

# **‘Realistic positivity’:** understanding the additional needs of young children placed for adoption, and supporting families when needs are unexpected

A report from the Council for Disabled Children

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National Children's  
Bureau



## Acknowledgements

We are extremely grateful to all the parents and professionals who contributed to this project by participating in interviews, completing surveys or sharing thoughts by email. Their desire to help improve the lives of adopted children and their families was strongly apparent. To this end, they discussed their own challenging experiences and views on complex, sensitive issues, and their openness is greatly appreciated.

We would also like to acknowledge everyone who informed our approach, facilitated **parents' and professionals' participation, shared information, or** contributed to this report. Particular thanks are owed to NCB staff Amanda Allard, Keith Clements, Andrew Fellowes, Catherine Godack, Kate Thomas; Harley Young and Hannah Warwick; NCB associates Sheryl Burton and Amy Edwards; Dr John Simmonds OBE from CoramBAAF; and two **adoption social workers in Emily's personal network.**

The report is based on independent research commissioned and funded by the National **Institute for Health Research (NIHR) Children's Policy Research Unit.** The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the National Institute for Health Research, the Department of Health and Social Care or its arm's length bodies, and other Government Departments.

We thank the funders for making this research possible.

## Glossary of abbreviations

ADHD	Attention deficit hyperactivity disorder
ASD	Autism spectrum disorder
ASF	Adoption Support Fund
BAAF	British Association for Adoption and Fostering, now CoramBAAF
CAMHS	Child and Adolescent Mental Health Services
CPR	<b>Child's permanence report</b>
EHCP	Education, Health and Care Plan
FAS	Foetal alcohol syndrome
FASD	Foetal alcohol spectrum disorders
LAC	Looked after children
OT	Occupational therapist
PTSD	Post-traumatic stress disorder
SEMH	Social, emotional and mental health
SEND	Special educational needs (SEN) and disability
SENDIASS	SEND Information Advice and Support Service
VSH	Virtual School Head



# Contents

Glossary of abbreviations.....	2
Contents .....	3
Introduction.....	4
Methodology.....	6
Policy context .....	9
Key processes .....	14
Literature review.....	15
Children adopted in England.....	15
Adopted children with additional needs.....	16
<b>Understanding adopted children’s health and development in the context of their early experiences</b> .....	16
<b>Gathering and communicating information on children’s health and development prior to placement for adoption</b> .....	21
SEND and adoption disruption.....	23
Support for young adopted children with additional needs and their families .....	24
Findings from interviews with parents and professionals.....	29
<b>1. Identifying and understanding children’s needs</b> .....	29
Findings from parents .....	30
Findings from professionals .....	31
<b>2. Communication and information pre-placement</b> .....	35
Findings from parents .....	35
Findings from professionals .....	38
<b>3. Supporting families at different stages and through transitions</b> .....	41
Findings from parents .....	42
Findings from professionals .....	44
<b>4. Parental engagement with services and community resources</b> .....	49
Findings from parents .....	49
Findings from professionals .....	55
<b>5. Responses to new or emerging concerns post-placement</b> .....	60
Findings from parents .....	60
Findings from professionals .....	64
Discussion.....	72
Recommendations for future research .....	81
References .....	82

## Introduction

Adoption is a significant event that changes the lives of the children and families involved forever. Today, the vast majority of children adopted in England have spent time in the **care system. Most of them became 'looked after' by a local authority following abuse or neglect. Adopters' love** for and commitment to children who have had difficult starts in life is powerfully evident in research and reported experience. Whilst adopted children and their families may thrive, particularly with the right support, many experience significant distress and occasionally adopted children have to leave the family home prematurely, **which is known as 'adoption disruption'.**

The legacy of adverse prenatal environments, insecure attachment, persistent trauma and changes in caregiver can be extremely challenging. These factors, along with issues relating to **professionals' involvement** and the emergence of needs over time, can make it difficult to recognise and respond to **children's needs including common conditions** such as autism. According to one adoption policy and practice expert interviewed for this project, the engagement of health professionals in the adoption sector is **'proactive' and 'very positive'**; nevertheless, many adopters feel that they were not provided with sufficient information about their child's **health and development** prior to **the child's placement.**

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***'The question about whether prospective adopters are actually being misled or the degree to which information is withheld is a very difficult one to be objective about because I can absolutely see that sometimes it may happen, but it's also in the context where professionals really are not very clear about how to predict from we know about what will actually happen in the future.'** – Adoption policy and practice expert*

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It is not clear how many adopted children are disabled or have special educational needs. However, we do know that parenting a disabled child or child with SEN can be a highly rewarding experience, but can become stressful when needs for information, advice or support are not met.

Adoption and disability are two complex areas of experience and each presents considerable challenges for professionals and services. This project aimed to understand and inform practice in supporting families for whom these areas intersect in unexpected ways. It addressed:

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***'Disability and adoption: it's like they're two completely abstract concepts and because they are a minority area it's not something that's generally combined.'** – Parent*

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- why the needs of care-experienced children may be difficult to identify or understand in the early years
- **how professional interpretations of children's** presenting behaviours and symptoms are formed and conveyed to prospective adopters pre-placement
- how adopters seek help when concerns arise about their young child's **health or development**, and the ways professionals and services respond
- how systems and professionals outside adoption interact with the adoption process **and adoption professionals in relation to young children's additional needs**
- **parents' and professionals' ideas** about how support for families could be improved.

The scope of the project included:

- the experiences of adopters and the practice of professionals based in England
- children who are placed for adoption, or in early permanence placements, with families not previously known to them
- **children's** needs that are not clearly apparent to, or anticipated by, professionals and/or parents prior to placement for adoption, but which cause concern during **children's** early years and transition to primary education
- needs other than, or additional to, SEMH needs, including those that are ambiguous or multifaceted.

The requirement for post-adoption support to be offered in all areas indicates that, to an extent, the adoption system anticipates and plans for the SEMH needs of adopted children. This project, therefore, focused on other areas of SEN and disability. Physical disability has not featured as strongly as learning disability, autism and other needs, possibly because physical impairments are more likely to have been identified and explained to parents prior to adoption.

There are many related situations and issues that are important and of interest but beyond scope. Some are occasionally drawn upon in relation to the points above.

This report explains the range of policy areas and key duties relevant to the topic. It goes on to examine the available literature, before presenting findings from interviews with six adoptive parents and thirteen professionals.

Interview findings are presented in five sections. The first addresses how professionals **identify and understand children's needs, and underpins all the others. Subsequent sections loosely reflect a child and family's journey, through:**

- **communication about children's health** and development between professionals and prospective adopters
- the stages and transitions involved in the early years of children's lives, including placement for adoption
- **parents' help**-seeking and engagement with services and community resources, to
- professional and service responses to new or emerging concerns post-placement.

This is followed by a discussion which draws upon both the literature and interview findings, summarises the practice challenges identified and considers how these might be addressed. Finally, some potential topics for future research are recommended.

This report gives a voice to parents and professionals, and explores the practice implications of what they have to say. Their experiences are placed in the context of policy and evidence spanning health, social care and education to support understanding of the complex and sensitive issues covered. It is hoped that this project will contribute to the development of good practice in addressing **young children's** additional needs and working with their families pre- and post-adoption.

A summary of this report and a *Realistic Positivity* practice briefing are available at: <http://bit.ly/RealisticPositivityRpt>

## Methodology

This project involved:

- initial internet-based scoping of literature and policy
- online survey seeking practice examples from a range of professionals
- interviews with adoptive parents and professionals
- revisiting literature review and policy analysis in light of interview findings.

### Initial scoping and online survey

The initial scoping and online survey explored how services support families with children aged 0-5 who are disabled or have complex needs and are adopted or in early permanence placements. In particular, it was concerned with children whose needs were emergent; unassessed or undiagnosed pre-placement; or poorly communicated to prospective adopters. The scoping focused on children in England, though some international literature was included where it addressed particular gaps.

This early phase of the project sought to identify examples of local practice that involved multiagency working to address **unexpected concerns about adopted children's health** and development. However, it found that practice in this area does not appear to be led by agencies or professionals jointly focusing on this issue. **It is characterised by professionals' encounters with adopters and each other in the course of broader work**, and cannot be separated from practice that **affects the 'expectedness' of children's needs**: i.e. how **children's presenting behaviours and symptoms** are interpreted through their early years, and how parents are prepared for adoption.

In the next phase, **the focus was shifted onto individual professionals' and parents' experiences of relevant issues**, and what changes they felt might improve support for families. Involvement was sought from a broader range of professionals. As a result of the initial scoping some changes were made to the scope, most significantly:

- extending the age range to cover transition to primary school
- specifying an interest in concerns relating to physical disability, learning disability or autism to ensure that the focus included needs other than SEMH.

### Interviews

Calls for parent and professional interviewees were disseminated through adoption- and disability-related networks. The aim was to gather experiences of parenting, or supporting families with, children:

- who had been placed for adoption or entered early permanence placements since 2010 (later extended to 2009)
- who were aged under five at the time
- for whom concerns relating to physical disability, learning disability or autism became apparent during or after adoption.

Interviews **focused on children's early years and transition into primary education.**

Semi-structured interviews were held with six parents first, followed by thirteen professionals. Most interviews were conducted by phone, with the exception of one parent and two professionals who were met in person. Topic guides were used for each group.

The six parent interviewees presented experiences of parenting eight different adopted children, describing needs including:

- ADHD
- attachment difficulties
- attachment disorder
- autism spectrum disorder and quasi-autism
- complex health needs including heart problems
- developmental delay
- developmental trauma
- developmental coordination disorder (dyspraxia)
- foetal alcohol spectrum disorders
- foetal alcohol syndrome
- genetic condition
- hearing loss
- learning difficulties
- sensory processing disorder or sensory issues.

Some of these needs had not been formally diagnosed. Several parents also listed symptoms and behaviours associated with developmental trauma or mental health issues, such as anxiety, violence and toileting issues.

Seven of the children were adopted from the UK care system, six of which across local authority boundaries. One child was adopted from overseas.

Professionals interviewed had some experience of planning, managing or delivering services for families in the circumstances described above.

In addition to seeking participants via professional networks, direct approaches were made to social work team managers in selected local authorities deemed by Ofsted to be either good or outstanding for both adoption and children in need. This approach aimed to maximise participation from professionals who may be well-placed to share good practice examples.

Participants worked in a range of professional areas:

- adoption social work
- adoption medical work
- adoption policy
- post-adoption therapeutic provision
- early years and education
- statutory services for children with SEN
- specialist CAMHS.

All were managers, service leads or practitioners, except one adoption policy and practice expert. One voluntary adoption support agency was represented. Interview questions were tailored for individuals if the topic guide was not sufficiently applicable to their particular perspective.

Interviews were transcribed verbatim and analysed thematically using the Framework approach.

Information from several other contributors was gathered by email.

## Further literature review and policy analysis

The initial internet-based scoping of literature and policy was built upon to incorporate recurring issues and key themes emerging from the interviews.

### Strengths and limitations

This study used a small sample of interviewees so findings are not representative of adopters generally, or of any or all relevant professional groups. Both parent and professional interviewees were self-selecting, which may affect the balance of the findings: for example, parents who have had difficult experiences may be particularly keen to inform a project that seeks to improve support for families.

The thirteen professional interviewees offered diverse professional perspectives. There was geographical variation with parents and professionals from both rural and urban local authorities participating.

Naturally, all accounts of events are unverified and represent the perspectives and **memories of individual participants. Events described often lack detail on children's age or adoption status at the time** (i.e. before or after the adoption order). For example, many comments made about EHC needs assessment and planning were not made with explicit reference to children in the early years or first year of primary education.

Interviewees also varied in terms of **how their families' experiences fit with key policy developments**, against which their accounts cannot easily be mapped. The most significant of these developments are the SEND reforms and introduction of the Adoption Support Fund.

Despite these limitations, in-depth discussions generated rich findings, many of which resonate with findings from larger-scale research.





## Policy context

The current agenda to regionalise adoption services (DfE, 2016) is changing how local authorities discharge their statutory duties. By 2020, the Government intends that new regional adoption agencies will carry out recruitment, matching and adoption support functions on behalf of all local authorities.

### Understanding and communicating information about a child's health and development during the adoption process

Statutory guidance on promoting the health and well-being of looked after children (DfE, 2015a) details the responsibilities local authorities have for assessing and reviewing the health of children in their care (paragraphs 40-54). It also set out what should happen when adoption is the planned permanence option for a looked after child (90-93).

Statutory guidance on adoption (DfE, 2013) explains legal duties enshrined in The Adoption and Children Act 2002 and associated regulations. A range of duties that apply to local authorities and voluntary adoption agencies are pertinent to this area of practice:

- The role of the adoption agency medical adviser, who is to be consulted where the agency arranges for the child to be examined, and in relation to accessing and disclosing health information about the child and birth family as required or permitted by law (paragraphs 1.6-1.8).
- **Obtaining information about the child and the child's family, including health assessments for children and seeking information from and about birth parents (2.53-2.61).**
- The preparation of reports produced at different stages of the adoption process, **including the child's permanence report (CPR), which** is submitted to the adoption panel (2.62-2.68). The CPR is compiled by a social worker and **must include 'all the information about the child and their family and a summary by the agency's medical adviser on the state of the child's current physical and mental health and behaviour and, if age appropriate, a developmental assessment, their health history and current and future health care needs'**.
- What information about the child must be shared by the adoption agency with the **family it considers most appropriate as a 'match', and how (4.23-4.24)**. This includes the CPR, which is a prospective adopter's principal source of written information about the child. The prospective adopter may also receive reports or **summaries on the child's health, education or special needs**. It is good practice, though not mandatory, for the medical adviser to meet with the prospective **adopter** 'to share all appropriate health information, to discuss the needs of the children with whom they are matched, and to provide a written report of this meeting'.

The work of medical advisers is not directed by further statutory guidance; however, practice guidance for them and other relevant professionals is available from CoramBAAF (Merredew and Sampeys, 2015 and 2017).

## Preparing for a child's placement and supporting adoptive families between placement and the adoption order

After a child's placement with their prospective adopter, they remain a looked after child until the adoption order is made, though parental responsibility is shared with the local authority. The prospective adopter triggers the finalisation of the adoption by issuing an adoption application to the court.

The statutory guidance on adoption explains **adoption agencies'** duties in relevant areas:

- **Assessments of the child and family's support needs when a match is being considered** (9.44), proposals for provision of support services (see below) and **planning for the child's placement** (4.27-4.30, 5.3-5.6)
- **The adoption agency's responsibilities towards the child and their adoptive family** between placement and the adoption order, including visits by social workers (5.24-5.28) and reviews (5.33-5.41)
- The inclusion of information on health (8.97-8.99) and adoption support arrangements (8.107) in the report accompanying an adoption application.

### Adoption support services

Chapter 9 of the statutory guidance on adoption covers **local authorities' responsibilities** for the provision of adoption support services, including entitlements to assessment of need, assessment procedures, support planning, and the provision and reviewing of **support**. **'Post-adoption support'** refers to support after a child's adoption order has been granted, and is provided by local authorities or Ofsted-regulated Adoption Support Agencies.

Local authorities are legally required to **assess families' post-adoption support** needs if requested, but the provision of support to meet identified needs is currently at the discretion of the local authority and not a statutory duty. Where the child is adopted across local authority boundaries, the placing authority is responsible for post-adoption support for the first three years, after which time it transfers to the local authority where the family lives (9.18-9.23). The same principles apply at a regional scale where regional adoption agencies deliver these functions.

The aspects of adoption support most relevant to this project are services to enable discussion of matters relating to adoption; therapeutic services; services to ensure the continuation of the adoptive relationship (including training for parents and respite care) and to assist in cases of disruption; counselling, advice and information; and financial support<sup>1</sup>.

The Adoption Support Fund (ASF) is the primary funding source for therapeutic services provided to adopted children and their families. It is available for children in England who have been adopted from care in the UK, left care under a Special Guardianship Order, or been adopted from overseas.

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<sup>1</sup> Further information about adoption support is available at <http://www.first4adoption.org.uk/adoption-support/>

In addition to therapeutic services, the ASF can be used to cover the cost of certain multidisciplinary assessments; these may be able to identify conditions such as foetal alcohol syndrome, autism and attachment disorder<sup>2</sup>. The Fund will pay for respite/short break care only where therapeutic input is provided. It does not cover support, guidance or training for schools.

## Special educational needs (SEN) and disability

The SEND Code of Practice (DfE, 2015b) is statutory guidance for organisations working with and supporting all children and young people who have special educational needs (SEN) or disabilities. A child or young person has SEN if they have a learning difficulty or disability which calls for special educational provision to be made for him or her. A child under compulsory school age has SEN if they are likely to fall within that definition when they reach compulsory school age or would do so if special educational provision was not made for them.

The SEND Code of Practice relates to Part 3 of the Children and Families Act 2014 and associated regulations. The principles underpinning the legislation and the guidance (Chapter 1) aim to enable children and their parents to participate in decision-making; **identify and respond to children's needs as early as possible; ensure high quality provision;** promote collaboration between services; foster inclusive practice; and remove barriers to learning.

Many of the duties explained by the SEND Code of Practice are relevant to the topics addressed in this report. In particular, the Code of Practice provides guidance on managing the circumstances of looked after children (3.49, Chapter 9, 10.1-10.11), including how SEN assessments and Education, Health and Care (EHC) planning for looked after children **should work 'in harmony'** with care planning. It also advises on joining up service provision to help achieve good outcomes for children with SEN and social care needs (10.13-10.20).

More broadly, disabled children have legal rights that touch on all aspects of their lives, including health, social care and education. These are explained in *Disabled children: a legal handbook* (Broach et al., 2016).

## Promoting children's educational achievement

Statutory guidance published in February 2018 explains roles and responsibilities in relation to promoting the educational achievement of looked after children and previously looked after children<sup>3</sup> (DfE, 2018a and 2018b). The duties covered, which are not identical for the two groups of children, apply to local authorities, education providers, Virtual School Heads (VSHs), social workers, designated teachers and other professionals.

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<sup>2</sup> The scope of the Adoption Support Fund is defined in the Service Categorisation Guidance, the most up-to-date version of which can be found at <http://www.adoption-supportfund.co.uk/>

<sup>3</sup> A previously looked-after child is one who is no longer looked after in England and Wales because s/he is the subject of an adoption order, special guardianship or child arrangements order, or has **been adopted from 'state care' outside England and Wales.**

Areas addressed by the guidance include:

- responsibilities for ensuring the SEND Code of Practice, as it relates to looked after children, is followed
- the process for developing and reviewing the Personal Education Plan (PEP)<sup>4</sup>, which forms part of the care plan for children of pre-school age and above
- responsibilities for understanding and responding to the emotional and behavioural needs of looked after children and previously looked after children
- duties and expectations relating to work with parents and carers
- **children's entitlements** in relation to funding and how this money should be used.

Early years providers and schools attract funding to improve education provided for previously looked after children: The Early Years Pupil Premium (EYPP) for three and four year olds and Pupil Premium Plus for children aged 5-16. They are also entitled to a free early education place from the age of two, and priority school admissions.

The 2018 statutory guidance supersedes the previous guidance, which was in force when interviews were conducted for this project (November and December 2017). The critical difference is the introduction of new duties towards previously looked after children in line with the Children and Social Work Act 2017.

At the time of the interviews, VSHs were required to ensure proper enactment of local **authorities'** duty to promote the educational achievement of looked after children. Maintained schools (including nursery schools) and academies were required to designate a teacher responsible for promoting the educational achievement of looked after children in their setting.

From 2018, local authorities are required to provide information and advice to parents, early years settings and schools for the purposes of promoting the educational achievement of previously looked after children. This includes promoting good practice on identifying and meeting **children's needs**. **The new** duty extends the role of the VSH, who can also undertake 'any activity they consider appropriate' **to benefit this group of** children.

The Children and Social Work Act 2017 also mandates access to a designated teacher for previously looked after children. Designated teachers operate at a whole school level as well as working to support individual children, including ensuring that SEN are identified and met.

## Children and young people's mental health services

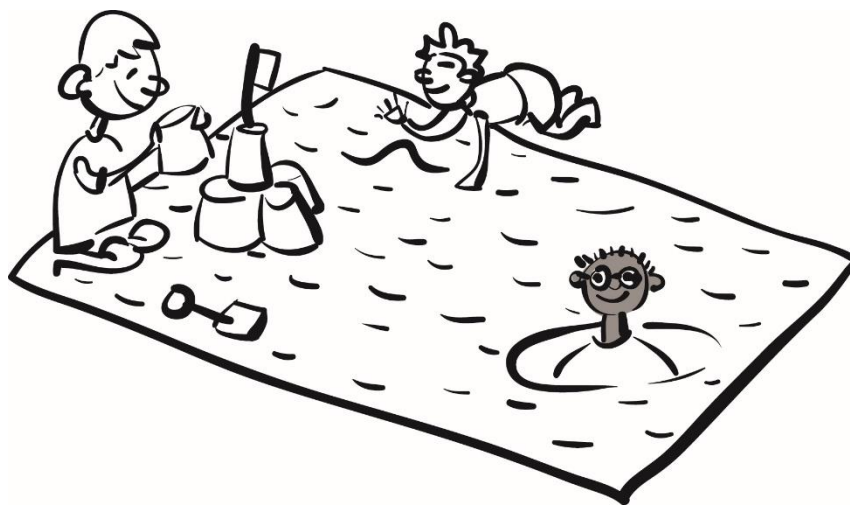
Since 2015, Clinical Commissioning Groups have been required to publish Local Transformation Plans on an annual basis, demonstrating how local services will invest resources to improve children **and young people's mental health**. **Guidance from NHS England (2015)** identifies adopted children and children with learning disabilities among the groups of vulnerable children owed special consideration in the preparation of these plans.

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<sup>4</sup> The PEP is an evolving record of what needs to happen to enable a looked after child to make expected progress and fulfil their potential, and includes transition support needs when a child is placed for adoption.

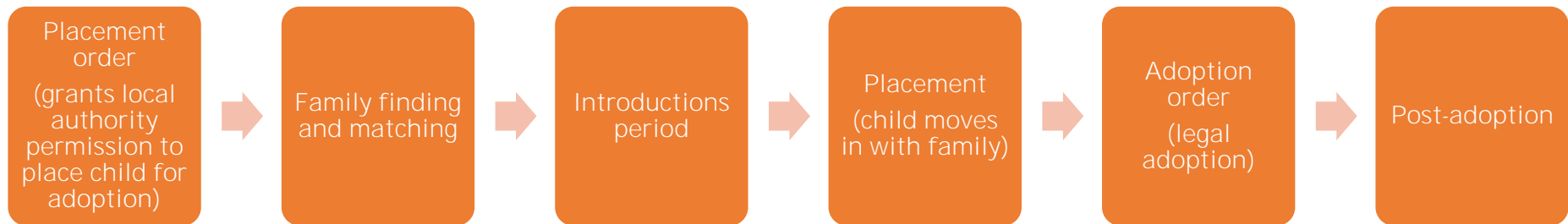
consulted on a Green Paper setting out proposals to improve mental health support for children and young people (DfE and DHSC, 2018). They had also reviewed the recommendations of an Expert Working Group set up in 2016 to ensure that the emotional and mental health needs of care-experienced children and young people would be better met (SCIE, 2017).

In setting out its response to the consultation, Government has confirmed that the proposals will be trialled in trailblazer areas. These areas will also test recommendations from the Expert Working Group, including those around joint working and access to specialist mental health support. Implementation of the Green Paper proposals will be linked to a pilot scheme testing improved mental health assessment approaches for looked after children. It also relates to the *Transforming Care* programme, which aims to improve health and care services for children and adults with learning disabilities, autism or both.



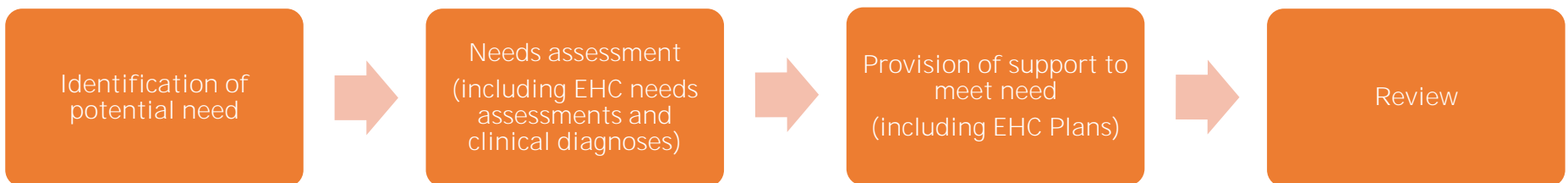
## Key processes

Adoption of a child from care



Responding to a child's additional needs in relation to:

- education
- health
- social care



## Literature review

This literature review addresses:

- what is known about the profile of disabled adopted children in England
- difficulties in understanding **adopted children's health and development**
- the implications of ambiguity for assessment, diagnosis and treatment or support
- **how professionals gather information on children's health and development prior to placement for adoption, and communicate this to prospective adopters**
- links between **children's** additional needs and adoption disruption
- how well post-adoption support, early years and education, and mental health provision addresses young **adopted children's additional needs**.

## Children adopted in England

Today, the vast majority of children adopted in England are **'looked after children'** adopted from local authority care, the majority of whom were taken into care following abuse or neglect (DfE, 2016). For the year ending in March 2017, 4,350 children were adopted from care, a reduction of 8 per cent compared to the previous year. This follows a period of increasing numbers of looked after children being adopted since 2011, which peaked in 2015 (DfE, 2017a).

The profile of children adopted in England today has changed greatly from when adoption was first enshrined in law in 1926. Adoption reached its peak in 1968: in that year, half of all children adopted in England and Wales were aged under 12 months, the vast majority of **whom were 'illegitimate' children** (Keating, 2009). Until the mid-1970s, **'when infants with even a slight disability were relinquished by their birth mothers, "unfit for adoption", was stamped on their file'** (Argent, 1996 cited in Baker, 2011).

The principle of **'permanence'** for all children has since become a driving force in **children's social care**. Permanence is **about ensuring that children have 'a secure, stable and loving family to support them through childhood and beyond and to give them a sense of security, continuity, commitment, identity and belonging'** (DfE, 2015c). A clear case must be made for removing a child from their birth family and, subsequently, for any **decision that it is not in the child's best interests to return to the birth family**. Adoption is now one of a range of options for achieving permanence for children in care who are not able to return home safely. A historic trend whereby children awaiting adoption have **outnumbered prospective adopters has reversed, incentivising 'sometimes quite desperate adopters' to 're-explore both their own aspirations and re-evaluate their presentation in order to make a positive impact on social workers in their selection from the long list'** (Simmonds, 2016).

The drive to promote permanence for all children has necessitated efforts to counter disability-related stigma, reduce the negative impact of disability-related labels, and encourage open-mindedness in professionals and prospective adopters (Cousins, 2003). **Despite this work and the 'supply and demand' imbalance mentioned, children identified as disabled are still considered 'harder to place' for adoption than non-disabled children: an issue formally recognised in adoption policy.**

In the year ending March 2017, the average age of adoption was 3 years and 4 months, with only 7 per cent of children adopted under the age of one (DfE, 2017a).

## Adopted children with additional needs

Defining and measuring ‘disability’ for looked after and adopted children is challenging, and the definitions used in the available research are varied.

Data collected on looked after children in England records their ‘primary need’: i.e. the main reason for them coming into care. In recent years, a stable 3 per cent of children have had disability as their primary need (DfE, 2017b). Disability is not recorded for the 97 per cent of children with other primary needs (most commonly abuse or neglect), even though disabled children are more likely to experience all types of abuse than non-disabled children (Miller and Brown, 2014). Evidence suggesting that a far higher proportion of looked after children are disabled includes data on special educational needs (SEN).

SEN is a relevant concept when considering definitions of disability for children. Recent data indicates that almost half of adopted children appear to have identified SEN at Key Stage 2 (DfE, 2018c). **The SEND Code of practice (DfE, 2015b) separates children’s SEN** into types of need; in most official SEN data that is published, **only a child’s primary type** of need is included. Social, emotional and mental health (SEMH) needs are the primary type for 43 per cent of primary school pupils who are looked after and have identified SEN; the next most common primary types are moderate learning difficulty and speech, language and communication needs (DfE, 2018d). The prevalence of SEMH needs among looked after children is far higher than in the broader population of children with SEN (DfE, 2018e), and a 2017 survey of UK adopters similarly indicates a disproportionate prevalence among their 2,084 adopted children (White, 2017).

Data focusing on educational needs can offer insight but does not account for needs that are not recognised within education. Also, data that is limited to **children’s primary type of need** cannot reveal how multiple types of need can combine to impact on children. LAC data cannot capture the impact of **placement for adoption on children’s development**, but published data on adopted children is limited and experimental.

Whilst mental health difficulties are known to be common among looked after children (Meltzer et al., 2003), there is very limited data on children under the age of five, when most adoptions take place. This may be **in part attributable to a ‘reluctance to label very young children’** and to the newness of standardised screening and assessment tools validated for use with very young children (Carter et al., 2004, Murphy and Fonagy, 2013, and Luke et al., 2014 cited in Moriarty, 2016). One London study identified at least one mental health disorder in 26 of 43 children in care aged 0–72 months (Hillen and Gafson, 2015).

## Understanding adopted **children’s health and development in the context of their early experiences**

Young adopted children’s needs must be considered within a context of possible experiences of adverse prenatal environments (for example, maternal stress or exposure to drugs and alcohol), genetic risk, insecure attachment, neglectful care, persistent trauma, and changes in caregiver. This review relates a large body of literature on these issues to young children about whom there are concerns relating to physical disability, learning disability and autism. It explores **how young children’s different needs interact, how they can be identified and understood, and why they may be experienced by adopters as unexpected.**



## Insecure attachment and developmental trauma

Professional approaches to understanding and addressing the needs of care-experienced children have been heavily influenced by attachment theory which originates in the work of John Bowlby (1969, 1973 and 1980) and was elaborated by Mary Ainsworth (Ainsworth et al., 1978). When **an infant's** primary attachment figure is absent, repeatedly changes, harms the child or fails to respond adequately to their attachment needs, the child **experiences 'insecure attachment'**. Insecure attachment can have wide-ranging impacts on children's social and emotional development, educational achievement and mental health (NICE, 2015).

Since Bowlby began formulating attachment theory in the 1950s, there has been much debate about the theory itself and its application in practice (for example, Prior and Glaser, 2006). More recently, there has been an increasing research focus on the impact of trauma on young children. Many children removed from their birth families will have had traumatising early experiences.

Herman (1992) **proposed a diagnosis of 'complex post-traumatic stress disorder' to describe traumatic stress symptoms in individuals who had experienced 'prolonged, repeated trauma' including childhood abuse, as opposed to PTSD which was associated with 'relatively circumscribed traumatic events'**. Cook et al. (2005) later elaborated on this, asserting that the PTSD diagnosis<sup>5</sup> did not capture the developmental effects of complex trauma exposure for children exposed to maltreatment, family violence, or loss of their caregivers, which may include emotional, physiological, attentional and behavioural dysregulation, and wide-ranging impairments in many domains of functioning. Bessel van der Kolk (2005) recommended **a new diagnosis of 'Developmental Trauma Disorder' to describe complex trauma in children, 'based on the concept that multiple exposures to interpersonal trauma [...] have consistent and predictable consequences that affect many areas of functioning', and suggested treatment implications.**

Burnell and Vaughan (2012) identified that the central principle of developmental trauma **'creates a more complex picture than the one painted by the attachment theory' because, when a child's primary attachment figure fails to meet their needs, 'not only are the infant's attachment relationships distorted but their neurological, physiological and cognitive development is compromised'**. Burnell and Vaughan also pointed out that, for many adopted children, this experience **'may have been preceded by negative, and toxic developmental influences in the womb', including drugs and alcohol.**

Attachment and trauma theory underpin widely used adoption support therapeutic interventions.

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<sup>5</sup> The *Diagnostic and Statistical Manual of Mental Disorders (DSM)* is published by the American Psychiatric Association and used by health care professionals around the world to diagnose mental disorders. The fourth edition (DSM-IV) did not include specific criteria for diagnosing PTSD in children, making it difficult to diagnose. The fifth edition (DSM-V) includes guidelines for diagnosing PTSD in children under the age of 6.

## The ambiguity of needs and diagnoses

Interpreting adopted **children's presenting symptoms and behaviours** can be challenging, due to complexity; emergence over time; gaps in background information; and changes in caregivers, childcare or education providers, health professionals and social workers.

**Children's needs may also be ambiguous** for various reasons, explored below. Their histories also vary widely, and the neurobiological impacts of maltreatment and neglect on children cannot be understood in a formulaic or deterministic way (Woolgar, 2013).

**Understanding children's needs is often more complicated than determining whether** one diagnosis or another applies. Dr Margaret DeJong leads a national multidisciplinary NHS outpatient service with specialist expertise in the assessment and treatment of children with a background of abuse, neglect or trauma. DeJong (2010) observed that psychiatric disorders common among care-experienced children tended to be **'part of a co-morbid picture', and that, often, 'a child may be sub-threshold on a number of different diagnoses; the resulting impairment is far greater than would be indicated by the diagnostic profile'**.

Some concepts are not yet well-developed, or not in relation to children adopted from UK care. DeJong (2010) concluded from clinical experience that **'sub-threshold forms of autism or patterns of social disturbance that have autistic-like features may be seen quite frequently'** in children accessing her service. **'Quasi-autism'** was first identified in children adopted from Romanian orphanages (Rutter et al., 1999) and features more flexibility in communication and a more marked, if abnormal, social approach than is usually observed in autism; its symptoms could potentially mimic other forms of autism or an attachment disorder. Green et al. (2016) investigated whether quasi-autism existed in children aged 6–11 who had been adopted from UK care after early disrupted care, neglect or maltreatment. Finding a strikingly high incidence of ASD in 11 per cent of the sample, with a further 18.5 per cent showing partial features, they described the clinical implications of **their results as 'immediate and significant'**:

**A common response to a child's difficulty** in engagement with an adoptive placement or destructive or disruptive behaviour has been to ascribe a psychological model of attachment disruption, emotional inhibition or post-traumatic disturbance. Clearly all of these phenomena may be significant in children with such pasts, but the presence of neurodevelopmental disorder such as **ASD is an important alternative explanation for the child's difficulties, with different implications.**

Some of the issues being identified by professionals are not formally recognised in standard diagnostic classifications. An Australian study of 347 children in foster and **kinship care concluded that 'a sizeable proportion of chronically maltreated children present with complex attachment- and trauma-related symptomatology that eludes coherent formulation'** within current diagnostic systems (Tarren-Sweeney, 2013). Cook et al. (2005) observed that children affected by complex trauma often met diagnostic criteria for other conditions including ADHD, conduct disorder, reactive attachment disorder and **communication disorders, asserting that 'each of these diagnoses captures a limited aspect of the traumatized child's complex self-regulatory and relational impairments'**; however, a proposal from van der Kolk et al. (2009) to include a new classification of Developmental Trauma Disorder in DSM-V was not accepted. Whilst the debate about diagnostic classification **continues, use of the term 'developmental trauma' in healthcare, social work**

and education has increased and the concept is influencing practice<sup>6</sup>. The assessment and treatment model developed by Family Futures, an adoption support agency rated outstanding by Ofsted, has been substantially informed by research on developmental trauma (Vaughan et al., 2016).

A condition may be formally recognised without having clear criteria or diagnostic pathways. There are no formal guidelines for diagnosing foetal alcohol spectrum disorders (FASD) in the UK and the diagnostic criteria for FASD are **'differing and poorly defined'** (BMA, 2016), with the exception of foetal alcohol syndrome (FAS). A British Medical Association report identified a range of factors contributing to the under-diagnosis of FASD including the lack of a specific diagnostic test; difficulties obtaining maternal alcohol history; the lack of multidisciplinary neurodevelopmental teams to complete comprehensive assessments; and insufficient professional knowledge, understanding and confidence in relation to FASD (BMA, 2016).

The specialist multidisciplinary assessments that may enable the best possible insight into children's needs are **resource intensive**. Children may not have access to them and may not meet thresholds for mental health services (HCEC, 2016). Findings from a mapping exercise exploring mental health provision in London for looked after children aged 0 – 5 **suggested that 'very young children experiencing trauma or depression but not presenting with behavioural problems would be very unlikely to meet the referral criteria'** for CAMHS (Moriarty, 2016).

When children are assessed, effective tools may not be available or used. DeJong (2010) identified 'an over reliance on tools developed for ordinary clinic and community populations' (**for example**, the Strengths and Difficulties Questionnaire widely used in emotional and behavioural screening for children and young people) rather than more specialised measures such as Tarren-Sweeney's Assessment Checklist (Denton et al., 2017). An Expert Working Group exploring the mental health of care-experienced children asserted that the SDQ alone is not effective for assessing these children and should be used in conjunction with other assessment methods (SCIE, 2017). They noted that it is unable to detect PTSD, attachment disorganisation and developmental issues such as autistic spectrum condition.

The meaning of clinical terms may become warped in popular usage, creating confusion for professionals and parents. **NICE guidance on children's attachment notes** that the terms 'attachment disorder' and 'insecure/disorganised attachment behaviour' are often confused and wrongly used interchangeably (NICE, 2015). Woolgar and Scott (2014) **have observed the widespread use of 'attachment disorder' to describe and explain 'complex presentations of children who have been neglected or maltreated' in ways that often bear 'little resemblance to the established diagnostic systems, nor indeed to attachment theory as conceptualised by Bowlby'**. Woolgar and Baldock (2015) reviewed the files of 49 adopted children and 51 looked after children referred to a specialist, Tier 4 CAMHS Adoption and Fostering Service across a four year period. In the referral letters,

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<sup>6</sup> A 2016 Practitioner Resource produced by Child Family Community Australia (part of the Australian Government's key research body in the area of family wellbeing) reviews evidence on the **effect of trauma on the brain development of children and offers 'Evidence-based principles for supporting the recovery of children in care'**. It is available at: <https://aifs.gov.au/cfca/publications/effect-trauma-brain-development-children>

which came from CAMHS psychiatrists, paediatricians, GPs and social services, 31 of the 100 children were described as having attachment problems. However, only three children were diagnosed with attachment disorders in the specialist clinic assessment. The study also found a tendency to under-identify common disorders across the referral letters. In the specialist clinic assessment, many such disorders were diagnosed more frequently than RAD/DAD<sup>7</sup>. The authors listed conduct problems, ADHD, anxiety, autism, encopresis/enuresis, neurodevelopmental problems, learning disability and specific **learning disability**'. They warned against 'a tendency to over-diagnose' attachment disorders and problems in looked after and adopted children, at the expense of identifying more common disorders with evidenced-based treatment or management options.

## The implications of ambiguity

**For the reasons explained above, a clear picture of an individual child's needs is often not available prior to adoption.** Mixed and inconclusive evidence, and practical challenges in assessment, present major challenges for practitioners and parents trying to understand and meet **children's needs**. This is compounded by barriers to gathering and communicating information, which are discussed below.

In this context of uncertainty, professionals operating within different frameworks may clash over how **children's** need should be understood and addressed, as this case example demonstrates.

### CASE EXAMPLE

Woolgar and Scott (2014) described the case of a 10 year old boy removed from his family at 18 months due to severe neglect and adopted at age three. The boy exhibited violent outbursts and difficulties with peer relationships, and his parents perceived him to be struggling with literacy. His school said he was meeting his targets and insisted on an attachment-based approach which led his parents to feel criticised; social care **'resisted becoming involved again with an adopted child who had found a permanency placement outside of care'**; while the authors' specialist health service diagnosed him with socialised conduct disorder and specific disorders of speech and language, but not attachment disorder. In this case, education, social care, health and parent intuition all took different paths. Whilst the school had good intentions, the authors judged that **'a child who was patently unsuitable for mainstream education was on the verge of being transferred to secondary school extremely poorly socialised, illiterate, with a history of significant risk events and with his high level of educational needs unrecognised'**.

This case also highlights the important role of professionals not routinely involved in grappling with issues affecting care-experienced children: in particular, education professionals. Woolgar and Scott concluded that, for this boy, **'the effective therapeutic input was to establish an appropriate educational placement to meet his needs, rather than any further input at the level of the child or the family'**.

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<sup>7</sup> Certain patterns of behaviours associated with grossly negligent care have been clinically defined as Reactive and Disinhibited Attachment Disorders (RAD/DAD).

Research on approaches to meeting **children's needs** tends to either focus on specific conditions like ASD, without considering adoption-related dimensions, or on evaluating single attachment- and trauma-focused interventions for adopted children and their families. Stock et al. (2016) have pointed out that this leaves knowledge gaps: for example, **'treatment shown to be effective in treating ASD, may not work for children with multiple issues including, but not restricted to, ASD'**. Having reviewed the available evidence for distinct post-adoption support interventions, Stock et al. recommended a follow-up review **using a 'needs-based' model**. They suggested that the scope include pervasive developmental disorders or other neurodevelopment difficulties, as well as difficulties that do not meet clinical diagnosis thresholds. The review could cover both single and combined interventions including holistic approaches designed to address multiple issues such as **Family Futures'** Neuro-Physiological Model, PAC-UK, and the adopted children and adolescent mental health service (AdCAMHS) in East Sussex.

## Gathering and communicating information on children's health and development prior to placement for adoption

In 1999, community paediatrician Dr **Mary Mather observed that** 'adoption social work practice and the medical skill and experience needed to support the substitute care of children have changed dramatically', **since the focus of adoption shifted from** 'finding healthy babies for childless couples' **towards achieving permanence for all children** (Mather, 1999). Children who have been removed from their birth families are more likely to have additional needs, and key background information may be missing. This might include details of parental physical or mental health problems, a family history of genetic disorder or a history of developmental or learning difficulties (Hill and Edwards, 2009; Woolgar, 2016), or information about adverse prenatal experiences such as exposure to alcohol (BMA, 2016).

Looked after children are entitled to statutory health assessments. For those who go on to be adopted, the adoption process is informed by input from the adoption agency medical adviser (see *Policy context*).

**The ways in which professionals interpret information about children's health or** development, and communicate its implications to each other and to prospective adopters, seem likely to affect how children are matched with their future parents: in terms of all **parties' decision-making**, confidence and expectations. Simmonds (2016) stressed that the impact of uncertainty on professionals is commonly overlooked and that trust and cooperation between professionals and prospective adopters can be difficult to maintain when making high-stakes decisions in which there is considerable emotional investment. Simmonds argued that linking and matching should be informed by 'the realities of what this is – a mixture of hope and expectation, love and commitment, uncertainty, anxiety and fear' **for all involved, in addition to 'the primary issues of separation, loss and grief' and the need to avoid delay for children whilst 'taking a long term perspective in the context of learning and adaptation'**.

Farmer et al. (2010) reviewed the case files of 149 children with adoption recommendations in ten local authorities. They found more poor matches (involving serious compromises on matching requirements or prospective adopters' preferences) when children's difficulties were underplayed with new parents and when matching children with significant health or developmental needs. Poorer quality matches were related to poorer outcomes six months after adoptive placement.

Full disclosure of available **information in a Child's Permanence Report is now considered** best practice, whilst also enabling the birth parents to comment on what has been written (CoramBAAF, 2014). Hill et al. (2010) observed a shift towards detailed discussions with prospective adopters **about children's** future health risks having **encouraged** 'a culture of **sharing rather than withholding information**'. **Changes in practice have in part responded** to cases of adopters who, feeling that information had been withheld, have taken legal action against local authorities. However, Wickramasinghe (2016) pointed out that neither the Adoption Agency Regulations 2005 nor statutory adoption guidance address whether and how health information obtained from birth parents can be shared with prospective adopters without consent.

Hill and Edwards (2009) surveyed 45 parents, representing 57 adoptions from 1987 to 2009, and found that whilst certain details may be shared with prospective adopters, information relating to birth parents can be hard to obtain as birth parents may be either difficult to engage or absent. In fact, health information was available for fewer than half **of the birth fathers, and information relating to parental mental health was 'rarely'** available. Parents commonly found information provided to have been inadequate, which caused them concern.

Wickramasinghe (2016) identified further barriers to information gathering: lack of **resources; families' mobility; issues with risk assessment for blood-borne** infections; and lack of understanding of the implications of information on the part of some social workers. Wickramasinghe evaluated a medical counselling service in one London borough, in which medical advisers met with 79 prospective adopters and five other long-term carers over a five-year period. Sessions were also attended by carers' social workers and children's social workers. Feedback from carers was extremely positive: 90 per cent felt that medical counselling had helped them to understand **the child's needs**. Half wanted to receive further medical information, but two thirds reported no reservations about proceeding after discussions with medical advisers. **Although carers' emotional responses to medical information were described as 'complex'**, explicitly explained risk was found to empower adopters, contradicting a **'widely held professional fear that adopters may in some way be "put off"'**. The author identified a need for further research on medical counselling in relation to long-term outcomes for adopted children and adopters.

The only national study on adoption disruption by Selwyn et al. (2014a) found that 69 per cent of 70 parents (whose children had either left home under the age of 18 or who were **finding parenting very difficult**) **felt that details about their child's history or birth family** and important medical information had not been shared with them prior to placement. Often, parents reported having been made aware of such details only **after their child's** adoption was legally finalised. Whilst a few parents attributed missing information to oversight, the majority believed that information had been purposefully withheld and that, when it had been provided, they had not been supported to understand its significance. Following the introductions period, a quarter of these parents reported having had concerns, **including 'that there were more difficulties than they had first thought'; before** deciding to proceed, most discussed their worries with professionals. Some were compelled **to proceed by an overwhelming desire to be a parent; some felt 'embroiled in a process over which they had little control'; and some felt they had made a commitment on which** they could not renege.

In the research report, *Beyond the Adoption Order: challenges, interventions and adoption disruption*, Selwyn et al. (2014a) noted how some of the parents reported a growing belief, **in the months following their children's placement, 'that they had not been told everything**

they needed to know about their child and that they were far more traumatised or developmentally delayed than they had first thought’.

More recently, a survey of 2,778 parents of domestically adopted children found that parents believed they did not receive full and correct information for 36 per cent of children during the adoption process (BBC/Adoption UK, 2017). It also found that, whilst 70 per cent indicated that they were not informed prior to adoption that their child was at risk of FASD, half as many had considered that their child might have FASD and 15 per cent had been advised post-adoption that their child may have FASD.

**The issues described above are part, but not all, of a complex picture of families’** experiences, which *Beyond the Adoption Order* presents in rich detail. It is not possible to isolate what particular information adopters lacked or to quantify the extent to which **unpreparedness for their children’s needs contributed to parenting challenges. However,** older research supports the view that inadequate provision of background information to prospective adopters increases the risk of adoption disruption (Rosenthal, 1993).

Antonelou and Hodes (2010) conducted a retrospective analysis of 47 paediatric appraisals of adopted and fostered children, which found that checking for new or previously unidentified health issues in children may contribute to supporting families in crisis. Family Futures is an independent adoption support agency in London which accepts referrals from social care for families facing the risk of placement breakdown. Following initial assessment, selected families are offered long-term therapeutic support, at which point children are assessed by a paediatrician: such children were included in this study. They had a mean age of 8.3 years and were assessed between 2005 and 2009, mostly having been referred because of behaviour problems. Sixty-eight per cent were adopted; 13 per cent had been placed with prospective adopters. Carers presented a range of concerns **relating to children’s physical health, development, behaviour and nutrition. The paediatric appraisals led to 20 new diagnoses, of which 60 per cent were physical and 40 per cent developmental. The researchers highlighted the complexity of adoption medical work and concluded that** ‘even if such children have been seen on many occasions by the medical adviser as recommended by BAAF, there are still undiagnosed problems and new issues to **address**’ later on.

## SEND and adoption disruption

Parenting children who have had traumatising early experiences can have a profound impact upon carers, affecting their mental and physical health and family relationships (Gordon and Wallace, 2015; Ottaway and Selwyn, 2016; King et al., 2017). This impact can include secondary trauma: ‘the natural consequent behaviours resulting from knowledge about a traumatising event experienced by a significant other. It is the stress resulting from helping or wanting to help a traumatised or suffering person’ (Figley, 1995, cited in Gordon and Wallace, 2015).

**In some cases, the difficulties faced by families can result in ‘adoption disruption’,** when children in leave the adoptive family home prematurely (under the age of 18 years), often returning to care.

Much of the research available looks at present-day outcomes and disruptions for children who were adopted many years ago, and consideration must be given to what was known and practiced during the time periods covered. Current research is also complicated by the fact that there are significant gaps in post-adoption data, which is in part due to the de-

linking of children's pre- and post-adoption social care, health and education records (Selwyn et al., 2014a).

Selwyn et al. (2014a) carried out the only national study on adoption disruption in England, using a range of methods. This study found adoption disruption to be unusual: Selwyn and colleagues estimated that 3 in 100 adoptions disrupted over a 12-year period (2000-2012).

**Predictive factors were the child's age at the time of the disruption** (young people aged 11 – 16 were ten times more likely to experience disruption than children under four), followed by older age at placement, and a longer waiting time between placement and adoption order. Children who had waited longer for an adoptive placement were also more likely to experience a disruption.

Developmental and mental health issues featured heavily in the study findings. About a quarter of 390 adoptive parents surveyed identified **'major challenges in caring for children who had multiple and overlapping difficulties'**. Nevertheless over a third of all parents surveyed described family life as **'going well'**. Seventy parents selected for interview, whose children had either left home under the age of 18 or who were finding parenting very difficult, reported **'extraordinarily high levels of social, emotional, and behavioural difficulties'**. The vast majority of their children scored in the clinical range for mental health problems and most had at least one diagnosed developmental or mental health conditions: these included attachment disorder, PTSD, ADHD, FASD and depression. A quarter had been diagnosed with an autistic spectrum disorder and 37 per cent had a statement of SEN (Selwyn et al., 2014b). **Of the parents who described family life as 'going well' in in-depth questionnaires**, 29 per cent reported that their child had at least one diagnosed condition.

Beyond this study, the literature on disability and adoption disruption is mixed. Some studies have shown that children with physical or learning disabilities are not at a higher risk of disruption (Fratter et al., 1991, cited in Selwyn et al., 2014a) and in fact some US research has found there to be a decreased risk of disruption for children with physical impairments (Boyne et al., 1984, and Glidden, 2000, cited in Selwyn et al., 2014a). Several studies have found adoption disruption to be significantly more likely for children classified as having **'special needs'**: one found only a modest association **between 'delayed or problematic skills or abilities' and disruption but a 'significant association' between challenging emotional/behavioural characteristics and disruption** (Barth et al., 1988, Rosenthal et al., 1988, and Berry and Barth, 1990, cited in Coakley and Berrick, 2008).

A large study of children in the English care system (Sinclair et al., 2007, cited in Baker, 2011) found some indicators for disruption to be more prevalent for disabled children than non-disabled children, such as older age when entering care; a greater time between entering care and placement; and displaying challenging behaviour.

## Support for young adopted children with additional needs and their families

### Post-adoption support

Post-adoption services include support from social workers; counselling, advice and information; therapeutic provision; and financial assistance. The Adoption Support Fund (ASF), introduced across England in May 2015, is now the primary funding source for therapeutic services provided to adopted children and their families. Its implementation has influenced the structure of local authority adoption support teams; professional roles



for social workers in particular; local procedures and systems; assessment methods; available provision; and delivery (King et al., 2017). A Fair Access Limit to the ASF came into force in late 2016.

Holmes et al. (2013) provided an overview of how post-adoption support teams and services were working in 2013, and Selywn et al. (2014a) researched **families' experiences** of these services in relation to adoption disruption. However, given that the operation and effect of post-adoption support services have changed in recent years and will continue to do so as the ASF evolves and the regionalisation of adoption agencies progresses, more recent research offers the most relevant insight. An evaluation of the ASF's **early** implementation by King et al. (2017) addressed the **Fund's** impact in detail, with some limited exploration of **families' experiences of adoption** support services beyond ASF-funded provision. Findings are not disaggregated by child age or type of need, but some findings clearly relate to issues explored in this project.

The evaluation found that families accessing the ASF had profound and long-standing **needs: 'the vast majority of adopted children within these families showed very high levels** of emotional, behavioural and developmental issues, with family relationships being **strained and challenging'**. **Parental mental health was found to be suffering**. This reflects findings from a recent survey of 2,778 adopters (BBC/Adoption UK, 2017) that most parents experienced significant violence from their children. Whilst the overwhelming majority were glad they adopted, more than a quarter said there were either serious challenges impacting the wider family, or that their adoption was at risk of disruption or had already disrupted. One third had received support through the ASF.

The ASF evaluation report (King et al., 2017) summarises key findings from surveys with hundreds of individuals including adopters, local authority employees and independent providers; 20 family interviews; and 10 local authority case studies.

Of the parents surveyed in 2016, 57 per cent agreed that they had understood the importance of adoption support during their time as a prospective adopter; many parents **indicated that 'looking back they may have needed support earlier that they sought it'**. However, some parents reported having struggled to get a response or assessment when they did seek help, and capacity was a significant issue for local authority employees.

**Adopters are entitled to request and receive an assessment of their families'** post-adoption support needs. In 2016, 84 per cent of parents who reported having requested an **assessment said that this had been carried out. The report explained that 'assessments of** need for post-adoption support services are localised and bespoke processes that are difficult to separate from the wider work of providing adoption support, which includes the ASF funded therapeutic interventions. However, assessments are now becoming more **formalised as a result of ASF requirements'**. **Parents who had accessed the ASF reported** high levels of satisfaction with the assessment process, the offer of support, the services received and their therapeutic providers. The majority believed that the ASF had helped their child and made the adoption more stable. However, a number of barriers to accessing provision and feeling supported were reported. For example, one family described a lack of professional understanding of FAS:

They spent the initial years of their adoptive placement trying to work out what connected all of the impairments and behaviours of their children and had not previously heard of foetal alcohol syndrome. Social workers did not suggest this and

since it was diagnosed for both children, the family were finding that they were informing workers about the condition and what that meant.

Families expressed a wish for more proactive support, with a quarter of the broader sample of parents surveyed describing their relationship with their adoption agency as poor or non-existent.

The evaluation identified three areas in which family experiences of adoption support **services could be improved: 'consistent, responsive, skilled and non-judgemental professionals; support in communicating with and accessing other, mainstream services; and transparency about what support was on offer and available'**. Parents interviewed suggested that regular review meetings throughout ASF provision and the post-adoption journey could improve their experience.

The Fair Access Limit was introduced mid-evaluation and its initial impact not fully captured; however, parents expressed concern about the potential negative effects of the Fair Access Limit and the **Fund's future sustainability**.

## Early years and education

In 2017, 39 per cent of adopted children reached the expected standard of attainment at Key Stage 2 compared to 61 per cent of pupils overall; for adopted children with SEN, this figure was 16 per cent (DfE, 2017c and 2018c). A systematic review by Brown et al. (2017) highlighted a paucity of evidence on the educational progress of children adopted from care in the UK but concluded that adoption was associated with lower academic attainment and elevated levels of behavioural problems, that work is needed to support adopted children to achieve the best possible outcomes, and that their school performance should be routinely monitored.

**These findings are borne out by Adoption UK's** 2017 survey of parents of 2,084 adopted children (White, 2017), which focused on school exclusions. Results indicated that 60 per cent of the adopted children with SEND have an EHC plan or equivalent compared to just over 20 per cent of children with SEND in England (DfE, 2017, cited in White, 2017), indicating a higher level of need. In addition, nine per cent of respondents noted that their adopted child was receiving SEND support without having undergone formal expert assessment, compared to five per cent in the DfE figures. The survey also found that adopted children are 16 times more likely to receive a fixed period exclusion at Key Stage 1 than their peers, and 11 times more likely at Key Stage 2.

White highlighted the range of challenges and changes faced by young adopted children starting primary education, and by adopters who may have brief or no parenting experience and limited support. The report also expressed concern that:

While many adopted children will at some point face mental health challenges, some of their initial difficulties are not intrinsically behavioural or mental health difficulties. It must be considered whether lack of awareness, or inappropriate interventions for difficulties caused by attachment, trauma, sensory integration disorders, FASD etc. can result in children responding with inappropriate behaviour, or difficulties being exacerbated or escalated, even leading to mental health problems.

**Adoption UK's recommendations include** continued support post-order; flexibility in school starting ages; a presumption of additional needs for all adopted children starting school; a review of procedures around SEND assessments and classifications; improved professional development; more comprehensive data collection; and better use of funding (White, 2017; Adoption UK, 2018). Parental concern about how soon children begin school also appeared in findings on adoption disruption from Selwyn et al. (2014a).

Families interviewed for the ASF evaluation described mixed experiences of support from schools (King et al., 2017). Some noted positive examples of schools identifying needs, facilitating assessments and putting support in place. However, frustrations in getting **children's needs understood and addressed, even to the extent that children changed schools**, were reported by many.

There is growing research and practice interest in how children affected by trauma and attachment difficulties can be supported within education. For example, a model developed by Louise Michelle Bombèr (2016) involves the allocation of a team of staff, including a key adult, to identified pupils, **within a school that works to be 'attachment aware'**.

In 2015, the **Children's Partnership** surveyed 108 early years providers on their needs for information, support and advice to meet the needs of care-experienced children (Clements, 2016). The survey found that 41 per cent of providers were confident that their staff had adequate knowledge and skills to meet the needs of children adopted from care. Parents were the most common source of information **about individual children's needs**.

**Respondents' suggestions about information-sharing** frequently referred to summary documents on individual **children's needs**, suggesting that the development or sharing of templates may be valued by early years providers.

## Children's mental health services

Difficulties for care-experienced children in accessing mental health services were clearly apparent in the literature (Sweeney et al., 2014a; HCEC, 2016; King et al., 2017; Tarren-Sweeney, 2017): **these included diagnostic thresholds; services' stances on whether** particular needs constitute mental health problems; and their stated remit (not working with attachment issues, for example).

King et al. (2017) found relationships between post-adoption teams and CAMHS to be **varied and affected by 'CAMHS's diminishing resources, capacity constraints or skills gaps'**. In the national study of adoption disruption (Selwyn et al., 2014a), many parents and local authority adoption managers complained about the lack of access to and appropriate support from CAMHS. However, there were examples of good practice 'where LA post-adoption teams and CAMHS had commissioned specific therapists or referred onto specialist Tier 4 CAMHS or adoption support agencies'. Adoptive parents rated these services highly.

Tarren-Sweeney (2017) has advocated for specialist mental health services to be integrated closely with social care, asserting that, to be effective, such services must support carers and children through long-term developmental recovery – 'in other words, abandoning the notion that an acute care service model can deliver effective treatment for children with complex attachment- and trauma-related psychopathology'. Tarren-Sweeney argued that developing clinical staff with specialised knowledge and skills 'makes better sense' than attempting to up-skill clinicians across the board in attachment and trauma work.

## Coordination and multi-agency collaboration

The ASF evaluation (King et al., 2017) found that many of the 20 families interviewed when beginning to receive ASF-funded support had had poor experiences of seeking help through other services and of multi-agency collaboration. The other services they considered most relevant to addressing their problems were CAMHS and schools.

The evaluation found that the ASF has raised awareness of adoption support services and **the needs of adoptive families**'. For example, **'a few adoption support teams either gave examples of working closer with CAMHS or the Virtual School which they attributed to a raised profile and the development of expertise', whilst some families reported that allocation of ASF funding had been a trigger for improved coordination with schools or prompted schools to mirror the recognition of need.**

Eight families had been able to use ASF-funded assessments to communicate with schools and support applications for ECH plans. The majority of local authority interviewees expressed a view that the exclusion of work in schools, such as training on attachment and the needs of adopted children, was a **limitation in the ASF's scope.**

Most of the families interviewed six months after the start of their ASF allocation continued to experience disjointed services, sometimes attributing this to resource constraints. The researchers identified the ASF **as a 'potential catalyst for improving the wider scaffolding of support around families' and suggested that local authorities could consider this 'as a longer-term investment'.**



# Findings from interviews with parents and professionals

Each of the following five sections presents findings from six parents followed by those from 13 professionals. Where possible, the same sub-headings are used for parents and professionals are mirrored; however, findings from the two groups do not always mirror as their concerns and perspectives relate to their particular roles.

## 1. Identifying and understanding children's needs

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*'The impact of trauma or a child's attachment style or separation can present in the same way as autistic behaviours or ADHD, or sometimes a learning disability, or developmental delay.'* – Social worker

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Professional responses to the needs of both adopted children and disabled children are **subject to significant debate, in terms of how children's needs are identified, assessed, diagnosed and addressed.**

This section considers how professionals interpret children's presenting behaviours and symptoms, and **how they conceptualise and influence each other's perspectives. It is about how they think about children's needs** before, during and after adoption, and the implications of this. Processes and practice issues involved in **assessing children's needs** post-adoption are addressed in Section 5: *Responses to new or emerging concerns post-placement*. However, the findings presented below include views on assessments **undertaken and reports produced prior to a child's placement** for adoption. This work is critical to how professionals understand children's health and development thereafter, and to how prospective adopters are informed about children during the matching process (covered in Section 2: *Communication and information pre-placement*).

Findings are presented under the following headings.

### Parents

- **Identification of children's needs** before placement for adoption
- **Professionals'** knowledge and expertise

### Professionals

- Gathering information and producing reports for adoption
- Dealing with uncertainty
- Developing shared understanding

## Findings from parents

### Identification of children's needs before placement for adoption

Several parents **suggested that their child's** needs had been missed by professionals prior to their placement for adoption. Parents sometimes reported learning that worries **about children's** behaviour, or requests for assessments and therapy, had been raised and not taken forward whilst children were in care. This information had emerged in conversations with foster carers or in reports received post-adoption.

One interviewee, in recommending early assessments, reflected existing requirements for health assessments, plans and reviews for children in care. This parent reasoned that **interpretations of a child's needs can be 'clouded' and delayed** because **'the huge trauma on top of everything he's already** experienced of moving from his foster family to his adoptive family' **makes it hard to tell what is 'driving the presentation'.**

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*'Foster carer did raise concerns, when daughter was 18 months old, that she was very much a sensory seeker, would climb radiators, windowsills [...] **Pretty much it said in the report that this was not followed up, it was just deemed as typical [...] This could have been done a long, long time ago and she's nearly four and we're picking this up now.'** – Parent*

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### Professionals' knowledge and expertise

Parents expressed appreciation for specialist health services, whereas most of those who mentioned having been signposted to GPs and health visitors suggested this had been unhelpful. A few parents described finding the loss of a specialist health visiting service difficult and feeling that the universal service was insufficient, given their **family's** particular needs. Those parents who mentioned local CAMHS described them as reluctant or lacking the necessary skillset, while experiences of specialist CAMHS services were presented more positively.

Parents also valued education professionals who were familiar with issues affecting care-experienced children. For example, gratitude was expressed for an educational psychologist who was able to identify FASD and appreciated its **impact on children's** learning:

[Children with FASD] are doing everything they can do to conform, to fit into that **classroom, so they're not noticeable.** And I was terrified of the Ed Psych going, 'Oh, **he's fine', like everyone was saying [...]** but she was good.

Other parents described distressing interactions with professionals who they perceived as **ill-informed, and how these impacted on efforts to address their children's needs.**

## CASE EXAMPLE

A parent reflected on the EHCP process being put into motion for her child. She considered that, between the teachers, head teacher, special educational needs coordinator (SENCO) and educational psychologist, nobody 'really understood trauma or attachment' or 'why our son was having play therapy, why he needed it, why he was presenting in this way at school and in this way at home'. The play therapy was stopped, instigating a 'year-long battle trying to get it reinstated'. The parent concluded that professionals not being informed about developmental trauma and attachment 'delays access to therapeutic services that children need'.

Several parents spoke about educating themselves and trying to pass their knowledge on to **their children's schools; however, they were not always in a position to do this effectively**. One parent of a child recently diagnosed with attachment disorder did not feel as though **the child's school 'understood the implications of that on top of her learning disabilities'**, but had found it difficult to educate school staff because 'research either looks at learning disabilities or attachment [...] I haven't found anything that relates to both'.

## Findings from professionals

The findings below demonstrate the critical role of the adoption agency medical adviser in **shaping perceptions of, and communication about, children's health needs**. The medical advisers interviewed valued practice sharing opportunities as well as research, pro formas and guidance from CoramBAAF. However, one interviewee felt that guidance from government could improve consistency in practice across the country.

## Gathering information and producing reports for adoption

Medical advisers produce adoption medical reports using details about children and their birth families which have been gathered by social workers, as well as health information. Their work informs **social workers' recommendations and conversations** with prospective adopters. Medical advisers also produce a comprehensive summary of relevant information in the CPR (see *Policy context*).

For children adopted from care, the initial and review health assessments undertaken whilst in care form important sources of information for medical advisers during the adoption process. One health professional noted how communication between looked **after children's health teams and health visiting teams can help inform good health** assessments for young children in care who may go on to be adopted. They suggested a new medical problem was more likely to be recognised, or a pre-existing medical problem to be recorded, during the initial health assessment than the adoption medical, because the latter summarises and refers to existing information unless new investigations are considered necessary.

Many of the professionals reflected on the difficulties of gathering information about **children's health and family history, and producing medical reports**, for the purposes of adoption. These included being unable to involve birth parents; relying on self-reported information; **not having birth parents' consent to access health records; receiving** information second-hand; being given details based on hearsay or rumour; and uncertainty about permission to share printouts of medical scans, for example, where the results of investigations cannot be easily described.

Several professionals also identified issues around including information about risks to children's health and development due to the need to stick to 'concrete facts' and 'clear evidence' even when 'good deductions' may be made. This was highlighted particularly in relation to children's potential prenatal exposure to alcohol or drugs.

## Dealing with uncertainty

There was broad agreement that understanding the needs of young adopted children involves grappling with difficult issues, including interpreting the results of genetic testing **and understanding the potential nature and causes of a child's needs**. In particular, professionals reported difficulties distinguishing between needs or conditions which display some of the same features. **They pointed out that children's needs often only manifest or become clear after they start school.**

Interviewees expressed a range of divergent opinions about how to handle this uncertainty. One paediatrician had found it **'exceptionally difficult' to convince social workers that** there are other diagnoses besides attachment problems. They attributed this to the clinical judgement of psychologists and therapists perceived to be **'obsessed with attachment disorder'** and to overlook the high incidence of developmental disorder in adopted children. A social worker **did say that 'although we know that for children who were adopted, there's a higher rate of ASD, ADHD and learning disability, my take on it would be that it's probably an attachment issue'**. However, therapists and social workers, including the interviewee quoted, tended to stress the difficulties in establishing diagnoses of autism or ADHD, for example, rather than denying their possibility.

**A professional working in an adoption support agency stated that 'we have lots of children with learning difficulties', noting that these difficulties have often gone unidentified until the agency facilitates children's access to specialist assessments,** at which point families are in distress. This professional saw children who have experienced adversity and trauma as particularly adept at masking difficulties, with important consequences:

These children have learnt incredible ways to survive and their survival strategies **are extraordinary [...]** **If your mum's going to hit you or your dad's getting violent,** you work out a strategy as to how to survive it, whereby you know how to manage the adults to a degree. But, of course, that becomes maladaptive and it starts being **unhelpful [...]** **Professionals are looking at them and thinking, 'No, that's trauma' or 'That's autism', where actually, it's trauma, autism, but they also have a learning difficulty. And no one's assessed them because the assumption is the behaviour's something else.**

The timing of assessments in a child's personal journey was identified **as a 'defining factor' in understanding whether needs are 'pervasive' or 'more situational'**. A paediatrician explained that significant change is often noticed in children soon after their initial entry **into the care system; professional judgements made at this point inform medical advisers'** later work for those children who are adopted.

Services face dilemmas in balancing early identification with avoiding the consequences of labelling children too young. A SEND professional described two adopted children who were both expected to go to special school, yet both entered mainstream education **'because we were able to raise those skill levels'**. In relation to emotional and behavioural difficulties, a policy and practice expert expressed **concern that many people 'don't accept that assessing under-fives is the right thing to do or that it can be done'**. This interviewee



said that assessment of young children was possible and worthwhile, given the presence of **'some early interventions which can be really helpful'**.

Some services explicitly avoid diagnosing certain conditions in the early years. Interviewees also mentioned age thresholds for ADHD assessments. A paediatrician described the need for judgments and actions around this **to be guided by an awareness of children's histories**, giving the example of a four year-old who had been excluded from school. This **professional deemed consideration of ADHD treatment for this child appropriate** 'because of the sheer risk factors', even though they would not normally treat a four year-old for ADHD.

**SEND professionals spoke about their emphasis on children's abilities and potential, and mentioned cases in which they had felt that 'other professionals were very much underestimating the child's ability'**. One professional explained how her service uses the Portage model:

What we say is, you can build on a **positive skill [...]** We need to find out what their skills are, and then support the parents to raise those skills, to make those **expectations [...]** We are the voice of positivity, but realistic positivity, and we do listen to what the parents say.

All of these issues have particular implications for social workers involved in adoption matching, **who are instrumental in huge decisions about how children's lives will move forward**. These decisions are made in the context of complex questions that cannot be resolved immediately, if ever, and pressures on local authorities to finalise adoption placements. One adoption support social worker observed that social work colleagues **involved in matching children with prospective adopters 'are optimistic people – they have to be'**. Their general outlook and their approach to handling uncertainties, anxieties and risks, will affect **how they explain children's health and development to prospective adopters** (see pp.39 – 40).

## Developing shared understanding

Many interviewees spoke about the importance of professionals from a wide range of disciplines understanding the needs of adopted children, especially the impact of attachment issues and trauma.

Early years and education, in particular, were seen to need help in this area. A Virtual School professional was working to disseminate resources produced by Adoption UK, PAC-UK and Inner World Work. A professional from an early years teaching school, who had experience of supporting other settings around the behaviour of children affected by attachment difficulties and trauma, reported having encountered poor awareness of these issues and the underpinning neuroscience. Training was not always seen to impact on **interpretations of children's behaviour in the classroom**. The interviewee's nursery school was described as particularly proactive: staff had been trained in Theraplay, for example, and accessed learning materials and opportunities. These efforts were attributed to the **nursery's own interest in this area** and their sense of its importance for children in general.

Some uneasiness was expressed about the insistence of some professionals and parents **that 'schools need to know about attachment'**. An adoption policy and practice expert identified a need for clarity about what exactly schools should know:

Schools are meant to provide a secure base but not in the way that is [...] scientifically defined as what the attachment system actually is. [...] I just think we need to be more precise because attachment [is] a system which gets stirred up when the child is separated from their primary caregivers.

This interviewee argued that other systems that enable children to deal with sibling and peer relationships, for example, **may affect children's** behaviour at school and **'should not be confused with attachment even if attachment may have some bearing' on them.**

Other perspectives highlighted how training and knowledge-sharing for universal services such as health visiting, and across disciplines, could help practitioners to interpret **children's presentation, recognise where specialist input may be needed, and realise that 'these children deserve facilitation of their referrals'.** For example, a health professional said that if a GP was unaware that 'there was anything special' **about** an adopted child, any referral for the child would depend on the **'vehemence' and advocacy** of their parent(s). Health professionals called for **'better information so everybody understands that children that are adopted are likely to be presenting with developmental disorders and significant developmental problems'.**

Factors that enabled knowledge-sharing included a specialist health service holding responsibility for training and development, so becoming familiar with other professionals; those with expertise in areas such as attachment disorder, FAS, ADHD and autism being proactive in offering teaching and training sessions; and services **running an 'open house' in terms of responding to the concerns of agencies about individual children.**



## 2. Communication and information pre-placement

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*'There's just nothing quite like actually living it really yourself.' – Parent*

*'We want them to know the child in the whole, not just any disability that they may have but the potential that they have as well.' – Social worker*

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This section is about how professionals communicate with prospective adopters about the health and development of individual children prior to matching panels, where matches are confirmed. In addition, comments from parents on general training for prospective adopters are included. Perspectives on adoption support planning are included here where they relate to **prospective adopters'** decision-making pre-placement.

Findings are presented under the following headings.

### Parents

- Gaining insight along with information
- **Perceptions of professionals'** honesty and realism
- Asking questions and making decisions

### Professionals

- **Prospective adopters' hopes and expectations**
- **Explaining children's health and development to prospective adopters**

## Findings from parents

### Gaining insight along with information

Some parents reflected on the challenge of relating information about abstract future possibilities to their individual child during the matching process.

High quality training for prospective adopters came across as necessary but not sufficient for providing insight as well as knowledge. Information about health conditions and disabilities can seem distancing and off-putting compared with getting to know an individual child. A prospective adopter may overlook details that do not align with what is known about the particular child they are considering.

Where the matching process had included opportunities for the prospective adopter to observe a child at nursery, or to speak with professionals involved with a child, these were appreciated. These included conversations with paediatricians, health visitors, nursery staff and foster carers. One parent **identified interactions with her child's foster carers during the introductions period as the main positive experience of learning about the child: 'we were there for six days and we were treated like family and it was lovely'.**

Meetings with professionals during matching did not always help parents to relate general information to the individual child they were considering adopting, and not all parents had

**the opportunity to meet with their adoption agency's medical adviser.** In this case, for instance, the parent would have liked more information on **the child's immediate needs:**

The medical officer gave a very generic description of how children who have experienced trauma and neglect might be affected in later life but there was no recognition or no highlighting that he might actually have very profound needs that would affect him in school and at home.

Another parent found that, when it became apparent that her child might have FAS, her own research into the condition and an online support group enabled her to adapt to this reality. She suggested **that 'more guest speakers on different conditions' and adopter-volunteers could improve training for prospective adopters, and had offered to share knowledge about FASD with local prospective adopters to 'quash some of the myths but be honest as well'.** This parent articulated a view, which was echoed by others, that parents, **unlike professionals, can give a fuller picture of how 'amazing, horrendous, challenging, phenomenal' it can be to live with a child affected by conditions like FASD.**

## Perceptions of professionals' honesty and realism

Parents commonly reported feeling that their children's **needs were 'downplayed'** by professionals during matching. Several parents would have liked professionals to have **been more 'brutally honest' with them about their children's likely needs during and beyond the matching process.** One described having been asked to decide whether to **progress with a possible match on the basis of a 'basic report', in which she felt key information had been 'deliberately left out'.** More often, **parents' conveyed a perception of professionals taking a perhaps unduly optimistic view in the context of uncertainty.**

One parent reported being assured that her daughter, who had heart problems associated with a genetic condition, would not need further surgery in her pre-school years, but felt **that medical professionals 'didn't emphasise that this was just their opinion'; two months after the daughter was placed, an urgent need for heart surgery was identified.** This **girl's mother described how 'a bit more reality' would have helped:**

They weren't going to be aware that everything **subsequently would go wrong [...]** but I just feel that I would rather they gave me all potential scenarios, even **including the worst case ones [...]** I probably wouldn't have said no to adopting her, but mentally I would have been prepared for the shock that came two months later.

Parents who raised concerns about their children's **needs sometimes felt that these had been dismissed by professionals.** Some parents also reported instances of professionals appearing to dismiss or gloss over the concerns or assessments of other professionals. One parent reflected on such an experience at the matching panel:

One professional did say, **'This is going to be really challenging',** and we asked about this and **then the social worker said, 'Oh, don't worry about her, she's always like that' – kind of spoilsport.**

## CASE EXAMPLE

A parent recalled noticing her son's dyspraxia on the first day of the introductions period:

He ran to me saying, 'Mummy!', but tripped up, smashed his head and was bleeding within 30 seconds at the foster carer's house. He then fell on the dog that bit him [...] I said, 'He's dyspraxic'. As a teacher, I could see that immediately, and they went, 'Oh no, it's just delay because of his early environments and everything', and I was thinking, 'Well, he's been in foster care two years, interesting...'

This parent reported having received a good quality Child's Permanence Report containing the available information. She supposed that professionals had been 'aware of delay, as in the majority of kids who are going to be adopted' but that 'they wouldn't diagnose anyway because he'd be too young [...] they'll say it could be down to the delay or a trauma'.

Although this parent did not think professionals believed her son to have difficulties beyond predictable developmental delay, she did say that **her child's needs had been downplayed to an extent: 'I don't think they lied. I think it was more underplayed a little bit because I think that's part of the adoption process'**.

This case illustrates how parents may lack answers about why their children's needs were not clearer earlier: what signs were present but not spotted; whether concerns were minimised or overlooked; or whether known issues were not explained adequately.

## Asking questions and making decisions

**Information given about a child's health and development during the matching process will influence a prospective adopter's thinking about whether to proceed with adopting the child.** It also informs their negotiations about support packages and their planning for the **child's initial placement** and beyond. **This was highlighted in one parent's reflections:**

I think if it was deemed that actually this little girl might just need somebody to be at home full time because of these issues – if they were honest and open enough to say actually we think there might possible autism, there might be possible foetal alcohol [...] **I would have given up my job a long time ago.**

Some parents reported having received information late, when under pressure to decide whether to proceed with adopting a child. One parent described being given 24 hours to confirm interest in a child, based on basic profile information, after several other couples who were considering the child decided not to go ahead. Another **reported 'difficulty getting hold of any paperwork ahead of matching' and being told she wasn't entitled to see information, then recalling her social worker 'rushing down to see us the day before matching panel, to bring us a medical report'**.

Some parents reflected on how advocacy from a professional helped, or might have helped, them to make more informed decisions, or be more assertive about their support needs. One parent **would urge new adopters to ‘be more cynical’ and not allow the ‘emotional element’ to detract from practical considerations.**

Another parent reflected that a mentor would have been valuable. With the benefit of hindsight, she felt she **would have ‘asked very different questions’ to ascertain that her child had a high level of need which would impact on his transition to school.** Advice from a local prospective adopters group run by adopters was experienced as helpful but not straightforward to interpret:

**I was in touch with people who had very extreme, very challenging outcomes [...] but also I knew that what I was being presented with by the social worker and the foster carer and everybody else that’s connected with our actual placement was a very positive view of how things would be and that [...] people that go to adoptive groups always tend to have more challenging and difficult experiences, that’s not typical [...] but they resonate with us very much unfortunately.**

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***‘You tend to look through a bit of rose tinted glasses a little bit because [...] you want this child, but you need to consider that the adoption agencies and the local authorities are going to do anything they can to get that child in a placement because it will be more cost effective for them – and that sounds harsh but that is the reality.’ – Parent***

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## Findings from professionals

### Prospective adopters’ hopes and expectations

Professionals spoke about how many prospective adopters ‘quite reasonably enter adoption optimistically, desperately wanting a child’ and may struggle later to process that their child has ‘huge difficulties which are not going to go away with just loving parenting’. One professional **perceived in some prospective adopters a hope that ‘because it’s a young child, the damage won’t be as profound’, despite the neurological damage that can be caused by prenatal exposure to drugs or alcohol.**

A social worker providing post-adoption support described conversations with colleagues involved in family finding:

**When we go back and say, ‘Oh my god – why weren’t these parents warned more?’, in a way, that the messages that we get back is they *were*. They just didn’t want to hear it [...] or they thought that they would be able to overcome it and then as time goes by and that’s not the case, then they aren’t good at remembering and they think that they weren’t told.**

Several professionals acknowledged that establishing realistic expectations was extremely difficult for prospective adopters. Giving information and warnings very clearly and encouraging help-seeking were thought to help, but the importance of having sufficient **support in place after a child’s placement was stressed, as this is when ‘the difficulties become more real, you’re living with it 24/7’.**

BAAF worked on piloting adoption activity days, which enable prospective adopters to meet and play with children considered hard to place. These remain controversial but are now widely used, and aim **to ensure that ‘the child is seen rather than their label’.**

## Explaining children's health and development to prospective adopters

The involvement of many professionals in children's lives over time was seen to potentially exacerbate confusion for prospective adopters: one therapist reported an adopter having been given **three 'rather contradictory' histories of her child**. Conversely, the involvement of few or no professionals may be problematic. When interviewees commented on intercountry adoptions, **they emphasised how limited prospective adopters' access to information usually is**.

Medical advisers focused on face-to-face meetings when discussing how they inform **prospective adopters about children's** health, family history and possible risk factors. These meetings might involve medical advisers quantifying risks to the best of their ability; giving information about conditions such as FAS or autism; explaining what needs may emerge based on available information; and exploring **the child's current health and development**. One medical adviser gave a hypothetical example:

You **would explain to them that although the child's doing well developmentally [...]** if both the parents have got learning problems, that may become apparent during **the next few years or even not until [...]** you're making **cognitive demands** on them later on in school.

Several key factors were identified as supporting effective consultations: sufficient time (at least one hour); plenty **of detail; 'honest', 'frank', 'factual' and 'transparent'** communication; and opportunities for prospective adopters to ask questions. Prospective adopters were said to particularly appreciate information based on **medical advisers'** contact with children and birth parents:

They are always very keen to know whether I have actually seen that child at any stage or is it just collation of information and facts and figures from other people.

Medical advisers observed how valuable these meetings could be for prospective adopters, who usually gave positive feedback.

One medical adviser's **approach was to meet with a child's** prospective adopter after the medical report had been shared with them but at least two weeks prior to matching panel. This was intended to allow the prospective adopter time to reflect after the consultation, seek information or clarification, or possibly change their minds about proceeding. In another area, the medical adviser would produce a short report for the prospective adopter summarising the meeting, with a **'little plan' giving** details of professionals currently involved with the child, potential health risks and areas requiring action or investigation. This was felt to be particularly important for out-of-area adoptions. The interviewee emphasised the importance of prospective adopters receiving clear written information, suggesting a **'medical passport' or 'equivalent of the red book'** for adopted children. They thought that a physical document **might reassure prospective adopters** 'because quite **often, especially when children are taken into care following abuse and neglect, they don't have anything'**.

Comments revealed potential tensions relating to social **workers' reliance on, and use of,** information from medical advisers in discussions with prospective adopters.

A medical adviser reported having encountered some social workers who belittle concerns or present an overly optimistic view, in which case, the medical adviser may feel framed as **'the evil person who's been weighing up all the facts and figures'**. However, social workers

interviewed also spoke about the need for prospective **adopters to be ‘fully briefed’** and given an honest picture, including worst case scenarios. In fact, one medical adviser praised social workers who contacted medical advisers prior to panel if they feel the medical report lacks detail or is vague or inaccessible.

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***‘You’re trying to create something which is positive and you’re trying to create a profile for the child which is attractive [...] Most adopters want children as young as possible, as healthy as possible and look like them as much as possible – that’s still a powerful part of the motivation of adopters and although there’s a lot that goes into the preparation and assessment of suitability which tries to open up what the issues are for these children, I think it’s still a difficult one.’** – Adoption policy and practice expert*

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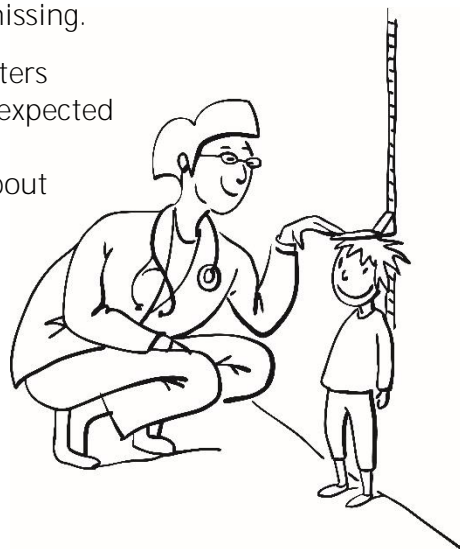
The matching process entails a range of pressures and dilemmas for social workers. Interviewees identified the potential impact of these on communication with prospective adopters **about children’s health and development**. Action learning sets run by BAAF for adoption social workers were mentioned as having provided a well-supported space and opportunity to reflect on the practice challenges involved in matching.

The potential for multidisciplinary approaches to inform prospective adopters’ **understanding of children’s health and development** was noted. In one local authority, **‘matching information meetings’** enabled prospective adopters to meet a range of practitioners, which may include nursery nurses, LAC nurses, health visitors and school nurses. This opportunity for face-to-face discussion was said to be greatly appreciated.

One medical adviser explained that, whilst local medical advisers no longer attend matching panel due to time constraints, prospective adopters are invited to contact them with any questions or concerns between the consultation and the panel, yet this had not **happened in the interviewees’ six years of experience**. Another spoke about how the involvement of multiple medical advisers **in a child’s case created the potential for confusion**:

We take it in turns so sometimes you attend the panel where the report for the child was prepared by your colleague, and your colleague actually met with the prospective adopters, **but you’re sitting on the panel. So although you definitely trust your colleagues [...]** little details could be missing.

Very few instances were mentioned of prospective adopters deciding not to proceed with a match after receiving unexpected health information, even if **‘they are a bit shocked and sometimes they do need to go away and have a think about that’**.





### 3. Supporting families at different stages and through transitions

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*‘We work very hard to put in that extra level of support commensurate with the unusual beginnings of this state of familyhood.’ – NHS therapist*

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This project focused primarily on two areas of families’ **experiences**:

- communication of information about a child before their adopter agrees to adopt, and experiences living with, the child (pre-placement)
- the adopter’s engagement with services and support after their child is settled in the family (often post-order) and concerns have arisen.

However, when young children are adopted, various changes coincide for them: they move between caregivers, early years or education settings, legal statuses, services, and often local authorities. These are significant shifts for children who have already experienced instability, during a life stage characterised by development and transitions from home through the early stages of education.

This section explores aspects of processes, occurrences or points of contact that interviewees suggested were important to understanding and addressing **young children’s** emerging or unexpected needs.

**Agencies’ duties to plan for, assess and meet families’ adoption support needs vary at different stages**, as do the barriers and enablers faced by professionals in carrying out this work. This section presents findings from professionals that address adoption support in the context of these stages, but that closely relate to content presented elsewhere, particularly in Sections 4 (*Parental engagement with services and community resources*) and 5 (*Responses to new or emerging concerns post-placement*).

Findings are presented under the following headings.

#### Parents

- **Balanced approaches to children’s and families’ needs during the ‘settling in’ phase**
- **The period between a child’s placement and legal adoption**

#### Professionals

- **Medical advisers’ involvement beyond matching**
- **Developing understanding of a child’s additional needs during the ‘settling in’ phase**
- **Supporting children through changes affecting their education**
- **Adoption support**

## Findings from parents

### Balanced approaches to children's and families' needs during the 'settling in' phase

Parents alluded to tensions between children's and families' need for time and space after placement, and their needs for intervention. One example in particular illustrated these tensions being resolved to the satisfaction of a parent:

**The OT assessed and said, 'Yeah, he's very delayed, but we can't label it at this age; you've just got him; he's been in traumatic situations for two years and then foster care for just short of two years. So we'll put some physio in and we'll see the improvements and we'll reassess'.**

Some parents perceived a professional drive to get children into education curtailing **parents' and children's time to get to know each other and 'build that trusting, secure relationship': an opportunity other families would have during a child's pre-school years.** According to one parent, her son's **entry into** reception two weeks after placement had been problematic:

We chose a school **not knowing our son [...]** It was harder for the school at times because they were told this lovely, enthusiastic, friendly five year old is coming into the school and they were completely unprepared for the level of need as well.

**Conversely, one parent perceived professionals' emphasis on 'settling in' as a barrier to getting her pre-school child's needs recognised.** Concerns about **the child's** behaviour were raised with social workers shortly after placement, and the parents had been advised to give the child time to adjust. A year later, **after the parents had 'realised it was not just settling in behaviour', their concerns were validated when the child started attending nursery:**

Second day at the nursery I got kept back. Nursery said [...] she is pretty much a **danger to herself and she's a danger to others. I pretty much said to the nursery, 'Look, we already know this, I'm really sorry [...]** Thank you for obviously backing me up here'.

Several parents called for more structured, proactive adoption support. For example, one parent proposed that an adoption support social worker should be allocated to each family **during the 'settling in' phase:**

**Not necessarily [...]** working with every family on a long term basis, but definitely checking in **after three months, six months [...]** like, 'Have you seen any behaviours? Is there **anything you're concerned about? Do we need to be looking at any appointments externally?'**

This view was **supported by another parent's observation** that children may experience a **'honeymoon period, when they're on good as gold behaviour to try and not lose another placement'** until, after settling into the family, **'their real concerns, worries, traumas come out'.**

**Whilst parents expressed a view that initial support following a child's placement was insufficient,** they did not appear to propose that proactive offers of support to individual families should continue indefinitely. Timescales of up to a year were mentioned.

Importantly, **parents'** suggestions imply that an adoption order should not automatically sever contact with services.

## The period between a child's placement and legal adoption

Several accounts from parents highlighted that the period between a **child's placement and the granting of an adoption order** may be highly sensitive in terms of relationships between prospective adopters and professionals.

### CASE EXAMPLE

One parent described delays in obtaining an adoption support plan due to high turnover of social workers, but also said **'the advice that we did have from everybody was not to agree to an adoption order until you had a post-adoption support plan and including an adoption allowance'**. She reported having been pressured to proceed with the adoption, despite having confirmed her intention to do so:

We kept being asked if we didn't have an adoption support plan, would we go ahead? [...] We kept being pushed to say 'but would you do it without the support?' And it was really unpleasant.

This child's adoption order was not made until three years after placement, by which time he had started school. His parent recalled meetings about the child during this period: **'because he was technically still looked after and then they have a Team Around the Child so everybody has to be present'**. She felt that questioning professionals meant **'you become labelled as somebody who's unable to work with professionals'**. After the adoption order, the interviewee said that she and her partner **could** **'be ourselves and not have this cloud of people criticising us and undermining us'**. Another issue with feeling surrounded by a multidisciplinary 'cloud' was that the parents found it difficult to discuss the child's violent behaviour at home: wanting to be open with adoption professionals about the family's need for support, but also finding it difficult **'because you're in front of his school teachers and I didn't want to present him as a violent child because he was an anxious, frightened boy'**. Contrasting this to a better experience with a subsequent adoption, the parent said: **'it's quite a messy process pre- adoption order because of the lack of recognition of the privacy a child might need and how you present information for them'**.

There was a positive example of support for parents in relation to delaying adoption orders. In this case, the parent interviewed had felt unable to celebrate and enjoy the **adoption due to violent behaviour from the child, and was also aware that the child's looked after status afforded priority access to school places<sup>8</sup>**. The parent praised the social worker from their child's placing authority, who **'completely understood'** but was clearly under pressure from the local authority and **'probably took the brunt of it from them but protected us'**.

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<sup>8</sup> Before this policy was extended to cover children adopted from care.

## Findings from professionals

### Medical advisers' involvement beyond matching

Interaction between a medical adviser and prospective adopter usually ends when the match with the child is confirmed at matching panel. Medical advisers may stay involved with children post-adoption in another capacity, as a community paediatrician, for example. One medical adviser checked up on children with developmental problems placed within the local authority or just **outside**: 'rather than just cast them to the wind as it were, I do actually offer them a follow-up appointment to make sure that everything is in hand'. However, this was not standard practice in the area and local commissioners were said to increasingly take issue with it for children placed in a neighbouring authority.

An adoption support social worker in a different area indicated that they could refer children to the medical adviser post-adoption. If necessary, the medical adviser would see the child and share a written assessment of their needs with their parent(s), social worker and GP. Further follow-up may be offered. This practice was established in the area, though the likelihood of referrals was linked to familiarity between individual professionals.

This issue of whether and how medical advisers stay involved post-adoption is pertinent to suggestions from professionals and parents presented elsewhere. These include allowing families access to medical advisers post-adoption, embedding health professionals in adoption teams, and commissioning specialist health services for adopted children.

### Developing understanding of a child's additional needs during the 'settling in' phase

**The 'settling in' phase**, as described by professionals, related to unspecified timeframes during which children became established in new families. Many professionals saw this as a critical and dynamic period not only for parents and children but also for setting the template for parental engagement with services. It could provide opportunities for observation, assessment and review of child and family needs.

Being placed for adoption is unsettling for children, but ultimately aims to create stability and positive experiences of family. Professionals recognised and took account of how, in **both those respects, placement for adoption could affect children's health and development**. For example, a SEND professional talked about preferring to form a view based on meeting a child and their family before reading earlier reports **to 'see if things have changed, because the child's in a very happy environment and being supported by their new parents'**.

Findings suggested that contact between SEND professionals and families around the time of the adoption could be beneficial. One example illustrated how, for a little girl who had 'quite profound difficulties' prior to adoption, the timely involvement of an early years SEND team **was able to inform prospective adopters and other professionals'** understanding of her needs:

I wrote a report, being very clear about what the child was like when I first met them with the foster family, how things had progressed, where my areas of concern were, where the good areas of development were and what I felt were good approaches for that child, and I tried to keep that up to date so that when she did

go, there was an up to date report always available to go with her [...] The more disabled child is harder for other people to get to know quickly, and my aim was to help other people to get to know that child quickly.

This interviewee explained that, more often, even if the early years SEND team know a child is about to be adopted, they would become involved **after** ‘that period where [the parents] **don’t want other professionals** in the house, just the “getting to know” period’.

One case was described of a child adopted from another local authority whilst undergoing an EHC needs assessment. The interviewee, a SEND professional, perceived rigid expectations from government around the completion of EHC needs assessments and plans within the statutory timeline<sup>9</sup>. This was deemed unhelpful for a child entering both an unfamiliar home environment and local authority, and an obstacle to the parents being **‘meaningfully at the centre’ of the assessment**.

The case **was particularly challenging because the professional ‘felt strongly that this lad had much more potential’ than his previous foster carers and local authority had recognised, and was at risk of being ‘railroaded down one life-defining route, based on one narrow view of him, and giving the adoptive parent most crucially no ownership of that whatsoever’**. **A few days after being placed with his adopters, ‘there was so much interaction, and so much language coming out already [...] You could see this lad just soaking it up’**. The SEND professional felt that, had the child been adopted within the local authority, **‘there would have been a much greater degree of confidence and cohesion’**.

SEND professionals described managers using their judgement to navigate such timing **issues. The service involved with this particular child did so ‘by being pragmatic, by talking to the parent concerned, and frankly, taking a hit on one of our on-time percentages’**, which was acceptable only because the service was otherwise doing well at adhering to statutory timelines.

Reflecting on how such scenarios might be avoided, the interviewee noted the benefits of initiating EHC assessment and planning for children as early as possible, and the risks of delaying the process until a child is settled following an out-of-area adoption. Flexibility about timeframes on a case-by-case basis was considered preferable to either waiting for stability or rushing ahead to meet administrative deadlines. This professional wanted to **see ‘more sophisticated’ measures of local authorities’ adherence to EHC needs assessment and planning timelines, and guidance addressing the scenario described in any revisions to the SEND Code of Practice**.

## Supporting children through changes affecting their education

Beginning to attend an early years setting or school is a significant step for any child under **five. Easing these transitions for children who have ‘had a lot to cope with’ was identified as particularly important**. A SEND professional explained how a one-page profile of a child, including the voice of the child and parent(s), can be used to summarise what has been learnt from home-based work in the early years; this information-sharing tool coupled with

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<sup>9</sup> The SEND Code of Practice outlines timescales for assessment and for preparation of an EHC plan (9.39-9.44), **noting a specific exemption when ‘exceptional personal circumstances affect the child or his/her parent’**. It also sets out what should happen when a child who has an EHC plan, or is in the midst of a needs assessment, moves between local authorities (9.157-9.165).

direct communication between professionals were seen to support **children's** transitions into new settings.

Children already attending early years settings or schools usually move to new ones upon placement with adopters or foster carers approved for adoption. Concern was expressed about a perceived expectation that children enter school very quickly after placement. A SEND professional suggested that they would like clear notification from their local authority adoption team when young children who may have additional needs were adopted from outside the area, and opportunities to work with colleagues in adoption to equip the education settings taking in these children. This should be standard practice **but this interviewee felt an 'early years link person' in adoption might be needed.**

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***'If support is put in early on, and perhaps a gradual introduction to school, more time at home, because if you haven't got a relationship with your parents, it's very hard to manage relationships in school. And then really good teaching of school as to what the child's history is. What their particular triggers and difficulties are, what's going to help them, how to keep a good relationship going with adoptive parents, or special guardians [...] Perhaps they don't do full-time in school initially.'** – Family therapist*

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A Virtual School professional had been considering ways to smooth the transition a child **experiences in education when their adoption order changes their legal status from 'looked after child' to 'previously looked after child'**:

We are looking to promote an early years PEP for children previously in care [...] What I would like to achieve is an expectation that previously in care PEP would follow on in the early years setting or in primary school. And then travel through with the child and even when they have an EHCP that the PEP can feed that into that EHCP.

Particular issues can arise for adopted children around the transition from early years settings into schools, even those who have previously been well-settled. One four-year-old mentioned was excluded shortly after starting school, not having presented with **'any major problems'** in nursery. A health professional involved felt:

It would have been better if it had been flagged up within the education system that he could have problems because he was a child that had been exposed to foetal alcohol.

They would have liked him to have had an individual education plan, and acknowledgement **that 'he was very young and it might not even be appropriate for him to start school full-time just at this stage'**.

An early years professional explained that the transition of a child with additional needs out of their setting would be supported in the same way whether or not the child was adopted, with proactive follow-up for those considered to be vulnerable. This is an example of professionals finding standard processes, when implemented well, very helpful.

## Adoption support

### *Adoption support planning before a child is placed*

Detailed exploration of adoption support planning pre-placement was not within the scope of the project. However, some professionals did proactively raise the subject (as did parents in relation to decision-making during matching, pp.37 – 38), primarily in the context of problems.

According to one social worker, not all social workers writing adoption support plans are well-informed about the impact of moves on children, and their possible future needs:

Often, what I see at panel is an adoption support plan that says, **'This child's doing all right, not really any tricky behaviour, no support needed'**, which would not be my take on it. My take would be that in 99 per cent of cases, children will need support.

**This social worker's** team, which worked with both looked after and adopted children, had hoped but struggled to establish a process whereby a pre-adoption worker would quality assure all adoption support plans; quality assurance and ideally monitoring were described as good practice.

One medical adviser said that educational needs in particular will often be unknown for young children but, insofar as needs may be anticipated, adoption support plans are frequently **'inadequate'**:

They only involve a Virtual School if there is a known issue, so if it's just risk factors, often that's very poorly presented by social workers [...] I have to say to them, **'These parents have got learning problems and you've not even mentioned that in your education support plan'**.

**For children with identified needs, ideally, 'the social worker would communicate with the Virtual School and ensure that any advice that the Virtual School was giving was in the adoption support plan'**.

### *The initial stage after a child's placement*

Perceptions about support needs may shift following a **child's placement**, as the child and their new family get to know each other. Adoption orders can be delayed when prospective adopters and local authorities disagree about adoption support plans. One professional **attributed this to insufficiency of available resources 'for a population of children who are so profoundly struggling in so many areas of their life'**. Delays were seen to occur because **adopters, many of whom are highly informed and articulate, 'know that once you sign the order you are sunk' and are 'fighting for their kids, seeing the lack of services that are available'**.

Prospective adopters were presented as needing information and advocacy between a **child's placement and adoption order**. One interviewee spoke about **encouraging them, at the time of the adoption application, to 'push a little harder [...] about what they can ask their solicitor to do on their behalf'**.

### *Post-adoption support*

**The term 'post-adoption support' refers to services which may be provided after a child's adoption order, when they are established in their family**. Engagement with post-adoption support is parent-led and usually in response to concerns arising after adoption, rather than a significant feature of adoption support plans formulated during matching. Families

seek help or are referred, often at a time of crisis: for example, after a child is excluded from school.

When this happens, professionals may have limited background information. Social workers explained that adoption support plans are not routinely shared between pre-adoption and post-adoption services within their local authorities, or families formally introduced to post-adoption workers; plans are not shared across local authorities.

One social worker sat within a team of therapeutic social workers for looked after and adopted children. The team structure, along with being on the adoption panel, allowed for some awareness of the children **'coming through' to adoption. It also enabled the social worker to support those children who had identified therapeutic needs 'as soon as they were placed practically', as part of a 'pre-adoption service' aimed at easing children's transitions into new families.** Such an arrangement allowed prospective adopters to become familiar with a post-adoption support service they may access later.



Difficulties for families who adopt children across local authority boundaries were highlighted, particularly within the first three years following an adoption order (see pp.49–50 for comments from parents). **During this period, the child's placing authority** has responsibility for post-adoption support, after which time it transfers to the local authority where they live. Post-adoption support services may not be informed about the placement of a child from out-of-area within their local authority unless they need to know about a specific issue or parents want to access local support groups. One social worker saw this as an imperfect approach explained by team structures and the de-linking of children's pre- and post-adoption identities: **'in an ideal world we'd be notified of a child moving into our authority, and we'd be sent their chronology and their CPR, to have on file'**. This idea could present challenges to some fundamental principles and current arrangements around adoption.

When the three-year period expires, a child's placing local authority is expected to send the local authority where the child lives details of post-adoption support provided to the child or family, if relevant. A social worker explained that the availability and quality of in-depth background on the child, as opposed to support **provided and money spent**, 'would depend on what the parent had'; **more detailed information may be shared by placing authorities** directly with providers. Several professionals depicted this transfer of responsibility as fraught with complication and variation in standards and priorities: a point at which families **could 'fall through the cracks'**.

Commissioning support for out-of-area children and families posed challenges for local authority post-adoption support services. One social worker said, **'We really struggle with those families and we often find that those families are the ones that struggle the most'**. Needs assessments undertaken by phone could leave parents feeling unsupported. Identifying suitable providers local to families could be difficult for professionals based elsewhere. An adoption team manager was disappointed that ASF administrators had not been able to compile a directory of registered providers.



## 4. Parental engagement with services and community resources

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***‘For parents, even capable parents who are used to filling out paperwork and all that sort of stuff, it’s really difficult navigating the system and the overwhelming number of professionals that get involved, and going into meetings with a whole room of professionals.’ – Early years professional***

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This section explores the availability of support and advice for parents from services and other parents; how parents navigate systems and services; what happens when they seek help; and their interactions with professionals.

Findings are presented under the following headings.

### Parents

- Information and signposting
- Professional availability, continuity and responsiveness
- Respecting, involving and empowering adopters
- Recognising and working with boundaries of responsibility
- Peer support

### Professionals

- Information and signposting
- Professional availability, continuity and responsiveness
- Respecting, involving and empowering adopters
- Recognising and working with boundaries of responsibility
- Peer support

## Findings from parents

### Information and signposting

Several parents conveyed dissatisfaction with advice they were given about how to seek help. One interviewee said that, pre-adoption, **professionals appeared ‘concerned that we wouldn’t just walk away and not seek help’, but the family ‘weren’t really told any avenues to go through’.**

In some instances, parents associated poor information with particular situations related to the structure of services, a lack of resources or high turnover of social workers. For example, one parent said that, when seeking help, she had been passed around between **‘duty’ workers, the disabled children’s team and post-adoption support team.** Also, **parenting a young child who does not attend nursery was described as a ‘limbo period’** in which limited contact with agencies makes it difficult to know what provision exists.

Other comments suggested **that parents’ satisfaction with signposting may have been linked to the perceived availability or helpfulness of the services being signposted.** Some parents, whilst recalling having been directed to GPs, CAMHS or post-adoption support, **said ‘we weren’t even told where to go, who to contact’ or ‘we didn’t get any signposting really’.** One found their Family Information Service unhelpful because **‘there wasn’t really the provision that was needed’.**

Many parents called for better provision of information about services. One parent felt that professionals with good knowledge of the system were particularly important for signposting parents to high quality support services that might otherwise remain invisible to parents.

A parent who spent months researching local provision would have appreciated social workers having a list signposting the local SENDIASS, service providers, sources of practical resources such as sensory equipment, and parent groups. However, this parent felt that **social services ‘don’t have the funding to keep on top of all this’**. As such, she suggested that an independent body should develop a **‘survival pack’ for all prospective and new adopters** in the local area, and update this annually.

Some parents had heard of the Local Offer; others had not<sup>10</sup>. One parent described how **Google became her ‘best friend’, but noted that there were risks regarding the accuracy of information found online**. This is why she valued her Local Offer and spent a lot of time working with her local authority to add information and keep it up to date. However, she still felt that the Local Offer needed further promotion to benefit families.

Parents expressed a wish to have had easier access to supportive connections with other people in similar circumstances to themselves.

## Professional availability, continuity and responsiveness

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*‘You could tell [the adoption support social worker] was experienced; she knew the team; she read up on everything about [my child]; and she knew what services were available to support me and [my child]. And to get us the assessments we needed. She was absolutely brilliant, still is to this day. The reason we got diagnosis is because of [her].’ – Parent*

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Many parents, when relating positive experiences, highlighted the competence, experience and care of individual professionals. Some linked these qualities to continuity – in terms of the **professional’s career and their involvement** with specific families.

Parents saw a lack of continuity in staff as contributing to difficulties, suggesting that better handover and communication could reduce the impact of changes in social workers, and possibly mentoring for social workers with less experience.

Whilst continuity was mostly mentioned in relation to social workers, one parent did express a wish for adoption agency medical advisers to stay involved beyond matching (see p.44 for **professionals’** views on this). **The medical adviser was seen as having ‘known this child come through the system’, met the child and produced reports, therefore being well-placed to ‘check over’ a child in the event of new concerns post-adoption**. The parent reflected **that it would have been a ‘massive help’ to have had the adoption agency ‘deal with it all in-house’**.

Some parents highlighted how out-of-area adoption could complicate access to appropriate and timely assessments and support (see p.48 for **professionals’ views**). Families could feel alienated from professionals and services in both their placing authority and local area in

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<sup>10</sup> Some of the experiences reported pre-date the requirement on local authorities to publish a Local Offer, introduced in 2014.

the three years following an adoption order. Nevertheless, one parent described great efforts by professionals to support her family from a distance.

Parents really appreciated professionals who appeared to have time for them: for example, **the ‘wonderful’ nursery Head who always welcomed one interviewee to ‘pop in’ to discuss her child if needed.** This was particularly important for parents when they received daunting new information about the nature or extent of **their child’s needs.** One parent **recounted the outcome of her child’s assessment by a specialist CAMHS service for looked after children, one month after his placement.** After receiving a letter concluding that her child had developmental trauma, this parent would have liked **‘someone to sit down and talk’:**

**They didn’t have time to talk to me so I was left feeling quite frightened I guess and worried thinking ‘this sounds huge, this sounds really serious, I don’t really know what it is’.**

Another parent reported **a better experience of learning about her child’s developmental trauma** from a supportive psychologist who, at the time of the interview, was preparing a report recommending support for the family. However, anticipating help in future did not appear to prevent the immediate experience of processing new information from feeling isolating. This parent **stated, ‘I’ve been told about books on developmental trauma so again I’m on my own’.**

## Respecting, involving and empowering adopters

A few parents spoke about the **‘rollercoaster journey’** of parenting an adopted child with additional needs and trying to access support, describing the toll this could take on individuals, couples and families. Some of the language used by parents conveyed a lot of anger and disappointment. For example, one parent **said that ‘it’s a system designed to fail the most vulnerable’, and that even** taking financial constraints into account, **‘a lot of it could have been different’.**

Disempowering or frustrating experiences could accumulate and risk tainting **families’ interactions with services in general, as one parent’s** account of taking her son to a medical consultation illustrates:

At that point I felt like I was fighting on every angle to get him the support he needed. Things were moving but I still felt like everything was a battle [...] **The paediatrician said, ‘You’ve had a bad experience, haven’t you?’ And I said, ‘Yes’, and he said, ‘Your back is up’. So, I’d walked in, I was polite, but I’d walked in ready to argue.**

**Parents’** identified a range of factors affecting the tone of their interactions with professionals.

A few parents described how the concerns they raised had been heard and validated (see pp.62 – 63). However, others **recalled having felt that their children’s** behaviour was shrugged off as liveliness or clumsiness, for example, or that their own interpretations were disregarded:

Research I’ve done has come back with sensory processing disorder. That was dismissed, pretty much told us to stop being so silly – it was developmental delay.

Some parents described having perceived professionals getting ‘stuck on the adoption thing’ and not fully recognising their perspectives or potential contribution to decision-making: ‘there’s often that feeling of “What do I know anyway? Because I’m not a proper mum, I didn’t have them from the beginning”’. Another parent expressed a similar view that health and education professionals did not always appreciate that ‘adoptive parents may be the only source of any information and what they know may be limited’; she said that, with a lack of historical information or documentation, ‘it can be difficult to get them to believe a parent’.

The extent to which professionals were perceived to treat parents as ‘part of a team’, or to problematise and exclude them or their children, was variable. One parent praised the approach of an adoption support agency whose staff ‘observed us parenting and supporting our children’, were ‘positive and supportive of our parenting’ and ‘understood what we were explaining’.

#### CASE EXAMPLE

After one child began school soon after placement for adoption, his parent had felt accused of causing his presenting difficulties:

The school immediately said, ‘Oh, his parents can’t look after this child, they can’t parent him’. Well, he doesn’t know us [...] And every time we tried to explain he’s terrified and anxious, all these other professionals [...] would say, ‘What are you doing to make him anxious?’ Well, just adopted him!

This parent perceived what followed as a ‘huge, year-long blame and shaming process’. She recounted a contrasting experience of working with a therapist who was ‘non-judgemental and very empathetic and also would find ways of educating us’, acknowledging the parents as ‘an important part of [the child’s] recovery’.

This interviewee felt disrespected by a perceived expectation to repeatedly prove that ‘I haven’t caused his trauma; I’m part of the solution’. She expressed disillusionment with parenting courses and reading material, describing them as a ‘hurdle’ to be overcome in order to access the ‘more complex therapeutic services’ she felt were needed.

Professionals seen to have demonstrated particular sensitivity or insight tended to have specialist expertise in working with care-experienced children and their caregivers. It was also suggested that, without such expertise, professionals may not recognise how their interactions with children and parents together, during medical appointments for example, can bolster or undermine the parent-child relationship. However, some parents felt empowered by professionals working in universal settings who helped them to understand and meet their children’s needs. For example, a parent of a child with sensory processing disorder, possible FAS and possible autism described her experience as ‘banging your head against a brick wall some days’, until nursery staff helped to explain her daughter’s behaviour and develop strategies to use at home:

They have like a chart at school and a sunshine cloud and a dark cloud [...] They said ‘Look, this is what we’re doing at school and it seems to be working because she can visually see what she’s done wrong and what she’s done right, whereas time out doesn’t work because she doesn’t fully understand’ [...] We’ve incorporated them at home and [...] so far she’s just doing really well with that.

Parents praised professionals and agencies that encouraged, advised or advocated for them. Voluntary sector organisations were identified as having provided helpful input, including adoption support agencies and charities (Coram, PAC-UK and Open Nest) and Contact, a national charity for families with disabled children. One parent was signposted **by her child's primary school** to her local SENDIASS. After explaining that she was being **passed between the family's local authority and the child's placing authority**, she reported being advised by SENDIASS:

**If you don't push and you don't fight**, the local authorities will not pay for adoption, **they'll not** apply for Adoption Support Fund. You need to keep going back and you need to push them and this is what you need to say.

After following detailed advice from SENDIASS, post-adoption support was forthcoming; **the parent concluded that 'SENDIASS were fantastic'**.

Whilst interviews focused on parental perspectives on **addressing children's needs**, one parent did also express a wish for **'better ways of [the child's] voice being heard'**.

## Recognising and working with boundaries of responsibility

Adoption and disability are both sensitive and complex areas **of children's practice**, in which the fulfilment of **families' rights and** the state's responsibilities can become contested. Parents **raised some important questions about prospective adopters'** expectations about entitlements and support, and about **parents' own roles** in ensuring **their children's needs are met**. Tensions relating to these issues may delay adoption orders (see p.43).

One parent supposed that prospective adopters may underestimate their need for help and overestimate the availability of help. She placed this in the context of relief and hope felt after the challenges of the adoption process:

I think people just **get through that and think**, **'Oh, it's all going to be rosy gardens and it's all going to be lovely and it's going to complete our family'** and all of this, **and actually that's not the case [...]** You have got to fight for absolutely every shred of help.

**Another parent suggested 'you can't prepare yourself enough' for parenting an adopted child** with additional needs.

Some parents took issue with changes in levels of professional concern, or in **children's rights and entitlements**, before and after adoption. These were often presented as jarring reductions in interest and support. For example:

**I've sat in** school seeing all these people troop in for Team Around the Child meetings because the child is in foster care and as soon as the child is adopted, no one actually has to do anything and so some of the resources completely pull out.

Comments were couched in terms of a need for authorities and agencies to expect and respect the level of need in this group, and the immediacy of some of those needs, **acknowledging that 'there's a reason they were adopted in the first place'** and **'nothing's magically cured'** for children after placement.

Expectations about post-adoption support may have a significant bearing on prospective **adopters' decision-making**, as illustrated by this case example.

## CASE EXAMPLE

After significant issues arose, one parent gave up work to care for her child, reached crisis point, and was referred for counselling by her GP. The parent stated that she had sought post-adoption support and been told that, since nothing had been identified at an earlier needs assessment, 'there was nothing they could do – "goodbye", basically'. She said, 'if I had known as much as I do now when I first went into it would I have adopted two children? Probably not'. This feeling was partly attributed to her older child's needs being far greater than expected, but also to believing that she was unprepared for 'the fact that if you don't make a fuss you really won't get anything': 'I always thought that if things got difficult I would get some help'.

Parents commonly reported specific conflicts with professionals or agencies that left them feeling betrayed or let down: one parent recalled accusing an adoption support social worker of '**pretty much washing your hands of any sort of aftercare**'. Comments suggested that, when parents experienced an accumulation of such disagreements and other difficulties in accessing support, they could feel left to shoulder responsibility for making the adoption work:

**If we weren't strong enough to push for any help on the SEN needs then actually her SEN would probably be worse and [...] I hate to say it, she would probably go down as actually a failed adoption placement [...] If I didn't push the school, if I didn't push this private clinic, if I didn't push post-adoption support, actually we would be no further forward.**

Many comments indicated that, whilst parents were willing to do anything necessary to obtain support or cope without it, they had expected authorities and agencies to take more ownership of their cases. **Parents' efforts to understand their children's additional needs**, to hold their families together and to access services were felt to demand significant energy, resilience, knowledge and competence. For example:

**I sit here with lots of files for my son because I've got my adoption file and then I've got his health file and then I've got his education file but they're three big A4 binders so I have to be really organised.**

**Parents spoke about wanting families' support needs to be anticipated** and addressed more proactively, and several interviewees suggested that **an overreliance on parents'** research and coordination created inequalities. Some parents had found their own professional backgrounds and personal networks to be assets: one parent ventured that, **without them**, 'I would have struggled horrendously'. A parent who worked as a teacher had managed to get access to an adoption support social worker, private occupational therapist and educational psychologist with specialist knowledge through 'pushing politely – never not politely – **and [...]** using contacts I had'. This parent praised the practitioners she had encountered for valuing her expertise whilst maintaining appropriate boundaries (see boxed quote).

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***'They've treated me as an adult, without being patronising, because I obviously know some of the system, but without letting me do it all because I know some of the system.'***  
– Parent

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## Peer support

Most parents mentioned other adopters as important sources of information and advice on **how to raise concerns about children's needs and obtain support** in a context of limited public resources. They highlighted the importance of sharing experiences **with 'the ones that understand it best'**, providing mutual encouragement **and the chance to 'offload'**.

Some parents had joined formalised local groups, but national organisations and social media also facilitated connections between parents with similar experiences, transcending geographical boundaries. One parent explained how she and three other single adopters whose children had similar **needs had started their own 'informal support network' online**. This parent had struggled to find parents with experience of both adoption and disability (see boxed quote). A clinical psychologist working for a voluntary adoption support agency **'tapped into' her family's social isolation and understood their need for signposting to such networks**.

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*'The focus tends to be on helping the children get through their childhood trauma, whereas that's not the focus that I've needed and I still haven't managed to find any kind of support group where there is that focus on adoption and disability. If I join a disability support group it's all about "Did you know during pregnancy?" [...] So we fall through the gaps, we don't really fit in any of the support areas.'* – Parent

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Experienced adopters were valued because they could reflect with hindsight on, for example, 'help that they would have asked for had they done **things differently**'. There was a view that parents could be **'very generous with their time and their experiences'**.

However, one parent reported barriers to connecting with other adoptive families. She felt that support groups and training had been promised by the local authority but not forthcoming, and that parent-led groups were not well-advertised and therefore difficult to find.

In terms of getting involved with groups for parents of disabled children, a parent of a child with developmental trauma and other presenting issues said:

It was quite hard because I think it took me a long time to actually realise – to use that language and frame it in that way – that our son was disabled.

## Findings from professionals

Professionals were alert to the significant difficulties faced by adopters in navigating the highly complex terrain described in this report. They cited the value and importance of a number of interlinking concepts and principles, which are threaded throughout the findings. For example, approachability of services – felt to be essential – was linked to various qualities explored below, including visibility, responsiveness and respect for adopters.

## Information and signposting

Professionals described both reactive and proactive information provision and signposting. For example, a Virtual School helpline enabled parents, carers, schools and other professionals to make enquiries relating to children previously in care. A SEND professional

mentioned signposting parents and other professionals to the National Portage Association website<sup>11</sup> as a helpful resource on how Portage principles could help parents to build their children's **skills and, where possible**, to access Portage services.

Several professionals mentioned the potential contribution that can be made by services that are not adoption-focused when they are aware of adoptive families. After linking up with a Virtual School professional, one SEN team had committed to including a question about care experience on their referral form, to help identify children previously in care. For one health professional, it was important that SENDIAS services be well-informed about adopted children and particular issues that might affect them.

Social workers spoke about schools signposting or referring families to post-adoption support **services; some had worked to raise schools' awareness of what they could offer**. Conversely, it was seen as important for social workers to be able to tell parents about the role of Virtual Schools and early years entitlements for previously looked after children. A Virtual School professional **identified helping social workers in this respect as 'a key area that I may need to work on'**.

Adoption support social workers explained how their teams tried to disseminate **information about services, events, entitlements and parents' groups**. One adoption team took a proactive approach to welcoming new families to the area:

**If we're notified that adopters have moved to [the area] we will automatically send them out a letter saying, 'We've heard you're here, here's our newsletter. This is us, this is who we are'.**

**This letter would offer to put them in touch with the local adopters' forum.**

Another professional reported that attempts to keep families updated via email had been hampered by information governance issues and a lack of capacity to address them. Such **issues were seen as 'a significant barrier', and their extent was perceived to vary widely** between local authorities.

## Professional availability, continuity and responsiveness

Many professionals emphasised the importance of being available and able to offer continuity for families. They saw the **value of maintaining 'light touch' relationships** with families over time:

They will come back to somebody like me, **a family therapist, and say, 'We haven't seen each other for a year, but we are so worried [...], can you help us?'** And then we do a kind of top-up, because we think that by treating those difficulties as very serious, and with the potential to collapse family resources, that we can do a better job if we intervene in this episodic kind of way.

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<sup>11</sup> <https://www.portage.org.uk/>



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***‘They can phone; they can speak; they can get an answer. Someone will come out if needs be [...] Sometimes that’s all it needs, if they just need to talk it through and then they’re back on track and they’re OK. But if you’re not available to do that, that’s when things can get really tricky and really difficult for the child.’ – Adoption team manager***

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Timely responses for families helped to de-escalate potential crises (see boxed quote). Adoption support social workers stressed the need for families to seek **help before ‘it’s gone too far wrong’**, but identified barriers to offering a **‘more proactive service’**. One social worker had heard of another local authority post-adoption team reviewing adoption support plans annually and checking in with parents. This was an aspiration seen to be currently out of reach for the **interviewee’s team**.

Active engagement was considered particularly important when providing post-adoption support for families living out-of-area (see p.48).

## Respecting, involving and empowering adopters

Respect for adopters, promoting participation and providing encouragement and emotional support were cited as key to effective engagement. Various professionals highlighted the competence they saw in many adopters, using words like **‘proactive’**, **‘able’**, **‘knowledgeable’** and **‘well-read’**. These qualities were not seen as universal among adopters, and the propensity for a difficult home life to create chaos was also acknowledged. Most professionals expressed frustration on behalf of adopters, for having to navigate complex systems and **‘fight’ for support**. One professional explained their **understanding of some adopters’ feelings**:

[They] have felt very disempowered and criticised by the system and lost **confidence, or can’t believe that they found themselves in this position, whereby they can’t actually get anyone to listen and they’re treated like they’re over-anxious, fussing parents when, actually, they’ll have been through hell at home.**

Professionals described various ways in which they supported parents emotionally in times of difficulty. These included **emphasising to adopters ‘you may not solve all of this for a very long time, or forever and it’s not going to be your fault’**, although this could be a **‘hard message’**. A therapist reflected:

How do you allow the unknowable to take a place in your thinking, but not to **eclipse all your other thinking? [...] You can sometimes put too much weight on this kind of unknowable bit of your child’s history, and it can be like a sort of demon in the household, so part of my job is to help families find out techniques of recognising it, but learning to live with it and not overdramatising it, because we think that works a lot better than it totally dictating family life. It is there, it’ll always be there.**

A SEND professional felt that working with any parents should involve active listening, **support around meetings, and celebration of what children achieve with their parents’** support. This interviewee had worked with some new adopters they found to be **‘cagey’** after negative experiences and suspicious that **SEND professionals will be ‘the same as everybody else’**. Eventually, they had felt able to establish trust:

They've actually realised that we can enhance their child's skills by enhancing the adults' skills, and I think that's what they've really liked. And we're not there to say, 'We know better than you'.

Many professionals emphasised the importance of involving and empowering adopters, **recognising how they can 'be the voice for their child' and seeing them as 'part of the solution'**. For example, one adoption support service was said to promote transparency and collaboration by trying to avoid **professional meetings where parents aren't involved**.

#### EMPOWERING FAMILIES IN THE EHCP PROCESS

Based on experience of guiding their own **family members through their adopted child's** ECHP process, a SEND professional suggested that adoptive families could benefit from:

- understanding how SEN support and EHC planning work, including the need for evidence to support requests for EHC assessments
- ensuring they are involved in planning, and working with all relevant agencies
- seeking help from SENCOs, Independent Supporters or SENDIASS as needed
- **scrutinising schools' use of Pupil Premium funding**
- understanding and promoting awareness of attachment issues.

#### Recognising and working with boundaries of responsibility

Several professionals recognised that adopted children are usually **'the same children who are present in our looked after children service, who are still suffering the impact of trauma'**, for whom the state is responsible. Whilst the state holds some duties towards previously looked after children, an adoption order grants adopters full parental responsibility for their child. Adoptive families do not have to identify themselves to services or settings; when they do, the professionals involved will not have access the kind of detailed information held about looked after children.

**In many cases 'a loving family goes a lot of the way' to meeting adopted children's needs**, but it is unlikely to be **'all sunshine and rainbows', as one professional put it. Adopters' engagement with post-adoption support is consensual and voluntary: 'legally [families] can go off and live their lives and never have anything to do with children's services ever again'**, unless safeguarding concerns are raised. A social worker spoke of how prospective adopters have to demonstrate that they have a robust social support network to be approved for adoption, **but that sometimes 'when it comes to it, all these people fall away'**. Families can become very isolated and reluctant to acknowledge their struggles until **'they're really going wrong'**, often when the child is older. In post-adoption support, a **'really fine line' was identified between attempting to engage adopters in need of help**, and challenging them when necessary. On the other hand, adoption support social workers emphasised that capacity issues affected work with those families who did seek help.

One social worker noted differences between adopters. Some were seen to want to avoid professional intervention or to engage mainly with universal services; others acted as **'quasi-professionals'**, gaining knowledge and expertise, sharing this to benefit other families, and appearing to embrace that role to different degrees.

## Peer support

Professionals expressed the belief that there is **'huge value in adopters being together'** in terms of emotional support, practical advice, advocacy or participation in strategic decision-making. Professionals wanted to be able to offer group activities and encourage participation. A social worker was aware of informal adopter-led initiatives, and suggested that finding out about and promoting these informal initiatives was valuable, if not always easy. At the other end of the scale, links to national organisations were highlighted as beneficial.

One professional had worked with schools to develop networks of adopters. Groups might provide social activities bringing families together; **opportunities for 'free chat'; and** more structured, topic-based sessions.

Parent groups and networks were not seen to be free from drawbacks. Some professionals **suggested that parents' comparisons of how services responded to their families' needs** were not always helpful. One adoption support professional was concerned that support groups could get dominated by particular voices and also leave new attendees feeling **'horrified by how bad things are'**. In addition to parent groups, this service tried to arrange **more 'light-hearted'** opportunities for adopters to meet each other, including family activities.

Bringing adopters together was presented as part of the creative approach needed to deliver effective support, especially when resources are limited. One interviewee from a small local authority **praised the local adopters' forum, which was run by adopters but 'we work really closely with them, we're invited. We have a very open relationship'**. They expressed hope that the adoption service could eventually become adopter-led.

In the example above, bringing parents and professionals together was felt to be highly beneficial. Interviewees identified other positive opportunities for information-sharing and dialogue between parents and professionals, including support groups, courses and workshops.



## 5. Responses to new or emerging concerns post-placement

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*‘There are gaps but when it suddenly works, when you get the appointments, or you get the right people involved, then the system can work.’ – Parent*

***‘I don't regret adopting; I just regret the fact that there isn't the support and the help when you need it and I know that a lot of it's due to funding, but you only then access any services when you are at crisis point, and if there were things around earlier you might not reach that crisis point.’ – Parent***

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This section focuses on how professionals and services react when parents raise concerns **about their children's health and development**. The findings below link closely to those in other sections. For example, access to services is affected by the approachability of professionals, discussed in Section 4: *Parental engagement with services and community resources*.

Post-adoption support services feature strongly, including as a route to accessing specialist assessments and provision. Experiences of other areas of social care and of healthcare and education are included where there is a clear adoption-related dimension.

Findings are presented under the following headings.

### Parents

- Accessibility of services
- Diagnoses and supporting evidence
- Joint working in assessment, planning and provision
- Funding

### Professionals

- **Establishing children's and families' needs**
- The significance of diagnosis
- Joint working in assessment, planning and provision
- Funding

## Findings from parents

### Accessibility of services

Accessing support was generally presented as a struggle, with parents frequently using **combative language like 'pushing', 'fighting' and 'battling' in relation to a range of agencies**. Several had made formal complaints after difficulties accessing post-adoption support. On the other hand, a SEND professional, commenting as a family member of a **young adopted child with additional needs, reflected that 'post-adoption support was offered to the parents from the outset [...] and with hindsight, they could have been more proactive in requesting this'**; once sought, support was provided and deemed helpful.

When explaining difficulties faced in accessing assessments and provision, or obtaining EHC plans for their children, parents mostly referred to inadequate coordination, resources or appreciation of need. Few parents **stated that their child or family had not met services' criteria for access.**

Delays were one of the greatest sources of frustration described. For example, one parent stated that it took almost two years to get an EHC plan for her son due to long waits for appointments with paediatricians and educational psychologists. Parents described waiting up to 18 months for post-adoption support needs assessments:

**We've had to scream at them to do it [...] Meetings are cancelled because they're called away to other things [...] It took for us to say, a few weeks ago, 'You have to come and help, you have to come and look at this or we will be asking for foster placement'.**

Even much shorter waits of several weeks could be extremely difficult for families **struggling with their children's behaviour.**

However, some parents had more positive experiences and praised services for providing timely responses. For example, one parent spoke of how the prompt actions of a paediatrician and occupational therapist facilitated quick access to physiotherapy for her three-year-old child who was **'severely delayed physically'**; she linked this to **efficient health services across the local area.** After relocating, **and following concerns about the child's sensory processing,** the family waited much longer for medical appointments. However, in the meantime, an adoption support social worker visited quickly to undertake a **'massive assessment'.**

Participants sometimes implied that a **child's adopted status** could help with securing assessments or provision. One parent speculated that **'just having that word "adoption"'** helped her autistic child to get a highly sought-after place at **'the best special needs nursery'.** A SEND professional who had guided their own relatives through their adopted **child's EHCP process suggested that being 'previously looked after' may have afforded the child a 'more sympathetic or prioritised approach within the EHCP process' compared to other children at the school.** In another case, a parent believed that playing **'the previously looked after child card'** had **expedited her child's appointment** with a paediatrician, whilst another parent surmised that her child may have been seen quickly at the Child Development Centre **because 'we've been putting rockets up Social Services'.**

On the other hand, one parent suggested that adopted children may face particular barriers to accessing assessments due to their early experiences. In the four years since his adoption, her child had often been unable to go through with assessments because service environments reminded him of family contact centres **and triggered 'huge anxiety'.** The family had developed a **strategy of 'rehearsing' for assessments:**

When he had to go to see the paediatrician for his EHCP assessment: one visit, **meet the receptionist and then, the next time we come back, she's got some sweets for him and he's spoken to everybody, he knows that he's going to go there, that his birth mum's not going to turn up and that it's going to be really friendly.**

Such approaches require professionals **to appreciate children's needs and be 'on board'.**

Parents had several ideas about improving the availability of support. One parent suggested that paediatricians, occupational therapists, educational psychologists and other **specialists should have 'a bank of appointments for previously looked after children':**

Imagine if we'd had an Ed Psych appointment for a previously looked after child in Year One and we'd seen a paediatrician under a previously looked after child appointment in Year One, and then all that would've meant he'd have had implementation of his EHCP before Key Stage Two, not at the end of Key Stage Two.

Another parent suggested that a timescale for completing post-adoption support needs assessments could be part of addressing capacity problems in post-adoption support services.

## Diagnoses and supporting evidence

The interviews featured a number of stories of parents seeking particular diagnoses for their children. One parent, **suspecting her child to have 'some sensory disorder'**, recalled telling her adoption support social worker, **'I don't want him labelled for the sake of it, but he needs the support'**. She said that the paediatrician who eventually diagnosed her son with dyspraxia and sensory processing disorder also suspected he would be on the foetal alcohol spectrum, but the lack of a diagnosis was frustrating:

**You hit a brick wall. If you don't have a diagnosis, you cannot get support. And there's a fault in that system, because there's no one test for foetal alcohol syndrome or spectrum disorders, and actually some doctors have never even heard of it.**

This parent explained how the EHCP process was delayed for a long time, until **'the foetal alcohol syndrome diagnosis and an Ed Psych appointment, and then everything flew'**. She described palpable relief at finally encountering a paediatrician with specialist knowledge of FASD who was able to make a diagnosis: **'He just looked at [my child] and he went, "He's got foetal alcohol syndrome", and I went (long sigh) and then deflated'**.

Another parent recounted how her son was diagnosed with autism earlier than he otherwise might have been, 'in order to get the right help otherwise we would have been totally lost':

He would have had to go to a mainstream school and he wouldn't have got the support he needed so for us it was important that he got a label and luckily enough it was the right label.

More than pushing for particular diagnoses, however, parents described how they pursued access to specialists and detailed, comprehensive assessments. These were deemed necessary to gain insight into children's multiple or ambiguous needs (see boxed quote).

All parents referred to reports, assigning great significance to documented evidence that backed up their concerns or helped them to obtain support. One parent said that, having struggled to get referrals via the GP, **'it's only when I go back with reports from other professionals that I can then be**

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**'The presentation looks like developmental trauma, looks like attachment issues, it looks like ADHD, can look like autistic spectrum, it can look like lots of different things and that's part of the problem and it's only now that we've got to go a specialist [...] where they have the skills to unpack all those different complex strands.'** – Parent

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**listened to and be taken seriously**'. She speculated about what might have happened had she sought help for her child from CAMHS without an assessment and report from an adoption support agency:

We would only have the social worker report which would have painted a very different picture. We would have had a longer time being stuck in CAMHS trying to demonstrate what the issues were.

The adoption support agency report was valued for being clear about **the child's needs** and **containing 'evidence of what [the parents] were doing' based on observation**. Parents also alluded to reports enhancing their own understanding of their children.

Some parents expressed frustration at reports not having been made available, or at professionals not appearing to treat reports – **or parents' interpretations of reports** – with the hoped-for gravity. For example, one parent described an assessment for post-adoption support in which a social worker allegedly dismissed a report **that 'clearly stated' that the child had severe sensory processing disorder**, insisting that the child had pica instead.

## Joint working in assessment, planning and provision

Parents described a range of issues relating to coordination and multidisciplinary involvement, often attributing these to resource constraints. Issues reflected experiences widely reported by parents of children with additional needs. They included a lack of **multidisciplinary meetings; a need for parents to 'play go-between' to ensure meetings** were held; failure of meetings to lead to meaningful action; and a lack of joined-up working in the EHCP process. One parent commented that health and social care services had insufficient input into EHC planning, although another parent had valued the participation of a therapist from an adoption support agency **in her child's** EHCP meetings.

According to one parent, the biggest potential improvement in support for adopted children with additional needs and their families involved joint working. This interviewee wanted to see well-resourced adoption teams that had specialist health professionals embedded in them, suggesting that, in mainstream services, **'often everything is just attributed to the delay and therefore you're sent away'**.

## Funding

Funding is a relevant backdrop to many comments from parents. Interviewees were not asked directly about funding, but many talked about what resource constraints in general meant for them and their families. They sometimes acknowledged that **professionals were 'trying their best' but described tackling** resource challenges at every stage, **or perceiving 'lots of talking but very little action'**.

All parents interviewed mentioned the Adoption Support Fund (ASF).

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***'We finally got [a post-adoption assessment of need] and accessed sensory integration through the ASF for him, which greatly helped him. Then he had a speech and language assessment for Autistic Spectrum Disorder but we were told there was no provision again for Ed Psych, so again we paid ourselves. Ultimately after 18 months a local authority Ed Psych did see him and he was in September diagnosed as being on the autistic spectrum, and a referral is in for the foetal alcohol clinic, but we've yet to secure funding for that.'** – Parent*

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A majority of them **were positive about the ASF, claiming they had been ‘saved’ by it or that it had ‘made a massive difference’ to addressing their children’s additional needs.** One parent, whose child was awaiting referral for assessment by a Tier 4 specialist service, emphasised the role of the ASF in facilitating access to the specialist input needed by children with developmental trauma.

Several parents commented on how the skills and knowledge of social workers influenced their access to the ASF. One parent attributed positive experiences to her social worker being knowledgeable and aware of what support was available, as well as experienced in writing bids. However, another parent spoke about paying for assessments privately, researching providers and sourcing quotes, because **the family’s social work team ‘really didn’t even know how to do successful bids with the ASF’.**

#### CASE EXAMPLE

In one family’s case, the ASF paid for an occupational therapist to set up a school-based motor programme for the child and a small group of other children. This included a teaching assistant attending a training course in another county. **The child’s parent said, ‘the difference it made was just remarkable. I mean he’s still dramatically behind his peers physically, but he doesn’t fall over all the time now’.** This support had been established between the launch of the ASF and the introduction of the Fair Access Limit. **The parent considered that ‘if it was beforehand, or now, we wouldn’t have got as much input as we did’.** In her view, there was a risk that the Fair Access Limit could **‘significantly limit the development of some children’.**

This parent also alluded to the repeated reviews and applications involved in meeting a **child’s long-term needs** using short-term packages of ASF funding:

They secured funding for [the OT] to implement a programme and reassess in July 2016, and then they paid for an extension to Christmas, and then they kept bidding and it was great, and then they got an extension all the way to summer 2017. **Because it’s a long-term thing, physicality.**

## Findings from professionals

### Establishing children’s and families’ needs

Professionals identified consistency of workers and getting to know children and families through observation as important to understanding children’s **health and development.** This was felt to be particularly true for adopted children who will have experienced more changes in caregivers and professional involvement than most children.

Some professionals attempted to structure assessment and review processes flexibly, acknowledging that needs may change as a result of disruption experienced early in **children’s lives and through the transition into adoptive families.** In one specialist health service, the stability of the team reportedly enabled a **‘longitudinal view’** to be taken; this was seen as helpful in managing the uncertainty involved with children placed for adoption at a young age following significant trauma.

**Therapists interviewed described detailed, holistic exploration of children’s experiences** and abilities as essential to understanding their needs and determining priorities for, and approaches to, support.



## EXAMPLE: DETAILED AND HOLISTIC ASSESSMENT

A member of staff in an adoption support agency emphasised a need for assessments to **'look at everything before any specialist assessments'**, the accessibility of which was seen to require improvement. Before meeting a family, the agency would try to get a **'sense of what sort of placement it is, how long the child's been there, how are the parents managing, what are the issues for them at this point'** as well as **'how the child's managing in all areas of their life'**. Then there would be an assessment, during which the family would be observed together, and the child individually and with siblings, if they had any. This would also include a paediatric assessment which may uncover previously unidentified issues:

One child had a very nasty burn on her foot from the birth family, which meant **her foot hadn't grown properly, which meant she was walking strangely and had put her back out**, so she needed to have foot surgery.

The first assessment would lead into any other, more in-depth ones: for example, cognitive assessments or sensory integration occupational therapy assessments.

This agency's holistic assessment aimed to **inform 'not just thinking about therapy needs'**, but would begin with thinking about a variety of different physiological and psychological constructs:

**The child's way of managing to do with their level of the brain; how much is in the body; how much is somatised in their system; how much is about physiological dysregulation that they need support with that – before you even go on to thinking about their attachment relationships and helping them feel more secure and safe in their family and at school, or with peers – before you could even think about life story work and helping them reflect on their experiences and make sense.**

**SEND professionals explicitly stated the need to emphasise children's abilities and potential and involve parents in understanding and promoting children's progress.** This was presented as refreshing for families who may have had more alienating or problem-focused interactions with professionals during the adoption process. One interviewee experienced **the process of completing a Developmental Journal for any child as 'a discussion with the parents' rather than an assessment, covering 'the whole child'**. The professional explained: **'we will give the parents a copy of the checklist that they can keep working through that if that's what they want', incorporating other tasks, for example those set by physiotherapists, into activities.**

Professionals also **identified a range of barriers to effectively ascertaining children's health and development needs.**

As identified earlier, completing detailed, holistic assessments could be hampered by gaps in the information available about children. An NHS therapist explained that, when the main source of information is the adoptive family, **accounts of children's pre-adoption experiences could naturally be far less specific than birth parents' accounts of their children's early lives.** **The sense that information** may not be reliable enough to inform diagnosis could be compounded in cases where parents **'don't really want to think'** about the trauma their child may have experienced, or have been given contradictory histories by different professionals.

Professionals reported struggling to complete assessment processes effectively and efficiently with limited resources. The time involved in local authority assessments of **families' adoption support needs was described** as varying from a phone call to **'forever'**, depending on complexity and urgency. Some local teams had committed to mirroring the timeframe for assessments for children in need, which are legally required to be completed within 45 working days. Beyond assessment, various practical issues were said to hamper the ASF application process.

Adoption support social workers described strategies for managing capacity and reducing the time families waited for support. One social worker completed assessments directly **with parents, incorporating their views about 'what's going on' for children in education and healthcare but not getting 'more involved' with other agencies unless** parents requested it or there were safeguarding concerns. Another social worker admitted that, in **prioritising timely responses to families' needs**, writing up the assessments often **'fell by the wayside'**.

Working in a therapeutic social work team and being trained in attachment therapies enabled one interviewee to support families as soon as they presented in crisis, whilst assessing needs and putting support in place. **This involved intervening to** 'help the parent settle down, give them strategies to manage the behaviour, think with them about where **this behaviour's coming from'**.

Several professionals called for greater prioritisation of adopted children in terms of accessing assessments. One health professional strongly felt that all areas needed a specialist, priority service staffed by experienced paediatricians. However, when considering what makes for effective initial responses to concerns about children, interviewees more often than not focused on existing services, emphasising the importance of knowledgeable and well-supported health visitors, GPs and education professionals.

## The significance of diagnosis

Many professionals expressed the view that diagnoses or labels should not be, but too **often are, 'the key to a door' in terms of children accessing support. However, aside from** condition-specific provision, for example for autism, they tended to suggest that diagnosis-related barriers to accessing support affected other services rather than their own. They **also described labels for children's needs being used to insist that they deliver services.**

This issue is **debated within the disabled children's sector more widely but has particular** implications for adopted children and children in care, for whom assessment and diagnosis is complicated by the need to factor in the potential impact of early experiences.

### CASE EXAMPLE

A paediatrician, who described constantly feeling under 'massive pressure' to assess children with particular diagnoses in mind, referred to a child who had previously 'kind of' fulfilled the criteria for autism. Although 'she had been very severely neglected and had a very bad start and I wanted to give her a bit more of a chance', the child's social worker reportedly insisted that "'She needs her diagnosis because the school are not supporting her properly'". The paediatrician concluded that **'most probably, I shall find my way round to giving her the diagnosis because I want these children to be properly supported'**.

The needs of these children may also not lend themselves to ‘the right “diagnosis” that attracts the early resources’. For example:

Currently in education a diagnosis of foetal alcohol syndrome does not attract all of **the resources that would be required [...] so, what they want is for you to give him the diagnosis of autism but sometimes you can’t [...] straight away.**

A lack of clear diagnostic pathway for FASD was linked to particular difficulties in **coordinating responses to children’s** behaviours and symptoms. One professional reflected on the confusion this could cause:

I think everybody just would be a bit baffled. They would mess around for some time and, because the school would be saying something like, ‘**Oh, perhaps he’s got ADHD**’, but then [health service] would say, ‘**Well, we don’t accept them at four for ADHD, you’ll have to wait till he’s seven**’.

Concern was also expressed about a perceived tendency towards complexity in how **children’s needs are conceptualised and categorised, driving demand for services** that target increasingly specific concerns. One social worker suggested that this had potential to detract from what might actually help children and families and be available through existing services.

Several adoption support social workers described difficulties in facilitating access to **disabled children’s services**. One social worker said, ‘**It’s really rare** that our kids have a **worker from the children’s disability team**’: children who ‘just’ have ADHD or autism ‘**don’t get a foot in the door**’; those that are allocated a worker tend to have suspected FASD or ‘some sort of genetic or chromosomal difficulty’. Another adoption social worker recalled **meeting with a manager from the local authority’s overstretched disabled children’s team** about this issue, and discussing barriers faced by adopted children to accessing the disability service:

I say quite loudly, ‘What could be more disabling than not being able to form relationships with other human beings?’ and the team manager in the disabilities **team said that [...] attachment disorder is not recognised by disability** and the problem with foetal alcohol and drug use **in pregnancy is [...] it’s really hard to prove [and] can be missed, or it can look like ADHD or it can look like autism.**

In contrast to their perspectives **of disabled children’s services**, interviewees did not convey any sense that the provision of adoption support for families was dependent on children having any diagnosis.

Professionals recognised that diagnosis may be seen by parents as offering some certainty, but that there is also **often** ‘a very pragmatic logic’ behind attempts to seek diagnoses for their children (see boxed quote). However, a

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*‘Many of the adopters really want to have a diagnosis of ADHD or autism because that makes sense to other teams and it makes sense to the medical profession and with that comes resources and at the end of the day all the **parents want. It’s not to assess their children to death so they can label them; it’s so they can access resources and the resources that are attached to disabilities team are the only team that works long term.**’ – Adoption support social worker*

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**'perception that adopters are fixated on getting a diagnosis for their children'** was also identified, and a view expressed that support groups for parents of disabled children can sometimes contribute, rather than merely react, to an unhealthy focus on diagnosis.

Conversely, one interviewee explained that some parents **of young children believe 'that we're probably wrong, and that their child will grow out of the difficulties'**. In these cases, the professional explained that it could be difficult to intervene and offer help:

**We're not in the business of trying to force families to accept something they don't [...] We want to work within what the family want themselves, and if it's not the right time, they can come back in a couple of years and talk to us again.**

## Joint working in assessment, planning and provision

Professionals' **views** reflected the importance of joint working when making referrals, agreeing responsibilities, coordinating assessment processes, allocating resources and delivering support.

### *Barriers and enablers to joint working*

Many interviewees indicated that **'there's a lot of goodwill out there and a lot of people who are prepared to collaborate'**. They characterised efforts to work together as indicative of individual professionals' commitment to children. However, this was seen as **'not something you can mandate'** and severely undermined by resource constraints, as shown by findings on roles and responsibilities, below.

Connections between local authority teams could be facilitated by professionals' interest in **each other's** work, including the support available to families and opportunities to collaborate. A SEND professional described being inspired to learn more about the local post-adoption support service so as to understand how children and families having Theraplay, for example, could be supported by any SEND professionals involved with them. For adoption professionals, understanding how and when adopted children and their families were in contact with other services could be difficult: one social worker noted, **'I couldn't tell you how many adopted children are in our Children's Disability Team, or how many adopted children have got an EHCP'**.

Professionals observed how co-location and strong relationships between staff from different services helped facilitate joint working, with some expressing concerns about the impact of regionalisation in this respect. In one small local authority, staff from the **adoption team and children's disability team were able to flag children to each other; make joint visits to assess children's and families' needs; collaborate to put packages of support together; and share reports.**

Particular issues with joint working were raised in relation to education. In anticipation of new duties coming into force, one Virtual School was developing activity relating to previously looked after children. The interviewee working in this service aimed to improve joint working by signposting relevant resources; acting as a catalyst to services coming together; pointing out opportunities; and explaining systems and processes. They had been building links with the local SEN team, adoption team, Family and Friends team, and others. The professional identified developing the early years element as a priority.

### *Roles and responsibilities*

**Assessment of children's needs appeared closely linked to issues** around how different services assigned, accepted and held responsibility. Professionals linked reluctance to offer or allow input, and barriers to **'thinking holistically'**, to a funding environment in which **'everybody is trying to protect their own resources'**.

**The ambiguity of children's needs was seen as contributing to children 'bouncing between services', with professionals possibly 'hoping somebody else will deal with the complexity'** (see also findings on diagnosis, above). One adoption support social worker described **'huge frustration with CAMHS not really picking up problems that we would see as mental health difficulties'**. This professional saw part of her role being to **'contain the frustrations' of families who 'go round and round' struggling to access support from schools, CAMHS or other services.**

There were also suggestions that agencies may try to use children's adoption status to deflect accountability:

Sometimes I **think when the word 'adoption' is mentioned it's like**, 'Oh well, straight over to post-adoption'. Well, actually these are children with a disability **first who happen to be adopted [...]** so we work very clearly with our colleagues to **look at 'What bit can we contribute to? What bits can you contribute to?'**

**The importance of having 'someone being in charge and running the case' was stressed by some professionals**, but one explained that their service often tried to do this and found it **to be 'a huge job'**.

Several professionals found the Common Assessment Framework and Team Around the Child/ Family approach helpful in encouraging a sense of shared responsibility. Others were exploring solutions to improve joint working at operational and strategic levels. For example, in one area, the Virtual School was involved with an adoption support services steering group. This group was setting up a sub-working group on EHCPs to ensure that they are **'truly multi-strategy' and not focused too single-mindedly on education.**

Whilst encouraging responsibility-taking by other agencies could be difficult, professionals also described **agencies' varying degrees of openness to involving others in their work.** One **adoption professional reported 'excellent collaborative working' with some schools on the EHCP process, and 'huge resistance' from others.**

### *Sharing information and professional opinions*

The ability to incorporate information from different agencies was seen as crucial for **effective assessments of young adopted children's needs.** A member of staff in an adoption support agency explained, referring to school-age children, how this contributed to their assessment process:

We do a lot of information gathering before a family actually comes here, so that we have the history, we have the psychometric data, we have information from the school, from the parents, from the local authority.

Sometimes, professionals faced barriers in contributing information held by their service to assessments led by other agencies. The exclusion of work in schools from the scope of the ASF was perceived as unhelpful in this regard:

It's really difficult to get any agreement that as a therapy organisation we can input **into the EHCP. The ASF doesn't fund [...] any educational support or liaison.** So we're constantly doing it without having funding to do it because it's just crazy. We have all this information. We've done the sensory integration assessment; we've done the therapy; we know the parents and the children really well. Of course we need to input into the EHCP.

**Local authority professionals reported some difficulties with social workers' involvement in the EHCP process, reflecting an issue that is recognised more broadly beyond adoption.** Multidisciplinary networks were mentioned as helpful, allowing social workers to **contribute a therapeutic perspective on the needs underlying a child's behaviour at school,** and what might help them. Network meetings could also assist with report-writing and allocation of actions. This joint working was said to happen on an *ad hoc* basis because **'there's no procedure that says, "If this child's adopted the school has to contact the post-adoption team"; one social worker reflected that 'unless somebody tells us about this child [...] we wouldn't know'.**

Comments from adoption support professionals also conveyed the importance of effective joint working between their services and specialist health services, particularly CAMHS. Examples of effective collaboration included managers working together at a strategic level; adapting referrals to CAMHS; and CAMHS locality workers providing consultation and **advice prior to a child's referral.** One interviewee explained the scenario they felt would be ideal:

Workers who are primarily concerned with looked after and adopted children in **CAMHS. And maybe the good work that they're doing with schools about consulting** and doing that initial screening might be helpful to be involved with us in post-adoption.

This professional was keen to explore the potential for **joined-up working 'at an earlier age when these kids are moving on to adoption', despite minimum age thresholds in CAMHS** for ADHD assessments.

Another interviewee mentioned that their area had a local CAMHS team devoted to looked after children (such teams may work with children placed for adoption before their adoption order, if not post-adoption), **expressing appreciation for this team's skills and experience.** This professional, explained that if **the looked after children's CAMHS team** struggled to interpret **a child's presenting** issues, they **could approach the interviewee's** own team, which focused on social and communication needs.

The idea of embedding collaboration and knowledge-sharing within the structure of health services was also raised, to inform the best possible understanding of children:

**I think you have to define a system approach that holds in mind both the child's physical paediatric developmental health and the child's mental health [...] trying to bring the advantages of both of those perspectives [...] So it's that kind of complexity of service model I think, and even if you can't do it as a post in that team, you ought to have colleagues in the team knowing enough about what they *don't* know to know that they should try to access that kind of thinking for a small proportion of the assessment or treatment work they're doing.**

## Funding

Professionals were acutely aware of resource constraints affecting their own and other services.

Post-adoption support services have a duty to assess families' support needs but are not legally required to provide the support needed. They can draw down money from the Adoption Support Fund; however, one social worker **described a 'disconnect' between the government's vision and services' capacity to put provision in place for families. A lack of statutory guidance was identified and described as encouraging flexibility but also inconsistency, and a perception of post-adoption support as 'a voluntary service within a statutory service'.**

Post-adoption therapeutic provision is funded via the Adoption Support Fund; anything outside the scope of the fund must be resourced in other ways, along with other services such as social work input. The introduction of the ASF was **described as 'fantastic' and 'inspired'**, although some concern was expressed about how ASF-funded services are defined, and perception of **the creation of an 'administrative category' that does not properly address disability or help join up the responsibilities of local authorities, education and health.** A local authority adoption support social worker described their changing role:

**[It's] becoming an administrative task where we're brokering funding packages and employing outside providers. So, apart from the needs assessment, we do very little or no direct work with the families and quite often we don't even get to meet the children.**

The ASF was seen to have **raised expectations among the children's workforce and prospective adopters**, but interviewees identified drawbacks of this, given the application of a Fair Access Limit. One adoption support social worker said of colleagues working in **disabled children's services, health and, to some extent, safeguarding: 'the minute they see that the child's adopted they think it's our job to sort it out'**. Education professionals were presented as having less awareness of the ASF. In the experience of one professional working in an independent adoption support agency, the ASF replaced some previous funding mechanisms that were not reinstated after the Fair Access Limit took effect, creating resource gaps for families facing serious problems in some localities.

In terms of additional entitlements in education, **schools' use of Pupil Premium Plus funding was discussed comparatively more than the smaller Early Years Pupil Premium (EYPP).** An adoption policy and practice expert highlighted that support for adopted **children in schools is a 'huge issue' and 'source of frustration for many adopters'**. Interviewees identified **'mixed ways of operating'** including funding being assigned to individual children; interventions or resources being offered based on analysis of collective need; or money being **'absorbed into the budget for the school'**. **The quality of decision-making, level of transparency and involvement of parents were presented as very variable.** Some professionals identified Virtual Schools as playing a role in supporting improvements in Pupil Premium Plus spending for adopted children, and expressed hope that changes introduced by the Children and Social Work Act 2017 will help further.

## Discussion

Findings from interviews and literature reveal that, due to histories of abuse or neglect, and sometimes the history of their support in care (for example, changes in social worker), young adopted children are often not well known and have significant gaps in their health stories. Arriving at definitive conclusions about the health and development of young care-experienced children is difficult and may be inappropriate: the importance of early identification and intervention must be weighed against the risks of applying labels and diagnoses to children too soon.

Sometimes it seems that professionals involved in adoption matching are not clear enough **with prospective adopters about children's** uncertain or likely needs. Sometimes they may be clear, but prospective adopters are not ready to hear what is being said.

The rarity of adoption disruption and findings on the challenges involved in adoption show that parents are often prepared to go to great lengths to preserve their adoptive families. However, they need to be well-supported. Many interviewees noted the difficulties – and paperwork – faced by adoptive parents of children with additional needs in **'dealing with thousands of different people all the time trying to navigate the system'**, as one professional put it.

A range of practice challenges relating to work with adoptive families are evident in the interview findings and literature:

- managing uncertainty, ambiguity and difference of opinion about what children may need and how they may present in the future, including when communicating with prospective adopters
- understanding and meeting the needs of children and families in the context of simultaneous or overlapping transitions
- empowering families to seek help when concerns arise
- helping families to feel supported and involved, including bridging potential gaps between **some parents'** and professionals' perspectives
- enabling access to appropriate and well-coordinated assessments and provision, and ensuring that the absence of a diagnosis is not an obstacle to addressing **children's needs**
- ensuring that all relevant professionals are sufficiently informed about the **adoption-related dimensions of young children's additional needs**.

These are difficult for professionals to manage, however deep their commitment to child-centred practice and supporting families.

This section reflects on how these challenges may be addressed through different areas of practice, based on learning from the interviews and available literature, including suggestions offered by parents and professionals. The areas will be tackled by existing guidance and resources to varying extents. **Some interviewees' ideas** challenge current policy on previously looked after children or imply a need for consideration of how available resources are deployed. Those that were emphasised strongly by parents or professionals are noted, but the discussion that follows aims to identify opportunities for good practice within existing arrangements and constraints.

Professionals and families are working together in a context of shifting service structures, responsibilities and resources: adoption is being regionalised, the impact of the ASF on



provision is evolving, and the Children and Social Work Act 2017 will introduce new duties particularly relevant to education. It is especially important, therefore, for practitioners to **carefully manage adopters' expectations, involve them in decision-making**, and seek their feedback. Distinct issues facing adopted children with additional needs and their families should be kept in mind as changes are implemented and evaluated, with a view to informing good practice.

## Professionals' knowledge and expertise

Findings from the interviews and literature underscore the difficulty of communicating **about children's health and development for the purposes of** adoption matching, and the need for both careful consideration and momentum to achieve permanence for children. Medical advisers and social workers should have access to well-supported opportunities to reflect on practice: for example practitioner networks and action learning sets. Their needs for support and guidance require ongoing consideration at local and national levels. For example, CoramBAAF work to address this through their membership offer, resources and events.

Many interviewees expressed a wish for **adopted children's needs to be** better understood by professionals working in unrelated disciplines or universal services and settings. Examples were given of practitioners accessing learning opportunities or seeking advice from specialists in relation to the needs of care-experienced children. Such practice should be encouraged, though it requires support from service leaders and resources. LAC health teams and Virtual Schools have important roles in informing and advising health, early years and education colleagues.

**Agencies should help practitioners' discover and use freely available resources that may** benefit their work with adopted children and their families. One interviewee mentioned education resources from Adoption UK<sup>12</sup>, PAC-UK<sup>13</sup> and Inner World Work<sup>14</sup>. MindEd, a government-funded series of e-learning modules on children and young people's mental health, includes content on children adopted or in care<sup>15</sup>.

## Communication with prospective adopters about children's health and development

Professionals need to enter the process of matching a child and prospective adopter with **as clear and full a picture of the child's health and development as possible**. Interviewees indicated the importance of robust health assessments and reviews for looked after children. Comments made by parents highlight the need for support for foster carers to identify issues, **and appreciation of foster carers' concerns**.

Parents and professionals both spoke about how information families receive about **children's needs may not feel 'real' until after placement**. **This seems inevitable to an** extent, but adoption agencies should consider any opportunities to impart information in ways that feel as tangible as possible: for example, ensuring the prospective adopter meets

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<sup>12</sup> <https://www.adoptionuk.org/>

<sup>13</sup> <http://www.pac-uk.org/>

<sup>14</sup> <http://www.innerworldwork.co.uk/>

<sup>15</sup> Available at <https://www.minded.org.uk> in MindEd Core Content (Universal) > Problems for specific ages and Vulnerable groups

**key individuals in the child's life, if not the child themselves; bringing them together with** experienced adopters; or using audio-visual resources in training. This is especially important when a prospective adopter is being told that the child they are considering may be affected by a particular issue despite a lack of evidence confirming either way: this may be the case for FASD, for example.

Face-to-face meetings **appeared important from both parents' and professionals'** viewpoints. Prospective adopters should have the opportunity to meet with the agency medical adviser. Written summaries of these important meetings could help prospective adopters to digest and recall the key points and actions discussed.

It is really important that prospective adopters have an opportunity to confirm their understanding and explore expectations, both in relation to information about children and to the process. No one meeting, or type of meeting, should be the only opportunity for prospective adopters to ask questions.

**Adopters' beliefs about** professionals withholding or downplaying information about children appear in the literature and also featured in interviews for this project. It seems possible that hindsight may also influence parental and professional views **about what was 'knowable' prior to a**

**child's adoption.** Naturally, all accounts of events are unverified and represent the perspectives and memories of individual **participants and should be considered alongside professionals' analysis of the situation** which is that sometimes parents do not hear what they are told. However, whatever the facts of each case, parents who perceived that information had been withheld or downplayed described significant distress and loss of trust in services, as might be expected.

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*'The medical information that I was subsequently given I think wasn't entirely truthful, not necessarily deliberately not truthful.'* – Parent

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When matching prospective adopters with children whose needs are uncertain, it is clear **that professional communication should be honest and open, whilst highlighting children's** individual attributes including strengths and abilities. Findings from this small sample of parents and professionals suggest that prospective adopters may come to terms with quite significant information about a child without changing their minds about the match. This echoes other research findings (Wickramasinghe, 2016) and is a positive indication of **adopters' adaptability. However, the literature review discusses risks associated with** prospective adopters compromising on their preferences (Farmer et al., 2010) or feeling unable to back out (Selwyn et al., 2014a) during matching.

In light of these issues, **the concept of 'realistic positivity'** (explained on p.33) seems valuable. The SEND professionals interviewed spoke about balancing realism and optimism **about children's needs with confidence and may be well-positioned to contribute to** adoption matching. Adoption agencies might consider ways to facilitate SEND **professionals' input into training and resources for adoption practitioners and prospective** adopters.

## Parents' awareness and expectations of support

Alongside information about individual children, prospective adopters should receive information about entitlements and support for adoptive families. Expectations about available help, which affect their decisions about whether to proceed with adopting children who may have additional needs, should be carefully managed. Introducing prospective adopters to Adoption Support Services Advisers may help them to seek post-adoption support as and when they need it.

Families also need to be able to access clear, up-to-date information about services at any time beyond the adoption order.

The evaluation **of the ASF's early implementation phase (King et al., 2017)** explored **adopters' awareness and understanding of post-adoption support**. It compared different communication methods, some of which were mentioned by participants in this project. The Government expects that regional adoption agencies will have regular contact with local adopters to understand their needs and inform them about available support (DfE, 2016). Local authorities and regional adoption agencies should take note of learning from the ASF evaluation and invite local families, including those who have not accessed post-adoption support, to inform approaches to communication.

Issues relating to post-adoption support arranged across local authorities are particularly difficult and will be impacted by regionalisation. Adoption support teams need to help each other, and the families with which they are placing children, to understand local services and providers, for example by providing directories or ensuring that they are aware of the SEND Local Offer.

Publicity material and information resources outlining adoption support should be explicit about what provision is offered to all adoptive families and what is subject to assessment of need. Adopters and prospective adopters should receive positive messages about adoption support and know that this is underpinned by statutory duties upon local authorities. However, they should also be made aware that there is no automatic right to services; that provision varies across local areas; and that changing availability of resources affects exactly what is available for individual families at a given point in time. Detailed national resources are available, but adopters also require this information to be placed in their local context.

**There is no statutory timeframe for assessing families' post-adoption support needs.** According to social workers interviewed, some local authorities have undertaken to assess **families' needs within 45 working days**. Clear commitments or greater transparency around timeframes for assessments and ASF applications may encourage adopters to seek help before reaching crisis point. However, the helpfulness of services encouraging timely help-seeking by adopters depends on their capacity to offer support to new families for whom adoption disruption is not an imminent risk.

## Relationships between families and services

### Before an adoption order

Findings from the interviews and literature (for example Selwyn et al., 2014a) reveal the potential for significant gaps or clashes between the perspectives of professionals and prospective adopters, **when it comes to children's health and development**. These may

arise during matching, placement planning or pre-order, or may be experienced with hindsight. In some of the experiences described by interviewees, the needs and requirements of the adoption system have also appeared to conflict with those of children awaiting adoption and the families being considered.

Advocacy for prospective adopters therefore seemed like an important suggestion. The complex decisions prospective adopters make in emotionally charged circumstances will impact on the rest of their own **and their children's lives; in most cases, parental responsibility is also being transferred to them by the state.** Findings from the literature **and interviews suggest that prospective adopters' access to individualised advice warrants** further consideration at local and national levels. Prospective adopters should be signposted to existing resources and informed that they can take a supporter with them to meetings where appropriate, for example with medical advisers.

## After an adoption order

Whilst policy and practice may encourage holistic approaches to working with children and families, **maintaining active and comprehensive oversight of a child's needs, and all professional involvement, is part of their parent's role** – unless the child is looked after. Fulfilling that role is a manageable task for the parents of many children in the general population. However, young adopted children with additional needs may have many professionals involved in their lives, in relation to adoption, health needs and SEN, which creates complexity. **Parents' attempts to get their children's needs met are further complicated by uncertainty about the past and future, shifting parental responsibility, budgetary constraints in public services and barriers to multiagency working.** Parents will vary in terms of how much involvement, control, autonomy and authority they want; where they feel the limits of their parental role should lie; and where the state should step in. These are significant questions with different implications for each child and family.

Professionals have difficult issues to navigate, then, when allowing adoptive families to be left in peace; encouraging adopters who need help to come forward; challenging them when needed; and supporting families when demand outstrips capacity. **Meeting parents' expectations of having both their capabilities and vulnerabilities acknowledged may be a challenge.**

Relationships between adopters and services are affected by all areas covered in this report. In terms of interactions between individuals, professionals mentioned several strategies involving carefully **listening to adopters' concerns**; demonstrating that adopters are trusted and valued as sources of insight and **'part of the solution'**; offering emotional support; and being positive about children. Parents gave some examples in which validation of their experiences went hand-in-hand with knowledgeable professionals taking action to achieve helpful outcomes (a paediatrician diagnosing FAS and SENDIASS advising on a conflict about post-adoption support).

**Parents' and professionals' expectations of themselves and each other warrant continued exploration.** This should happen both through conversations between individuals and **dialogue between adopters' groups and local authorities/regional adoption agencies.**

## Participation and peer support

Interviewees explained how prospective adopters can gain insight and advice from existing adopters that cannot be provided by professionals. Involving adoptive parents in training for prospective adopters is good practice, and some parents expressed satisfaction at having participated in this.

Engagement with parent groups or events post-placement was also identified as helpful by both parents and professionals. Adopters may be able to access, to different extents, adoption- and disability-focused groups locally, nationally or online. There may be room for more or better peer support addressing how disability- and adoption-related issues intersect. Small online networks appear to have a role in this space, in which case adoption services and organisations may be able to help improve their visibility and promote good practice.

Continued effort is needed to harness the benefits of parent groups and to create bridges between such groups and professionals. Professionals gave positive examples of parent groups within which professionals were sometimes involved but not the focal point, for example parent-led groups working in partnership with services, or group-based interventions that encourage social relationships to develop. Such arrangements may help to foster trust, increase dialogue and inform service improvements.

Adoption services should have clear mechanisms for seeking and acting on feedback from adopters and prospective adopters.

## Access to appropriate assessments and provision

Approaches to assessment and diagnosis need to be careful, open-minded and child-centred, since there may be **multiple possible explanations for young adopted children's** presenting symptoms and behaviours. Barriers to accessing services without a diagnosis are particularly unhelpful for this group. Care-experienced children may have multiple difficulties that have a significant collective impact without meeting thresholds for any single diagnosis, as explained by DeJong (2010). Findings from the interviews and literature indicate the need for good generalist paediatric services with wide and sufficient – but not expert – knowledge of specialist areas. Dedicated services for adopted or care-experienced children also appear to be highly valued by parents and professionals. Service models that bring together multidisciplinary professionals who are familiar with this population can hopefully support holistic working; reduce the risk of assessments or intervention becoming burdensome for children and families; and improve access to effective support. Many interviewees also stressed the importance of timely assessments.

**As mentioned above, interviewees' suggestions sometimes challenge current policy** on previously looked after children or allocation of resources: for example, requirements for all areas to commission dedicated services or for priority access to specialist assessments. However, a desire for large-scale change was also expressed by the Expert Working Group set up in 2016 to ensure that the emotional and mental health needs of care-experienced children and young people would be better met. **One of the group's strongest views was that assessment and services must be 'responsive and flexible'. Their report** (SCIE, 2017) acknowledged the value of diagnosis, but stated that the current model of delivering care relies too much on it and advocated a needs-led model. It described **assessments as 'a snapshot' which should be kept under continuous review.**

Parent and professional interviewees stressed the importance of health, social care, early years and education professionals being able to offer availability, continuity and responsiveness, with services ideally **keeping an ‘open door’** or periodically reviewing needs. In particular, they wanted local authorities to be able to provide more proactive post-adoption support, based on a presumption of need: an area for improvement also identified by the ASF evaluation (King et al., 2017). Whilst difficult to achieve, these recommendations were couched in terms of preventing serious problems from developing or worsening. Interviewees also wanted to see increased access to health expertise through post-adoption support services.

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*‘The processes to get [post-adoption] support is long winded and difficult, but once you can secure it and get it, there is some good support out there.’*  
– Parent

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**Adopted children’s access to assessments and provision merits ongoing consideration at local and national levels.**

## Promoting children’s development and education

SEND professionals reported positive experiences of working with children and families before and soon after placement: observing how children respond to their new home environment, focusing on their potential, and empowering and upskilling parents. This **seems potentially powerful given that the process of familiarisation with children’s needs is** very different for adopters than for birth parents. SEND professionals are also able to form and communicate their professional opinions without responsibility for the particular dilemmas of adoption-related decision-making. Their relationships with families may be eased by their distance from the adoption process.

Parent interviewees who reflected on early years settings often portrayed them as responsive to children’s **additional needs and** able to reassure or empower parents. However, experiences of schools appeared more mixed. In particular, concerns about children starting too young or too soon after placement were raised in both parent and professional interviews. These reflect findings from the national study of adoption disruption (Selwyn et al., 2014a) and a recent survey of adopters (White 2017). Adoption UK has called for a review of current procedures concerning school starting age, considering the need for greater flexibility and possible benefits of flexi-schooling.

Professional interviewees spoke about the risk of SEN needs assessments and support becoming disjointed during adoption. The development of Personal Education Plans (PEPs) for previously looked after children was suggested as one way of addressing this.

Professional interviewees indicated that relevant professionals are not always able to input into EHC planning. Anecdotal evidence from the field suggests that this may point to a wider issue around EHCPs and social care, and a need for more targeted work to engage social care staff in the process. Interviewees saw the benefit of bringing professionals together, mentioning multidisciplinary networks and a sub-working group on EHC planning within an adoption support services steering group. Given the exclusion of work in schools from **the ASF’s scope, there is also a need to consider how adoption professionals’ input** into EHC planning can be resourced.

All areas should have a clear protocol for inviting social workers into the EHCP process, with a shared understanding of roles and responsibilities regarding their involvement.

Social workers need to be supported to understand EHC planning and the most effective ways to contribute. Professionals should consider opportunities to align EHC planning with other assessments, plans and reviews for children whom the local authority proposes to place for adoption.

## Coordination and collaboration

**The issue of families ‘bouncing between services’, as one social worker** put it, was an important one for many interviewees. This echoes experiences reported by parents of disabled children generally. However, interviews suggest that adopted children may be particularly susceptible to this because of the potential ambiguity of their needs and range of agencies involved.

Within interviews for this project, and in discussions of related issues **across the children’s** sector, allocating oversight to an individual practitioner or agency has often been identified as the ideal solution. However, as many professionals and parents have acknowledged, it is not an easy one to implement, especially if such oversight is intended to span education, health and social care.

It is important, therefore, that a range of professionals have opportunities to interact and inform each other. Local areas could consider the opportunities available for strengthening connections between, for example:

- medical advisers and social workers
- social workers working with children and adopters pre- and post-adoption, if these are not the same individuals or located within single teams (for example, one area offered a pre-adoption transition service)
- adoption professionals and those working in other specialist areas including SEND
- adoption professionals and those working in universal services including primary care, health visiting and early years provision.

Strong connections between professionals enable philosophies, approaches and experiences to be shared. This should inform well-evidenced and balanced views of what is **known and knowable about a child’s health and development, and how best to convey this** to prospective adopters. This is important in light of findings from the interviews and literature indicating a lack of professional **consensus about how to best interpret children’s** presenting behaviours or symptoms. Multidisciplinary learning opportunities could help to address polarisation in the views of individuals or professional fields. These should be informed by research and explore different perspectives, thereby providing guided support and challenge in spaces which allow reflection and honest exchange.

Familiarity and opportunities for joint working also help practitioners to coordinate their involvement with children and families. Staff in local authority adoption, SEN and disability teams – and regional adoption agencies as they develop – will benefit **from awareness of each other’s work including** access criteria and resource constraints (for example, the ASF scope and Fair Access Limit). It seems that greater information-sharing across teams or boundaries on an opt-in basis might also be appreciated by some families.

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***‘[Families] can spend a lot of time spinning in this wheel between health, education and us, and everybody is making referrals to non-existent support services.’ – Adoption support social worker***

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Both the interviews and literature reveal a need for more effective joint working between post-adoption support services and specialist health services, particularly children and **young people’s mental health services**. **This requires strategic thinking at a local level**. The adopted children and adolescent mental health service (AdCAMHS) in East Sussex is an example of mental health and post-adoption support services working in partnership to deliver a specialist service. Examples of specific work to address the needs of adopted children can be found in some Local Transformation Plans (see *Policy context*).

**Managers could consider how staff could be supported to contribute to each other’s assessments**, given the potential variation in different **teams’ approaches and documentation**. Multidisciplinary input into EHC planning is discussed above.

## Funding

Parents whose children have multiple or ambiguous needs may be particularly concerned about access to, and limitations of, funding allocated for adoption children.

The Adoption Support Fund was introduced in 2015 and post-adoption support services are still adapting to it. Many participants in this project described the ASF as a welcome initiative with potential to make huge positive differences, but also identified barriers to access and areas for improvement. This reflects the recent ASF evaluation (King et al., 2017), which explores the implications of findings for policy and practice, including for contacting families, reviewing needs and measuring impact.

Pupil Premium Plus and Early Years Pupil Premium funding were also introduced quite recently, in 2013 and 2015 respectively. Comments from interviewees suggest that the management of additional funding for previously looked after children could be of more consistent quality. Measures introduced in the Children and Social Work Act 2017 will be important in addressing this.





## Recommendations for future research

This project focused on how the additional needs of young adopted children are identified, understood and responded to – concentrating on needs that parents did not expect or feel prepared for. Particular attention has been paid to needs other than, or additional to, SEMH needs, and the interface between adoption-related and other processes and professionals.

Practice does not appear to be led by agencies or professionals jointly focusing on these issues specifically; instead, a wide range of policy and practice areas seem to have some bearing on how they are addressed. The coordination of multiagency involvement in these **families'** lives seems worthy of further exploration, possibly through a model or pilot.

Valuable further research could be undertaken from a range of angles, exploring:

- adoption-related dimensions of specific areas of SEND practice
- areas of adoption practice and particular implications for children with additional needs: for example, the role, impact and value of medical counselling for prospective adopters in relation to long-term outcomes, as recommended by Wickramasinghe (2016)
- particular **aspects of adopters' experiences**, such as engagement with peer support in relation **to children's additional needs, or of children's own perspectives**
- **parents'** views on ideas for practice improvements and their implications, with findings used to inform clear guidance for professionals (one example from interviews with professionals was a view that more information-sharing for the purposes of post-adoption support might benefit families).

Investigation of some practice issues could be informed by, or inform, learning from other fields. For example, how professionals who are unable to offer the answers or interventions parents have in mind (for example, due to the complexity of issues, resource constraints or other practical obstacles) can help parents to still feel as validated, involved and supported as possible.

There is a growing body of research into the impact of adverse childhood experiences and **developmental trauma on children, which will hopefully continue to inform how children's** needs are interpreted. However, professionals are trying to support adopted children with additional needs and their families without a clear evidence base on which approaches are effective. This creates difficulties for those receiving, delivering and making decisions about services. The government has committed to strengthening the evidence base of **'what works' in adoption support, building on the work of Stock et al. (2016)** (DfE, 2016). Our project findings support the need for the kind of follow-up evidence review proposed by Stock et al. (see p.21).

As mentioned above, service structures, responsibilities and resources are changing. Local or national impact evaluations of significant changes could be used to inform good practice, and should consider particular issues for adopted children with additional needs and their families.

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## About the Council for Disabled Children

The Council for Disabled Children (CDC) is the umbrella body for the disabled **children's** sector in England, with links to the other UK nations. CDC works to influence national policy that impacts upon disabled children and children with Special Educational Needs (SEN) and their families. The CDC membership is made up of a variety of professional, voluntary and statutory organisations, including disabled young people and parent representatives. **CDC's** broad based membership and extensive networks of contacts provides a unique overview of current issues. It also enables us to promote collaborative and partnership working among organisations.

CDC hosts the following networks and projects:

- IASS Network
- Making Ourselves Heard
- Special Educational Consortium
- The Information, Advice and Support Programme
- Transition Information Network

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