fostered and integrated into the lives of foster families. However, there is some work to be done in encouraging the fostering of disabled children and in providing ongoing support to these families. Structured long-term support may enable the security of foster care for disabled looked after children, who are reported to benefit from inclusion in family life, being part of an extended family circle and feeling like a valued member of a family. Recommended foster carer supports include access to skilled professionals, the provision of information on medical needs and educational supports and the opportunity to avail of community support and therapeutic input.

The permanence of the family home can be undermined by insufficient in-home support to families with a disabled child with high support needs, which may include care in relation to a combination of medical, social and behavioural needs. The literature highlights a concerning situation where, without adequate in-home support, families are sometimes placed in a position where they feel unable to continue to cope with the ongoing demands of their caring role. Whilst national and international policy is underpinned by the principle of disabled children having a right to family life, this choice is sometimes undermined by the limited range of family and community supports available. The literature on short breaks clearly highlights the benefits of short breaks to parents (as well as to children and young people), in some instances enabling them to continue to care for their disabled child at home for most of the time (McConkey et al., 2004). The value of short breaks is, therefore, not simply providing a break for parents or a social outlet for disabled children. In some cases, it enables children who might otherwise drift into care to remain at home and enjoy the potential for improved life chances as a consequence.

9.4 Disabled Young People Leaving Care

Reflecting the lack of research addressing the experiences of disabled looked after children, there is a very limited range of literature on the lives of disabled care leavers as they progress from public care into their young adult lives. The impact of pre-care and in-care experiences on their post-care lives is under-researched. Similarly, very little is known about the transitional experiences of disabled young people as they move from child to adult service systems. Extant care leaving and transition literature does indicate that disabled care leavers are vulnerable to poorer outcomes in young adult life and are likely to need continued and specialist support during this transitional process. However, further research with disabled care leavers is necessary to develop further insights into their particular views and experiences.

Inequality of opportunity for disabled children who are living in and leaving the public care system is apparent, with fewer experiencing the opportunity to live in family situations, higher numbers living in congregate settings, fewer returning home and poorer outcomes in young adult life. Morris (1997) suggests that there is a tolerance of levels of care for disabled children and young people which would not be accepted for non-disabled children.

The research community has the opportunity to test this, not least through the greater inclusion of the voices and perspectives of children and young people in empirical work. Young people's voices have not been well represented to date, with a few notable exceptions, but through their inclusion the story of being looked after can become understood from the perspectives of those for whom this has been lived experience.

10. Implications for Policy and Research

The review of literature has highlighted particular gaps in knowledge and priority issues for future research and policy developments. As this literature review has been prepared as part of a wider study, it is hoped that the next stage of the project involving empirical research will address some of the identified issues. However, wider research and policy implications that require a strategic focus on disabled children and young people who are looked after in research and policy contexts are outlined below.

10.1 Implications for Policy

1. The literature is clear on the challenges relating to accurately reporting on numbers of disabled looked after children. As secondary data sources and different service systems use varied and conflated definitions of disability, it is not possible to build an accurate profile of this population. There is a need for a single accepted definition of disability in relation to looked after children and for regular, quality assured recording to be implemented. This would enable adequate population-based and outcomes-focused planning both in relation to current and prospective service need.

2. There are strong indications in the literature that unmet family support needs impact on parental ability to continue caring for their disabled child at home, particularly for parents of children presenting with multiple and complex needs or challenging behaviour. Insufficient domiciliary or residential short break support is reported to cause some families to seek permanent out-of-home placement for their child. The literature indicates that additional practical and emotional support, including increased short break provision, may enable families whose children are ‘on the edge’ of care to remain within their family home.

3. Whilst looked after disabled children are now firmly on the permanency agenda, their chances of achieving stability in a permanent substitute family are less than that of their non-disabled peers. As disabled children and young people are reported to be more likely to find a type of permanence in long term foster placements, policy

changes that enhance the parental status of foster parents may strengthen the sense of permanency that can be achieved in fostering arrangements.

4. Transition to young adult life is a complex and challenging time for any disabled young person and their family. For disabled young people leaving care, those challenges are further compounded. This group of care leavers is very likely to require access to adult services when they make the transition from public care and may have specialist support needs. Policy guidance on person-centred transition planning for disabled care leavers with clearly defined professional roles and multi-agency responsibilities from child through to adult services is essential to ensure the varied and often complex transition needs of disabled care leavers are met.

5. The voice of disabled children and young people who are looked after is largely absent in the evaluation of services and policy development for this population. There is a present need to improve the inclusion of disabled children and young people who are looked after in consultation on matters which affect them. In order to avoid tokenistic participation, such inclusion should lead to clear outcomes that inform the continued development of policy and practice initiatives.

10.2 Implications for Future Research

1. A significant gap in current research relates to establishing prevalence data on the population of disabled children who are looked after in Northern Ireland. Prevalence studies of disabled children and young people within the looked after population based on clear and agreed definitions would help to develop knowledge of the numbers and characteristics of this population.

2. An investigation of the features of family support that effectively enables families to provide ongoing care for their disabled child would support person centred planning in this area, inform efforts to prevent admission to care, and underpin the permanency agenda for disabled children on the ‘edge of care’.

3. There is a need for rigorous empirical research which focuses on outcomes for disabled looked after children in terms of education and physical, social and emotional wellbeing.

4. Investigation into the needs and experiences of disabled care leavers is not covered by existing literature and represents an additional important gap in knowledge. Moreover, we know little about how the experiences of disabled care leavers compare to that of non-disabled care leavers or how impairment categories and placement types impact on outcomes for disabled care leavers.

5. Future research in this area should be attentive to the inclusion of the views and perspectives of disabled children and young people where it is methodologically relevant and potentially impactful. The views of disabled looked after children are under-represented and those of disabled care leavers are almost absent from the literature. The inclusion of disabled children and young people on project steering committees should be standard practice and the development of participatory studies actively seeking the views and opinions of disabled children and young people living in and leaving public care should be prioritised.

References

Akister, J., Owens, M. & Goodyer, I. M. (2010) Leaving Care and Mental Health: Outcomes for children in out-of-home care during the transition to adulthood. *Health Research Policy and Systems, 8,* 1-10.

Akrami, N., Ekehammar, B., Claesson, M. & Sonnander, K. (2006) Classical and Modern Prejudice: Attitudes towards people with intellectual disabilities. *Research in Developmental Disabilities, 27, 605-617.*

Anderson, G. (2001) The Motives of Foster Parents, their Family and Work Characteristics. *British Journal of Social Work, 31,* 235-248.

Argent, H. (1984) *Find Me a Family.* London: Souvenir Press.

Aubrey, C. & Dahl, S. (2006) Children's Voices: The views of vulnerable children on their service providers and the relevance of services they receive. *British Journal of Social Work, 23,* 21-39.

Avery, R. J. (2000) Perceptions and Practice: Agency efforts for the hardest-to-place children. *Children and Youth Services Review, 22 (6)* 399-420.

Baines, C. (2009) Disabled Children with Communication Impairments. In: Burns, C. (ed) *Disabled Children Living Away From Home.* London: MacKeith Press.

Baker, C. (2007) Disabled Children's Experience of Permanency in the Looked After System. *British Journal of Social Work,* 37, 1173-1188.

Baldwin, S. & Carlisle, J. (1994) *Social Support for Disabled Children and their Families: A review of the literature.* London: HMSO.

Balogh, R., Bretherton, K., Whibley, S., Berney, T., Graham, S., Richold, P., Worsley, C. & Firth, H. (2001) Sexual Abuse in Children and Adolescents with Intellectual Disability. *Journal of Intellectual Disability Research, 45,* 194-201.

Benedrix, Y., Nordstrom, B. & Sivberg, B. (2006) Parents' Experience of Having a Child with Autism and Learning Disabilities Living in a Group Home: A case study. *Autism, 10(6),* 629-641.

Beresford, B. & Oldman, C. (2002) *Housing Matters: Evidence relating to disabled children and their housing.* Bristol: The Policy Press.

Beresford, B. (2004) On the Road to Nowhere? Young disabled people and transition. *Child: Care, Health and Development, 30(6),* 58-587.

Bergman, K., Sarkar, P., O'Connor, T.G., Modi, N. & Glover V. (2007) Maternal Stress During Pregnancy Predicts Cognitive Ability and Fearfulness in Infancy. *Journal of the American Academy of Child and Adolescent Psychiatry*, *46*, 1454–1463.

Berlin, M., Vinnerljung, B. & Hjern, A. (2011) School Performance in Primary School and Psychosocial Problems in Young Adulthood Among Care Leavers from Long- term Foster Care. *Children and Youth Services Review, 33,* 2489–2497.

Blackburn, C.M., Spencer, N.J. & Read, J.M. (2010) Prevalence of Childhood Disability and the Characteristics and Circumstances of Disabled Children in the UK: Secondary analysis of the Family Resources Survey. *BMC Pediatrics, 10(21),* 1-12.

Blower, S., Addo, A., Hodgson, J., Lamington, L. & Towlon, K. (2004) Mental Health of Looked after Children: A needs assessment. *Clinical Child Psychology and Psychiatry, 9(1),* 117-129.

Bone, M. & Meltzer, H. (1989) *OPCS Surveys and Disability in Great Britain, Report 3. The Prevalence of Disability amongst Children.* London: HMSO.

Braddock, D., Emerson, E., Felce, D. & Stancliffe, R.J. (2001) Living Circumstances of Children and Adults with Mental Retardation or Developmental Disabilities in the United States, Canada, England and Wales, and Australia. *Mental Retardation and Developmental Disabilities Research Reviews, 7,* 115-121.

Broad, B. (1999) Improving the Health of Children and Young People Leaving Care. *Adoption & Fostering, 23,* 40-48.

Brown, J. D. & Rodger, S. (2009) Children with Disabilities: Problems faced by foster parents. *Children and Youth Services Review, 31,* 40-46.

Brown, R. I., Geider, S., Primrose, A. & Jokinen, N.S. (2011) Family Life and the Impact of Previous and Present Residential and Day Care Support for Children with Major Cognitive and Behavioural Challenges: A dilemma for services and policy. *Journal of Intellectual Disability Research, 55,* 904-917.

Bruhn, C. M. (2003) Children with Disabilities: Abuse, neglect, and the child welfare system. *Journal of Aggression, Maltreatment and Trauma, 8 (1/2),* 173-203.

Burns, C. (2009) *Disabled Children Living Away From Home: In Foster Care and Residential Settings.* London: Mac Keith Press.

Cashmore, J. & Paxman, M. (2007), *Wards Leaving Care Four to Five Years On: A longitudinal study.* Sydney: Social Policy Research Centre, University of New South Wales.

Cavet, J. & Sloper, P. (2004) The Participation of Children and Young People in Decisions About UK Service Development. *Child; Care, Health and Development, 30,* 613-621.

Chamberlain, P., Price, J., Reid, J., LAndsverk, J., Fisher, P. & Stoolmiller, M. (2006) Who Disrupts from Placement in Foster and Kinship Care? *Child Abuse and Neglect, 30,* 409-424.

Chan, J.B. & Sigafoos, J. (2000) A Review of Child and Family Characteristics Related to the Use of Respite Care in Developmental Disability Services. *Child Youth Care Forum, 29,* 27-37.

Cooke, P. & Standon, P.J. (2002) Abuse and Disabled Children: Hidden needs….? *Child Abuse Review, 11,* 10-18.

Cotterill, L., Hayes, L., Flynn, M. & Sloper, P. (1997) Reviewing Respite Services: Some lessons from the literature. *Disability & Society, 12*, 775-788.

Cousins, J. (2006) *Every Child is Special: Placing Disabled Children for Permanence.* London: British Association for Adoption and Fostering.

Cousins, J. (2009) Disabled Children: Pathways to care. *In: C. Burns (ed) Disabled Children Living Away From Home; In Foster Care and Residential Settings.* London: MacKeith Press.

Cousins, W., Taggart, L. & Milner, S. (2010) Looked after or Overlooked? An exploratory investigation of the mental health issues of adolescents living in state care in Northern Ireland. *Psychology, Health & Medicine,* 15 (5), 497-506.

Crawford, M. (2006) Health of Children in Out-of-home Care: Can we do better? *Journal of Paediatrics & Child Health, 42,* 77-78.

Cuddeback, E. (2004) Kinship Family Foster Care: A methodological and substantive analysis of research. *Children and Youth Services Review, 26(7),* 623-639.

Damiani, G., Rosenbaum, P., Swinton, M. & Russell, D. (2004) Frequency and Determinants of Formal Respite Service Use Among Caregivers of Children with Cerebral Palsy in Ontario. *Child: Care, Health and Development, 30,* 77-86.

Davis, J. & Wright, J. (2008) Children's Voices: A review of literature pertinent to looked-after children's views of mental health services. *Child and Adolescent Mental Health, 13 (1),* 26-31.

Dejong, M. (2010) Some Reflections on the Use of Psychiatric Diagnosis in the Looked After or "In Care" Child Population. *Clinical Child Psychology & Psychiatry, 15 (4),* 589-599.

Dekker, M.C., Koot, H.M., van der Ende, J. & Verhuslt, F. (2002) *Emotional and Behavioural Problems in Children and Adolescents with and without Intellectual Disabilities in Northern Ireland.* Belfast; DHSSPSNI.

Department for Children, Schools and Families (2008) *Children Looked After in England (including adoptions and care leavers) Year Ending 31 March 2008.* London DSCF. (www.dcsf.gov.uk/rsgateway/D8/SFR/s000810/index.shtml)

Department for Education and Skills (2004) *Disabled Children in Residential Placements.* London: DfES.

Department for Education and Skills (2003) *Every Child Matters.* London: Stationery Office.

DENI (2010) *Attendance at Grant-Aided Primary, Post-Primary and Special Schools 2008/2009: Detailed Statistics.* Belfast Department for Education Northern Ireland.

DHSSPSNI (2006a) *The Bamford Review of Mental Health and Learning Disability (Northern Ireland): A Vision Of A Comprehensive Child And Adolescent Mental Health Services*. Belfast: DHSSPSNI.

DHSSPSNI (2006b) *The Bamford Review of Mental Health and Learning Disability (Northern Ireland): Equal Lives: Review of Policy and Services for People with a Learning Disability in Northern Ireland*. Belfast: DHSSPSNI.

DHSSPSNI (2007) *Care Matters In Northern Ireland: A Bridge to a Better Future.* Belfast: DHSSPSNI.

DHSSPSNI (2009) *Families Matter: Supporting Families in Northern Ireland, Regional family and Parenting Strategy.* Belfast: DHSSPSNI.

DHSSPSNI (2009) *Statistics About the Wellbeing of Young People Leaving Care – September 2008.* Belfast: DHSSPSNI.

DHSSPSNI (2010a) *Outcome Indicators for Looked After Children: year Ending 30th September 2009.* Belfast: DHSSPSNI.

DHSSPSNI (2010b) *Child Care in Northern Ireland 2008/9: Statistical Bulletin.* Belfast: DHSSPSNI.

DHSSPSNI (2011) *Transforming Your Care: A Review of Health and Social Care in Northern Ireland.* Belfast: DHSSPSNI.

DHSSPSNI (2011) *Northern Ireland Care Leavers Aged 19 Statistical Bulletin 2009/10*. Belfast: DHSSPSNI.

DHSSPSNI (2012) *Children in Care in Northern Ireland 2009/2010 Statistical Bulletin*. Belfast: DHSSPSNI & NISRA.

Diminigen, G., Del Priore, C., Butler, S., Evans, S., Ferguson, L. & Swan, M. (1999) Psychiatric Disorder Among Children at the Time of Entering Local Authority Care. Questionnaire Survey: *British Medical Journal, 319,* 675.

Dixon, J. (2008) Young People Leaving Care: Health, well-being and outcomes**.** *Child & Family Social Work*, *13,* 207-217.

Dozier, M., Peloso, E., Lindheim, O., Gordon, M.K., Manni, M,. Sepilveda, S., Ackerman, J. Bernier, A. & Levine, S. (2006) Developing Evidence Based Interventions for Foster Children: An example of a randomised controlled clinical trial with infants and toddlers. *Journal of Social Issues, 62,* 767-785.

Egelund, T. & Lausten, M. (2009) Prevalence of Mental Health Problems Among Children Placed in Out-of-home Care in Denmark. *Child & Family Social Work, 14(2,)* 136-165.

Emerson, E., Barron, D. A., Blacher, J. et al. (2012) *Better Health, Better Lives: Research Priorities.* Geneva: World Health Organisation.

Emerson, E. (2012) Understanding Disabled Childhoods: What we can learn from population-based studies? *Children & Society, 26 (3),* 214-222.

Emerson, E. (2010) Deprivation, Ethnicity and the Prevalence of Intellectual and Developmental Disabilities. *Journal of Epidemiology and Community Health, 68,* 218-224.

Emerson, E. & Hatton, C. (2007) The Socio-Economic Circumstances of Children at Risk of Disability in Britain. *Disability & Society, 22,* 563-580.

Emerson, E. & Hatton, C. (2007b) The Contribution of Socioeconomic Position to the Health Inequalities Faced by Children and Adolescents with Intellectual Disabilities in Britain. *American Journal on Mental Retardation, 112(2),* 140-150.

Emerson, E. (2005) Use of the Strengths and Difficulties Questionnaire to Assess the Mental Health Needs of Children and Adolescents with Intellectual Disabilities. *Journal of Intellectual and Developmental Disability, 30 (1)* 1-10.

Emerson, E. (2003) The Prevalence of Psychiatric Disorders in Children and Adolescents With and Without Intellectual Disabilities. *Journal of Intellectual Disability Research, 47,* 51-58.

Everson-Hock, E.S., Jones, R., Guillaume, L., Clapton, J., Goyder, E., Chilcott, J., Payne, N., Duenas, A., Sheppard, L.M. & Swan, C. (2011) The Effectiveness of Training and Support for Carers and Other Professionals on the Physical and Emotional Health and Well-Being of Looked After Children and Young People: A systematic review. *Child: Care, Health and Development, 38(2),* 162-174.

Ford T., Vostanis, P., Meltzer, H. & Goodman, R. (2007) Psychiatric Disorder among British Children Looked After by Local Authorities: Comparison with children living in private households. *British Journal of Psychiatry, 190 (Apr.),* 319-325.

Frensch, K.M. & Cameron, G. (2002) Treatment and Choice or a Last Resort? A review of residential mental health placements for children and youth. *Child & Youth Care Forum, 31,* 307-339.

Fudge Schormans, A., Coniega, M. & Renwick, R. (2006). Enhancing quality of life for children with developmental disabilities in child welfare: Significance of placement stability. *Families in Society, 87 (4),* 521-528.

Gallimore, R., Weisner, T.S., Bernheimer, L.P., Guthrie, D. & Nihira, K. (1993) Family Responses to Young Children with Developmental Delays: Accommodation activity in ecological and cultural context. *American Journal of Mental Retardation, 94,* 250-258.

Geenen, S. J., Powers, L. E., Hogansen, J. M., & Pittman, J. O. E. (2007). Youth with Disabilities in Foster Care: Developing self-determination within a context of struggle and disempowerment. *Exceptionality, 15,* 17-30.

Glaser, D. (2000) Child Abuse and Neglect and the Brain: A review. *Journal of Child Psychology and Psychiatry*, *41*, 97–116.

Goetting, A. & Goetting, M.G. (1993) Voluntary Parents to Multiple Children with Special Needs: A profile. *Journal of Child and Family Studies, 2 (4),* 353-369.

Goldblatt, B., Edwards, R., McHugh, M., Katz, I., Abello, D., Eastman, C. & Heese, K. (2010) *Evaluation of the Leaving Care Program.* Sydney: Social Policy Research Centre, University of New South Wales.

Golding, K. S. (2010) Multi-agency and Specialist Working to Meet the Mental Health Needs of Children in Care and Adopted. *Clinical Child Psychology and Psychiatry, 15(4),* 573-587.

Goodman, R., Ford T., Corbin, T. & Meltzer, H. (2004) Using the Strengths and Difficulties Questionnaire (SDQ) Multi-Informant Algorithm to Screen Looked-After Children for Psychiatric Disorders. *European Child and Adolescent Psychiatry, Supplement, 13(2),* II/25-II/31.

Gordon, D,. Parker, R. & Loughrin, F. (2000) *Disabled Children in Britain: A Re-analysis of the OPCS Disability Survey*. London; Stationery Office.

Grieg, A. & Taylor, J. (2007) *Doing Research with Children, 2nd Edition* Thousand Oaks: Sage Publications.

Grigal, M., Hart, D. & Migliore, A. (2011) Comparing the Transition Planning, Postsecondary Education, and Employment Outcomes of Students With Intellectual and Other Disabilities. *Career Development for Exceptional Individuals, 34* (4) 4-17.

Helton, J. J. (2011) Children with Behavioural, Non-Behavioural and Multiple Disabilities, and the Risk Of Out-of-home Placement Disruption. *Child Abuse and Neglect, 35,* 956-964.

Hill, K. (2012) Permanency and Placement Planning for Older Youth with Disabilities in Out-of-home Placement. *Children and Youth Services Review, 34,* 14118-1424.

Hill, C. & Thompson, M. (2003) Mental and Physical Health Co-morbidity in Looked After Children. *Clinical Child Psychology and Psychiatry, 8 (3,)* 315-321.

Hill, C. M. & Watkins, J. (2003) Statutory Health Assessments for Looked After Children. What do they achieve? *Child: Care, Health and Development, 29***,** 3–13.

Hunt, E. (2003) *Family and Friends Carers: Scoping Paper Prepared for the Department of Health.* London: Department of Health.

Jackson, S. & McParlin, P. (2006) The Education of Children in Care. *The Psychologist*, *19*, 90-93.

Jones, L. Bellis, M.B. Wood, S. Hughes, K. McCoy, E. Eckley, L. Bates, G. Christopher, M. Shakespeare, T. Officer, A. (2012) *Prevalence and Risk of Violence Against Children with Disabilities: a Systemativ Review and Meta-analysis of Observational Studies.* The Lancet: Published online; http://dx.doi.org/10.1016/50140-6736(12)606928

Katz, L., Au, W., Singal, D., Brownell, M., Roos, N., Martens, P.J., Chateau, D., Enns, M.W., Kozyrskyi, A.L. & Sareen, J. (2011) Suicide and Suicide Attempts in Children and Adolescents in the Child Welfare System. *CMAJ, November 22, 183(17),* 1977-1981.

Kelly, C., Allan, S., Roscoe, P. & Herrick, E. (2003) The Mental Health Needs of Looked After Children: An integrated multi-agency model of care. *Clinical Child Psychology and Psychiatry. 8 (3),* 323-335.

Kelly, B., McColgan, M. & Scally, M. (2000) ‘A Chance to Say: Involving Children with Learning Disabilities in a pilot study on family support services’, *Journal of Intellectual Disabilities, 4(2),* 115–27.

Kelly, B. (2007) Methodological Issues for Qualitative Research Involving Learning Disabled Children. *International Journal of Social Research Methodology: Theory and Practice, 10(1),* 21-35.

Kerker, B.D. & Dore, M.M. (2006) Mental Health Needs and Treatment of Foster Youth: Barriers and opportunities. *American Journal of Orthopsychiatry, 76 (1),* 138-147.

Laan, N. M. A., Loots, G. M. P., Janssen, C. G. C. & Stolk, J. (2001) Foster Care and Children with Mental Retardation and Challenging Behaviour: A follow-up study. *The British Journal of Developmental Disabilities, 47(1),* 3-13.

Lightfoot, E. Hill, K. & LaLiberte, T. (2011) Prevalence of Children with Disabilities in the Child Welfare System and Out Of Home Placement: An examination of administrative records. *Children and Youth Services Review,* 33, 2069-2075.

Llewellyn, G. Dunn, P. Fante, M. Turnbull, L. & Grace, R. (1999) Family Factors Influencing Out-of-home Placement Decisions. *Journal of Intellectual Disability Research, 43(3),* 219-233.

Lowe, N., Murch, M., Bader, K., Borokowski, M., Copner, R., Lisles, C. & Shearman, J. (2002) *The Plan for the Child: Adoption or Long-Term Fostering.* London: BAAF.

MacArthur, J., Sharp, S., Kelly, B. & Gaffney, M. (2007) Disabled Children Negotiating School Life: Agency, difference and teaching practice. *International Journal of Children's Rights, 15,* 99–120*.*

MacDonald, G. & Turner, W. (2005) An Experiment in Helping Foster-Carers to Manage Challenging Behaviour. *British Journal of Social Work, 35,* 1265-1282.

Macaskill, C. (1985) *Against The Odds.* London: British Agencies for Adoption and Fostering.

Marchant, R. & Jones, M. (2000) Assessing the Needs of Disabled Children and their Families. In Department of Health *Assessing Children in Need and their Families*. London: The Stationery Office.

McCann, J., James, A., Wilson, S. & Dunn, G. (1996) Prevalence of Psychiatric Disorders Among Young People in the Care System. *British Medical Journal, 313,* 1529-1530*.*

McAuley, C. & Young, C. (2006) The Mental Health of Looked After Children: Challenges for CAMHS provision. *Journal of Social Work Practice, 20 (1),* 91-103.

McAuley, C. & Davis, T. (2009) Emotional Well-Being and Mental Health of Looked After Children in England. *Child & Family Social Work, 14(2),* 147-155.

McConkey, R., Kelly, F. & Craig, S. (2012) A National Comparative Study Over One Decade of Children with Intellectual Disabilities Living Away From their Natural Parents. *British Journal of Social Work (forthcoming)*

McConkey, R. Gent, C. & Scowcroft, E. (2011) Critical Features of Short Break and Community Support Services to Families and Disabled Young People Whose Behaviour is Severely Challenging. *Journal of Intellectual Disabilities, 15(4),* 252-268.

McConkey, R., Nixon, T., Donaghy, E. & Mulhern, D. (2004a) The Characteristics of Children with a Disability Looked After away from Home and their Future Service Needs. *British Journal of Social Work, 34 (4),* 561-576.

McConkey, R., Truesdale, M. & Conliffe, C. (2004b) The Features of Short-Break Residential Services Valued by Families who have Children with Multiple Disabilities. *Journal of Social Work, 4,* 61-75.

McConkey, R. & Adams, L. (2000) Matching Short Break Services for Children with Learning Disabilities to Family Need Preferences. *Child: Care, Health and Development, 26(5),* 429-444.

McGill, P., Papachristoforou, E. & Cooper, V. (2006) Support for Family Carers of Children and Young People with Developmental Disabilities and Challenging Behaviour. *Child: Care, Health and Development, 32,* 159-165.

McNicholls, F., O'Connor, N., Bandyopadhyay, G., Doyle, P., O'Donovan, A. & Belton, M. (2011) Looked After Children in Dublin and their Mental Health Needs. *Irish medical journal, 104, (4),* 105-108.

Meltzer, H., Gatward, T., Goodman, R. & Ford, T. (2000) *Mental Health of Children and Adults in Great Britain.* London: Mental Health Foundation.

Meltzer, H., Gatward, T., Corbin, T., Goodman, R. & Ford, T. (2003) *The Mental Health of Young People Looked after by Local Authorities in England.* London: Stationery Office.

Messing, J. (2006) From the Child's Perspective: A qualitative analysis of kinship care placements. *Children and Youth Services Review. 28 (12),* 1415-1435.

Milburn, N.L., Lynch, M. & Jackson, J. (2008) Early Identification of Mental Health Needs for Children in Care. *Clinical Psychology and Psychiatry, 13 (1),* 31-47.

Minnis, H., Pelosi, A., Knapp, M. & Dunn, J. (2001) Mental Health and Foster Care Training. *Archive of Disease in Childhood, 84,* 302-306*.*

Mirfin- Veitch, B., Bray, A. & Ross, N. (2003) It Was the Hardest and Most Painful Decision of My Life! Seeking permanent out-of-home placement for sons and daughters with intellectual disabilities. *Journal of Intellectual & Developmental Disabilities. 28 (2),* 99-111.

Mooney, A., Statham, J. & Monck, E. (2009) *Promoting the Health of Looked After Children: A study to inform revision of the 2002 guidance*. London: Institute of Education, University of London.

Morris J. (1997) Gone missing? Disabled Children Living Away From their Families. *Disability and Society, 12 (2),* 241-258.

Morris, J. (1999) Disabled Children, Child Protection Systems and the Children Act 1989. *Child Abuse Review, 8,* 91-108.

Morris, J. (2000) *Having Someone Who Carse? Barriers to Change in the Public Care of Children*. London; National Children's Bureau and Joseph Rowntree Foundation.

Morris, J., Abbott, D. & Ward, L. (2002) At Home or Away? An Exploration of Policy and Practice in the Placement of Disabled Children at Residential Schools. *Children & Society, 16,* 3-16.

Morris, J. (2002) A Lot to Say: A Guide for Social Workers, Personal Advisors, and Others Working with Disabled Children and Young People with Communication Aids. *London: Scope.*

Mount, J., Lister, A. & Bennun, I. (2012) Identifying Mental Health Needs of Looked After Children. *Clinical Child Psychiatry and Psychology, 9(3),* 363-382.

Mullan, C. & Fitzsimons, L. (2006) *CASPAR Project: The Mental Health of Looked After Children/Care Leavers in Northern Ireland: A Literature Review*. Belfast: Voice of Young People in Care (VOYPIC).

Mullan, C., McAlister, S., Tollock, F. & Fitzsimons, L. (2007) 'Care Just Changes Your Life.': Factors Impacting upon the Mental Health of Children and Young People with Experiences of Care in Northern Ireland. *Child Care in Practice, 13(4)* 417-434.

Nankervis, K., Rosewarne, A. & Vassos, M. (2011a) Why Do Families Relinquish Care? An investigation of the factors that lead to relinquishment into out-of-home respite care. *Journal of Intellectual Disability Research. 55(4),* 422-433.

Nankervis, K., Rosewarne, A. & Vassos, M. (2011b) Respite and Parental Relinquishment of Care: Comprehensive review of the available literature. *Journal of Policy and Practice in Intellectual Disabilities, 8(3),* 150-162.

National Foster Care Association (2000) *Rights of Passage: The transition from foster care to adult life: a study of young people with learning difficulties.* London. National Foster Care Association

Northern Ireland Statistics and Research Agency. (2007) *The Prevalence of Disability and Activity Limitations amongst Adults and Children Living in Private Households in Northern Ireland. First Report from the Northern Ireland Survey of People with Activity Limitations and Disabilities.* NISRA: Belfast.

O'Brien, V. (2012) The Benefits and Challenges Of Kinship Care. *Child Care in Practice, 18 (2),* 127-146.

O'Brien, V. (2002) Relative Care: Issues for social workers. *Irish Journal of Applied Social Studies. 3,* 51-68.

O'Brien, V. (2009) *Contact and Kinship care.* Paper presented at the International Foster Care Conference: Linking Global Foster Care, University College Dublin.

O'Connell M. E., Boat T. & Warner K.E. (Ed.) (2009) *Preventing Mental, Emotional, and Behavioral Disorders Among Young People: Progress and Possibilities.* Washington, DC: The National Academies Press.

OFMDFM (2006) *Our Children, Our Pledge: A 10-Year Strategy for Children and Young People in Northern Ireland. 2006-2016.*

O'Toole, B. & McConkey, R. (1995) *Innovations in Developing Countries for People with Intellectual Disabilities.* Chorley Lancs, Lisieux hall Publications.

Oswin, M. (1978) *Children Living in Long-Stay Hospitals.* London: Spastics International Medical Publications.

Oswin, M. (1984) *They Keep Going Away: A Critical Study of Short-Term Residential Care Services for Children who are Mentally Handicapped.* London: King Edwards Hospital Fund.

Paul, A. & Cawson, P. (2002) Safeguarding Disabled Children in Residential Settings. *Child Abuse Review. 11,* 262-281.

Pecora, P.J., White, C.R., Jackson, L.J. & Wiggins, T. (2009) Mental Health of Current and Former Recipients of Foster Care: A review of recent studies in the USA. *Child & Family Social Work, 14 (2),* 132-146.

Philips, R. (1998) Disabled Children in Permanent Substitute Families. *In: Robinson, C. & Stalker, K. (eds) Growing Up with Disability.* London and Philadelphia, Jessica Kingsley Publishers.

Pithouse, A. Hill-Tout, J. & Lowe, K. (2002) Training Foster Carers in Challenging Behaviour: A case study in disappointment? *Child and Family Social Work, 7,* 203-214.

Polnay, L. & Ward, H. (2000) Promoting the Health of Looked After Children. *British Medical Journal*, *320,* 661–662.

Preece, D. (2002) Consultation with Children with Autistic Spectrum Disorders about their Experience of Short-term Residential Care. *British Journal of Learning Disabilities, 30,* 97-104.

Rabiee, P. Priestley, M. & Knowles, J. (2001). *Whatever Next? Young disabled people leaving care*. Leeds: First Key.

Read, J. & Harrison, C. (2002) Disabled Children Living Away From Home in the UK: Recognising hazards and promoting good practice. *Journal of Social Work, 2(2),* 211-231.

Read, J. Blackburn, C. & Watson, N. (2012) Disabled Children and their Families: A decade of policy change. *Children and Society 26,* 223-233.

Richardson, J. & Lelliott, P. (2003) Mental Health of Looked After Children. *Advances in Psychiatric Treatment, 9,* 249-257.

Roach, M.A. & Orsmond, G.I. (1999) Mothers and Fathers of Children with Down Syndrome: Parental stress and involvement in child care. *American Journal of Mental Retardation, 104 (5),* 422-436.

Robinson, C. & Stalker, K. (1998) *Growing Up with Disability.* London: Jessica Kingsley.

Robinson, C. Jackson, P. & Townsley, R. (2001) Short Breaks for Families Caring for a Disabled Child with Complex Health Needs. *Child and Family Social Work, 6,* 67-75.

Romney , S.C., Litrownik, A.J., Newton, R.R. & Lau, A. (2006) The Relationship between Child Disability and Living Arrangement in Child Welfare. *Child Welfare, 85(6),* 965-984.

Rosenberg, S.A. & Robinson, C.C. (2004) Out-of-home Placement for Young Children with Developmental and Medical Conditions. *Children and Youth Services Review. 26,* 711-723.

Rowe, J. & Lambert, L. (1973) *Children Who Wait.* London: The Association of British Adoption Agencies.

Sawbridge, P. (1975) *Opening new Doors.*London: British Agencies for Adoption and Fostering.

Schofield, G., Thoburn, J., Howell, D. & Dickens, J. (2007) The Search for Stability and Permanence: Modelling Pathways of Long-Stay Looked After Children. *British Journal of Social Work, 37.* 619-642.

Shakespeare, T. & Watson, N. (1998) Theoretical Perspectives on Research with Disabled Children. In: Robinson, C. & Stalker, K. (eds) *Growing Up with Disability.* London: Jessica Kingsley.

Silberman, P., Bodfish, J., Brown, A. T., Wainwright, L., Yorkery, B., Lichstein, J., Alexander-Bratcher, K., Davis, C. S., Lerche, J. & Holmes, M. (2009) Successful Transitions for People with Intellectual and Other Developmental Disabilities. *North Carolina Medical Journal*, 70 (6), 519-26.

Sinclair, I., Wilson, K. & Gibbs, I. (2004) *Foster placements: Why Some Succeed and Some Fail.* London: Jessica Kingsley.

Sinclair, I., Baker, C., Wilson, K. & Gibbs, I. (2005) *Foster Children: Where They Go and How They Get On.* London: Jessica Kingsley.

Slevin, E., Taggart, L., McConkey, R., Cousins, W., Truesdale-Kennedy, M. & Dowling, S. (2011) *Supporting People with Intellectual Disabilities who Challenge or who are Ageing: A Rapid Review of Evidence*. Belfast: University of Ulster.

Sobsey, D. (1994) *Violence and Abuse in the Lives of People with Disabilities. The End of Silent Acceptance?* Baltimore, MD: Paul H. Brookes.

Sprang, G. (2008) The efficacy of a Relational Treatment for Maltreated Children and their Families. Journal of *Child and Adolescent Trauma, 2,* 242-252.

Stalker, K. & McArthur, K. (2012) Child Abuse, Child Protection and Disabled Children; A review of recent research. *Child Abuse Review, 21,* 24-40.

Stein, M. (2008) 'Transitions from Care to Adulthood: Messages from Research for Policy and Practice', in Stein, M. and E. Munro (eds.) *Young People's Transitions from Care to Adulthood: International research and practice,* London: Jessica Kingsley (pp. 289-306).

Stein, M. & Dumaret. A. (2011) The Mental Health of Young People Ageing Out of Care and Entering Adulthood: Exploring the evidence from England and France. *Children and Youth Services Review 33,* 2504–2511.

Stein, M. & Munro, E. (Eds.) (2008) *Young People's Transitions from Care to Adulthood: International research and practice.* London: Jessica Kingsley.

Sullivan, P. M. & Knutson, J. (2000) The Association between Child Maltreatment and Disabilities in a Hospital-Based Epidemiological Study. *Child Abuse & Neglect,* 22, 271-288.

Taggart, L., Cousins, W. & Milner, S. (2007) Young People with Learning Disabilities Living in State Care: Their emotional, behavioural and mental health status. *Child Care in Practice. 13 (4),* 401-416.

Tarren-Sweeney, M. (2008) The Mental Health of Children in Out-of-home Care. *Current Opinion in Psychiatry, 21,* 345-349.

Teggart, T. & Menary, J. (2005) An Investigation of the Mental Health Needs of Children Looked After by Craigavon and Banbridge Health and Social Services Trust. *Child Care in Practice, 11 (1),* 39-49.

Treneman, M., Corkery, A., Dowdney, L. & Hammond, J. (1997) Respite-Care Needs – Met and Unmet Need: Assessment of needs for children with a disability. *Developmental Medicine and Child Neurology, 39,* 548-553.

Trout, A. L., Casey, K., Chmelka, M.B., DeSalvo, C., Reid, R., & Epstein, M.H. (2009) Overlooked: Children with Disabilities in Residential Care. *Child Welfare League of America, 88(2),* 111- 136.

UNICEF. (2007) *Children's Rights and Responsibilities.* UNICEF: Florence.

United Nations (1989) Convention on the Rights of the Child. New York and Geneva: United Nations.

United Nations. (2006) Convention on the Rights of Persons with Disabilities and Optional Protocol. New York and Geneva: United Nations.

Unwin, G., Le Mesurier, N., Bathia, N. & Deb, S. (2008) Transition for Adolescents and Young Adults with Learning Disabilities and Mental Health Problems/Challenging Behaviours: The parent carers' views. *Advances in Mental Health and Learning Disabilities*, *2* (1) 22-28.

Vinnerljung, B., Hjern, A. & Lindblad, F. (2006) Suicide Attempts and Severe Psychiatric Morbidity among Former Child Welfare Clients: A National Cohort Study. *Journal of Child Psychology and Psychiatry, 47* (7), 723–733.

Vostanis, P. (2005) 'Meeting the Mental Health Needs of Young People Leaving Care: Strategies and challenges', in B. Broad, *Improving the health and wellbeing of young people leaving care.* Dorset: Russell House Publishing (pp. 108-116).

Wade, J. and Munro, E. (2008) 'United Kingdom', in Stein, M. and E. Munro (eds.) *Young People's Transitions from Care to Adulthood: International research and practice,* London: Jessica Kingsley (pp. 225-238).

Ward, L., Mallett, R., Heslop, P. and Simons, K. (2003) Transition Planning: How well does it work for young people with learning disabilities and their families? *British Journal of Special Education, 30* (3) 132–137.

Westcott, H.L. & Jones, D. (1999) Annotation: The abuse of children. *Journal of Child Psychology and Psychiatry, 40,* 497-506.

Winokaur, M., Holtan, A., & Valentine, D. (2009) Kinship Care for the Safety, Permanency and Wellbeing of Children Removed from Home for Maltreatment. *Cochrane Database of Systematic Reviews, 1, Article no. CD006546, doi: 10.1002/14651858.CD006546pub2.*

Winter, K. & Connolly, P. (2005) A Small Scale Study of the Relationship Between Child Care Referrals and Measures of Deprivation. *British Journal of Social Work*, *35*, 937–952.

Winter, K. (2006) Widening our Knowledge Concerning Young Looked After Children: The care for research using sociological models of childhood. *Child and Family Social Work, 11,* 55-64.

World Health Organisation. (2001) *The World Mental Health Report 2001, Mental Health New Understanding, New Hope.* World Health Organisation: Geneva.

Zeitlin, A. (2006) The Experiences of Foster Children and Youth in Special Education. *Journal of Intellectual and Developmental Disability, 31,* 161-165.

Zivani, J. Feeney, R. Cuskelly, M. Meredith, P. & Hunt. K. (2012) Effectiveness of Support Services for Children and Young People with Challenging Behaviours Related to or Secondary to Disability, Who are in Out-of-home Care: A systematic review. *Children and Youth Services Review, 34,* 758-770.

Appendix 1: Review Methods

Inclusion Criteria

Working within these parameters the following inclusion criteria have guided the selection of papers that have been to be included in the review; these criteria are subject to review following initial searching and screening of results:

a) Papers should be published between 2000 and the present day but with the inclusion of seminal papers or those produced by known experts in the field published prior to that date.
b) Papers should be published in English in peer-reviewed journals[5].
c) Papers should refer to the population of interest to this review and should be directly relevant to at least one of the research questions.

Searching Databases

Searches have been conducted on the following databases; selected on the basis that they hold a range of references across the social, medical and health sciences.

- **ASSIA: Applied Social Sciences Index and Abstracts** covers topics relevant to this review including health, social services, psychology, sociology, and education;
- **Campbell collaboration**
- **ChildData covers b**ooks, reports and journal articles on children and young people, including the Highlight series and all articles from Children & Society.
- **Cinahl Plus** provides indexing from the fields of nursing and allied health;
- **Cochrane**
- **Directory of Open Access Journals**
- **EPPI Centre**
- **OVID Medline** covers the international literature on biomedicine, including the allied health fields and the biological and physical sciences, humanities, and information science as they relate to medicine and health care. Information is indexed from approximately 5,400 journals published world-wide.

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[5] After the initial search of databases for published peer reviewed literature, consideration will be given to the inclusion of grey literature, namely research reports and policy documents.

- **PsycINFO** provides abstracts and citations to the scholarly literature in the psychological, social, behavioral, and health sciences;
- **SCOPUS** covers nearly 20,000 academic journals from a wide range of subjects and dates from 1996 to the present.
- **Social Care Online**, a UK database of information and research on all aspects of social care and social work including legislation, government documents, practice and guidance, systematic reviews, research briefings, reports and journal articles.
- **Web of Science** carries indexed references across 55 social science disciplines, as well as selected items from 3,500 of the world's leading scientific and technical journals.

Search Strategy

The keywords below were used to search for literature using the databases outlined. Cross searches were carried out using the combinations detailed in points 15-18. However, in addition a number of discrete focused searches were made with lesser numbers of key words in each search to enable more manageable numbers of returns as well as lowering the chance of missing relevant papers.

Keywords

1. Looked after
2. In care or public care or care order or foster care or residential care or living away from home or out-of-home placement
3. Residential school* or hospital
4. Short break* or respite
5. 1+2+3
6. 5+4
7. Child protection or abuse or neglect
8. Intellectual disabilit* / impairment or learning disabilit* or learning difficult* or developmental disability* or mental retard* or cognitive impairment
9. Sensory disabilit*/impairment or blind* or partially sight* or deaf* or hearing impair*
10. Physical disabilit* or wheel chair user

11. Mental health or mental ill* or mental incapacity* or CAMHS or psychiatr* or psychosis or schizophren *
12. Down syndrome or cerebral palsy or Attention Deficit Hyperactivity Disorder or Attention Deficit Disorder or autism or autistic spectrum
13. 7 and 8 and 9 and 10 and 11 and 12
14. Child* or young people, or young person* or teen* or adolescen*
15. 13 and 14
16. 5 and 15
17. 6 and 15
18. 7 and 15

Screening Process

A first screen of results from searches of databases was undertaken by removing any duplicates and then carefully reading the titles of all papers. Those that were clearly not relevant were deleted at this stage, whilst those that appeared broadly or specifically relevant were saved to 'Refworks', a reference management software. A significant number of papers were removed following this first screen of titles returned, most commonly because they focused on disabled children and young people who were not looked after or looked after children and young people who were not disabled.

References which survived the first screening were stored within *Refworks* for the second screening procedure. This process was completed through a careful reading of the abstract for each paper. Papers at this stage were again judged against the inclusion criteria and were included if they met this criteria. Reference lists of included papers were also screened to identify any further relevant publications which were not found through searching databases. A record of the numbers of papers returned from database searches and the numbers of papers removed at each stage of the screening process is provided below. At the end of the screening process, 57 empirical and/or theoretical papers met the criteria for inclusion in the review and a further 70 background papers were included to generally inform the discussion.

Flow Chart 1: Search and Screening Results

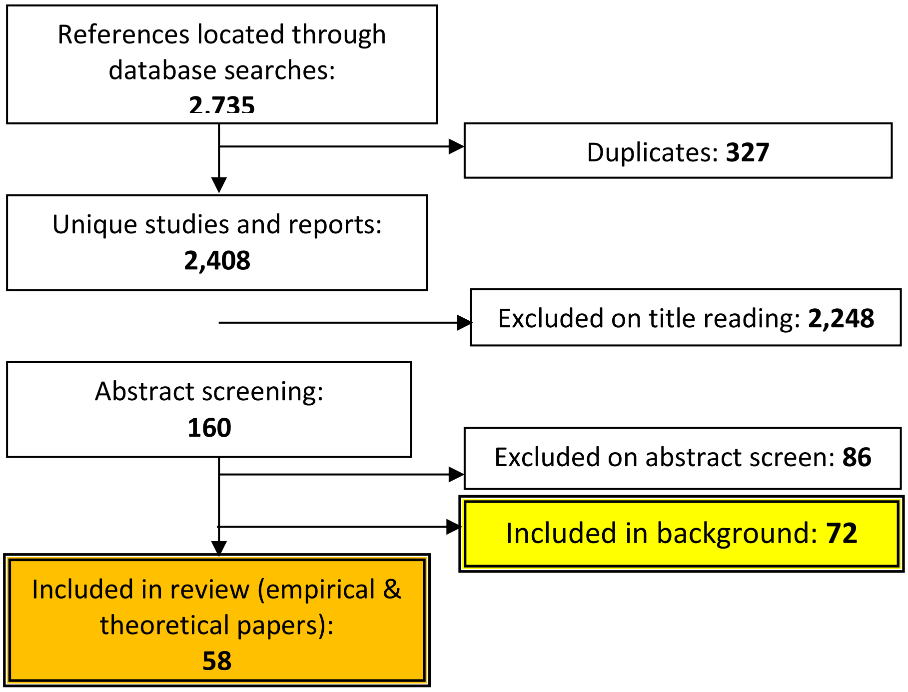

Table 1: Geographical origins of included papers

Country	Papers
Northern Ireland	8
UK (excluding NI)	25
USA & Canada	14
Australia & New Zealand	5
Other	6

Table 2: Profile of Papers

Type	#	Focus of paper (May be more than one category)	#
Empirical	**28**	Mental health	**26**
		Intellectual disability	**6**
		Sensory disability	**1**
Theory / Commentary	**30**	Disability (aggregated)[6]	**26**
		Children's voices	**5**
		Abuse/child protection	**4**
		Autism/ADHD	**2**
Total	58	Prevalence	**12**

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[6] No papers were solely dedicated to physical disability although some papers addressing disability generally or multiple disabilities (aggregated) included physical disability to a greater or lesser degree.

Appendix 2:

Quality Assessment & Evidence Tables

Table 1: Quality Assessment of Studies

<table>
<tr><th colspan="5">Criteria used for quality assessment of included studies.</th></tr>
<tr><td></td><td>Reporting, transparency</td><td>Appropriateness of study design</td><td>Quality of execution</td><td>Relevance</td></tr>
<tr><td>High</td><td>The aims of the study are clearly stated; information about methods and participants is complete; analytical strategy is made explicit.</td><td>The methods and sampling strategy used to answer the research question are adequate.</td><td>The methodological strategy is soundly carried out.</td><td>To population and topic under investigation is relevant to the aim of our review.</td></tr>
<tr><td>Mid</td><td>Some of the above are missing, but the study is still broadly transparent and could be replicated.</td><td>A better alternative approach could have been deployed, certain decisions remain controversial, the sample size is too small for the methodology used, or insufficient information is provided.</td><td>The study is sufficiently reliable, although there are some quality issues.</td><td>The study addresses the topic in a way or in a context that is not directly relevant to this review's research question.</td></tr>
<tr><td>Low</td><td>Most of the above are missing, severely limiting the possibility of evaluating the study. This necessarily has a negative impact for the rest of the appraisal.</td><td>There is a serious mismatch between the aims and the methods or no information is provided.</td><td>There are serious flaws in the execution, or not enough information is provided.</td><td>The focus or the approach of the study is only minimally relevant.</td></tr>
<tr><td colspan="5">NB: these criteria were not used to decide on the inclusion or exclusion of papers. The limited numbers of relevant studies were included if they met our basic inclusion criteria, described in the methodology section (appendix 1) above. These criteria were used to provide a general assessment of research quality across research design and in terms of their relevance to the review.</td></tr>
</table>

TABLE 2: EVIDENCE TABLES – EMPIRICAL STUDIES

Study	Population	Study methods	Findings	Limitations
Study ID: Abbott et al. 2002 **Study Aims:** To explore the effectiveness of current legislation and guidance in protecting the interests of disabled children who attend residential schools. **Quality Assessment:** **Mid +**	**Population:** Disabled children who attend residential schools. **Country:** UK – England **Sample Size:**	**Study Design:** Policy and practice review and case study. **Sample Selection:** Local authority providers were selected for their representativeness in terms of type of authority, region, numbers of pupils with SEN and percentage of pupils in special schools. A purposive sample of 32 case studies (parents and their children was selected). **Data Collection:** Data were collected by interview with managers in local authorities, as well as a review of policy and practice. Qualitative interviews were carried out with children and parents.	**Findings:** Headline findings in this large scale study are: Parents approached local authorities about residential schools were home support and educational provision was inadequate. Residential school offered new opportunities to some children. Local authorities had ideological objections to residential schools, and there were disagreements between educational and social services that could lead to delay in decisions being reached. Placements funded solely by the education authority received little monitoring of care standards. There was confusion	**Limitations:** This study is carried out within a specific legislative framework and service structure – in England. Whilst many of the findings are specific to this context, and are not fully generalisable, there are some salient points, which are relevant across the UK.

		Intervention/evaluation/analysis: Not reported	amongst the 21 local authorities as to their statutory duties towards children in residential schools. Current legislative practice is not adequately protecting and promoting the interests of children in residential schools.	
Study ID: Benedrix et al. 2006 **Study Aims:** To describe the experiences of five couples who had a child with autism and learning disability. **Quality assessment:** **Mid**	**Population:** Parents of children with autism and learning disability who lived in a group home. **Country:** Sweden **Sample Size:** n=10	**Study Design:** Qualitative; Case study. **Sample Selection:** Self-selected – study commissioned by the sample. **Data Collection:** Data was collected by interview with couples. Interviews were underpinned by hermeneutic phenomenological theory. Interviews were carried out prior to the child entering the residential facility and again two years after they had been living there.	**Findings:** Six key themes prior to child moving to group home were identified: 1. Parental grief at not having a typically developing child. 2. Because of having a child with a disability, parents had found their attitudes to others in challenging life situations had altered. 3. Parents felt they were not always able to regulate their child's behaviour. 4. Parents described experiencing total exhaustion. 5. Parents described	**Limitations:** There are three key limitations to this study: 1. The findings are based on a small sample size. 2. The study is located in one area and related to the families of all of the children who live in one group home. 3. The children's views and perspectives are entirely absent from the findings, thus giving an unbalanced view of the impact of moving to a group home on everyone involved.

		Intervention/evaluation/analysis: A collaborative analysis was carried out amongst researchers using thematic coding to uncover or isolate key themes relating to parents experiences.	experiencing social isolation. 6. Siblings were being negatively affected. Six further themes were highlighted after the move of the child to the group home: 1. The family experienced relief after the disabled child moved to the group home. 2. Parents felt guilty at entrusting the care of their child to others. 3. Some parents were satisfied with the group home as they felt their child was improving. 4. Some parents were dissatisfied with the group home as child was anxious returning after visits home. 5. It was helpful to share their experiences with other parents. 6. Parents felt more hopeful for their child's future.	

Study ID: Blower et al. 2004 **Study Aims:** The study aimed to undertake a needs assessment of mental health services for looked after young people in on local authority area. **Quality Assessment:** **Mid**	**Population:** Looked after young people aged 7-17 years. **Country:** UK (Scotland) **Sample Size:** n=48 first stage participants, n=22 second stage participants.	**Study Design:** Mixed methods - needs assessment. **Sample Selection:** The total sample of looked after children between the ages of 7-17 were invited to take part in the study, 48 consented. **Data Collection:** The first stage of data collection involved the psychological screening using a battery of tests including: Child Behaviour Checklist, Mood and Feelings Questionnaire; Trauma Symptoms Checklist for Children; In addition children were interviewed using the Harter Self- Esteem questionnaire. 27/48 scored above the threshold or had abnormal scores and were referred to stage 2. 22/27 progressed to stage 2 and took part in a semi-structured interview/focus group. **Intervention/evaluation/analysis:**	**Findings:** N=27 of the first stage participants displayed significant psychological morbidity. N=35 had lowered self-esteem. High levels of psychiatric disorder and co-morbidity were identified in 21/22 of the second stage participants. This demonstrates a prevalence of almost 50% of participants with a potential mental health condition. This study included the perspectives of young people themselves; however authors reflect on their own subjectivity and professional framework of interpretation and highlight how this can obstruct taking children's views and experiences as described, at face value.	**Limitations:** Challenges in recruiting children and young people from some sections of the looked after population are identified by the authors as a limitation – for instance they were unable to attract children who were living in foster care as carers expressed concerns that the study would bring about harm/anxiety for the young people.

		Qualitative data were analysed using the framework method.		
Study ID: Brown et al. 2011 **Study Aims:** To investigate family quality of life pre- and post the admission of their disabled son/daughter to residential school. **Quality Assessment:** **Mid**	**Population:** Parents of intellectually disabled children with *'major challenging behaviour'.* **Country:** UK. **Sample Size**: Child sample n=23 Parent sample n=19	**Study Design:** Cross-sectional, qualitative study. **Sample Selection:** Convenience sample – Children. Random selection and parent availability -Parents **Data Collection:** Demographic data as well as information about 'compounding conditions' of children were reported (how these data were collected is not well described in the paper). Qualitative data were collected by 1-1 interview with parents and by focus groups with parents. **Intervention/evaluation/analysis** Data was analysed by a mixed methods approach – firstly conducting a thematic analysis of interview transcripts to identify key themes, and them quantifying common responses as to their frequency.	**Findings:** Prior to their child's admission to the residential school families faced many challenges in maintaining their child at home. A move to residential care was reported to precipitate improvements in family life and in terms of improvements in the disabled child's behaviour. Family life was reported to be more stable, siblings became more involved in community life and spouses found their relationships improved. Overall families reported major improvements in their quality of life.	**Limitations:** A high percentage - ¾ of the families whose children attended the school at the time of the study did not consent to take part in this study, this raises questions as to their particular circumstances/experiences, which may have precipitated this decision. Children's perspectives are not represented in this study in any detail and when referred to it is based on proxy information – no attempt was made to seek the views of the young person themselves. Reference is made to improved outcomes – in terms of behaviour – amongst children since they were placed in the school, this is not independently assessed or even triangulated by the views of

				another party besides parents.
Study ID: Cousins et al. 2010 **Study Aims:** The study aimed to examine the Mental Health needs of young people aged 10-15 years in state care in Northern Ireland. **Quality Assessment:** **Mid+**	**Population:** Young people living in state care. **Country:** Northern Ireland **Sample Size:** N=165	**Study Design:** Cross-sectional study using a mixed methods approach. **Sample Selection:** A purposive sample of those children and young people between the ages of 10-15 years living in residential care and in foster care. Data were collected on 64% of the 259 adolescents who met the criteria for selection. **Data Collection:** Data were collected through: 1. Case file analysis – including risk factors for young people's removal from home, family history, care plans and young people's characteristics. 2. Outcome data were collected via questionnaire and completed by social workers. 3. Social workers also completed the Strengths and Difficulties Questionnaire – a measure of children's behaviour, emotions	**Findings:** The authors report that a variety of complex and interwoven reasons were cited for young people becoming looked after. Both parental factors affecting the birth families ability to provide appropriate care and characteristics in the young person, which made them difficult to parent. Social workers reported that 12.7% of the sample had self-harming behaviour, and 10.3% had attempted suicide. The SDQ results indicated that 70.3% of the sample were at high risk of developing mental ill health. However, social workers reported that in their opinion 92% of the young people enjoyed health as good as or better than other young people.	**Limitations:** The authors identify limitations of this study, that findings relied on social worker report, and used a single short screening questionnaire to assess mental health vulnerability. No data were collected from parents or young people themselves.

		and functional impairment, which is widely used to screen for mental health problems. Follow-up interviews were conducted with some social workers to clarify questionnaire data. **Intervention/evaluation/analysis:** Descriptive statistics were generated from data gathered, and further statistical analysis conducted to examine gender differences, and differences according to placement type in relation to Mental Health need.		
Study ID: Fudge Schormans et al. 2006 **Study Aims:** To examine the quality of life for children with developmental disabilities placed in foster, adoptive or kinship care. **Quality Assessment: Mid**	**Population:** Substitute caregivers of children with developmental disabilities, aged 3-12 years. **Country:** Canada **Sample Size:** n=30	**Study Design:** An exploratory cross-sectional design was used, underpinned by a health promotion approach to quality of life and the grounded theory methodology. **Sample Selection:** Purposive convenience sampling across six community educational/ developmental support agencies.	**Findings:** Placement stability is identified as a key contributing factor to quality of life for this group of children with developmental disabilities. Additionally, the importance of meeting the child's needs, provision of a family environment, inclusion within the wider family circle, enabling the child to	**Limitations:** This study would have been enhanced by eliciting information from the young people themselves.

		Data Collection: Audio-taped, face-to-face, in-depth interviews were conducted with participants using semi-structured and open-ended questions. **Intervention/evaluation/analysis:** Grounded theory analysis using Nvivo software for the management and working of data.	maintain contact (where possible) with their birth family and the importance of support being available for families to provide ongoing support to the fostered/adopted child.	
Study ID: Hill 2012 **Study Aims:** The study aims to examine whether having a diagnosis of a disability impacts the stability of out-of-home placement for young people; whether the presence of disability impacts on placement outcomes and whether young people with a diagnosed intellectual disability or emotional/behavioural disability experience	**Population:** Young people entered on the state child welfare data system. **Country:** USA **Sample Size:** n=2187	**Study Design:** Cross-sectional comparative study using qualitative analysis of secondary data. **Sample selection** Young people were included if they were aged 17+ at the time of the study, had been in an out-of home placement during the preceding 3 years and were determined to be in long-term foster care, defined as in care for 32 days or more. **Data Collection:** Data was drawn from a state-wide child welfare data system. Data was collected by case workers as	**Findings:** 1312 of the 2187 had a diagnosis of disability within the education system. Young people with disabilities were found to spend a longer period of time in out-of-home placement and to have a higher number of placements (avg. 5.5); they were also found to be less likely to have a permanency plan. Differences in the experience of out-of-home placement were reported depending on the disability type – those described as	**Limitations:** The data on which the findings of this study are based is drawn from administrative records created by child welfare professionals. It was not created for research purposes, and therefore there may be a lack of consistency in recording of for instance definitions/diagnoses of disability. The findings should therefore be approached with some caution.

different placement/ permanency outcomes to their peers with other types of disability. **Quality Assessment:** **Mid-**		case records rather than for research purposes. **Intervention/evaluation/analysis:** Descriptive statistics were generated to determine the prevalence of disability, gender, race and other demographic characteristics for the entire sample. Young people with a disability diagnosis were then compared to those without a diagnosis.	having an emotional/behavioural disability were more likely to be spend longer in out-of-home placement, but to have fewer changes in placement; those with intellectual disabilities were likely to spend less time in out-of-home placement than those with 'other disabilities' and also to have fewer placements.	
Study ID: Kelly 2000 **Study Aims:** To test methodological approaches to be used in a main study which aimed to examine family support services for children who have a learning disability in the context of salient social policy and legislation. **Quality Assessment: Mid**	**Population:** Parents of children with intellectual disabilities, children with ID and social workers. **Country:** Northern Ireland. **Sample Size:** 3 parents 3 children 4 social workers	**Study Design:** Pilot study, qualitative methods. **Sample Selection:** Social workers represented the 4 DHSSPS Trust involved in the main study. Purposive random selection of children across a range of age groups from a list generated by social workers. **Data Collection:** Data were collected by qualitative interview. **Intervention/evaluation/analysis:**	**Findings:** Children were able commentators on their experiences of family support and short breaks. Children contradicted concerns about one short break service saying they liked it and enjoyed going there – they held views independent of adults. Children appreciated having a chance to have their say. The researcher realised a need to develop makaton skills. Other requirements	**Limitations:** The authors acknowledge that as a pilot study the findings can be regarded as exploratory rather than generalisable, given the very small sample size.

		Not reported	such as working at the child's pace, be flexible and patient in interview sessions were important lessons.	
Study ID: Laan et al. 2001. **Study Aims:** To describe the characteristics of children included in a supported fostering programme; To examine the content of counselling support to foster parents; to assess the extent to which foster placements were successful; in what way are unsuccessful placements related to either the characteristics of the child or the content of the counselling and what were the formal reasons given for placement breakdown.	**Population:** Foster families of fostered children who had been in their placement for at least 2+ years. **Country:** Netherlands. **Sample Size:** N=78, with a follow-up of n=42 of the original sample.	**Study Design:** Programme evaluation. **Sample Selection:** Participants were included in the sample if they continued to foster their child + two years after entry to the fostering support programme (PIP). **Data Collection:** Data were collected in two stages: 1. Case file audit – data gathered in tow checklists, one to itemise demographic/factual data and one to detail topics covered in counselling with parents. 2. Postal questionnaire – to measure the satisfaction of parents regarding the	**Findings:** 74% of the placements were reported to be successful. Foster parents judged the programme to also be successful in supporting them to maintain the placement. It was apparent that the support counselling did help to deal with a number of challenging issues. Negative impact was reported where there was evidence that the counsellor providing support had limited knowledge of the child or when there was a frequent change of counsellors. Overall this study concludes that with sufficient	**Limitations:** This study evaluated a specific and well-developed programme of support, which was culturally specific. Whilst there are lessons for good practice, there is a need to recognise caution in generalising from these specific findings.

Quality Assessment: **Mid +**		PIP counselling. **Intervention/evaluation/analysis:** Statistical analysis was applied to data collected from the case file audit and postal questionnaire.	preparation and support children with intellectual disabilities and complex needs can be successfully fostered.	
Study ID: Lightfoot et al. 2011 **Study Aims:** To explore the prevalence and characteristics of children with disabilities and substantiated maltreatment within the child welfare system. To explore relationships among demographic characteristics and the likelihood that a child with substantiated maltreatment has been identified as having a disability; to examine the likelihood that	**Population:** Children (0-18) with substantiated maltreatment **Country:** USA **Sample Size:** n=6270	**Study Design:** Cross-sectional study. Quantitative secondary data analysis. **Sample Selection:** The sample was made up of children and young people entered a database in a one-year period with substantiated maltreatment. **Data Collection:** Data was drawn from a state-wide child protection database. Data was collected by case workers as case records rather than for research purposes.	**Findings:** 22% of children with a substantiated record of maltreatment are labelled in the database as having a disability. Children with disabilities were found to be 1.87 times more likely to be in out-of-home placement than children without disabilities and this figure rose to a likelihood of 2.16 times for children over the age of five years.	**Limitations:** The major limitation of this study is that data analysed was not originally collected for research purposes. Data recorded on disability does not use a standard definition, nor is there any indication as to the time of diagnosis, severity of disability, nor consistency in the codes used to describe disability. Data is recorded by case workers who are likely to have varied levels of training in ascertaining disability status. There is no means

a child with a disability has been placed in a formal out of home placement. **Quality Assessment:** **Mid -**		**Intervention/evaluation/analysis:** Descriptive statistics were calculated around the prevalence of children with disabilities within the child welfare system who had substantiated maltreatment, and the characteristics of these children including type of disability, geographic location and type of out-of-home placement. Analyses of relationship between independent variables were carried out to estimate the likelihood of diagnosis based on age, gender, race and geographic location.		of recording multiple disabilities. Researchers are not aware of the criteria used by case workers in choosing particular codes to describe disability in specific cases.
Study ID: Llewellyn et al. 1999 **Study Aims:** This study aimed to explore the factors, which influenced families to care for their children at home or to place them out-of – home. **Quality Assessment: Mid +**	**Population:** Families with young disabled children (aged 15 months-6 years) with high support needs. **Country:** Australia. **Sample Size:** N=167 families.	**Study Design:** Cross-sectional explorative study. **Sample Selection:** Families were recruited through service agencies in Sydney, two regional urban areas and a rural area with small towns and remote farms – sampled to broadly represent the metropolitan/urban/rural mix. Families were required to meet	**Findings:** 75% reported that they would definitely not seek an out-of-home placement; 19% were undecided; 10% had placed or were actively seeking placement for their child. The majority of the families therefore did not want an out-of-home placement. The authors report that	**Limitations:** As the authors identify the total sample represented on only 6% of the families who had placed their child out-of-home. These families were difficult to contact or unwilling to take part. The views of families who had placed their children out-of-home were retrospective rather than

		eligibility criteria – namely, the child is aged between birth and 6 years, has a physical, sensory, intellectual or multiple disability; parents or care givers identify that the child has high support needs, local generic support services are not able to meet the child's high intensity support needs. **Data Collection:** Data were collected by: 1. Family completed a questionnaire, which gathered information on demographic data, family daily routine, and financial resources. 2. Families were interviewed at home at their own convenience. Two overall areas of interest were investigated at interview – firstly, the adaptations to families everyday life to accommodate their child's care needs; secondly, families opinions regarding whether or not to seek out-of-home placement for their child. **Intervention/evaluation/analysis:**	these families are distinguished by a *'positive family affect factor'*, comprised of meaningfulness and sustainability of daily routine, and congruence between the needs of the disabled child and other family members. They also demonstrated positive views on the inclusion of their family and local community networks. This group also had strongly held views about their feelings of responsibility and ability to care for their child. Around ¼ of the families in this study were undecided about out-of-home placement or had actively sought placement.	current – and these families are likely to construct an *'acceptable rationale for contentious actions. (p. 229).* This study also depends on a particular theoretical approach, - eco-cultural theory, which may have influenced how questions are framed and posed, thus potentially influencing study findings.

		Questionnaire data (quantitative) and interview data (qualitative) were synthesised for analysis. Qualitative data were coded and checked by independent reviewer in analysis. Constant comparative analysis was used to analyse qualitative data – NUD.IST software was used to manage the data.		
Study ID: McConkey et al. 2012 **Study Aims:** To describe the care arrangements made for children with disabilities who live away from their birth family and compare this with that of their non-disabled peers; to identify changes in care arrangements in the past 10 years, and to examine the extent to which looked after children with intellectual disabilities have moved from residential to family based settings or	**Population:** Looked after children with intellectual disabilities compared with looked after children without intellectual disabilities. **Country:** Ireland **Sample Size:** Data collected on sample of disabled children and young people living in care at two time points: Children without ID: 1999 n=4216 2008 n=5357 Children with ID:	**Study Design:** Cohort study – quantitative **Sample Selection:** n/a **Data Collection:** Data re: children with intellectual disabilities were drawn from National Intellectual Disability Database (NIDD), information on non-disabled children were sourced from published data produced by the department of health. **Intervention/evaluation/analysis:** Descriptive comparative statistics were produced relating to the two	**Findings:** There was a much greater likelihood that children with ID would be placed in care (by rates per 1000 of respective populations) than other children. Children with ID in care tend to be older than the remaining children. Children without ID were more likely to be placed in foster care, whereas children with ID were more likely to be placed in a residential establishment, although this had decreased over the 10 year period with at the later date a higher	**Limitations:** The authors identify study limitations: The databases do not provide information as to why children and young people are in care. Details were also not available on children's health care needs. It is also possible that there were further changes of placement over the ten-year period, which was not identified as data were collected at two time points.

returned to their birth families. Additionally to what extent do age/gender and degree of intellectual disability affect care arrangements? **Quality Assessment:** **Mid +**	1999 n=707 2009 n=467	data sets.	proportion of children with ID being in foster care – though this was still less than the non-ID sample. Younger children were more likely to be placed in foster care, however there were a significant number of young children with ID in congregate settings and group homes. The dominant model of care for older children with ID was in congregate settings, however this has decreased over the ten-year period with more older children in foster care. Type of placement varied according to type of ID, with those with mild/moderate ID more likely to be placed in foster care, and those with severe and profound ID more likely to be placed in residential settings. In terms of consistency of care, 2/3 of those on the data base in 1999 were	

			tracked though 2009 – of those children placed in congregate settings 77% continued in group care 10 years later, with n=70 moving to more intensive placements. Some transferred to group homes and a very few moved to independent living arrangements. Those who lived in group homes in 1999, many remained in this type of setting, though 21% transferred to congregate settings and some of these to intensive placements for challenging behaviour. Those in foster care either continued with these arrangements or moved to their birth family. Some moved to congregate settings (mostly intensive placements for challenging behaviour) or to group homes or independent living.	

Study ID: McConkey 2011 **Study Aims:** To use a multi-informant approach to document the essential features of a successful short and community support service delivered by a National voluntary sector organisation – Action for Children. **Quality Assessment:** Mid+	**Population:** Families and children with behaviour, which is severely challenging who use a specialist short break service. **Country:** Northern Ireland **Sample Size:** 3 service sites.	**Study Design:** Descriptive study. **Sample Selection:** Sample was selected on the basis of delivery or receipt of services. **Data Collection:** Data were gathered from 4 sources: 1.Documentary analysis 2. Interviews with service managers 3. Focus groups with parents of children in receipt of the service 4. Commentary and responses to a draft report on the service. **Intervention/evaluation/analysis** The service being evaluated is a combined residential and domiciliary specialist support model which offers short breaks to children whose behaviour is severely challenging. The service is based on assessed need.	**Findings:** Six key elements of the programme are described and include the multi-agency referral process, the fact that all families have an appointed key worker, that the service is has a strong ethos and is value led which impacts on the development of relationships with families and the approach to supporting children, the service has defined aims and processes and is delivered by a highly trained workforce, residential support is homely, structured, regular and designed to encourage behaviour management and skill development, domiciliary support aims to develop behaviour management skills amongst parents and to promote social inclusion through the	**Limitations:** The evidence provided by this descriptive study offers strong guidance as to the features of this service. Its multi-method approach makes strengthens findings and that it was conducted in three locations further reinforces the evidence. The inclusion of the views and perspectives of young people who use the service would have further strengthened the findings.

			involvement of children in community activities; onward referrals are made to other short break providers, or to adult service. However, similar services may not be available through adult provision.	
Study ID: McConkey et al. 2004a **Study Aims:** To document the characteristics of disabled looked after children in one administrative area of Northern Ireland; to describe their current out-of-home placement, and to estimate the future needs of these children. **Quality Assessment:** **Mid+**	**Population:** Looked after disabled children (spending 90+days away from home in a 12 month period). **Country:** Northern Ireland **Sample Size:** n=108	**Study Design:** Cross-sectional study. **Sample Selection:** Data were collected on all disabled looked after young people with physical, sensory or intellectual impairments **Data Collection:** A structured interview was conducted with the key-worker of each child or young person, using a standard pro-forma. **Intervention/evaluation/analysis:** Data was analysed using Chi-square tests and Kruskal-Wallis One-was analysis of variance.	**Findings:** Detailed findings are provided in the paper: in summary children's characteristics showed that the age range was 1-19 years, with one 25% aged under 10 years. More than half of the children were aged over 14 years. 80% of the children had server learning disabilities or profound multiple disabilities with no children solely have sensory impairments or chronic illness. Child needs were reported to place extra demands on families – communication	**Limitations:** The authors identify limitations that the sample is skewed towards children and young people known to a Disability Programme of Care and further towards children with intellectual disability because of present availability of services. Further, no record is kept of children who cease to be in contact with services, as records of these families are not kept. It was difficult to track children admitted to acute hospitals of 90+ days in a 12 month period who met the inclusion criteria;

			impairments, challenging behaviours, autism or technological dependency. Many of the sample children came from families who experienced social and health problems, there were instances of suspected neglect/abuse of the child, parents with physical and mental health problems and those abusing drugs/alcohol as well as parents who themselves has an ID or who were coping with two or more children with ID. 1/3 of the children were living in residential provision, some of these included hospitals of residential homes for adults with intellectual disabilities. Just under ¼ lived with foster parents or in family placement, these children were generally younger or those with physical disabilities. Few with autism or who were technologically	additionally it was difficult to track children aged 14+ as they regional hospital does not cater for children beyond this age. The study was undertaken in one geographical area, this may limit the findings generalisability given the variations in services in different areas.

			dependent lived with foster carers, most of these children lived most of the time with their natural families.	
Study ID: McConkey et al. 2004b **Study Aims:** To explore what features of shout break services are valued by parents of children with disabilities. **Quality Assessment:** **Mid+**	**Population:** Parents of children with disabilities as well as carers and service professionals. **Country:** Northern Ireland. **Sample Size:** Phase 1 – 108 parents Phase 2 – 30 carers and service professionals and subsequently 59 families.	**Study Design:** Cross-sectional qualitative study. **Sample Selection:** Parents who used short breaks were identified and contacted by social workers. **Data Collection:** Phase 1. parents responded to open questions about the services they received, a thematic analysis was undertaken and themes validated in consultation with carers and professionals. Phase 2. Parents used the items derived from phase 1 to rate the service they received. **Intervention/evaluation/analysis:** Thematic analysis and ranked descriptive statistics.	**Findings:** Twelve distinguishing features were identified regarding short break services across different areas. 8 of these were characteristics of the service, 2 related to benefits to the child and two related to benefits to the carers. There were some variations in carers' expectations of short breaks services.	**Limitations:** This study may be limited by its regional particularity, in that it is located within particular service context. However, there are lessons regarding the characteristics that of short breaks that are valued by parents, which are more widely applicable. The study would have been enhanced by including young people's views on the characteristics they value in short break services.

Study ID: McConkey & Adams 2000 **Study Aims:** Study 1. To undertake a census in one Board area of Northern Ireland, of all short breaks which families with a disabled child had taken in the preceding 12-month period. Study 2. To collect information about families experience of use of short breaks and their stated preferences. **Quality Assessment:** **Mid+**	**Population:** Families with a disabled child who use short breaks. **Country:** Northern Ireland **Sample Size:** N=476 families for the census and N=76 for the second stage of the research – qualitative study.	**Study Design:** Cohort study with mixed methods of data collection. **Sample Selection:** The sample for the census included the total population in one board area. The sample in the second study were drawn from families of children with an intellectual disability who received services in one Trust area of NI on an identified date. 76 of the 131 families registered agreed to take part in the study. **Data Collection:** Study 1. Data were collected by completion of a standard proforma by four Community Health and Social Service Trusts. Study 2. Data were collected by structured interview based on a questionnaire using a mix of open and closed questions. **Intervention/evaluation/analysis:** Study 1. Summary statistics were prepared and compared with data	**Findings:** Detailed findings are reported and general points made – these include: 1. There are not enough short breaks to meet demand. 2. Breaks in hospital settings are not a preferred option. 3. There is a preference for services which benefit the child as well as giving the parents a break. 4. Family income appears to influence the type of breaks they receive.	**Limitations:**

		collected in study 2. Study 2. Data were coded and analysed for frequencies of responses.		
Study ID: McNichols et al. 2011 **Study Aims:** The study aims to describe placement histories, service use and mental health needs of looked after children in two CAMHS catchment areas in Dublin. **Quality Assessment:** **Mid**	**Population:** Looked after children in tow catchment areas of Dublin. **Country:** Ireland. **Sample Size:** N= 174	**Study Design:** Cross-sectional study. **Sample Selection:** The sample represented the respondents drawn from the total sample of looked after children in two areas of Dublin. **Data Collection:** Data were collected by postal questionnaire. There was 56.6% response rate. Demographic data were collected, as well as characteristics of family history and child's use of or referral to CAMHS services. **Intervention/evaluation/analysis:** Descriptive statistics were produced from data gathered.	**Findings:** Findings demonstrated an association between type, number and duration of placements and mental health. Children living in residential care were significantly more likely to have contact with mental health services than those in foster care or kinship care. Whilst there is a relationship between placement disruption and developing mental health need, however, it is unclear whether mental health problems are consequent to placement disruption or a consequence of multiple placements.	**Limitations:** This study is limited by a small sample size, low response rate and lack of information directly from young people themselves. These limitations are acknowledged by the authors.

Study ID: Morris et al. 2002 **Study Aims:** To examine policies and practices in relation to placing disabled children in residential schools in a representative sample of 21 education and social service authorities in England. **Quality Assessment:** **Mid+**	**Population:** Education and social service authorities in England. **Country:** UK – England **Sample Size:** N=21 local authorities	**Study Design:** Policy and practice review. **Sample Selection:** Local authorities were chosen for their representativeness – in terms of type of authority, region, numbers of pupils with SEN and percentage of pupils in special schools. **Data Collection:** Policy and procedural documents were analysed; interviews were conducted with key education and social service officers and stats relating to residential school placements were gathered for each area. A second stage of the research focusing on 4 case study areas included interviews with parents and young people about their experiences of residential school. **Intervention/evaluation/analysis:**	**Findings:** Key findings: 1. Slight evidence base for current policy and practice relating to placement in residential schools, with some divergence of ideas between social service and education. 2. There is a lack of clarity as to the statutory responsibility of social service authorities towards these children. Findings show that placements happen with little regard for the quality of the placement, whether children are happy or whether they are able to maintain contact with their parents. 3. There is a lack of safeguards for children's human rights e.g. to be active participants in their community; to remain part of their families. Lack of clarity as to whether	**Limitations:** This study raises important issues about the status and welfare of disabled children placed in residential schools. Ideally regular review of policy and practice in this area would enable greater understanding in a world of changing policy and practice.

			these children are 'looked after' and the requirements associated with this has lead to children not receiving the protections they should.	
Study ID: Mullan et al. 2007 **Study Aims:** To identify the emotional, psychological and mental health needs of looked after children and care leavers aged 12-25 years, and to review and explore service development for care leavers, as well as to document current policy and practice developments. **Quality Assessment:** **Mid+**	**Population:** Looked after young people and care leavers. **Country:** Northern Ireland. **Sample Size:** N=51.	**Study Design:** Cross-sectional mixed methods study. **Sample Selection:** In liaison with an individual from each of four participating Health and Social Care Trusts, compiled a list of people who met the inclusion criteria – namely aged between 12-17 years, 'looked after' or aged 18-25 and entitled to leaving care services. A total of 655 potential participants were identified. The research team randomly selected from this list (every nth number), and information sheet/consent form were sent to these participants by the Trust liaison person. Of the 288 young people contacted 51 consented to take part – their details were then passed onto the research team.	**Findings:** Findings challenge the tendency to pathologies or label young people in care and negative behaviours and instead understand behaviours as a normal reaction to a highly stressful and unnatural living situation. Young people expressed disorientation and limited understanding of the reason for being placed in care or indeed continuing to be there. The care system to some extent reflects this disorientation. The system could better meet the needs of young people by understanding their responses to situations are not unnatural but should be expected given the	**Limitations:** This study gives voice to looked after young people and care leavers. It would be strengthened by a higher response rate – larger sample size. Additionally analysis of data stratified by some key characteristics – placement type, disability etc, would further enhance the salience of this powerful work.

		Data Collection: Data were collected by postal questionnaire to carers, as well a in-depth interviews and focus groups with young people (this paper reports on the latter aspects of the study). **Intervention/evaluation/analysis:** A thematic content analysis was used to analyse qualitative data.	circumstances they find themselves in.	

Study ID: Nankervis et al. 2012a Study Aims: To explore factors that lead families to relinquish care of their disabled son/daughter and have them placed in a residential care facility. Quality Assessment: Mid	Population: Families of disabled children. Country: Australia Sample Size: N=17 residential care staff in relation to n=32 clients.	Study Design: Cross-sectional study. Sample Selection: Convenience sample. Data Collection: 1. Case file audit 2. 1-1 interviews with staff members in the facilities into which children had been placed. Intervention/evaluation/analysis: A thematic analysis was applied to both case file notes and transcribed interviews.	Findings: <1% of the total population of disabled children who use respite services in the study area (four regions in one South Australian state) were relinquished into care Findings which explained the relinquishment of care were divided into three sections: 1. Factors inherent in the individual, such as, high levels of challenging behaviour, need for constant vigilance – high medical needs, carer inability to manage behaviour particularly as the individual grew in size and strength, an extreme risk of harm to the carer or siblings. 2. Factors inherent in the family – carers experiencing stress/exhaustion, single parents being overwhelmed by their disabled child's care needs as well as the needs of siblings, marital breakdown, a desire to have a 'normal' life, carer illness.	Limitations: Authors report that they considered the issues under examination too sensitive to interview parents directly about their decisions to place their child in care, in particular as for most this had happened relatively recently. In fact they report that all but 5 of the parents were uncontactable. However, the strength of findings would have been improved through the inclusion of parent's perspectives directly. The views of siblings would also be valuable. Relinquished children and young people are also not included in the study and their views would add much to the findings.

Study ID: Pithouse et al. 2002. **Study Aims:** To examine the impact of training foster carers in techniques to manage challenging behaviours. **Quality Assessment:** **Mid-**	**Population:** Foster carers of children with behaviour that could be defined as challenging. **Country:** UK - Wales **Sample Size:** N=103 (N=54 in the intervention group and N=49 in the control group).	**Study Design:** Controlled trial with pre and post intervention quantitative data collection. **Sample Selection:** Working across 4 local authorities in one area of Wales fostered children with behaviour which was described as challenging were identified, 114 met the criteria, and 103 foster parents of these children agreed to take part. **Data Collection:** Baseline data were collected before the training course and again 5-7 weeks after completion of the course. Data collected included the demographic information on the child, as well as a battery of checklists intended to measure child behaviour, community integration and behaviour problems. Carer profiles were also collected via demographic data as well as by using checklists to assess responses to challenging behaviour, emotional and physical well-being, self-evaluation and insight into behavioural responses.	**Findings:** Carers responded positively to the training and reported that they felt better equipped to cope. However, there was a limited measured change in the outcome measures of carer effect of change in the child's behaviour.	**Limitations:** The authors report that the timescale of the research meant that there was a need to collect data within 7 weeks post intervention, however it is possible that any measurable effect may have taken longer to achieve.

		Intervention/evaluation/analysis: Training designed to assist carers to understand and manage behaviour through skills that have a preventative dimension around problematic conduct. The training was delivered by clinical psychologists to groups of 15 carers at a time, over a period of 3 days. There was a follow-up 3-4 weeks later and carers were given training materials to keep. In analysis statistical calculations were made using Mann Whitney U-test and Wilcoxon Matched-Pairs Signed-Ranks test.		

Study ID: Preece, 2002 **Study Aims:** To examine the impact of characteristics of autism on researchers abilities to elicit children's experience of short-term residential care. **Quality Assessment:** **Mid**	**Population:** Children (aged between 7-14 years) with autism who attended a 6-bed residential unit for short breaks. **Country:** UK (England) **Sample Size:** n=3	**Study Design:** Case study design. **Sample Selection:** How the sample was selected is not reported, however, the authors do report on the consent/assent they achieved from participants, and the need for young people's assent to be a continuous process. **Data Collection:** Data were collected in a number of ways: 1. Interviews with parents. 2. Observing children in their classroom and short-term care settings. 3. Teachers (familiar persons) interviewed 2 of the children. 4. Field notes made from observations of 3rd child who could not take part in interviews because of a severe intellectual disability. **Intervention/evaluation/analysis:** Data were examined to assess the impact of impairments in social interaction, impairments in communication and the need for routine and resistance to change, following Wing (1993) Triad of Impairments.	**Findings:** Findings reported on characteristics of this sample which challenged the process of eliciting information: - their use of speech was limited and idiosyncratic - they found open questions and choice difficult - their social anxiety shortened the consultation sessions Factors which assisted were also reported: -having a familiar person conducting the interview reduced social anxiety - visual methods mediated and strengthened communication -importance of having prior knowledge of children's communication strategies. The authors recommend the value of triangulating data so as to check accuracy and add to what may be partial data collected from children.	**Limitations:** The authors point to the difficulty in making any generalisations based on such a small sample size, however, they point out that even with a much bigger ample generalisations may be difficult given the very individual nature of Autism and ASD. Nevertheless, these findings are good common sense guidelines to working with children, disabled children as well as those with autism/ASD. The need to complete preparatory work in interviewing this population is clear.

Study ID: Romney et al. 2006. **Study Aims:** To determine the relationship between specific child disability types and types of permanent placement. **Quality Assessment:** **Mid+**	**Population:** Children with disabilities removed from their birth families due to substantiated maltreatment. **Country:** USA. **Sample Size:** N=277	**Study Design:** Cross-sectional study using a mixed methods approach to data collection. **Sample Selection:** A sub-sample of one US city sample of the Longitudinal Studies of Child Abuse and Neglect (LONGSCAN). Participants were selected if they had completed data sets at age 4 and 6. **Data Collection:** Baseline assessments were collected at age 4 and 5. Predictor variable of 4 categories of disability were reported by caregivers – cognitive disability, communication disability, physical disability and emotional disability. Four placement types were also identified, these included: reunified, adopted, kinship foster care, non-kin foster care. Demographic data were also collected. **Intervention/evaluation/analysis:** Multinominal logistic regression whether carers perception of disability type at age 4, predicted the child's placement type at age 6.	**Findings:** Findings indicate that cognitive, emotional and physical disabilities were associated with non-kin foster placement compared to reunification – the presence of medical or developmental impairments were a barrier to reunification. The authors report that the findings have important service delivery implications, in particular with regard to allocating resources and in developing targeted interventions to facilitate successful reunification and to minimise the number of placement changes where reunification is not possible.	**Limitations:** The findings of this study are not necessarily generalisable to other geographical locations or to older children as the children in the present study were 3.5 years or younger at the time of removal from their families and remained away from their family for at least 5 months. These findings would need to be tested with older children and in differing geographical locations to increase their applicability more widely.

Study ID: Schofield et al. 2007 **Study Aims:** To investigate stability and permanence amongst looked after children. **Quality Assessment:** **Mid-**	**Population:** Children looked after for 4+ years across 24 English local authorities **Country:** UK – England **Sample Size:** N=324	**Study Design:** Cross-sectional, mixed methods study. **Sample Selection:** Social workers for total sample of children looked after for 4+ years were contacted and the n=324 was the sample who returned questionnaires. **Data Collection:** Data were collected by postal questionnaire which contained both quantitative and qualitative information, including data on individual cases and explanations for decisions taken. **Intervention/evaluation/analysis:**	**Findings:** (of interest to the present study) 68% of the sample had experienced abuse or neglect, which is likely to contribute to complex needs in terms of achieving placement stability. 34% of the total sample were recorded as having a disability or ongoing health condition, which for a number of children meant multiple or complex disability.	**Limitations:** The data collected may have provided the opportunity to consider specific sub-groups in relation to stability and permanency. For instance the group identified as disabled – how this impacted on type of placement and achievement of stability.

Study ID: Stanley 2007 Study Aims: To elicit ideas and experiences of looked after children. Quality Assessment: **Mid**	Population: Looked after children. Country: UK – England Sample Size: 14 young people 159 parent responses	Study Design: Cross-sectional, exploratory. Sample Selection: Data Collection: Data were collected by postal questionnaires (parents) and focus groups (young people). Intervention/evaluation/analysis: Not reported	Findings: Young people and carers were agreed in highlighting the damaging effects of the discontinuity and change experienced in the looked-after system. Young people emphasized the importance of exercising choice and control when seeking and receiving support and identified the value of positive role models provided by 'survivors' of the care system. Carers reported high levels of risk behaviour, particularly self-harm, among young people in children's homes. The authors recommend that these differing perspectives need to be openly acknowledged and negotiated within care settings in order that relevant and accessible therapeutic and support services can be offered to looked-after adolescents.	Limitations: This study is limited by localised geographical location and the specific socio-cultural conditions, which pertain to it. The child sample was also relatively small from which to draw gereralisations.

Study ID: Taggart et al. 2007 **Study Aims:** The study aims to: 1. describe the individual and familial characteristics of a group of young people with intellectual disabilities living in state care, 2. to explore the emotional and behavioural problems of these young people 3. to investigate the mental health status of young people living in state care 4. to compare and contrast the emotional and behavioural issues and mental health status of these young people with intellectual disabilities and a group without intellectual disabilities. **Quality Assessment:** **Mid +**	**Population:** Young people with intellectual disabilities living in state care (residential and foster care) and aged between 10-15 years. **Country:** Northern Ireland **Sample Size:** n=165, N=37 with an intellectual disability and n=128 without an intellectual disability.	**Study Design:** Cross-sectional comparative study. **Sample Selection:** Purposive sampling of young people who met the inclusion criteria from SOSCARE- government administrative database. **Data Collection:** Data were collected using the Strengths and Difficulties Questionnaire (SDQ) which is a measure of children's emotions, behaviours and functional impairment and is widely used to screen for mental health problems; and through postal questionnaire/ face-to-face interview with social workers to collect information on pathways to care, care planning and child characteristics with respect to emotional and behavioural problems. **Intervention/evaluation/analysis:** Descriptive statistics were	**Findings:** More males than females with intellectual disabilities were found to be living in state care; this was comparable with the non-disabled population. A range of complex and inter-woven reasons were reported as catalyst for entry to care, these included problems with parental practices (abuse/neglect etc) and challenges said to be posed by the child – disruptive/confrontational behaviours. The study reported that young people with intellectual disability were found to be significantly more likely to be emotionally or behaviourally distressed than their non-disabled peers. Moreover, ¾ of the young people with intellectual disability were found to be within the 'abnormal' range in the SDQ	**Limitations:** The sample upon which the findings of this study are based may not be representative of children with intellectual disability living in state care across NI – because of the difficulties in identifying this population, the varying degrees of disability and the different settings in which they are housed. Moreover, this study's population was within a limited age range of 10-15 years and findings may not be gereralisbable to younger or older children and young people.

		generated regarding individual and family demographics. Statistical analysis of the SDQ data was conducted to examine differences in emotional and behavioural problems amongst the ID and non-Id Cohorts.	scores therefore were potentially vulnerable to developing mental health problems.	
Study ID: Teggart 2005. **Study Aims:** The study aimed to investigate rates of mental health difficulties among children in substitute care in one geographical area of Northern Ireland. **Quality Assessment:** **Mid+**	**Population:** Children aged 4-16years living in substitute care – 89% in some form of foster care, 11% in residential care. **Country:** Northern Ireland. **Sample Size:** N=64.	**Study Design:** This questionnaire study employed a cohort design. **Sample Selection:** A purposive sample of children and young people from the Trust area were selected if they were aged between 4-16 years and did not have an intellectual disability – the latter exclusion criteria was based on the fact that the mental health needs of children with intellectual disabilities were the responsibility of Disability Services. **Data Collection:**	**Findings:** The findings are consistent with other studies investigating the prevalence of mental health difficulties in looked after children and young people. More than 60% of the 4-10 year olds were assessed as potentially having a diagnosable mental health disorder, almost 50% of the 11-16 year olds were found to have a probable mental health disorder. This sample was also assessed as having higher rates of emotional symptoms, conduct problems and	**Limitations:** This study is limited by circumscribed geographical location. However, the findings are comparable with other prevalence studies regarding the mental health needs of looked after children. As the authors point out, whilst the study identifies need it does not highlight unmet need. This forms part of a follow-up study relating to services being offered to and used by young people.

		The data were collected in several ways: 1. The parent version of the Strengths and Difficulties Questionnaire (SDQ) was sent to carers of children in the sample. 2. The teacher version of the SDQ was sent to all teachers of the sample children (where children were not excluded from school). 3. Interviews were carried out with the older young people (11-16 years olds) and their carers. During this interview the self-report version of the SDQ was completed by carers. The overall response rate was high with low rates of attrition. **Intervention/evaluation/analysis** Descriptive summary results for the SDQ were calculated.	inattention-hyperactivity. They also had higher levels of problems in their relationships with peers and were assessed as having demonstrated less pro-social behaviour.	
Study ID: Trout et al. (2011) **Study Aims**: To evaluate the characteristics of children with and without disabilities at entry to	**Population:** Children and young people entering a treatment programme at a residential facility, which serves 'abused, abandoned and neglected'	**Study design:** Cross-sectional – descriptive **Sample selection:** All children and young people entering the facility during an 8 month period.	Few demographic differences were found between groups with and without disabilities; however more males were identified with disabilities and likely to be placed in out	Three limitations were identified: 1. All participants came from one residential setting and due to regional variations in population demographics it may be

residential care to see if differences exist, and to relate these to a risk framework in relation to predictors of educational, behavioural and mental health outcomes. **Quality Assessment**: Mid +	children and young people. **Country:** USA. **Sample size:** n=123 children (50 girls and 73 boys) with an average age of 15.32 (with a range of 10.9-12.3 years); n= 36 were identified as having a disability.	**Data Collection:** Data were collected from two sources; case files created during child intake interviews with the child's parent /guardian; and data collated following a 2 day orientation programme at the outset of the child's stay. Four data domains were collected: 1. child demographic characteristics 2. behavioural functioning collected by proxy (parent/guardian) using Child Behaviour Checklist; (Achenbach & Rescorla 2001) 3. Mental health functioning by self-report using the NIMH DISC IV; (Shaffer et al. 2000) 4. Academic performance, by individual test using the WJ III; (Woodcock et al 2001). **Evaluation/intervention/analysis** Data were analysed to compare young people with and without disabilities at time of admission, using statistical calculations to	of home settings than females. A below population* average number of young people from minority communities were identified as having a disability, whilst the minority rates in the non-disabled sample were higher than the local population average. * Population served by the facility. Few differences were found in relation to behavioural and mental health problems. However, children without disabilities scored more highly on scales of externalising behaviours – rule breaking and aggression, whilst children with disabilities were more highly scored on social and attention problems. Academic measure revealed that those with disabilities were more challenged in core academic skills such as	that the findings are not generalizable to other settings. 2. Some of the young people may not have had a diagnosis of disability or have been in the process of assessment when moved from their school/home environment to the residential facility, therefore may have been lacking appropriate educational/social support. 3. Limitations of the sample size prevented analysis of difference within different types of disability; therefore the sample of young people with a diagnosed disability was aggregated in analysis into a single group.

		determine differences on academic, mental health and behavioural variations.	reading. The authors conclude that outcomes for children and young people with disabilities in residential care are highly challenged because of the combined risks of poor academic and social and emotional functioning.	