Permanence for Disabled Children and Young People through Foster Care and Adoption: A selective review of international literature

Abstract

Children who have been removed from their parents need stability and permanence; this is as true for disabled children as it is for others. Yet many children are subject to extended periods of uncertainty and instability. Growing attention has been paid to the need to achieve permanence within a timescale which meets children's needs. As disabled children are over-represented in looked after (in care) populations it is especially important that their needs are considered when formulating policy and practice in this area.

This review of literature covers international material related to stability and permanence for disabled children, in particular permanence achieved through fostering and adoption. A scoping method was used to identify and analyse a broad range of material. Ninety texts were included in the review, including material from the US, the UK, Canada, Australia, China and the Netherlands. Empirical research included quantitative, mixed methods and qualitative studies. Other sources included literature reviews and a small number of research-based 'think pieces' and briefings.

Disabled children often have permanence outcomes and experiences which differ from those of other children; most often they are disadvantaged by systematic features of services and by the latent disablism of decision-makers, professionals, carers and potential carers. The findings also show that disabled children are not a homogenous group and that characteristics such as age, gender, ethnicity and impairment type show complex relationships with permanence through adoption and foster care.

Important gaps in current knowledge are identified, including disabled children's views and experiences in relation to achieving permanence. Several areas of policy and practice are highlighted where effort to improve permanence needs to be made. These range from tackling negative professional attitudes about the prospects of placing disabled children to further development of non-traditional approaches to the recruitment of foster carers and adopters.

1. Introduction

Children may be in care (looked after) for a number of reasons; this is as true for disabled children as for their peers. Disabled children are over-represented in looked after children populations and it is estimated that between 10 and 25% of looked after children are disabled. The precise proportion will depend on how disability is defined and counted (Baker, 2007, 2011). In the UK, and elsewhere, there has been a recent escalation of concern about achieving stability and timely permanence for children; these concerns have fuelled significant policy and practice changes. These concerns and changes urgently need to be explored in the context of disabled children who often have markedly different experiences from their peers.

Maintaining a focus on issues relevant to UK permanence practice and policy, this review of literature covers international material related to stability and permanence for disabled children, in particular that achieved through fostering and adoption. The review employed a scoping method outlined by Arksey and O'Malley (2005) initially identifying a broad range of material and selecting relevant texts. The review had limited resources and took place over a relatively short period of time.

1.1. What do we mean by permanence?

Children's development and wellbeing is influenced by the context and conditions within which they live; particular attention has been paid to the presence or absence of a sense of belonging, security and stability. Over several decades there has been concern about looked after children who are often separated from their birth families and placed in alternative settings including kinship care, foster care and residential (group) homes. When children are removed from their birth families there is rarely agreement that the separation will be permanent; instead, most children are subjected to uncertainty whilst decisions are made about their future care (Sinclair, Baker, Lee, & Gibbs, 2007). These decisions have fundamental and lasting implications for the child, often determining whether they will return to their birth family or be settled into a new family through adoption or another process. The period of uncertainty may be protracted and children may experience more than one placement': some experience a series of different situations with different carers in different forms of care (Munro & Hardy, 2006).

Since the 1980s findings have repeatedly suggested that children spend long periods 'drifting' in care systems, with little effective effort being made to decide their future care (J. Thoburn & Courtney, 2011). The poor outcomes of many looked after children have been in part attributed to the failure of care systems to promote a sense of belonging, security and stability. Calls for decisions to be

made more quickly and assertions that pending decision-making children should receive quality care with minimal disruption have led to a number of policy and practice responses designed to promote 'permanence' for looked after children.

UK political debate centred on measures to expedite adoption with less attention paid to permanence in foster care, kinship care, residential placement or resettlement with birth families. In other jurisdictions permanence most always refers to adoption. Policy and practice responses have tended to be focused on achieving 'legal permanence', that is, a legal determination of parental responsibility through adoption or measures such as special guardianship or kinship care orders. Clearly, families are more than mechanisms to determine legal responsibility; they comprise complex and enduring relationships and connections that exist over time and across generations (Biehal, Ellison, Baker, & Sinclair, 2010; Jones & Hackett, 2011; Ramaekers & Suissa, 2012; Schofield, Beek, & Ward, 2012).

Similarly, permanence concerns more than legal status or even continuity; it involves an element of identification and belonging, a sense of being an integral part of something more than the individual. Several writers caution against the implicit development of a 'hierarchy of permanence', in particular the tendency to see adoption as the gold standard; they suggest that for some children other forms of permanence may be preferable (Bullock, Courtney, Parker, Sinclair, & Thoburn, 2006; Neil, 2012; Rees & Selwyn, 2009). Thus a sense of permanence may be attained in various forms of 'family' including long term kinship care (Stanley, 2007), foster care (Schofield et al., 2012) and potentially residential care (Clough, 2006). Irrespective of placement type, permanence is promoted by intended commitment to the long-term (Biehal, Ellison, Baker, & Sinclair, 2009).

1.2. What do we mean by disability?

This review is also concerned with 'disability' and how this impacts on permanence. As with 'permanence', 'disability' is a term which is used in diverse ways. Our own view of disability is broadly informed by the social model of disability (Oliver, 1990, 1996) and social-relational theories (Connors & Stalker, 2007; Thomas, 2007).

Very little of the material included in this review is explicit about disability. Few authors offer their theoretical or ideological stance; most seem to presume a common understanding of 'disability'. We decided to include all approaches in this review. This decision was somewhat pragmatic; the addition of further selection criteria would have reduced the sources available. We wished to maximise potentially relevant material, not least because:

There is one point that it is important to make with regard to disability and childhood: research on disabled children is still marginalised. (Watson, 2012)

In this review, therefore, the term 'disabled children' is used inclusively and amongst others, covers those with physical or sensory impairments, intellectual disabilities, 'challenging behaviour', mental distress or on the autistic spectrum.

2. Methods

The research used a framework for scoping studies detailed by Arksey and O'Malley (2005). Scoping studies are suitable for addressing broad, rather than narrow or specific, research questions, and when the review will involve a range of different study designs. This framework has six stages:

2.1. Stage 1: Identifying the research questions

The study aimed to review international literature in order to identify and explore what is and is not known about achieving permanence for disabled children and young people in foster care and adoption. The research questions were:

- What barriers exist to achieving permanence for looked after disabled children and young people in foster care or adoption?
- How can such barriers be overcome and what other facilitators of permanence in foster care or adoption exist?
- What works in achieving permanence for looked after disabled children and young people in foster care or adoption?

2.2. Stage 2: Identifying relevant studies

Inclusion and exclusion criteria were agreed. It was decided to include published, 'grey' and international research, published between 1998 and 2013. Literature not available in English, practice-based texts and policy documents were excluded.

Systematic searches were made of the Scopus and Social Care Online electronic databases. Given the limited time and resources available for the study, Scopus was chosen as the biggest abstract and citation database for peer-reviewed literature, covering some 53 million records, 5000 publishers and articles in press. Social Care Online was selected as the UK's most comprehensive free database listing items related to social care including research, reviews and UK grey literature. The main search terms used for Scopus are shown in Box 1 and for Social Care online in Box 2:

Box 1: Main search terms: Scopus

TITLE-ABS-KEY(child* OR young OR youth) AND TITLE-ABS-KEY(foster* OR adoption OR permanency OR permanence) AND TITLE-ABS-KEY(disab*)) AND SUBAREA(mult OR medi OR nurs OR heal OR mult OR psyc OR soci) AND PUBYEAR > 1997.

PublicationYear:'1998 2013'
AND PublicationTitle:'child* and disab* and permanence or permanency or foster* or adoption*'
OR AbstractOmitNorms:'child* and disab* and permanence or permanency or foster* or adoption*'

Scopus searches identified 657 documents (after duplicates had been removed) and Social Care Online, 47, of which 24 had not appeared on Scopus.

In addition, members of an Achieving Permanence Research Group (see below) were asked to identify relevant research and contact was made with 12 third sector agencies to ascertain if they had conducted relevant unpublished studies. There were six positive responses.

2.3.   Stage 3: Study selection

Abstracts and/or information about each study were scrutinised to ensure their fit with the inclusion criteria. Full texts were obtained for 130 items, after which a final decision was made, in consultation with another author where necessary. A small number of texts identified during preparation of the research proposal (N=13) or by colleagues were also included. The final number included in the review was 90.

2.4.   Stage 4: Charting the data

A proforma was developed to systematically extract and record data for each text which were entered into Excel.

2.5.   Stage 5: Collating, summarising and reporting the results

The main findings were brought together thematically and summarised by topic. Following Arksey and O'Malley (2005, p27) we aim to provide a narrative account rather than aggregate or synthesise data. In particular, we do not infer different weights to studies according to a judgement about the relative merits of the methodological approach taken.

2.6.   Stage 6: Consultation with stakeholders

An Achieving Permanence Research Group, comprising colleagues from three universities, a 'centre for excellence' for looked after children, two voluntary sector agencies and a foster carer, acted as an advisory group. They contributed research references and commented on emerging findings, gaps in the evidence base and priorities for future research.

3. Overview of literature reviewed

Of the 90 texts reviewed, 54 emanated from the US, 20 from the UK, 10 from Canada, four from Australia and one each from China and the Netherlands. As Table 1 shows, almost half the texts

reported empirical quantitative studies, with mixed methods and qualitative studies the next most frequent categories. Others reported literature reviews while research-based 'think pieces' and briefings made up the rest:

Table 1: Type of texts included in review

Type of study/text	Frequency
Empirical quantitative	42
Empirical mixed methods	13
Empirical qualitative	15
Literature review	7
'Think piece'*	11
Briefing	3
Total	**90**

NOTES: * One text, primarily a think piece, also drew on focus groups.

In addition, 12 of the empirical studies shown in Table 1 had a longitudinal element, the majority using quantitative methods although two employed mixed methods and one was qualitative.

The empirical studies drew on a range of research methods, most often analysis of case files/ agency records or interviews, followed by questionnaires: see Table 2:

Table 2: Research methods used in reviewed texts

Methods used	Frequency*
Analysis of agency records	29
Interviews	28
Survey/ questionnaires	14
Literature review	8
Focus groups	7
Secondary analysis of research data	3
Case study	2
Other**	5
Not applicable***	13

NOTES: *Some studies used more than one method
** Observation, ethnography, RCT and measurement scales (the latter as sole method).
*** Think pieces / briefings with no empirical element

Reflecting the variety of methods used, sample sizes varied enormously, the smallest being four and the largest, 655,536. Table 3 gives an overview.

Table 3: Sample sizes in reviewed texts reporting empirical studies

Sample size	Frequency
1-20	12
21-50	11
51-100	9
101-1000	19
1001 - 10,000	15
Over 10,000	6
Not applicable	21
Total	**90**

Most papers had a strongly applied focus and did not dwell on the theoretical frameworks informing the research. Seven claimed to be using grounded theory, while disability theory, family narrative theory or ecological systems theory were discussed by a handful.

The texts reviewed used a variety of terms to refer to children's impairments, including emotional and/or behavioural difficulties. For ease of reference, we use 'umbrella' terms such as 'behavioural disabilities' and 'mental health needs' to denote broad categories but, when referring to individual papers, we use the term employed by the authors.

This material also uses a number of terms to describe the children's legal or residential status, for example the term 'looked after' is often used in texts from the UK and some other countries. This equates to the concept of being in state care or being formally supervised by the state. In Scotland, 'looked after' can also refer to a group of children who are formally supervised by the state but live with their birth families. Given our current focus on foster care and adoption our general use of the term looked after refers to children who are 'in care' away from their birth family.

Differences between countries should be borne in mind when interpreting results or comparing findings from diverse areas. For example, it may be that children enter care under different circumstances with greater use of voluntary care in the UK than the USA. Consideration should also be given to differences in how permanence is perceived in different countries, with broader and more flexible definitions being increasingly used in the UK and some other countries such as the use of shared care, long-term foster or kinship care as well as reunification. These jurisdictional differences may account for some of the observed differences between countries.

4. Findings

We begin by providing evidence of the differential placement outcomes for disabled children and summarise what is known about the relationships between certain child characteristics and outcomes.

4.1. Outcomes

Disabled children in out-of-home placements are half as likely than others to have either 'reunification with birth family' or 'relative care' as part of their care plan (Hill, 2012) and they are less likely to return home (Grant & Thomas, 2013; Hayward & DePanfilis, 2007; Romney, Litrownik, Newton, & Lau, 2006). Akin (2011), in a US study, tracked 3351 children for 30-42 months after entering foster care and found that 58.7% of non-disabled children returned home compared to only 27.5% of disabled children. (Baker, 2007) conducted a longitudinal study tracing outcomes for 596 foster children in England, three years after placement. Non-disabled participants were again more likely to return to their birth families, although the difference, 21% of non-disabled and 15% of disabled children, was smaller than that reported by Akin.

Swann and Sylvester (2006) found that disabled children were 1.6 - 1.7 times more likely than other children to be placed in kinship foster care arranged and supported by child welfare services. However, of all children placed into foster care, Beeman, Kim, and Bullerdick (2000) found that disabled children were less likely to be placed into kinship foster care, more often being placed in non-kinship foster care (odds 0.43).

A longitudinal study of 3351 children who entered foster care in the US in 2006 found that 32% of the disabled children were adopted, compared to 8.3% of their non-disabled peers: however, this was because the majority of the latter returned home (Akin, 2011). Baker's (2007) longitudinal study found no evidence that, overall, disabled children were less likely to be adopted than others, except those with intellectual disabilities whatever their age or other impairments), the latter point being supported by research in mid-west America (Schmidt-Tieszen & McDonald, 1998). Although disabled children in the US and UK typically wait longer to be adopted than other youngsters (Avery, 2000; Baker, 2011; Dept for Education, 2014; Grant & Thomas, 2013), for the most part these adoptions succeed and children achieve permanence (Baker, 2007; Clark, Thigpen, & Yates, 2006; Glidden & Johnson, 1999; Haugaard, Moed, & West, 2000).

Disabled children remain in foster care and other out-of-home placements longer than others (Grant & Thomas, 2013; Romney et al., 2006; Simmel, Morton, & Cucinotta, 2012), some achieving a form of permanency through foster care (Baker, 2007; Schmidt-Tieszen & McDonald, 1998). However, some studies found that disabled children are more likely than others to be placed out-of-authority or state (Dowling, Kelly, & Winter, 2012; Slayter & Springer, 2011) or in 'inappropriate' placements, the latter referring to independent living arrangements poorly rated by former foster-carers and workers (Baker, 2007). It is worth highlighting the scale of Slayter and Springer's (2011) secondary analysis which drew on data from the Adoption and Foster Care Reporting Systems in 46 US states,

the District of Columbia and Puerto Rico and compared records for 17,714 young people with intellectual disabilities to those for 655,536 young people without intellectual disability.

4.1.1. Disruption

There is mixed evidence about placement disruption for disabled children. Some studies have concluded they are more subject to disruption than other young people (M. Courtney & Zinn, 2009; Helton, 2011; Lin, 2012) although Helton found this was less true of those in kinship care. Among a sample of 423,773 children in foster care in the US, the 8047 recorded as having run away had higher rates of all kinds of 'disability diagnoses' than non-runaways (Lin, 2012). However, other research has shown that it is children with specific impairments (behavioural disabilities and certain mental health diagnoses) who are more likely to experience disruption. Strijker and Van De Loo (2010), in a retrospective longitudinal study of 99 children with intellectual disabilities in foster care in Holland, found the number of placement breakdowns was similar to that for other children. The main risk factors included age at start of placement and, again, problematic behaviour. Similarly, a study of multiple foster care placements in five states in the US reported no overall difference between disabled and non-disabled children, except for those with behavioural disabilities, who had more moves, and 'possibly' mental health issues (Steen & Harlow, 2012).

4.1.2. Harmful effects of impermanence

Not surprisingly, there is evidence that impermanence and/or high rates of placement turnover have adverse effects on disabled children. These include poor mental health (Harden, 2004; Pasztor, Hollinger, Inkelas, & Halfon, 2006; Steen & Harlow, 2012; Tarren-Sweeney, 2008); attachment/security disorders (Harden, 2004; Tarren-Sweeney, 2008); poor physical health (Harden, 2004; Robertson, 2006); developmental disorders (Harden, 2004) and 'compromised brain functioning' (Harden, 2004). Importantly, however, not enough is known about how far poor experiences of care exacerbate conditions children may have had prior to entering care, or create new ones. Multiple placements may have a further negative impact on children with pre-existing 'special health and mental health needs' (Pasztor et al., 2006).

4.2. Children's Characteristics

In this section, we consider the relationship between achieving permanence and four characteristics: age, gender, ethnicity and impairment. The latter receives the most attention in the research reviewed, possibly indicating a medical model of disability. However, there are significant differences in outcomes for children with different impairments.

4.2.1. Age

Disabled children typically enter the care system at an older age than non-disabled children (Baker, 2011). Slayter and Springer (2011) found the average ages were 7 years 1 month and 6 years 9 months respectively.

Younger disabled children are more likely to be adopted than older ones, but this reduces significantly from the age of six (Grant & Thomas, 2013). Baker (2007), in a non-systematic literature review on permanence and stability for looked-after disabled children, found that the average age of adoption for non-disabled children was 2.4 compared to 4.7 for disabled children, probably due to the latter being adopted by their foster carers. A younger age at adoption is associated with better outcomes (Haugaard et al., 2000).

Older disabled children are more likely to have disrupted placements than younger ones, irrespective of setting (Farmer, Mustillo, Burns, & Holden, 2008; Helton, 2011; Hill, 2012; Strijker & Van De Loo, 2010) and to spend longer in out-of-home placements (Farmer et al., 2008; Hill, 2012). However, the age range of the young people in these studies varied considerably: Farmer et al included children aged 5-18, and noted that the critical factor in relation to disruption was age on entering care; although those in Helton's sample were aged 3-10, this author also reported that age at entry to care was crucial; Hill only included young people aged 17 or over but examined their records for the previous three years.

4.2.2. Gender

Although gender has been considered in terms of the wider population of children in adoption and foster care, it has received less attention for disabled children. Among the latter, there are more boys than girls in foster care (Slayter & Springer, 2011; Smith, 2002). Boys in foster care face higher levels of 'restrictiveness' than girls in relation to communication, movement around the foster home and accessing the community (Schmidt et al., 2013). In a sample of 77 young people in Minnesota, 88% of whom were disabled, boys were more likely than girls to experience long delays for adoption, the average wait overall being 11.8 years (Avery, 2000).

4.2.3. Ethnicity

Studies of foster care and adoption populations in the US have shown that African-American children are disproportionately represented (Slayter & Springer, 2011; Smith, 2002). Among young people with mental health problems in out-of-home care, those from Hispanic communities experienced greater placement disruption than others (Farmer et al., 2008) while White disabled

youth in foster care were found to experience more restrictions in accessing the community (Schmidt et al., 2013).

A study in England and Wales found that Black disabled children were more likely to be placed with White carers than children who were Black but not disabled (Dowling et al., 2012). Research into adoptive families of disabled children in the US reported few differences in 'family adjustment' between those who had adopted transracially, in-racially or both, adjustment being good in all cases (Lazarus, Evans, Glidden, & Flaherty, 2002). However, the challenges for White adoptive parents of meeting the needs of non-disabled Black and minority ethnic children in terms of developing a positive racial and cultural identity, understanding origins and addressing racism have been recognised, and similar challenges will apply to disabled Black and minority ethnic children (Kirton, Feast, & Howe, 2000; J Thoburn, Norford, & Rashid, 2000).

4.3. Impairment

4.3.1. Children with behavioural disabilities

Forty percent of 1008 Scots said they were willing to consider fostering a child with 'emotional/ behavioural problems' (YouGov Plc, 2012). However, several studies have shown that children with behavioural disabilities, as well as those who have 'challenging behaviours' alongside other impairments, experience more disruption than others and/or have more placements (Baker, 2011; J. Courtney & Prophet, 2011; Farmer et al., 2008; Steen & Harlow, 2012; Strijker & Van De Loo, 2010).

In a sample of 2156 disabled children aged 14-28, Hill (2012) found that young people with 'emotional/behavioural disabilities' spent longer in out-of-home care but had fewer placements than other disabled children, a point which appears to conflict with findings above. Foster carers have particular difficulties dealing with children's aggression, mood swings and sexual acting out (Brown & Rodger, 2009). Children with 'emotional/behavioural disabilities' are among those less likely to reunify with their parents (Romney et al., 2006) and are more likely to experience poorer outcomes in adoption (Haugaard et al., 2000). On a more positive note, a systematic review of interventions designed to enhance placement stability for disabled children with 'challenging behaviours' identified a number of gains, although the nature and extent of these varied across outcomes (Ziviani, Feeney, Cuskelly, Meredith, & Hunt, 2012).

4.3.2. Children with mental health needs

'Emotionally disturbed' children in care were one of four groups in New Mexico 'significantly more likely' (3.6 times) than others to experience placement instability (J. Courtney & Prophet, 2011). However, a US study comparing 8047 children who ran away from foster care with 415,726 who did

not, reports conflicting findings about whether or not those with a 'mental health disability' were more or less likely to run away (Lin, 2012). Older children and those with less stable placements were more likely to do so; thus, the combination of these attributes with mental health needs may be the deciding factor.

Children with mental health needs are less likely than others to reunify with birth families, (Akin, 2011), twice less likely to have a successful exit from foster care (Becker, Jordan, & Larsen, 2007), have less chance of timely adoption (McDonald, Press, Billings, & Moore, 2007) and are 10 times less likely to be given a probationary adoption placement (Burge, 2007). A Scottish study of 182 fostered children, of whom 60% showed evidence of mental health problems, concluded that although they received a high level of support from various agencies, Child and Adolescent Mental Health Services were failing them (Minnis, Everett, Pelosi, Dunn, & Knapp, 2006). Difficulties accessing appropriate mental health services for foster children are also reported in the US by Pasztor et al. (2006).

4.3.3. Children with intellectual disabilities

Children with intellectual disabilities are less likely to be adopted than non-disabled children (Baker, 2007) or to have a 'timely' adoption (McDonald et al., 2007). They are less likely to reunify with birth parents or enter kinship care; non-kinship foster care is more likely (Romney et al., 2006).

Other research evidence about achieving permanence for this group is conflicting. While one study found them less likely than non-disabled children to experience placement breakdown (Sinclair et al., quoted in Baker, 2011), other research has reported it more likely (Cleaver, 2000 cited in Baker, 2011) while in Holland it was found neither more nor less likely (Strijker & Van De Loo, 2010). Inconsistent findings have also been reported in relation to placement turnover: a US study examining permanence for older disabled children (aged 14-18) found that those with intellectual disabilities were nearly five times as likely to have fewer placements than those with other types of impairment and to spend less time in care (Hill, 2012), while another concluded that children with intellectual disabilities had 'slightly more' removals (1.4 v. 1.3) (Slayter & Springer, 2011). The latter sample had an average age of 11, so age may contribute to these different findings.

4.3.4. Children with physical/sensory impairments

Research specifically about children with physical/sensory impairments is patchy. Studies in the US and UK have found them 'no less likely' to be adopted than non-disabled children (Baker, 2007; McDonald et al., 2007), while in mid-west America, Akin (2011) found this was *more* likely. Research in San Diego reported that children with physical impairments were over four times more likely than

typical children to live permanently in non-kin foster care (Romney et al., 2006). A lack of adequate foster care placements for deaf children has been reported in the US (Lomas & Johnson, 2012).

4.3.5. Children exposed to parental substance misuse

Several studies report the damaging effects on children's physical and mental well-being of parental substance misuse and note rising numbers of babies, affected by prenatal exposure, who need long-term placements (Davies & Bledsoe, 2005; Marcellus, 2010; McNichol & Tash, 2001; Takayama, Wolfe, & Coulter, 1998). Beeman et al. (2000) found that children in care due to parental substance misuse were more likely to be placed in kinship care than foster care. McNichol (1999) compared outcomes for 204 infants, some with known exposure to illegal drugs during gestation, some with suspected exposure and others with no known exposure. Although the first group had significantly more health and care needs, there was little difference between the three groups in terms of finding permanent placements. There is some evidence of these children making significant gains in foster care (McNichol and Tash 2001) while Davies and Bledsoe (2005) discuss the potential of adoption as a 'remarkable intervention' in the lives of children with pre-natal substance exposure.

4.3.6. Children on the autistic spectrum

Our search terms uncovered one study about young people on the autistic spectrum (Mullan, McAlister, Rollock, & Fitzsimons, 2007).This Illinois research reported that children with autism faced an 'excessively long time to permanence' with high levels of placement instability. Average length of stay in out-of-home care was 1.6 times that of other children.

4.4. Disabled children and young people's views of permanence

There is a stark lack of literature exploring children's thoughts about permanence and related barriers and facilitators and several authors suggest that looked after disabled children's views are under-represented in research studies (Clark et al., 2006; Lightfoot, Hill, & LaLiberte, 2011; Orme, Cherry, & Cox, 2013; Orme, Cherry, & Krcek, 2013; Schmidt-Tieszen & McDonald, 1998).

We found no empirical research on disabled children's views or first-hand accounts of permanence. A small number of studies successfully included disabled children's evaluations of services using structured measures. Schmidt et al. (2013) used a standardised measure to examine how young people in foster care viewed the restrictiveness of their care environment. They found that disabled children found it more restrictive than other children.

In a recent review of the literature relating to disabled children and young people who are looked after, Dowling et al. (2012) note that some attention has been given to the experiences of looked after children with mental health needs (Blower, Addo, Hodgson, Lamington, & Towlson, 2004; Mullan et al., 2007;

Stanley, 2007). However, these studies tell us little regarding children and young people's views and experiences of permanence. They tend to focus instead on the relationship between looked after status and mental wellbeing and how best to support mental health. Notably, Mullan's (2007) and Stanley's (2007) findings suggest that children with mental health needs in foster care report feeling different from peers, stigmatised by society and lacking a sense of belonging or stability.

Some sources included in this review either drew attention to the lack of knowledge (Dept for Education, 2014) or advocated for disabled children's views to be sought in relation to care planning and decision-making (Baker, 2011; Cousins, 2009b; Lomas & Johnson, 2012). It is noted that particular groups of disabled children may be more disadvantaged than others in this respect, including those who use augmented communication systems (Baker, 2006, 2011) and deaf or hearing-impaired children (Lomas & Johnson, 2012). Blakeslee et al. (2013) suggest a number of strategies to ensure disabled foster children's participation in longitudinal studies including systematically sampling for disabled children, working with welfare and education staff, providing extra support, adjusting protocols and measures where needed and carefully tracking children's whereabouts over time.

While children's direct accounts of permanence are relatively absent, a number of general approaches to securing disabled children's views are discussed in the literature: these include computer packages such as *In My Shoes* or involvement in *placement parties* at which children can meet prospective adopters (Cousins, 2009a). Lomas and Johnson (2012) consider specific methods for communication with deaf children and suggest that individuals with relevant skills should be used as communicators and as foster parents. They suggest this might include deaf people, parents of deaf children and sign language interpreters. Other authors focus on the role of social workers, suggesting that improved communication training is needed and stressing the importance of sufficient time and resource (Baker, 2006, 2011).

4.5. Meeting the needs of disabled children effectively

There is limited research regarding the process of matching disabled children and foster carers or adopters. The evidence suggests that it can be unhelpful to make overly restrictive assumptions regarding categories of children to which carers and adopters can be matched. Burge and Jamieson's (2009) qualitative study of placement decision-making suggests that adopters adjust preferences and their notion of a 'good match' as the family finding process unfolds. Some adopters become more open to considering a disabled child when presented with a child's profile. Similarly, Marcellus (2010) reports that foster carers' understanding of their capacity to care for particular children and the fit between children and the foster family became clearer after a child was placed.

There is consensus in the literature that the provision of specialist services is crucial to placing disabled children successfully (Brown, Moraes, & Mayhew, 2005; Lauver, 2008; Mather, 1999; Shannon & Tappan, 2011). Specialist services include therapeutic services, mobility equipment, learning aids, community nursing, mental health services, dental services, housing adaptations, specialist educational and recreational services and transition services. Several studies, report that access to these is often problematic and identify unmet needs of disabled children (Barton, 1998; Brown, 2007; Brown et al., 2005; Haugaard et al., 2000; Lauver, 2008; Shannon & Tappan, 2011).

Robertson's (2006) review of the literature relating to the assessment of young children in foster care raises the problem of a lack of good quality assessment tools capable of identifying the difficulties experienced by children. Additionally, some studies suggest that better integration or coordination of services is needed across public systems, such as education, health, mental health, and rehabilitative services (Mullan et al., 2007; Ziviani, Darlington, Feeney, Meredith, & Head, 2013).

Access to information about a child and their background is thought by foster carers to be crucial to successful placement (Brown et al., 2005; Lauver, 2008). Studies have particularly focused on the importance of good medical information to inform permanence planning (Mather, 1999) and to assist potential adopters in their decision-making (Perry & Henry, 2009). This information can be difficult to obtain where it relies on the co-operation of birth parents (Mather, 1999). However, It appears that even basic background information can be lacking when children are placed in foster care; for example, such information as bedtime routines, favourite foods, or preferred ways to calm and settle the child (Marcellus, 2008).

It appears that disabled foster children are less likely to have contact with birth families than their non-disabled peers despite the need for contact being the same. Some potential reasons include lack of birth parent reliability, child's behavioural issues after visits and a perception that the child will find it difficult to understand contact (Baker, 2006). Different groups of disabled children may have a different experience of contact. Children with developmental disabilities may find it particularly difficult to understand why they cannot live with their birth family and may need help to develop a positive relationship with them. Failure to do so may result in worsening of attachment problems and feelings of abandonment (Schormans, Coniega, & Renwick, 2006).

One major barrier to achieving permanency for disabled children is the negative attitude towards disability of staff within permanency services (Cousins, 2009a). Workers can be pessimistic about the chances of finding adoptive families for disabled children and some children are considered 'unadoptable' due to physical, psychiatric or behavioural problems (Avery, 2000).

4.5.1. Recruitment of foster carers and adopters of disabled children

Inadequate recruitment of carers for disabled children can lead to inappropriate placements including the use of residential care (Shannon & Tappan, 2011).

Reported motivations to care for or adopt a disabled child are varied and are influenced both by biography and personal values. Influences include: personal experience of fostering such as growing up in a biological family that provided foster care; personal experience of challenges in childhood; religious beliefs or a sense of social responsibility (Burge & Jamieson, 2009; Clark et al., 2006; Marcellus, 2008, 2010).

The literature differentiates 'specialists' who have existing knowledge or experience of disability (personal or professional) and are specifically seeking the placement of a disabled child and 'generalists' who are not seeking such placements but may consider one (Gould, 2010). Evidence suggests that while personal or professional experience of disability can build a potential carer's confidence, it is not an essential prerequisite, and instead, both specialists and generalists can be successful carers.

These two groups present different challenges in terms of recruitment (Beek & Schofield, 2004; Burge & Jamieson, 2009; Gould, 2010). For specialists, recruitment activity may need to be targeted at areas where they are more likely to be found such as hospitals or special schools or through the specialist press. Generalists, on the other hand, may be harder to reach and more likely to hold stereotypical views of disabled children so that any recruitment strategy will need to address misconceptions and fears in order for them to consider caring for a disabled child.

Beek and Schofield (2004) suggest that during the recruitment process potential foster carers without knowledge of disability could be enabled to see how their current parenting skills could be adapted for a disabled child. Similarly, Brown et al. (2007) found that carers of children with alcohol-related impairments had no professional experience of caring for disabled children but instead learned about this group through training workshops.

In findings from a study of 304 foster mothers in the US, Orme, Cherry and Krcek (2013) make a further distinction between carers who are open to fostering children with various impairments and those who feel able to care for children with specific characteristics or circumstances. They describe these as 'unconditional mothers' and 'selective mothers'. They found that around three-quarters of all foster carers surveyed were willing to foster a disabled child. Unconditional mothers fostered more disabled children for longer and were more likely to adopt their foster children. No relationship was found between willingness to foster a disabled child and demographic factors such

as family income, employment or ethnicity. Orme, Cherry and Cox (2013) developed a standardised measure of motivation to care for a disabled foster child called the 'Willingness to Foster Scale – Disabilities and Medical Conditions'. They reported that mothers with high WTF-DMC scores fostered longer, fostered and adopted more children and requested removal of a smaller number of children.

4.5.2. Assessment, preparation and training of adopters/foster carers

Research indicates that carers and professionals associate caring for a disabled child with particular skills. These include the ability to harness community resources, build networks of support for disabled children with peers, school and family, and advocate on behalf of the disabled child (Brown et al., 2007; Lauver, 2008).

In addition, carers need coping skills to manage stress associated with caring, arranging supports for a disabled child and managing contact with birth relatives (Brown et al., 2007; Lauver, 2008). Research informants have suggested that training is not always adequate (Barton, 1998; Peake, 2009) and more bespoke and intense training for carers of disabled children is needed (Avery, 2000; Schormans et al., 2006). Foster carers of disabled children value training and support from their peers (Barton, 1998).

4.5.3. Supporting foster carers and adopters of disabled children

The need for ongoing support for carers and adopters is now well recognised but there is some evidence that the health and wellbeing of carers is poorly addressed (Brown & Rodger, 2009). Marcellus (2008), in a Canadian study involving interviews with three experienced social workers and 11 foster families with varying levels of experience, looking after infants with pre-natal substance exposure, reported that caring for these children can be demanding, leading to fatigue and social isolation. A range of responses will probably be required as support needs are likely to vary from placement to placement and may depend on a number of factors relating to the child, carer, or wider family. Specific types of support valued by carers of disabled children include emotional support (Lauver, 2008), advocacy (Beek & Schofield, 2004), short breaks (Avery, 2000; Brown et al., 2005; Lauver, 2008) and support and advice with financial matters (Beek & Schofield, 2004; Brown et al., 2005; Schormans et al., 2006). The impact of caring on the foster carer's birth children is under-researched but is also likely to be of importance (Lauver, 2008).

There can be some tensions in the relationship between foster carers and social workers with social workers being seen as a source both of support and conflict (Beek & Schofield, 2004; Marcellus, 2008, 2010). Marcellus's (2008) study reports that foster parents were generally positive about

social workers but felt thwarted in their efforts to build relationships with workers due to high social worker caseloads and turnover. Continuity of support was particularly valued by carers (Pasztor et al., 2006) and where social workers worked with a family long-term the family was more likely to feel listened to (Marcellus, 2008). Some foster carers were highly critical of social workers and used phrases such as 'fighting' to be listened to/for support (Brown & Rodger, 2009). Adopters express a preference for support from other adopters (Molinari & Freeborn, 2006).

4.5.4. Satisfactions expressed by foster carers and adopters of disabled children

Despite the social barriers and service challenges they face, foster carers and adopters of disabled children express a number of satisfactions. These include developing a positive relationship with the child, receiving affection from the child and seeing a disabled child develop and flourish (Brown, 2008; Brown et al., 2007; Marcellus, 2008). In particular, carers enjoy observing small changes achieved by disabled children in the face of significant challenges (Brown et al., 2007). Having an emotional connection with a disabled child was viewed by carers as contributing to the success of a placement (Clark et al., 2006). Other satisfactions expressed include helping a child return home (Brown, 2008) or maintaining a child's connections with family and community (Brown et al., 2007). As well as making a difference to a child's life, further satisfactions included improved relationships between carers and their own biological children and gaining the recognition of others for what they do (Brown, 2008). These satisfactions may also motivate subsequent foster care placements or adoptions of disabled children.

4.6. Gaps in research and knowledge

Many of the papers included in this review identified gaps in knowledge or noted opportunities for further research; we summarise this material here. It should be noted that these areas are determined by the interests of existing authors and that, conversely, in areas where there is little or no existing research, gaps may be unrecognised.

Gaps tend to fall into three groups: those related to certain groups of disabled children or types of service and those arising from methodological shortcomings such as the lack of children's and sometimes carers' perspectives in research.

An example of the latter is provided by Lightfoot et al. (2011) who, noting an over-representation of disabled looked after children in out-of-home placements, suggest that little is known about their views and experiences or about how experiences might differ between children with different types of impairment. The views of young disabled people in foster care is an area which has received little attention (Schmidt-Tieszen & McDonald, 1998). Similarly, Clark et al. (2006) suggest that it is

necessary to conduct more research to understand children's and family members' experiences where adoption is not wholly successful. Orme, Cherry, and Cox (2013) and Orme, Cherry, and Krcek (2013) suggest that more research is needed into parents' motivations for adopting a disabled child.

In terms of groups of children, writing in the general context of permanence, Farmer et al. (2008) draw attention to the fact that there is insufficient knowledge about which groups of young people are located in different placement types and what promotes stability for different children. A number of specific groups are mentioned by different authors; Slayter and Springer (2011) call for more research into why young people with intellectual disabilities are more likely than other children to be placed in institutional settings, Burge (2007) calls for better understanding of the links between permanency planning and young people's mental health and Ziviani et al. (2012) call for more research into the efficacy of support for children and young people with challenging behaviours.

In terms of services, a number of sources highlight a lack of information about adoption and disabled children, in particular what represents best practice for adoption (Dept for Education, 2014). Grant and Thomas (2013) suggest that this reflects both a lack of research and a lack of reliable statistical information. Simmel et al. (2012) note that there is insufficient knowledge about disabled children in foster care (including those with intellectual disabilities); they suggest that the presence of disability is likely to impact on aspects of care such as length of stay and placement type. Foster care is also an area where many authors call for more research; this includes research to address barriers to the provision of foster care for disabled children (Orme, Cherry, & Cox, 2013; Orme, Cherry, & Krcek, 2013). These authors also call for longitudinal research to explore the longer-term experience of foster carers who have a disabled child. Similarly Peake (2009) identifies a need for greater understanding of the skills and training needed by foster carers who are looking after disabled children, whilst Brown and Rodger (2009) highlight the need for greater understanding of the impact of community and financial matters on foster families. Slayter and Springer (2011) seek further research into potential barriers to kinship foster care for young people with intellectual disabilities.

Some wider research gaps are also mentioned, including a lack of knowledge about whether practitioners in welfare services are well prepared to work with disabled young people (Slayter & Springer, 2011).

5. Discussion and conclusion

There are a number of weaknesses in this body of literature. Research addressing systemic issues related to permanence is rare; instead most is focused on individual factors and characteristics of

children and their impairments. This reflects and reinforces modes of thinking which locate problems with individuals rather than systems. Thus, we call for research to address systemic factors influencing permanence for disabled children. The literature includes explanatory studies which provide valuable insights and quantitative work capable of identifying associations. However, some methodological limitations or gaps are apparent in the studies reviewed. Among the empirical research reported, outcome studies predominate. These are most often retrospective studies and prospective studies are rare. There is little or no research that is able to confirm causation. This is not uncommon with respect to complex issues and interventions such as social work, however, it does limit what can be concluded. Thus we advocate for research which is methodologically capable of attributing cause, including randomised controlled trials. There are a number of studies that describe good practice but more experimental and quasi-experimental designs examining service or support effectiveness are needed. The near absence of the views of disabled children is widely acknowledged, this may reflect a lack of familiarity or confidence amongst researchers with methodologies that allow the direct participation of disabled children or may perhaps be related to issues of gatekeeping and access to disabled children. Qualitative studies that set out to achieve inductive theory building are also lacking. Finally, increased use of longitudinal designs to understand the changing needs of disabled children across the lifecourse would be valuable.

Looked after children are individuals who have different needs; the services and systems that care for them are better able to recognise and respond to some needs than others. It is perhaps unsurprising therefore to find that as a whole, disabled children and their non-disabled peers have outcomes which are similar in some respects and different in others. For example, research discussed showed that disabled children in out-of-home care are less likely than others to return home and that they wait longer than others to be adopted, although findings suggest that those without intellectual disabilities are no less likely to be adopted and that most adoptions succeed.

This review aimed to address a number of research questions; we consider each of these in turn below:

5.1. What barriers exist to achieving permanence for looked after disabled children and young people in foster care or adoption?

Qualitative research identifies a number of potential weaknesses within current systems. These include the relative invisibility of disabled children within permanency services and the lack of consolidated expertise in achieving permanency for this group.

Given that disablism is widespread throughout society, it is likely to be a feature of service provision and permeate some adoption and fostering research.

There are concerns regarding the unmet support needs of adopters and carers. The same appears to be true of disabled children.

One important aspect of permanence is stability: this is addressed in literature related to placement disruption. It appears that particular combinations of factors place children at most risk of disrupted placements. Notably this includes certain mental health diagnoses, older age at placement and challenging behaviours and it is suggested that foster carers have more difficulty dealing with some behaviours than others. We found evidence to suggest that placement disruption may itself have deleterious effects, including being detrimental to mental health, thus potentially setting up a vicious circle.

In terms of permanence outcomes, older age at adoption is typically associated with poorer outcomes, for example, having less chance of being adopted. It seems that this effect is exacerbated for disabled children because they typically enter the care system at an older age than their peers. Whilst there is little evidence related to gender, there is some indication that disabled boys may wait longer for permanence.

In terms of the suitability of placements, disabled children may be at a disadvantage; for example, there are not enough BME foster carers and adopters to provide same-race placements for Black disabled children.

5.2. How can such barriers be overcome and what other facilitators of permanence in foster care or adoption exist?

As discussed above, service providers and decision-makers need to undertake detailed work to identify the features of systems that contribute to delays and blockages. In general terms more robust assessment and interventions are needed that acknowledge the increasingly complex needs of children requiring permanent placements and, therefore, the complexity of the carer's role. Proactive steps, such as routine provision of disability equality training, are likely to be needed to address disablism amongst professionals, potential and current foster carers and adopters, policy makers and researchers.

The review directed us towards a number of innovative initiatives; however, there has been disappointingly little progress in scaling up such initiatives or sharing of the lessons learned. One

barrier to this may be the lack of investment in robust studies of what works. Another may be the lack of political will to resource such work.

The existing research may provide helpful guidance to where efforts could begin, but does not always identify specific systematic changes that will work. For example, research suggests a need to recruit more Black foster carers/adopters but does not test how this should be done or what other permanence measures may benefit Black disabled children. Equally, research suggests that if delays in adoption systems can be avoided for younger disabled children, they will be more likely to be adopted, but it does not indicate how the systematic barriers that have prevented this from happening so far can be overcome. Similarly, research indicates that consideration should be given to issues that may prevent disabled boys from finding permanent placements but it is not clear what combination of attitudinal change, additional recruitment or education may achieve this.

The absence or insufficiency of certain services or interventions seems to be an issue, although little is known about how barriers to their funding and delivery can be overcome. For example, several studies have called for training programmes for foster carers and adopters in dealing with specific challenging behaviours. Similarly there are calls for the provision of more ongoing individual support and specialist services such as mental health provision.

Some barriers facing disabled children in out-of-home placements are similar to those experienced by the wider population of disabled children this suggests that general investment in services for disabled children could benefit looked after disabled children.

5.3.   What works in achieving permanence for looked after disabled children and young people in foster care or adoption?

It is not possible to provide a comprehensive answer to this question; there is very limited evidence for certain types of intervention that will help some groups of children. For example, interventions designed to increase placement stability for children with challenging behaviours have been shown to be beneficial. The following are some areas, concepts or approaches which appear worthy of further development or testing:

- The introduction of broad and inclusive ideas into policy, practice and training in order to shift the emphasis away from an individual deficit model; for example, the 'social model of disability', 'strengths-based approaches' or 'whole-child approaches' (Brown, 2008; Cousins, 2009b; Gould, 2010).

- Increasing awareness and visibility of disabled children and their views such that they are fully integrated into assessment protocols, decision-making, recruitment and preparation of carers.

- Further development of non-traditional approaches, such as adoption parties, videos, carer-led family finding, technological innovations, and assistive communication to facilitate interaction between the child, worker and carers.

It is clear that if we are to understand more about what works, further research is needed; for example, we need to understand the processes of assessment and decision-making for disabled children and how decisions link to their longer-term outcomes. Similarly, more research is needed to identify how different issues and characteristics intersect with each other, such as the links between disability and gender, and ethnicity and gender, in relation to achieving permanence for disabled children. Research is also needed for clarification, such as regarding the extent and nature of disruption for children with mental health needs or intellectual disability, as there are conflicting findings.

5.4.   Conclusion

This review has covered a wide range of literature related to permanence in foster care and adoption for disabled children. We have shown that disabled children experience various disadvantages in relation both to permanence outcomes and aspects of permanence such as placement stability. In addition to addressing the knowledge and attitudes of decision-makers, workers, carers and potential carers, remedying this will require concerted effort to change the systems that create disadvantage.

Acknowledgements

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