ACHIEVING PERMANENCE FOR DISABLED CHILDREN AND YOUNG PEOPLE IN FOSTER CARE AND ADOPTION



Review of literature Kirsten Stalker, Vicki Welch and Chris Jones

With thanks to Alasdair Stewart

What do we mean by permanence?

- More than a legal status
- It involves intention and expectation
- It is a sense of belonging, identity, security and stability in a 'family' that endures over time, across generations and locations.

- With the birth family or alternative care such as:
 - Adoptive family
 - Long term foster
 - Long term kinship
 - Long term residential

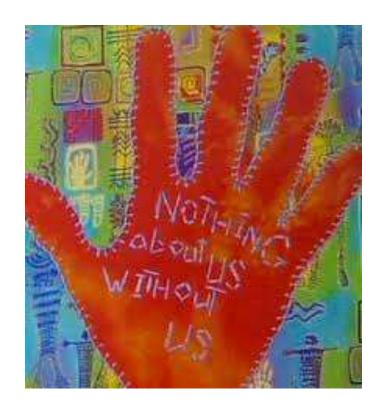
Why this is important?

- When children are removed, it is usually the start of a period of uncertainty
- Yet permanence (and lack of it) has a great effect on children's daily experiences, their development and their longer term outcomes



What do we understand by disability?

- Disability is not a simple thing
- Disability includes impairments, but also effects from social, cultural, economic and physical environments.
- We feel that disability should be defined with participation from those who experience it.



How were 'permanence' and 'disability' defined in the literature study?

Different authors take different stances to disability

 Different authors are interested in different aspects or forms of permanence

 We included all approaches since we wanted to maximise the material we could potentially use

How did we perform the literature study?

- We followed a process for scoping studies developed by Arskey and O'Malley (2005).
- Six steps:
 - Identify our questions
 - Identify relevant studies
 - Select appropriate studies
 - Chart / extract the information
 - Collate, summarise and report the results
 - Consult / validate with stakeholders

What's the nature of the findings?

- Different research approaches
- Significant interest in some areas, less in others
- Contested perspectives and (sometimes) seemingly contradictory findings
- A picture of diversity and nuance

ACHIEVING PERMANENCE FOR DISABLED CHILDREN AND YOUNG PEOPLE IN FOSTER CARE AND ADOPTION

Review of outcome studies

Overview of literature - location

| Location | Frequency |
|-------------|-----------|
| USA | 54 |
| UK | 17 |
| Canada | 10 |
| Australia | 5 |
| China | 1 |
| Netherlands | 1 |
| Total | 88 |

Overview of literature – type of text

| Type of text | Frequency |
|-------------------------|-----------|
| Empirical quantitative | 43 |
| Empirical mixed methods | 12 |
| Empirical qualitative | 12 |
| Literature review | 7 |
| 'Think piece' | 11 |
| Briefing | 3 |
| Total | 88 |

Overview of literature – research methods

| Method | Frequency |
|-------------------------------------|-----------|
| Analysis of agency records | 29 |
| Interviews | 26 |
| Survey/questionnaire | 14 |
| Literature review | 7 |
| Focus groups | 4 |
| Secondary analysis of research data | 3 |
| Case study | 2 |
| Other | 4 |

Outcomes

- Disabled children less likely than others to reunify
- No less likely to be adopted, except those with intellectual disabilities
- Disabled children wait longer than others to be adopted
- At an older age, more likely to be adopted than non-disabled children of same age
- Disabled children stay in foster care longer than their peers
- They may achieve a form of permanence in foster care
- More likely than other children to be placed out of authority/ state or in inappropriate placements

Akin 2011; Avery 2000; Baker 2007, 2011; Dept of Education 2014; Hayward & Depanfilis 2007; Romney et al 2006; Schimdt-Tiezsen & McDonald 1998; Simmel et al 2012; Simon & Dance 2000; Slayter & Springer 2011.

Outcomes - disruption

- Overall, disabled children experience more disruption than others - except in kinship care
- Those with behavioural disabilities and mental health issues at particular risk
- Some research has found disabled children over-represented among 'runaways' from foster care
 - other studies report children with learning disabilities and some mental health diagnoses less likely to run away
- Mix of factors likely to be key age and impairment type



Baker 2011; Baker 2007; Courtney and Prophet 2011; Courtney & Zin 2009; Farmer et al 2008; Haugaard et al 2000; Helton 2011; Lin 2012; Steen and Harlow 2012; Strijker and van de Loo 2010.

Outcomes and age

- Younger disabled children more likely to be adopted than older ones
- At older age, disabled children more likely to be adopted than non-disabled peers
- Adoption at younger age > better outcomes
- Older disabled children face more disruption, in all settings
- Older children spend longer in out of home placements

Baker 2011; Farmer 2008; Grant & Thomas 2013; Haugaard et al 2000; Helton 2011; Hill 2012; Strijker and van de Loo 2010.

Outcomes and gender

- Not much attention paid to gender and disabled children
- More disabled boys than disabled girls in foster care
- Boys face higher levels of restrictiveness in foster care
- One study found boys waited longer for adoption than girls



Avery 2000; Schmidt 2013; Slayer & Springer 2011; Smith 2002;

Outcomes and ethnicity

- African-American children disproportionally represented in US foster care and adoption
- Young people from Hispanic communities face greater disruption in out of home placements in the US
- In the UK, black disabled children more likely than black non-disabled children to be placed with white carers
- US research found few differences in family adjustment between transracial and in-racial adoptions

Farmer et al 2008; Lazarus et al 2002; Simon and Dance 2000; Slayter & Springer 2011; Smith 2002.

Outcomes and impairment

- Many studies focus on children with particular impairments, especially...
- Children with 'behavioural disabilities'
- Children with mental health needs
- Children with intellectual disabilities

Akin 2011; Baker 2007, 2011; Becker et al 2007; Brown & Rodger 2008; Burge 2007; Courtney & Prophet 2011; Farmer et al 2008; Haugaard et al 2000; Hill 2012; Lin 2012; McDonald et al 2007; Minnis et al 2006; Romney et al 2006; Slayter & Springer 2011; Steen & Harlow 2012; Strijker and van de Loo 2010; YouGov 2012; Ziviani et al 2012

ACHIEVING PERMANENCE FOR DISABLED CHILDREN AND YOUNG PEOPLE IN FOSTER CARE AND ADOPTION

Review of qualitative studies

Theme 1: Listening to disabled children

- A stark lack of literature exploring disabled children's views of permanence and related issues.
- Review found no reports of children's direct accounts.



- This gap is frequently highlighted in papers but not addressed.
- Particular groups of disabled children may be more disadvantaged than others.

Baker, 2011; Cousins, 2009b; Lomas & Johnson, 2012, Clark, Thigpen, & Yates, 2006; Lightfoot, Hill, & LaLiberte, 2011; Orme, Cherry, & Cox, 2013; Orme, Cherry, & Krcek, 2013; Schmidt-Tieszen & McDonald, 1998

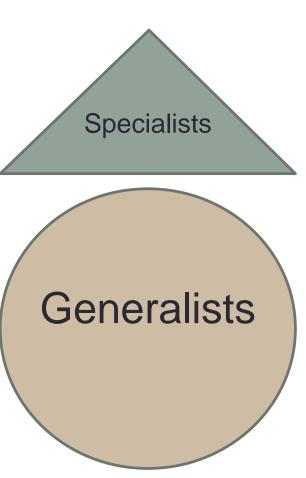
Theme 2: Recruitment of carers and adopters of disabled children

- The motivations of carers and adopters of disabled children are varied.
- Decision to care for a disabled child influenced by biography and personal values:
 - personal experience of fostering (e.g. in childhood),
 - personal experience of challenges in childhood,
 - religious beliefs,
 - sense of social responsibility.
- Experience builds confidence but is not an essential prerequisite.

Barton 1998; Brown et al 2007; Brown 2008; Burge and Jamieson 2009; Clark et al. 2006; Lauver 2008; Marcellus 2008, Schofiled and Beek 2004; Shannon & Tappan 2011

Theme 2: Recruitment of carers and adopters of disabled children

- 'Recruit 'specialists' through hospitals, special schools, specialist press.
- Recruitment of 'generalists' likely to require action to address barriers such as stereotypical views of disabled children, misconceptions and fears.
- Enable experienced foster carers to extend parenting skills to meet needs of disabled child.



Cousin 2005; Glidden 2000; Gould 2010; Schofiled and Beek 2004

Theme 3: Assessment, preparation and training of adopters/carers

- Caring for a disabled child requires particular skills:
 - networking; harnessing resources; coping skills; advocacy; including families of origin.
- These may not all be present during assessment but can develop over time.
- More bespoke training for carers of disabled children needed.
- Foster carers of disabled children value training and support from peers.

Theme 4: Supporting carers/adopters of disabled children

- Caring for children with significant needs can be demanding leading to fatigue and social isolation.
- Financial concerns can contribute to stress.
- Health and wellbeing of carers often poorly addressed.
- Some foster carers highly critical of social workers and use phrases such as "fighting" to be listened to/for support.



Beek and Schofield 2004; Brown 2005, 2008; Brown & Rodger 2009; Marcellus 2008; Lauver 2008.

Theme 4: Supporting carers/adopters of disabled children

- Specific types of support valued by foster carers of disabled children include emotional support, advocacy, help with securing benefits or entitlements and respite care.
- Continuity of relationships important: can be difficult to maintain where workers have high caseloads and move frequently.
- Access to accurate information about a child and their background crucial to successful placement.
- Adopters resistant to professional support and prefer help from informal networks.

Barton 1998; Beek and Schofield 2004; Brown 2005, 2008; Brown & Rodger 2009; Lauver 2008; Marcellus 2008, 2010; Molinari & Freeborn 2006; Pasztor et al. 2006; Schormans et al. 2006

Theme 5: Meeting the needs of disabled children

- Specialist services viewed as crucial by carers/adopters.
- Access to these often problematic.
- Mainstream day care, educational and recreational activities also difficult to access.
- Important role of medics particularly highlighted.
- Negative attitudes regarding disability act as a barrier

Avery, 2000; Baker 2006; Barton 1998; Bilaver 2006; Brown 2005, 2007; Brown & Rodger 2009; Cousins 2005; Haugaard 2000; Lauver 2008; Mather 1999; Pasztor et al. 2006; Peake 2009; Robertson 2006; Shannon & Tappan 2011; Zivani 2013

Theme 5: Meeting the needs of disabled children

- Adopt a 'strengths based approach' or a 'whole child approach' that does not focus primarily on impairment
- Increase the visibility of disabled children and promote success stories.
- Promote the social model of disability within permanency planning.
- Integrate disability issues throughout preparation
- Make use of computer technologies to facilitate communication between a child and worker.



Theme 6: Satisfactions expressed by carers of disabled children

- Developing a positive relationship with the disabled child & receiving affection
- Seeing a disabled child develop.
- Observing small changes achieved by disabled children in the face of significant challenges.
- Helping a disabled child return home.
- Maintaining a disabled child's connections with family and community.
- Improved relationships between the carer and their own biological children



Barton 1998; Brown et al 2007; Brown 2008; Lauver 2008; Marcellus 2008

ACHIEVING PERMANENCE FOR DISABLED CHILDREN AND YOUNG PEOPLE IN FOSTER CARE AND ADOPTION

Conclusions

Research gaps identified in the literature

- Many authors highlight gaps
- Other gaps may go un-noticed
- Gaps relate to certain groups
- Gaps relate to certain service types
- Gaps relate to research approaches
- Overall very little on:
 - The UK context
 - Meeting individual needs
 - Children's views
 - Longitudinal research

Where next for the research?

- Publications:
 - Journal paper(s)
 - Briefing(s)
 - Other outputs or activities?
- Further research:
 - At least one research funding proposal
 - Identifying priorities?
 - Identifying partnerships?

Revisiting the headlines 1:

- More literature from the USA than elsewhere.
- Included mainly empirical studies & some other sources.
- Disabled children had poorer outcomes than other children in terms of:
 - reunification,
 - adoption chances,
 - adoption timing,
 - located in local area,
 - stability / disruption.
- As far as we can tell: Age matters, Gender matters, Ethnicity matters, Impairment type matters.
- Different groups of disabled children have different experiences.

Revisiting the headlines 2:

- In services there is a lack of expertise but plenty of pessimism.
- Disabled children are often excluded from decision making... and research.
- Providing specialist support is complex.
- Different types of adopters and carers have different recruitment and support needs.
- Outcomes can include positive experiences for carers and adopters.

Next steps for practice and policy?

We have come together today to begin the process of thinking about what these findings mean for policy and practice, and we need your help...

Handover to the activity