Understanding the health and wellbeing needs of looked after children, young people and adoptive families

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July 2015
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Executive summary

Engaging with the voice of looked after and adopted children and young people

The content of this Healthwatch Norfolk report follows an initial period of six month’s “mobilisation” which saw us increase our work with and on behalf of children, young people and families. In setting our areas of focus for this mobilisation phase of work we looked at those groups of children and young people for whom health and wellbeing outcomes were significantly worse than their peers across Norfolk.

The group for whom health and wellbeing outcomes remains consistently low is those children and young people who are classed as looked after or who have spent time in the care system (before being adopted or returning to their birth families).

The scope of our engagement work to date has been to understand how effectively the needs of looked after and adopted children, young people, foster carers and adoptive parents, are met by services in Norfolk.

It is one of Healthwatch Norfolk’s great strengths that our remit not only allows but requires us to be led in our work by what service users are telling us. Our work to date has then been shaped by the response to our initial engagement. This has most obviously been the case in our work with adoptive parents where the response to our initial approaches led to over 70 hours of interviews, producing a valuable and deep record of their experiences of services. This engagement-led approach is reflected throughout this report.

This approach has seen us focus not only on the voice of children and young people in the care system, but also those adults who have the closest relationships with them once they are no longer able to live with their birth families. Consequently, our findings and recommendations are set out in three sections in this report:

- Part 1 - The voice of looked after children and young people in care.
- Part 2 - Children with disabilities and additional needs in the care system - the foster carers’ perspective.
- Part 3 - Meeting the needs of adopted children and their families.

We are aware that this is only the beginning of our work in this area and many of the recommendations made throughout this report (and brought together below in this executive summary) are directed at things we should do to ensure that Healthwatch Norfolk is a robust and credible voice for looked after and adopted children and young people.

By focusing on individuals’ experiences of services we hope that we have begun to make a contribution. We appreciate that commissioners and providers of services continually strive to do their best for these children and young people, and stories of good practice and valued support have emerged from our work. At the same time there is still much to do to ensure that services are as good as they can be to meet children and young people’s often complex needs and those of the adults who give them homes.

We have already shared our findings and recommendations with key individuals in health and social care services in Norfolk who have important roles in helping looked after and adopted children and young people to achieve better outcomes. In the weeks and months following the publication of this report we will be working to ensure that the voices and experiences captured in the following pages are heard and taken seriously by commissioners and providers of services.

This report is intended for all commissioners and providers of services for looked after children and young people, adoptive parents and foster carers in Norfolk. Some of those professionals will be
concerned with very targeted services but the findings in this report also apply to universal services and we make recommendations about how they may better meet the needs of looked after and adopted children, young people and adoptive parents. It should also be pointed out that while our concern is with people in Norfolk some of our recommendations apply to commissioning bodies, policy makers or professional organisations at a national level.

How we have presented our findings

The findings captured in this report represent what people have told us and we have used the language that they used to describe health and wellbeing needs and their experiences of services.

In many cases the people we spoke to (particularly foster carers and adoptive parents) had extensive and detailed knowledge of the way services are structured and were able to make well-informed comparisons between different service delivery models that they had experienced. However, we have retained a strong emphasis in the report of what individuals have told us about their own experiences.

We have taken the decision to include as many quotes from the people we spoke to as possible, to ensure that the voice of looked after children, young people, adoptive parents and foster carers is at the heart of the report and will be clearly heard by those who read it.

Our recommendations have been entirely shaped by what people told us of their health and wellbeing needs and their experiences of services. Many of these findings and the recommendations set out below are challenging and make for troubling reading. We would simply like to emphasise that these are the truths we were told.

Recommendations

The recommendations arising from the work described in this report are grouped according to the different element of our engagement work from which they arise:

- Engagement with looked after young people.
- Engagement with foster carers of children with complex needs.
- Engagement with adoptive parents.
- Recommendations from all engagement work.

**NB when identifying “who” the following recommendations are for we have usually set out the top-level organisation with accountability and/or responsibility for outcomes in any given area. For example, a recommendation identified as being “for” Norfolk County Council (NCC) should be taken to include all relevant departments and/or roles within that organisation.**

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<tr>
<th>Recommendations arising from engagement with looked after young people:</th>
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<tr>
<td>Senior leaders in children’s services and the NHS ensure that processes are in place to actively listen to and involve children and young people.</td>
<td>NCC (including Children’s Services and Public Health)/CCGs</td>
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<tr>
<td>Medical professionals (of universal services) should receive appropriate training and/or guidance to allow them to better understand the needs of children and young people in care.</td>
<td>National training bodies/NCC/CCGs</td>
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<td>That specialist services for young people, particularly mental health services are more accessible, and that commissioners and providers give active consideration to delivering services in less clinical environments.</td>
<td>CCGs/NSFT</td>
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**Children and young people are given more and better information about how services might help them, how long they may need to wait to access a service and what the follow on steps might be.**  
*NSFT/GPs/CCGs*

**Leaders from all relevant statutory services explore co-ordinated or joint consultation and data gathering activities which will inform Norfolk’s Joint Strategic Needs Assessment (JSNA).**  
*NCC/CCGs/NHS England/Public Health England/provider organisations*

**Leaders from all relevant statutory services explore joint engagement and involvement activities which will widen participation and deepen understanding while reducing the number of consultation exercises.**  
*NCC/CCGs/NHS England/provider organisations*

**Healthwatch Norfolk will continue work to widen our engagement with and understanding of the needs of children and young people in care and those who have recently left care. This work will include:**  
- Working with partner organisations.  
- Work with specialist agencies to understand more about the experiences and needs of care leavers who are in the criminal justice system.  
- Alignment with other elements of our 2015-2017 work programme, particularly Child and Adolescence Mental Health Services (CAMHS) related work and work relating to service users.  

**Recommendations arising from engagement with Foster carers of children with complex needs:**  
*Who for*  

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<tr>
<td>Leaders of Children’s services should ensure that foster carers’ views and insights are given due weight in a review of Health assessments, LAC reviews and strengths and difficulties questionnaires (SDQs) to ensure that processes are better aligned and give more prominence to the voice of children and young people with disabilities.</td>
<td>NCC</td>
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<td>NCC explores ways of improving the respite care offered to foster carers.</td>
<td>NCC</td>
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<td>Healthwatch Norfolk ensures that the needs of looked after children are appropriately reflected in its ongoing work in relation to CAMHS in Norfolk.</td>
<td>HWN/UEA/MAP (teams carrying out Healthwatch-commissioned research)</td>
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**Recommendations arising from engagement with adoptive families:**  
*Who for*  

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<td>That NCC reviews its preparation for adoptive parents and includes specific training on team parenting and examples of play therapy sessions and other techniques tailored to the likely needs of their adopted child. Continuing professional development for social workers and other professionals should be matched with an ongoing programme of support for adoptive families.</td>
<td>NCC</td>
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<td>That NCC adopts an evidence-led approach to post adoption support and shares information about what works and what does not. This should include meaningful opportunities for professionals to share what they do and learn from each other to inform service improvement.</td>
<td>NCC</td>
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<td>Norfolk Adoption Services (NAS) and CAMHS providers should establish more robust and regular opportunities to learn from each other’s practice and explore the opportunities for more integrated provision which better addresses the needs of adoptive families.</td>
<td>NAS/NSFT/NHS England</td>
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<td><strong>Recommendations arising from all Healthwatch Norfolk work regarding looked after and adopted children and young people:</strong></td>
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<td>NAS and CAMHS should look at practical forms of integration to deliver a more joined up and effective service to meet the needs of adoptive families.</td>
<td>NAS/CAMHS (commissioners and providers)</td>
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<td>That adoptive parents are actively involved in service design and throughout relevant commissioning processes.</td>
<td>NCC/CCGs/NHS England</td>
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<td>Healthwatch Norfolk should make representation through Healthwatch England and other national channels that the training for GPs/school staff/health visitors should include guidance on understanding the needs of adoptive families.</td>
<td>HWN/NHS England/Healthwatch England/DFE</td>
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<td>Ongoing engagement with looked after and adopted young people (including those who have recently left the care system or the adoptive home) in such a way to widen the evidence base without over-consulting with a small number of individuals.</td>
<td>HWN</td>
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<td>Ensure that the views and experiences of looked after children and young people are effectively considered in all relevant strands of Healthwatch Norfolk’s work (e.g. ongoing work relating to CAMHS).</td>
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<td>Explore with commissioners and service leaders the potential added value of Healthwatch Norfolk conducting or facilitating a structured, confidential consultation with professionals, which captures frontline insight into strengths and weaknesses of current service delivery arrangements. This should be across service boundaries and reflect the full range of professional involvement along the care/adoption pathway.</td>
<td>HWN/NCC/CCGs/NHS England/</td>
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<td>Pursue all the recommendations made in this report and provide updates on progress through our normal communication channels and events.</td>
<td>HWN</td>
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Introduction

Context

Healthwatch Norfolk was created in April 2013 to represent the voice and interest of everyone who lives and works in Norfolk in relation to all publicly funded health and social care in the county. Crucially the remit for Healthwatch Norfolk differs from that of its predecessor organisation, the Local Involvement Network, in that it extends to children’s health services and social care provision.

Norfolk is often characterised as an elderly and ageing county, yet one third of the population is aged between 0 and 25. Though generally people in this age group use health and social care services much less than older people, they are the group who will inherit the decisions that are being made now about how NHS and social care services are structured, what is commissioned and how and where it is delivered. Additionally, that group of young people includes some of those who draw heavily on the NHS services or for whom health and wellbeing outcomes are among the worst. These include children and young people with a physical or learning disability, children and young people providing substantial levels of care for a family member, looked after children and those who have been adopted.

From its inception Healthwatch Norfolk recognised that working with and on behalf of young people was going to be one of our most important challenges. Historically, organisations like ours have not always been good at connecting the voice of children, young people and families with decision makers. At the same time, NHS services (in particular) have not always been good at involving children and young people throughout the commissioning process to make sure that services properly address their needs and are delivered in the most effective way possible. NHS commissioners themselves are usually quick to acknowledge this is a failing of the past and are eager to improve practice in the future, yet are often working inside structures and a culture that characterises children and young people as “hard to reach”.

NCC has good consultative structures for young people including the Youth Advisory Boards and involvement of young people when services are being re-commissioned. However, the way that services are structured can mean that this involvement is within service silos and may miss the opportunity to identify innovative and integrated service responses to the health and wellbeing needs of children and young people.

At the time of Healthwatch Norfolk’s creation there was a widespread concern that the previous coalition Government’s removal of the requirement for top-tier local authorities to have Children’s Trust arrangements in place had removed the focus on the benefits of integration, co-ordination or co-location of children’s services and that there was a resultant risk to outcomes for children and young people. While educational provision and performance falls outside the remit of Healthwatch Norfolk, the interdependence of health and wellbeing outcomes and educational achievement has long been recognised and is a crucial factor in social inequality. The principles of service integration in Norfolk are central to planning for the Better Care Fund and other joint planning and commissioning activity for older people.

Put simply, there is always more that services can do to support better outcomes for children and young people, to contribute to them going on to lead happy, healthy and fulfilling lives. The imperative to do so is both moral and practical. With the reality of tightened resources not going away any time soon getting services right for children and young people is an opportunity to avoid them needing to access expensive services in later life.

There are, of course, many local and national organisations that work with children, young people and families, that have long championed their views and that often have highly specific expertise
and understanding that an organisation like Healthwatch Norfolk could not hope to replicate (nor would we want to duplicate existing good work). We are committed to working in partnership with those organisations, as well as commissioners and providers who face the day-to-day challenge of ensuring the best possible service provision. What Healthwatch Norfolk has the potential to do is be an additional independent voice, with an overview and understanding of the wider health and social care economy and with the statutory powers that we have, to raise concerns locally and nationally.

Healthwatch Norfolk knows that to be a truly effective organisation we have to be credible and evidence led. The engagement, findings and recommendations captured in this report come at the beginning of a long term commitment to engage more widely with children and young people and deepen our understanding of their needs.

Our engagement with children and young people

During the summer of 2014, Healthwatch Norfolk worked on a strategy to significantly increase the extent to which we engaged with and were able to represent the views of children and young people. We felt that this was the right time to increase our activity to the desired proportion of the overall Healthwatch effort, having established our ways of working and established our credibility with commissioners and providers. In part, the timing of this “ramp up” of our work with children and young people was an acknowledgement that with them, perhaps more than any group, it was essential that we got things right from the beginning, rather than risk alienating them while we were still finding our organisational feet.

However, we had already undertaken the following significant activities which all made a contribution to setting our initial strategy:

- As one of our first priority projects we commissioned the University of East Anglia (UEA) to carry out a study into Tier 4 (in patient provision) CAMHS. The report captured the experience of service users and made a series of recommendations that Healthwatch Norfolk has taken forward with commissioners and providers. The report was published in February 2014.

- We commissioned Momentum, Mancroft Advisory Project (MAP) and West Norfolk Voluntary and Community Action to undertake a “mapping and gapping” exercise to help us understand how and where the voice of children and young people was being heard and influencing the way in which services were commissioned and developed and where it was not.

- A Healthwatch Norfolk intern undertook a pilot study to help us understand the health needs, concerns and views of children and young people. The result of this pilot work Health and wellbeing of children and young people in Norfolk - a first view was published in December 2014.

- From the beginning of Healthwatch Norfolk our extensive programme of public engagement has captured the voices of children, young people and families including those with a specific need such as young carers.

In preparing our initial strategy we also worked with young people, senior leaders in NCC, local NHS organisations and elected representatives to validate our understanding of where our priorities for children and young people should lie.
In October 2014 we brought together stakeholders from across NHS, NCC, representative organisations and providers to share our plans for a mobilisation phase for our children and young people’s work, to last approximately six months until the end of April 2015. For this mobilisation phase we identified the following work streams which reflected our understanding of where the greatest health and wellbeing needs were and also, the importance of engaging with the widest possible group of children, and young people and to build awareness of the role of Healthwatch Norfolk.

The four initial priority areas were:

- Understanding the health and wellbeing needs of looked after children and young people.
- Understanding the health and wellbeing needs of children, young people and families in disadvantaged communities.
- Engaging with young people.
- Engaging with children and families.

These priorities and our plans for the mobilisation phase of our work were also validated and challenged by a steering group which we convened with senior representation from NCC children’s services and Public Health, Norfolk Community Health and Care, Family Voice and Momentum.

This report - Understanding the health and wellbeing needs of looked after and adopted children and young people.

The case for making the health and wellbeing needs of looked after children and young people one of our strategic priorities was compelling, the outcomes for this group are consistently poor across the United Kingdom. In addition, the 2013 Ofsted inspection of Norfolk’s children’s services had concluded that services for looked after children and young people were inadequate.

There was also the added resonance of this group with the element of Healthwatch Norfolk’s core remit that requires us to ensure the voice of seldom heard groups is appropriately represented through our work.

This strand of work was primarily an engagement exercise rather than a piece of predefined research. The scope of our engagement has been led by the extent to which different stakeholder groups responded to our approaches. This is entirely appropriate for an organisation like Healthwatch Norfolk, particularly during this initial mobilisation phase of work. The most obvious affect of this approach is that it was soon obvious to us that we should be talking about looked after and adopted children and young people rather than simply those currently looked after. This is most obviously reflected in Part 3, below, which captures the voices of adoptive parents.

Another impact of this engagement approach is that our conversations with foster carers have focused on those caring for children with disabilities or significant additional needs. Again, the experiences we heard were too compelling for us not to be led by what we were being told and Part 2 reflects that emphasis.

It is also worth emphasising the different engagement approaches that were required for different stakeholder groups. These are described briefly in each of the report’s sections, set out below.

While the findings set out in the report are necessarily interim, there have been elements of our engagement work that have been sufficiently robust and compelling to point to clear recommendations even in this early stage of our work. These recommendations have been reviewed by our independent steering group to ensure that they are expressed in such a way that they are most likely to be listened to and acted on by the relevant bodies. However, we make no apologies
for also highlighting where change is needed at a national level to ensure looked after and adopted children are better served, this may be harder to achieve but is no less important.

The findings set out in this report are divided into three sections:

1) Part 1 - The voice of children and young people in care.

2) Part 2 - Children with disabilities and additional needs in the care system - The foster carer perspective.

3) Part 3 - Improving outcomes for adopted children.
Part 1 - The voice of children and young people in care

1.1 Approach

Children and young people in care have important stories to tell which could help make services better for them and those who come into the care of NCC in future years. They are the real experts in what it feels like to be corporately parented. This section describes the work we have done to date to directly engage with their voice, what they told us and what recommendations we are making. Our recommendations acknowledge that there is more work for Healthwatch Norfolk to do and that our commitment to work with and on behalf of this group needs to be ongoing and long-term.

Having already developed a survey which had been used with young people and which focused on general attitudes towards health and wellbeing we decided to adopt the same approach with questionnaires. This would allow us to draw comparisons between responses from our universal engagement with children and young people and those in the care system, with the first group acting as a control. This approach also acknowledged the ethical and practical difficulties in seeking to engage looked after children and young people in more qualitative, (one-to-one or small group) consultations, particularly at this early stage of our work.

We were keen to validate this approach with our target group and so worked with the Norfolk in Care Council (the representative body for all looked after children in the county) and shared what we wanted to achieve. Having looked at our initial survey draft over a two week period they made the following recommendations:

- Shorten the survey where possible,
- The wording should address the children and young people in a “grown up” way,
- Allow children and young people to respond online,
- An incentive should be offered to encourage people to complete the survey.

The recommendations of the NCC were all taken on board while preserving the ability to make comparisons between looked after children and young people’s responses and responses made through our universal engagement work (e.g. through schools). The survey questions that we asked looked after children and young people are included at Appendix A of this report.

NCC facilitated the distribution of the link to the online survey to all looked after children in the county. A copy of the survey was distributed to every foster carer employed by NCC encouraging them to ask the young person/people they care for to complete it. We also suggested that where it might not be possible for the young person to complete it then the foster carer could represent their voice.

As our work progressed we identified further channels for engaging looked after children and young people in the survey process. These included asking independent reviewing officers (IROs), LAC team social workers, the YMCA and mentors working for the charity Break to distribute surveys on our behalf.

In total, 45 survey responses were received from looked after children and young people. Out of an overall number of looked after children and young people in Norfolk of 1,060 (NCC’s official figure in January 2015). The response rate, is not unusual when factors contributing to ability to respond and likelihood of response (e.g. age, negative experience of public service provision) are taken into account. That said there are lessons to be learned for Healthwatch Norfolk about the methods of engagement with this group and these are already being taken into account for the next phase of our work. The statistically low number of survey responses should not in any way undermine the value of what these looked after children and young people told us.
1.2 Survey Results

The survey questions that we asked children and young people (see Appendix A) placed an emphasis on open ended questions that allowed children and young people (for foster carers completing the survey with/for them) to provide free-text responses.

The following section provides analysis of looked after children and young people’s responses under each of the question headings used in the survey.

Q1. What affects the health and wellbeing of young people?

When asked what the top two things were that affected the wellbeing of a young person, the overwhelming response was “Family.” Similarly, when asked more specifically what might cause a young person to be stressed or anxious, family issues were identified as the main cause. “Young people might be stressed because they need a foster carer to look after them…” and “Falling out with my mum affects me the most because she has the biggest influence on my emotions.”

These responses were different to those collected from our universal survey (largely distributed through schools) where results indicated the general health and wellbeing of children and young people was most likely to be affected by smoking, alcohol and diet, and that a specific cause of stress or anxiety might be exam stress.

The results strongly suggest that while looked after children have the same core health needs as those children who remain with their birth families, dealing with the trauma of being separated from their family affects the wellbeing of the young person in care above anything else. Even when a looked after child or young person mentioned drugs or alcohol it was in the context of being used as a coping mechanism for mental health, rather than a stand-alone public health message such as “too much alcohol is bad for you.” Pressure at school was also set within the context of being cared for, as demonstrated in the following remarks:

“A young person might be going through exams and they are not being looked after properly…”

“There’s lots of pressure on us to achieve in education and sometimes people feel that too much is expected of them…family and social groups have a really big influence on young people and fallouts can cause isolation and feeling down.”

“We worry about our family because we are not with them and we don’t know if they are ok…”

“…I need to know my carer is there…”

The voice of children and young people in care tells us that their needs are multi-layered. It is reasonable to infer that the needs of children and young people in care are more complex than a child who has remained in a stable home environment. The “universal” pressures of school, and life as a young person are, of course, present but are overlaid with additional needs arising from the emotional stress of being separated from family and the need to create trusting relationships.

These additional socio-emotional needs are reflected in the sorts of services children and young people in the care system told us they accessed which included mentors, youth workers, psychiatrists, counsellors, therapists, social workers and medical consultants.
Q2. What would make health services better?

We have grouped responses to this question under themes indicated by what children and young people told us.

1.2a Access to Health Services

Young people in the care system talked about services being more accessible in general which mirrors the results from the initial survey, “there should be more appointments and same day doctor’s appointments for important issues.” However, this was not the case for hospital appointments. Two young people commented on the fact they had been seen very quickly. “I seemed to get priority because I am in the care system” and “I got an appointment straight away.” One young person commented that he had to wait three hours when he turned up for a hospital appointment and then “the consultant could not find his notes.”

The perception that children and young people in the care system’s experience of wellbeing and mental health services was less positive resonates with our findings from our general survey and consultation evenings with Youth Groups. Young people in care expressed the importance of being seen quickly. We want “someone to be there”, they should “be available.” There should be “regular visits from social workers.” They commented that the venue should be “somewhere informal.” Other comments included:

“...They should use McDonalds/Burger King/coffee shops as venues for access to counselling.”

“...It is important for me to know what is going to happen and when. I don’t cope with people not doing what they said they would, when they said they would do it. They might do it as a job but it’s my life.”

“Provide people who will follow up and do what they say they will do.”

Young people described access to the children and young people’s mental health services as “slow” and that waiting for an appointment once referred is “stressful.”

Young people in care have suffered huge instability, different placements, not being certain about their future or the future of their birth families and the survey highlighted that this causes high levels of anxiety. It is reasonable to assume that this anxiety is exacerbated by long referral waiting times and not understanding what to expect when they do get an appointment. As one young person commented: “What affects me the most is feeling safe and knowing what is happening...”

1.2b The need to be listened to and understood by all health professionals

Many of the young people in our sample talked about the need to be listened to and understood by medical staff. There was an overriding sense that communication between young people and medical professionals is not always good. Young people told us that to improve services you need doctors who are “willing to listen.” Other comments included:
“They (GP) should not look at the computer screen so much.”

“Staff seemed rush, and I did not feel taken seriously.”

“The doctor didn’t ask any questions, he just referred me to the counsellor.”

“We need young doctors who understand us more.”

“….My first time using adult services at hospital was not a good experience…they just didn’t seem to have much experience of people with very complex needs.”

By definition, young people who are in care have been let down by adults and are often extremely cautious in who they trust, professionals are not exempt from these attitudes. For children and young people in the care system relationships are key and this is highlighted in a comparison between their responses when we asked who the young person might turn to for support and those of the universal group. The universal survey suggests that most children and young people would ask teachers, and doctors for support whilst the responses of those in the care system identified their social worker or youth worker as the person they would talk to, someone they know well and feel they can trust.

Health professionals do not, of course, have the opportunity to form relationships in the same way as social workers or youth workers do, but “showing they genuinely care” is hugely important. Young people need to feel that they are accepted, not merely tolerated and much of this will be picked up through body language. “The auxiliary nurse smiled…it made me feel more comfortable during a sensitive appointment.”

Interestingly, the comments made about the need to be understood referred equally to those professionals working in mental health. The comments suggest that young people do not always think this is the case. They told us that what would improve mental health services, would be to: “provide people who will listen and care”, allowing them to “speak to someone who is non-judgmental” or talking to someone who “starts by listening, doesn’t assume, and gives me some time for when I’m ready to talk.” They also placed high value on “people taking time to explain to me and listen.”

1.3 Representing the voice of children and young people in care

Engaging with children and young people, particularly those who are more vulnerable is time consuming since it relies on working in partnership with both statutory and voluntary sector organisations, all with their own timetables and own agendas. Yet effective consultation and involvement throughout commissioning cycles must be at the heart of successful service design and delivery.

Even when looking at quite high-level data availability there is remarkably little information shared between statutory agencies which could and should be the beginning of understanding need. Currently, Norfolk’s Joint Strategic Needs Assessment (JSNA) does not contain sufficient information about looked after children and young people to make it a useful tool for commissioners of services.

There is a clear tension between the need to consult with, involve and understand the needs of looked after children and young people and the risk that current representative structures might mean a relatively small subset of looked after young people are being continually approached for their views.
It was felt by some professionals that looked after children have been over-consulted and an example of this was a reluctance for our survey to be distributed via their teams. At the same time we met with commissioners, particularly from the NHS, who felt that they were *locked out* from consultative arrangements and left without the necessary understanding of need to shape effective service responses.

There is a clear need for co-ordinated or joint data gathering and involvement of looked after children and young people. While confidential data about individuals must of course be respected, there is a clear and urgent case for a new approach to engagement and data sharing that crosses service boundaries and confronts issues of “turf” or professional expertise and which puts the needs of looked after children and young people at the heart of a system which:

- Is better at sharing and updating information about the demographic breakdown of looked after children and young people and their needs.
- Reduces the instances but improves the quality of consultation with and involvement of children and young people.
- Involves more looked after children and young people in consultation and involvement activities.
- Looks at innovative engagement and involvement activities that will improve participation levels.
- Establishes the principle of co-production across services for looked after children and young people in Norfolk.

There will need to be mutual understanding and compromise, based on a recognition of common purpose. An audit of reviews and surveys that already go out via NCC social care teams would go some way to identifying the extent of the consultation burden on current structures, notably the *Norfolk In Care Council*, and help establish the business case for a different approach.

### 1.4 Recommendations

Based on what looked after children and young people have told us, and what we have heard from professionals about existing engagement and involvement processes, we are making the following recommendations that will contribute to services being properly influenced by those who use them:

- **Senior leaders in children’s services and the NHS** ensure that processes are in place to actively listen to and involve children and young people.

- **Medical professionals (of universal services)** should receive appropriate training and/or guidance to allow them to better understand the needs children and young people in care.

- **That specialist services for young people, particularly mental health services** are more accessible, and that commissioners and providers give active consideration to delivering services in less clinical environments.

- **Children and young people** are given more and better information about how services might help them, how long they may need to wait to access a service and what the follow on steps might be.
- Leaders from all relevant statutory services explore co-ordinated or joint consultation and data gathering activities which will inform Norfolk’s Joint Strategic Needs Assessment (JSNA).

- Leaders from all relevant statutory services explore joint engagement and involvement activities which will widen participation and deepen understanding while reducing the number of consultation exercises.

- Healthwatch Norfolk will continue work to widen our engagement with and understanding of the needs of children and young people in care and those who have recently left care. This work will include:
  - Working with partner organisations.
  - Work with specialist agencies to understand more about the experiences and needs of care leavers who are in the criminal justice system.
  - Alignment with other elements of our 2015-2017 work programme, particularly Child and Adolescence Mental Health Services (CAMHS) related work and work relating to service users.
Part 2 - Looked after children with disabilities: The voice of the Foster carer.

2.1 Approach

All children and young people who are looked after have been separated from their birth family and our responses showed that “family” had a significant emotional impact on the looked after children and young people in Part 1 of this report.

How children in care deal with separation and trauma and how this might present in terms of behavioural needs continues well into adoption and is explored in Part 3 of the report (below). What our initial survey of looked after children and young people did not capture was the voice of looked after children with disabilities. This was highlighted by the small sample of 12 foster carers who completed our initial survey, which asked carers to identify the types of needs the children they care for have.

Consequently, we sought to consult with experienced foster carers who give looked after children with complex needs a voice. We facilitated two focus groups and listened to the experiences of 11 foster carers. We followed this up with four one-to-one interviews to deepen our understanding. In total, 25 foster carers shared their experiences with us.

2.2 Children in care with disabilities

Our initial survey (see Part 1) was completed by foster carers who cared for a child or children with profound learning disabilities, physical disabilities or long-term medical conditions. This reflects the high proportion of looked after children who have disabilities and is in line with national findings (Cousins, 2006).

- Disabled children are nine times more likely to become looked after than non-disabled children.
- About a quarter of all looked after children are disabled.
- Two-thirds of looked after children have special educational needs.

There is often confusion with the terminology used to describe disabilities. In our sample, nearly all the children had a primary diagnosis which meant the carer’s attention was in the first instance focussed on meeting the medical or physical needs of the child in their care. That said, carers also spoke about disability in terms of developmental behavioural disorders (ADHD, ASD) and the mental health or emotional wellbeing of their children.

Therefore, when we talk about children with disabilities in our report, this incorporates physical, medical and developmental impairment with the additional layer of being looked after and having suffered loss and separation.

Section 2.3 provides an insight into the needs of looked after children with disabilities as described by the foster carers in our sample.
2.3 The Needs of Looked after Children

2.3.1 What the questionnaire told us

Our initial questionnaire told us that whilst foster carers were caring for a child with physical disabilities or long-term medical conditions, there were other needs presenting simultaneously in addition to the primary diagnosis. In total, foster carers identified 28 needs for our sample of 12 children. All children, without exception, had at least one additional need, 2 children in our sample had 2 additional needs. Our questionnaire revealed that neuro-developmental disorders such as autism, attention deficit hyperactivity disorder, sensory processing and attachment-related issues were all “additional add-ons.”

2.3.2 What the Focus Groups and 1-1 interviews told us

Our focus groups and in depth interviews gave us a deeper insight into the complex needs of looked after children with disabilities relating to feeding, breathing, mobility, heart problems, genetic conditions, speech, language and communication needs.

Three foster carers described the needs of their children with cerebral palsy, which included a number of problems. The children are unable to support themselves and two children are fed by gastric tube because they are unable to swallow food safely. Two children had also been diagnosed with epilepsy in addition to cerebral palsy.

“He’s blind. He has cerebral palsy in all his limbs so he can’t support himself, move his arms, legs as he’s like to. He’s fed by a gastric tube in his tummy, so he gets nothing fed to him via his mouth…”

“He has been diagnosed with cerebral palsy and epilepsy and there was initially much concern around his future...he’s had some awful seizures and we’ve had to call an ambulance, some real ‘blue light moments…””

There were also examples of children who had inherited genetic conditions such as Turner Syndrome (TS) and William Syndrome (WS). These conditions require regular health check- ups and are also characterised by global developmental delay and learning disabilities. Daily tasks can be challenging, so the children may require therapeutic input in addition to medical support and / or intervention such as speech and occupational therapy. Three foster carers told us that they had cared for or do care for children with Downs Syndrome (DS). These children experienced various health conditions including glue ear, congenital heart defects (pulmonary hypertension) and thyroid problems.

What adds to the complexity of the needs of the children in our sample is that almost without exception, all children present with two or more illnesses or disorders simultaneously. Our questionnaire revealed that just under half the children (48%) in our sample had also been diagnosed with neuro-developmental disorders such as ASD, AS, ADHD and or sensory processing difficulties (SPD/SID). As one parent described:

“I never realised that a child with Downs’s Syndrome could also be autistic.”
Whilst children had generally not been formally diagnosed with anxiety and attachment difficulties (possibly due to diagnostic overshadowing, see glossary), foster carers indicated that just over half the children (55%) also presented with high levels of anxiety and attachment-based behaviours which are symptomatic of children who have experienced early trauma, loss and neglect. Three foster carers spoke of the very high levels of anxiety displayed by their children.

One foster carer described the separation anxiety displayed by his little boy when he first arrived at their home.

“You can’t hoover, you can’t clean...you had to be cuddling him or standing with him otherwise as far as he’s concerned, you left him.”

Another foster carer described the extreme levels of anxiety the child in her care had suffered leading up to hospital checks:

“There was fear all the time...if it rained the world’s going to flood, what if we run out of petrol and he started wetting the bed every night. This was leading up to surgery and he was biting his fingers terribly. He asked what it was like to be in a coffin.”

The initial diagnosis of one child in care was global developmental delay and gastroenteritis (multiple food intolerances). The child was later diagnosed with a severe attachment disorder, ADHD and a sensory processing disorder.

“X was very withdrawn, she didn’t cry, really seek attention, whimpered if she needed feeding. She was diagnosed with a serious attachment disorder...she finds it difficult to regulate emotions and she can become quite aggressive.”

Our sample demonstrated that children with neuro-developmental disorders and or physical disabilities also display the emotional needs which are common in children who have been abused and neglected. One foster carer described how the child in her care needed to experience control which is a typical survival mechanism of children who have been in care.

“He’d come in smiling, before you knew it you’ve got a punch out of nowhere. We don’t understand why he’s done it...he will turn very suddenly....I can’t leave him alone with the dog because he has kicked him before...”

2.4 The needs of foster carers

The foster carers in our sample had a broad range of skills: In addition to understanding complex health conditions and responding to the immediate emotional and behavioural needs of the children in their care, they attend numerous appointments and manage relationships with birth families, social workers and for some, approved adopters.

In order to meet the needs of the children in their care the needs of the foster carers must also be met. During our focus group sessions the comments of foster carers identified three things they felt they needed in order to be the best carers they could be:

- Knowledge, Information and skills
- Support
- Access to Health and Mental Health Services
The next part of the report, is based on the comments of foster carers provides a snapshot of if the needs of foster carers are being effectively met.

2.4.1 Knowledge, Information and skills

It is clear from our focus group discussions that foster carers need to be knowledgeable about the medical and physical conditions of the children coming into their care. Our one-to-one interviews gave us an insight into what they needed to be knowledgeable of, including *peg feeding, dealing with seizures* and *organising multiple medications*. One carer had found it useful to understand other means of communication so the child in her care could reach their maximum level of understanding. “*X is not deaf but I sometimes use Makaton, to reinforce things...*”

The foster carers interviewed spoke passionately about the children that were or had been in their care and comments suggest that their knowledge and expertise had in some cases enabled them to exceed the expectations of medical professionals.

“She’s not supposed to grow anymore so I was told, and we went to an appointment yesterday and she has grown three centimetres.”

“I have been told that it’s quite unusual for children with cerebral palsy to grow out of epilepsy but he’s been seizure free for about 5 years now and weaned off medication.”

Our second focus group and one-to-one interviews uncovered an *equal* need for carers to demonstrate expertise in managing the behaviour and emotional needs of the children in their care.

“If you were a prospective foster carer I would tell you that you really do need a background in some kind of care, preferable high needs or learning disabilities and challenging behaviour as well and to get all that training under the belt before placement.”

The foster carers we spoke to used language derived from attachment-based and neuro-developmental theory which demonstrated they understood the complex multi-layered needs of the children in their care. There were examples of foster carers providing ongoing therapy for their children, exploring feelings and doing life story work. “*We didn’t feel we needed someone to come out and do any play therapy with us, we already to it at home...*”

The foster carers we spoke to were knowledgeable not only because they were experienced carers but felt they had come into fostering when there was *good training* and *specialist advice* available. They told us that when they were part of a specialist team they had training in essential day-to-day practical care such as “*moving and handling*” and “*medication training*”. However, foster carers said that more recently the children with disabilities team has been disbanded. For this reason, they expressed significant concerns that there was no longer a specialist team in place which was not a good thing. One carer felt that “*training for children with disabilities had gone down the pan,*” another told us “*I have got a child in a wheelchair but I’ve had no training.*”

Not only did foster carers indicate they might not have access to the amount of training they would like, we also received comments to suggest they had not always received all the information they
needed with regard to the health and medical needs of children before they took them into their care. As one carer suggested:

“When I saw the medical form she had a thyroid problem, she needed medication at night to help her sleep and she was on low dose of antibiotics that you have to make up and I didn’t even know she was still in nappies...”

One foster carer told us of two carers she knew of who had not received all the information about the child they were about to take into their care:

“My friends have just got a little boy and they said he’s got some kind of syndrome. But when she spoke to the community nurse it turned out he had spent the first few months of his life in hospital and had most of his bowel removed and he’s got this and you need to lay him flat and he can’t breathe and there’s this and that...they were not telling her the half of it.”

“Another foster carer was told the little boy she was caring for had had lots of operations but ‘not to worry.’ When she picked him up they handed her this wad of notes and said ‘there’s all his appointments and don’t lay him flat because he will stop breathing...’ they should have told her that she would be spending a lot of time at hospital with him because she has her own children too.”

Foster carers who provide short-term placements in addition to having long-term placements for children with complex health needs told us they were not always given all the information they needed about the child coming into care. Foster carers told us they needed to know as much as possible if they are to meet the needs of the children in their care, particularly those who are unable to communicate what their needs are.

“It is a problem when you don’t have all the information on the child...if the behavioural needs of children needing respite are extremely challenging it does not work when you have other vulnerable children in your care...”

One carer told us they had not been forewarned about a young person coming into their care who had displayed highly sexualised and disturbing behaviours:

“They actually put someone really dangerous in my house...it was all on his records...I’ve got vulnerable people with disabilities...the young person had to go...”

Another foster carer talked about the effect it had on the other children in her care:

“Our children were young and this poor little girl was desperate and would often have screaming rages and would cry and weep. I would go into the boys bedroom and the youngest would be curled up in the foetal position on his bed and I thought, I can’t do this to them for much longer.”
Understanding the needs of the child coming into placement not only gives the foster carer the opportunity to make an informed choice as to whether they can meet the child’s needs in the first place but enable them to interpret the behaviours they are facing.

“We need more information. X had a lot of moves within a short space of time and we needed to know what the triggers were. Certain information had not been shared with us and as horrendous as it is you need to know so it makes sense. I mean at the time we didn’t know what an earth to do. Pans came crashing out, she cowered and different stuff…”

The foster carers we spoke to were not only concerned that some carers may not have received appropriate support with regard to specific training. They pointed out that the skills of foster carers to provide what they considered to be good care on a day-to-day basis “varied.” The NICE public health guidelines (2013) describe foster carers who deliver high quality care as those that have:

“A consistent parenting style that combines clear guidance and boundary setting with emotional warmth, nurturing and good physical care.”

(NICE, 2013, p75)

Fourteen out of our 39 adoptive parents raised concerns about the introductory period (where they visit the child they have been matched with at the home of the foster carer) suggesting that there are inconsistencies in the skills of carers. Seven comments we received suggested a small minority of carers had a “good enough attitude” about the children in their care. Adoptive parents had not always felt that that the care provided by foster carers around basic needs such as nutrition, cleanliness and clothing was of a good enough standard.

“When we were having introductions she put him to bed and she said, ‘he’ll settle now’ and we could hear him crying and screaming… we wondered how many nights he was left screaming…and the foster carer seemed to have him looked after by multiple other people. The daughter looked after him, the daughter’s husband looked after him. The foster carer’s adult son looked after him. The foster carer’s mother looked after him and that’s just in one home.”

“When we visited the foster home for introductions, his babygrow had been put on back-to-front and done up to the neck….the carer told me it was so he couldn’t rip it off first thing in the morning and pooh everywhere. He was so red, sweaty and crying; clearly distressed…”

“She gave him a breadstick for lunch and said ‘that will do’…I didn’t feel she had been looking after him very well…my feeling is that little one had switched off because he hadn’t been looked after well…I think she just sort of ignored him and left him to sleep all the time.”

“They hadn’t been washed. Their hair hadn’t been combed. Their clothes stank. Their clothes didn’t fit them….I said, there’s something terribly wrong here…we’ve got to get these kids out.”
One foster carer described how at handover, the previous foster carer had described the child’s daily routine. The receiving foster carer felt concerned that the routine was very isolating; the young person spent “a lot of time” playing on the XBOX in their room and they did not eat tea with the rest of the foster family. The foster carer told us that a lack of effort to engage and interact with the child can miss opportunities to revisit and fill in the gaps in the child’s developmental journey.

“He didn’t know how to use a knife and fork. Nobody had bothered to teach him. So he has his tea on his own….In the end, he was able to join us at restaurants.”

Whilst the comments above suggest a lack of care, we received six comments about foster carers who spoke about the introduction period positively “it went really well.” Adoptive parents felt that good foster carers had structured the day, promoted good social skills and made the children in their care feel part of the family:

“We were really lucky because our children went to an exceptionally strong foster placement. They put boundaries in, gave them routine with appropriate toileting behaviour or manners...”

“My children had clearly flourished in foster care. They had fantastic foster parents. The children had belonged, they (foster carers) even named their pets after them!”

Adoptive parents also liked foster carers who helped them to feel welcome during the introduction period and had helped them to take the lead:

“As soon as I arrived the foster carer prompted me to just start playing and join in. I needed to be told that because it’s all rather overwhelming and you almost forget to be normal? She sort of made me feel that I was already the parent and in charge. I got lunch and drinks...I got to bath X on the first day, which was really nice. Yes she was very good.”

2.4.2 Support

It is clear that foster carers provide an essential service to some of the most vulnerable children and young people in our community. Foster carers are looking after children and young people with highly complex physical and emotional needs who are usually placed at a point of crisis. Despite being forewarned about the challenges they are likely to encounter in their initial training, many foster carers can understandably feel tired and stressed, providing around the clock care for children with complex physical needs and / or for those with severe mental health disorders such as schizophrenia. Ultimately, if the foster carer’s own needs are not addressed this will have a negative impact on the lives of those in their care. The comments we collected told us that in order to feel adequately supported, our foster carers needed:

- Respite care (2.4.2a)
- Quality social worker support (2.4.2b)
- The opportunity to meet with other foster carers (2.4.2c)
- To be treated as professionals - fair rewards (2.4.2d)
2.4.2a The need for respite care provision

Foster carers talked about the need for respite when caring for a child/children with high-level needs. It is recognised that in order for carers to remain sensitive to the needs of the child they need rest. Put simply, therapeutic parenting and/or providing medical attention is tiring.

The daily routine of the carers we spoke to was dedicated to meeting the needs of their children rather than their own. During one interview with a carer we were warned that “the timer is about to go!” This was so the child in her care who had a learning disability understood when he would be eating. Another carer apologised and said she “might be a bit tired because the child in her care had needed her in the night,” which was assumed as not unusual.

It is reasonable to assume that foster carers will be unable to attune to and respond well to the needs of children with complex needs if they are exhausted. Without exception, the foster carers we spoke to felt that a lack of respite care was a huge problem and pointed out that this jeopardised placement stability.

“What would I say our biggest need is? Our worst challenge has been respite. We went a year last year without respite and that annoyed me because I felt that no-one was listening to us.”

“We’re saying, look, we’re going to burn out and they’re not listening…”

The Social Care Institute for Excellence (SCIE) has carried out research on “what keeps foster carers fostering” and guaranteed respite is a key finding. Our foster carers told us that without respite “placements will break down.” The knock-on effect is another move for the child. NICE public health guidance (2013) identifies the importance of less moves in care for looked after children.

“Frequent placement changes can severely lesson the sense of identity and self-esteem of a child or young person...repeated separations or moves may therefore be regarded as indicators of emotional harm.” (NICE, 2013, p73) (Looked after children and young people April 2013, 3.2 Quality of Care and placement stability)

Foster carers emphasised that the availability of respite care must be taken seriously, but also stressed that provision needed to ensure the recruitment of those with the right skill set.

“Because of his needs he can’t...he needs a special bed...he has to have a number of medicines. The food has to go...you can’t just give him over to someone…”

Foster carers told us that they understood that in the current economic climate the local authority is under pressure to cut funding. One carer felt that the solution was to create a group of specialist carers that could provide respite for each other. However, they were currently unable to do this. Foster carers told us that the current system is set up so they are only allowed to care for the child
for whom you have had specific training. Where one child clearly has similar needs to that of another, carers felt that not being able to care for each other’s children was “ridiculous.”

“Even if you are trained in something you can’t have the child because you’ve got to be trained for that particular child. I have peg fed my son since the age of 10, and he’s now 29. But I am not allowed to peg feed my friend’s foster child until someone comes out from the hospital. When the nurse came round she said ‘I’m sorry, I’m not going to insult you by going over everything.’ You might need a refresher…why don’t we have gastronomy training every other/three years to make sure you’re fresh. Its pointless red tape.”

2.4.2b The need for quality social worker support

In our sample, the foster carers spoke warmly of their allocated support worker whom they feel provides them with sound advice around the needs of children with disabilities and shows concern for their wellbeing.

“My support worker is the bee’s knees. He knows everything and he touches base, asks after us if we are ill and about our health.”

One foster carer said he appreciated having honest discussions with the social worker. Foster carers are in challenging situations and they do not have the time or the energy for tokenistic gestures.

“I can be brutally honest…the social worker is very good because he will come back and agree or he will say ‘well actually, you don’t know what’s going on here.’ So he really does listen and take things on board.”

Foster Carers recognised that good quality support from their social worker helps them to stay well and do their job better.

“I think there’s a lot of emphasis on the child but don’t forget what the foster parent is hearing, what is disclosed to them by these children and what we deal with. Our wellbeing is just as important.”

The foster carers we met all expressed that, in general, they had “good working relationships” with social workers and they “get on with them” but did feel that some were not experienced enough to support carers who were responsible for children with very complex needs.

“The support worker came along and you’re talking about all these medical problems and it’s just above their head. They’ve got no idea; they don’t know what you’re talking about…for children with disabilities; the specialist teams should come back…you can’t have support workers who know nothing about children with disabilities...”
2.4.2c The opportunity to meet with other foster carers

The Social Care Institute for Excellence (SCIE) advise that in order to support and retain foster carers there should be opportunities for them to meet other foster carers. “It’s important to have a coffee with people who understand and talk about things.” We were able to observe how well two foster carer support groups worked in providing a safe environment for carers to share experiences and discuss concerns; they clearly felt supported by one another.

“We come across totally different things as carers of children that are life-limited. Hospital appointments, lots of things going on, and epilepsy...it’s nice to share ideas. ‘Oh, have you got problems with granulation around the peg? Oh, well, I’ve tried this ointment; that one works for me.’”

2.4.2d The need to be treated as a professional: Fair rewards

In the Fostering Carer’s Charter, (NCC, 2012) it states there will be pay/fees that reflect the task (section 7, Terms and Conditions). Three foster carers felt it was unfair for those carers dealing with children with complex needs to receive the same pay as carers who are fostering children who require far less intensive care or supervision:

“Specialist carers who get no respite, no sleep, they should be paid more. It’s not the same as someone who takes a child to school, is free all day, meets up with friends, having lunch in the pub...you ought to try caring for the really hard children. Why should people get paid the same?”

It might be reasonable to think that if foster carers become demotivated it might mean they are more difficult to retain. The Social Care Institute for Excellence (SCIE) references several pieces of research that suggest that the number of foster carers who leave fostering is nationally, relatively low. However, there is a struggle to recruit new foster carers particularly those who are prepared and skilled enough to look after children with disabilities. Norfolk is no exception.

“Norfolk needs more foster carers to support teenagers, children with disabilities, groups of brothers and sisters and young people waiting for a court appearance.” (EDP, 2015)

Our sample of comments is too small to make any formal recommendations, but consulting with foster carers with regard to what they consider to be a fair pay structure might reduce the frustration felt by current foster carers. It may be assumed that positive carers are able to carry out their role better and help to recruit new carers.

2.4.3 Access to health and mental health services

Overall, our comments suggested that foster carers were knowledgeable of the services they needed to access to meet the needs of their children. The results of our initial questionnaire showed that 67% of foster carers had recently accessed medical and / or paediatric services. 40% had accessed some form of therapeutic intervention and 42% of foster carers had accessed CAMHS services. This section of the report brings together comments from foster carers, which related to the accessibility of services.
2.4.3a Health Services

Many of the foster carers we consulted spoke of the multiple appointments they attended in order to meet the health needs of the children in their care, “the calendar is pretty full”. The children cared for by the sample group received physiotherapy, help with sensory processing, occupational therapy and attend various hospital appointments. It was not uncommon for at least three health professionals to be involved in meeting the needs of the children in their care. “She’s got an epilepsy nurse, a doctor for her genetic condition and the school paediatrician.”

2.4.3b Hospitals

Our foster carers did not speak in detail about their experiences of hospital visits. However, the few comments we received suggested that children who had required surgery or specialist treatment had received good or excellent care.

“The consultant paediatrician was excellent. He was absolutely fabulous. Anything I needed doing or wanted to know, I just had to ask him. Even though I was caring for a child with a life-limiting condition who might not make it to his teens, it was helped an awful lot because of the excellent care he got.”

Foster carers stated that children who have suffered trauma are not good at managing their own anxiety and stress levels and that this is particularly evident in a hospital environment. Hospitals are busy and unpredictable places. The children in our sample struggled in such environments more than most. One carer spoke of an emergency during the night in the ward where the child in her care was sleeping.

“The doctors had, to remove a child from the ward quickly in the night. I think there was some kind of emergency and they had to return to intensive care...she thought she might be taken too...she was extremely anxious already because you are not allowed to spend the night on a high dependency ward...I had problems with getting her to sleep at home after that.”

Given the fears of children who have been in care, it is especially important that clinical staff are able to engage with children and help to manage their anxiety levels, which is recognised by the Intercollegiate Role Framework (2015):

“Clinical staff should have the skills to communicate and engage with looked after children, ensuring they have the opportunity to participate in decisions affecting them.” (Royal College of Nursing and the Royal College of Paediatrics and Child Health, 2015, p20)

We received one comment which exemplifies the importance of clinical staff being sensitive in what they say around children so they help to manage their stress levels rather than add to them. Whilst it was never the intention of staff to worry the child in their care, the example below illustrates how a conversation between a doctor and a consultant fuelled the child’s anxiety levels:
“Before surgery, we had to go to the GP because of her increased anxiety levels...the consultant was obviously a very clever man but he stood at the bottom of the bed and explained why he would be operating and said things like ‘she hasn’t got a heart like you and me and if that hole closes the heart will stop. She will have a heart attack and die.’ I thought, ‘did you really have to say that in front of her?’”

Foster carers are subjected to the same restraints in the NHS that can affect anyone at any age. There is a general consensus that appointment systems are not always efficient. Carers reported that “hospital receptionists do not always seem to know what’s going on, appointments are sometimes cancelled and new appointments are sometimes made at short notice.” Whilst changes in appointments is frustrating for all service users, for foster carers it can be more so. Foster carers explained that changes in appointments were difficult to manage because they often had other appointments to attend:

“Then they send a letter out and you have an appointment in seven days. When your child has as many appointments as ours does, you can’t fit it in...”

Another foster carer highlighted that children in care find it difficult to manage transitions and emotions, so they often display appointments on the calendar so the child can prepare. When they are changed at the last minute there can be “considerable fall out.”

2.4.3c General practice

Although we did not receive many comments about GPs, two carers told us that GP referrals were not always efficient. One carer told us that the referral was on hold because the doctor was on annual leave and it didn’t seem to have taken priority.

“...The doctor went on annual leave and the secretary had a backlog of paperwork and to anyone else it just didn’t seem urgent...In the end I got them to write it and I personally collected it.”

Another carer we spoke to at a support meeting had not found it easy to get appointments at the doctors and asked us if GP practices prioritised the needs of looked after children: “Is it flagged up on their screen? Are we supposed to get appointments more quickly?”

Statutory guidance for local authorities, clinical commissioning groups and NHS England makes it clear that it is the “responsibility of all services to ensure the timely and effective delivery of health services to looked after children.” (Department of Health, 2015, p8)
2.4.3d Therapeutic Services

Foster carers told us that provision for children with very complex physical and learning needs is good, because they attend specialist status schools where therapeutic provision is on-site. One foster carer of a child attending a special school for children aged between 0-19 years told us about the sensory room which is “used to stimulate and develop specific senses.”

For those children not attending special schools but for whom therapeutic intervention has been identified to address sensory processing or mobility difficulties, the few comments we received suggested access to these services was not always easy. Further work is needed to ascertain the extent of any gaps in provision and whether this is a countywide issue. In the future we will be focussing on therapeutic service provision in our next phase of work (see Healthwatch recommendations).

“There has been some committed help but also some very worrying lack of support, especially with speech therapy...life can seem an uphill struggle...”

2.4.3e Mental Health Services

Our questionnaire showed that just under half of the foster carers in our sample had accessed some level of support for the emotional wellbeing of the child in their care. However, foster carers felt that the mental health and emotional needs of children were not always identified by professionals and even if they were, it was difficult to access support from CAMHS across all ages.

i) Assessing the mental health and emotional needs of children and young people in care

The Foster carers we spoke to expressed the need to address the mental health needs of looked after children in the same way that physical health needs were identified. They told us that children were coming into care with a baggage of damage and that this damage is not being assessed or addressed. Recent NICE health guidelines (2013) emphasise the need to assess mental health issues early on:

“Early intervention to promote mental health and wellbeing can prevent the escalation of challenging behaviours and reduce the risk of placement breakdown. Flexible and accessible mental health services are needed that offer skilled interventions to looked after children and young people and their carers.” (NICE, 2013, p24) (NICE public health guidance)

We received examples of the mental health or emotional needs of children not being identified by clinicians designated to promote the mental health of looked after children. The Royal College of Medicine identified the need for all medical staff to have an understanding of attachment difficulties, and the emotional and mental health needs of looked after children. Our carers’ comments suggested this was not always the case, even when foster carers had expressed there was something wrong.

“It took two years to get a diagnosis. I was told by the person from CAMHS that the behaviours were simply due to the child ‘needing to settle in’ but I knew it was more than that...they were later diagnosed with autism.”
“There is a shortage of qualified child and adolescent mental health practitioners who specifically understand the experiences of looked after children…”

The comments suggest that there is inconsistency in the skills of professionals to recognise developmental disorders and mental health problems in children with disabilities and even if needs were identified, referrals to CAMHS are not straight forward. As one carer highlighted:

“My doctor wrote a referral to CAMHS. CAMHS came back saying ‘sorry we can’t see you.’”

Indeed, the perception of some of the foster carers from our sample is that CAMHS are reluctant to work with children until they are in a permanent placement. Foster carers spoke of the urgent need for early intervention:

“The children that come into care need to be psychologically assessed early so there is a baseline…they leave it and leave it.”

“She needs some theraplay or something…the chances are they won’t be able to stay in a long-term placement without support now…”

“I have come across many teenagers with drug problems and low self-esteem who need someone to care and understand their feelings whilst they are children…before their problems get so big, they are out of control.”

Guidelines are in place both on a national and local level to ensure children in short term placements get the right support. Indeed, CAMHS also states that placement stability is not a reason to delay intervention:

“We will try to avoid two extreme positions that either placement stability is required before therapy can start, or that therapy can compensate for ongoing environmental adversities.” (Norfolk Enhanced CAMHS Service for LAAC Operations Policy, 2009, p5)

The comments we received highlighted that foster carers are unsure how efficient existing processes are particularly in identifying and meeting the mental health needs of children. Unidentified and untreated emotional and mental health needs are a concern, and if permanency is achieved either through long-term fostering or adoption, it is unlikely that the new carer will be able to effectively meet the needs of the child or young person in their care. From our comments we identified four opportunities for assessing need:

A. Strengths and difficulties questionnaires
B. Health assessments
C. Looked After Children Reviews
D. The role of the independent reviewing officer
The next section of the report will briefly describe each of these assessment processes and foster carers’ perspectives.

A. **Strengths and Difficulties Questionnaire (SDQ)**

The SDQ is a screening tool which identifies those children at higher risk of either having a mental health illness or mental health problems that significantly affect their life. It is a clinically validated behavioural screening questionnaire for use with 4-17 or 2-4 year olds. NICE guidelines (2013) recommend that the SDQ is sent out ahead of the child’s health assessment so it can inform the health assessment. It can also be used to help social workers form a view about the emotional needs of looked after children and those carrying out health checks. If the SDQ completed by the carer suggests a child’s score is outside the normal range, consideration should be given to using a diagnostic tool to enable appropriate intervention to be identified. In other words, a referral might be made to CAMHS.

The LAC community hub based at children’s services has recently been made responsible for sending the SDQ to foster carers, collecting and recording the responses and ensuring the social workers and LAC Health teams also receive the data. It is not for us to speculate the extent to which this information is used at health assessments and LAC reviews, but foster carers have expressed they do not receive feedback and are “sceptical” about the exercise.

> “I fill out the form (SDQ) but nothing happens.”
> “We do those SDQs but I don’t think anything happens with them.”

Not only did foster carers express uncertainly about how the SDQ was used by professionals to achieve a referral to CAMHS. They also felt that it was not a suitable tool to use for children with disabilities “it doesn’t work for them.” Foster carers said there should be a greater effort to engage with children with disabilities in care so their voice is heard. This will be looked at in the last section of our report.

B. **Health assessments**

**Health assessments** are carried out once every six months for a child under five years and once in every 12-months for those five years of age and over. The Norfolk Community Health Care (NCH&C) Child Development Unit is commissioned to carry out health assessments for four of Norfolk’s CCG areas, while East Coast Health Care, is the provider for the east of the county.

Statutory guidelines on promoting the health and wellbeing of looked after children identify 12 objectives that should underpin all health assessments for looked after children. One of these objectives is to “**assess current health and mental health concerns and identify unrecognised health needs,**” (7.3). The importance of a holistic assessment that takes into account mental health is also highlighted in the NHS England statutory guidance (2015):

> “Local authorities are responsible for making sure a health assessment of physical, emotional and mental health needs is carried out for every child they look after.” (Department of Health, 2015, p15)
In the focus groups we attended and during one-to-one interviews carers felt that given the amount of appointments they already had with health professionals the health assessment reviews did not tell them “anything new”. We do not know whether these comments were made because other assessments have already identified areas of need or because the assessment procedure carried out by the LAC nurse is not efficient at picking up potential problems particularly mental health ones. One foster carer did not feel that a holistic assessment of the child had taken place:

“The LAC nurses. I mean, they’re trained as nurses but I don’t feel they have understanding of looked after children? It’s more of a physical assessment. For example, self-harming. I had no help with that.”

Not all foster carers could ‘see the point’ of the health assessment given all the appointments they attended, to meet the medical needs of their children.

“I think it’s fair enough for a health assessment if you’ve got a child who is relatively well and hardly sees anybody…but if you’ve got someone who is being monitored all the time, by so many health professionals, do they really need another health assessment?”

“Couldn’t a medical professional that you are already seeing sign something? It would save on resources.”

“The nurse doesn’t tell you anything we don’t already know. I think they should prioritise. See children who are not in the health system like ours are.”

This could also suggest that foster carers do not consider it is the role of the LAC nurse to identify additional emotional or wellbeing needs and were not always convinced of their expertise when communicating with children with disabilities. During our interviews one foster carer felt the inability of the nurse to understand autism may have triggered her child to become obsessive about their eating habits.

“The health assessment was utterly ridiculous. The LAC nurse says to ‘do you eat chocolate every day?’ And X says ‘yes’...so the nurse says ‘well perhaps you shouldn’t, have it every other day.’ Being autistic X took that literally...for about 6 months, she wouldn’t even drink chocolate milkshake or hot chocolate. She then had something every other day and she’s lost half a stone...I asked at the last LAC review that she wasn’t weighed. It’s become a problem.”

Our comments suggest foster carers consider health assessments to be an assessment of physical or medical needs. This raises an important question. Are the emotional or mental health needs of children in care not being diagnosed?
C. Looked after children reviews

There is guidance in place to ensure the needs of looked after children and young people are reviewed regularly. Every child that comes into care should have a health check within 20 working days of the date on which the child became looked after. The second review must be carried out not more than three months after the first review and subsequent reviews must be carried out at intervals of no more than six months.

Foster carers describe the LAC reviews as a “good idea in principle”, “a good idea on paper” and a “nice idea.” The language foster carers used to describe LAC reviews suggests that whilst they understood the principles behind them, in practice they found the reviews “all a bit unnecessary.” We did not receive comments that suggested LAC reviews had been prevalent in detecting emotional or wellbeing needs, but that is not to say that is not the case. Carers’ comments were about the practical day-to-day things that they needed such as specialist equipment. That said, foster carers did not express much faith in the reviews as a mechanism for getting things done.

“…But they just come round and talk. It goes down on paper and then nothing happens...It’s not just social services, it’s the NHS, it’s everyone.”

“I keep saying that she needs this or that and nothing happens.”

An absence of discussion of mental health raises the question of how practitioners involved in the care planning for children with disabilities make informed decisions. What do they base the care plan on to ensure a holistic approach? What happens to the information following the review?

D. The role of the independent reviewing officer (IRO)

In addition to statutory health reviews, a system of IRO’s was introduced in 2004 to oversee the effectiveness of the care planning, a legal requirement under section 118 of the Adoption and Children Act 2002. The IRO should ensure care plans for looked after children are based on a detailed and informed assessment, are up-to-date, effective and provide a genuine response to each child’s needs and identify any gaps in the assessment process or provision of service.

Although we did not receive any comments from carers that were directly about the role of the independent reviewing officer, the fact foster carers felt “nothing gets done” raises questions about the whole system including the effectiveness of the role of the IROs. Interestingly, The Centre for Research on the Child and Family (CRCF) at the UEA has recently completed local research on ‘care planning and the role of the IRO’(August 2012-October 2014). Their findings suggested the role of the IRO was hindered by the volume of reports they have to complete and “poor quality of template forms”. The CRCF also noted there were implications regarding “following up after a review had a taken place.” The other role of the IRO is to promote the interests of all looked after children including those with disabilities. The CRCF found that, in terms of providing or promoting the child’s voice, just under 25% of IROs had visited “most children” between reviews and just over half felt that they were “not involving children appropriately”.

Our evidence suggests that the processes in place to assess and meet the mental health needs of children in the care system may need refining and there is certainly a need for integrated multi-agency working. Section 2.5 of the report acknowledges the comments we received from foster carers, which asks for the voice of children in care with disabilities to be heard.
2.5 The need for children with complex needs to have a voice

During our engagement work, foster carers often raised concerns that the processes described above were not sufficient to ensure that the voice of a child or young person with a disability was appropriately listened to, and given proper weight in decisions affecting their lives.

They also felt that a more general failure to properly listen to their voices meant that some children with disabilities who are neglected tend to come into care later because they are not identified in the system. “We need to be better at recognising children with disabilities who are neglected and or abused…”

Foster carers also talked about the need for children and young people with a disability to be heard and to be involved in decision-making processes. Particular concerns were raised in the context of the recent emphasis on exploring if reunification with the birth family is possible and appropriate. Commenting on this “push”, one foster carer protested:

“It’s awful…[X] has been away from his birth family for years…it would be so unsettling for her to return to their care…I had to of course mention that there was going to be a meeting about it…now everything is up in the air again…I can’t see how this is in the best interests of the child.”

Another foster carer spoke about contact with the birth family:

“There needs to be a greater effort to understand the needs of children with disabilities…the behaviour of one child was saying that he did not want direct contact and this was unnoticed for a long time…it went on too long and this was upsetting for the child…a placement plan should be right for each individual child…wishes and feelings work needs to be done and staff trained to do it.”

Foster carers also raised concerns about the availability of placements and quality of equipment, which meet the needs of children and young people with an additional physical need.

Foster carers in our focus group told us that there is not enough suitable accommodation for children who use wheelchairs or need wet rooms or hoists:

“This means that the needs of the child sometimes come second and there is not adequate choice in terms of where the child is placed.”

The carers we spoke to were advocates for their children. They would not accept second best or substandard equipment for the children in their care. One carer disclosed she had organised a wheelchair herself as the one provided by the NHS “continually broke.”

“His wheel chair was horrendous…the foot plate broke off sometimes twice a week and then the school would phone…I went to the wheelchair service and said we can’t manage like this…I got a company to come out to assess him and I ordered a new one…”
2.6 Recommendations

The dedication and expertise of foster carers in Norfolk is crucial in providing an effective, robust and caring system of care. The foster carers we spoke to were overwhelmingly looking after some of the most vulnerable children and young people with complex needs and disabilities. They are at the sharp end of the care system but a clear feeling emerged that their expertise was not always being harnessed to help shape and improve services. In addition there was evidence that the support needs for foster carers themselves were not being addressed. While there is further work to do to fully engage with foster carers, the evidence we have gathered through our engagement activity points to the following recommendations:

- Leaders of Children’s services should ensure that foster carers’ views and insights are given due weight in a review of Health assessments, LAC reviews and SDQs to ensure that processes are better aligned and give more prominence to the voice of children and young people with disabilities.

- NCC explores ways of improving the respite care offered to foster carers.

- Healthwatch Norfolk ensures that the needs of looked after children are appropriately reflected in its ongoing work in relation to CAMHS in Norfolk.
PART 3 - Improving outcomes for adopted children

3.1 Context

One hundred and forty one children were adopted in Norfolk between 2013-2015. It is generally accepted that finding a permanent home will lead to better outcomes for looked after children than those who remain in foster care. At first glance, the national and local statistics look good, recent research carried out by the University of Bristol (*Beyond the Adoption Order: challenges, interventions and disruption, April 2014*) found that only 3% of adoptions disrupt. Similarly, Norfolk’s disruption rate only amounts to 2.8% (2013-2015).

It might be reasonable to assume that outcomes for looked after children (who are then adopted) are therefore good, if the target is to achieve a permanent placement. However, the success of adoption in terms of improving *life outcomes* for looked after children is another matter.

Government guidelines and frameworks such as the Every Child Matters agenda and The Healthy Child Programme have identified positive outcomes as those which promote and nurture healthy emotional, social and cognitive development.

During our engagement work the realities of parenting children who have suffered abuse and trauma became quickly apparent. Adoption is not a quick fix. Positive developmental outcomes are influenced by complex packages of multi-agency support and timely interventions along the entire pathway from entry to the care system (pre adoption) and beyond (post adoption).

3.2 The approach

In October 2014, Healthwatch Norfolk wrote to all adoptive families in Norfolk (facilitated by the NAS, formerly the Adoption Family Finding Unit) inviting them to share their experiences as service users with us. We offered to conduct one-to-one interviews at people’s homes or another location of their choosing. We also offered the opportunity to meet as a group or to complete an online survey, which was available both via the Healthwatch Norfolk and Adoption UK websites.

Adoptive parents were keen for someone to interview them informally at their home largely due to the fact that parents preferred interviews to take place in between the school run. Between November 2014 and January 2015 we carried out 45 home visits and listened to the experiences of adoptive parents, mainly mothers. Five interviews included contributions from adoptive fathers. The age of the children that adoptive parents talked about ranged between 2 and 17 years. We also interviewed two families whose adopted children were now grown up (aged 20 years old to 40 years old). These interviews were recorded with the participants’ permission and over 70 hours of conversation were transcribed and formed the evidence base of these findings.

In order to increase our own knowledge base of the services that exist in terms of adoption support and to be able to provide a context for the comments we received, we informally met with a range of professionals who have direct contact with adoptive families. We are extremely grateful for the time they gave in order to increase our understanding of the needs of adopted children and the type of support they might require.
### 3.3 The needs of adopted children

It is well documented that the needs of adopted children are very similar to those children who are in care. Experts in social care and child development openly concede that “most children adopted from care have elevated risks for developmental, emotional or behavioural challenges” *(Facilitating adoptions from care; The Donaldson Adoption Institute BAAF, 2014)*

In comparison to our foster carers, our sample shows a complete shift in the balance of physical and behavioural need. Of the adoptive parents involved who had identified their children with specific needs, 84% spoke of a range of neuro-developmental disorders characterised by difficulties to socialise, form relationships and or regulate emotions. To break this down further, over half of those children were described as having attachment difficulties (54%) and 37% had been diagnosed as ADD, ADHD or ASD. In term of physiological needs, 15% of our sample group were thought to have sensory processing disorder and 9% of the children were identified as having speech and language delay. Only 3% of adopted children in our sample were diagnosed with a genetic condition, such as Downs Syndrome.

The majority of comments we received were about behavioural needs that impact on parent-child relationships which adoptive parents described as being ‘attachment related’ (see 3.3.1 below). Our adoptive parents explained that the impact of early trauma and neglect meant their children had not experienced secure attachments to their primary carer. The first bond between mother and baby is thought to be the relationship which creates a template for all other relationships. When a baby cries, is neglected or hurt it will learn it cannot depend on its carer and even when transported to a new place which is safe, they resist trusting the adult carer. How do they know that the same will not happen again?

Secondly, adoptive parents pointed out the emotional needs of their children (3.3.2). Parents and professionals explained to us that when the needs of a baby are not met they remain in a “high state of alert”. Children are unable to deal with stress effectively or self-regulate their emotions because they have not been shown how. Tantrums and outbursts were highlighted and with a lack of “cause and effect thinking”.

Thirdly parents talked about the specific developmental needs of children such as sensory processing, motor skills and co-ordination (3.3.3).

Section 3.3.4 describes the learning needs of children in the school environment. The learning needs of adoptive children are essentially determined by the wider emotional, behavioural and developmental needs introduced above. Unsurprisingly, if adopted children have not gained emotional or physiological competence by the time they reach school age they are clearly at a disadvantage.

#### 3.3.1 Attachment-based behaviours

84% of the adoptive parents we interviewed talked about the emotional and behavioral problems of their children and in particular how these behaviors create a barrier to forming a healthy parent-child relationship. Our interviewees told us that because children who have been in the care system have been let down by adults before, their instinct is not to trust adults, particularly the primary carer but reject them.

They spoke about the ‘disorganised attachment style’ of adopted children which made it extremely difficult to form a healthy parent-child relationship. The adoptive parents from our sample cited
several examples of younger children *kicking, biting, punching* and *hissing*, one parent described the behaviour of her child as “*feral.*”

Our findings also suggested that children were more likely to be physically violent towards the adoptive mother which is synonymous with recent findings published by Bristol University. In a report entitled *Beyond the Adoption order: challenges, interventions and disruptions,* they wrote “*we had not expected child to parent violence to feature so strongly in parental accounts and challenging behaviours. Young people were mainly violent to their mothers.*” (Selwyn, Wijedasa & Meakings, 2014, p278)

Adoptive mothers in Norfolk were no exception when it came to facing challenging physical behaviours directed at them as one mother acknowledged how her son “*really struggles with me as a mother figure.*” The primary carer told us about continuous physical rejection which included being spat on, pinched, scratched, kicked and poked.

“*...X pulled my hair out, scratching, biting...slapping...lot of anger verbally and throwing items about...then his ultimate sort of thing would be to take his clothes off and wee on me...*”

Adoptive mothers also told us of serious incidents which had taken place in the home. One adoptive mother described being “*hit with a chair and wrestled to the floor.*” Another told us she had been “*hit over the head so hard she was sick from concussion*” another was “*punched in the face*” whilst a further three adoptive mothers had been threatened with knives.

Travelling in the car could also be dangerous. One adoptive mother described being hit whilst driving. “*He was saying, I'm going to crash the car. I'm going to kill you.*” Two adoptive mothers told us of similar incidents when driving. Both involved the child pulling the seatbelt around the neck of the parent driving and one parent was kicked in the back of the head.

“*He took his seatbelt off while I was driving and pulled my seatbelt around my neck...I crashed the car.*”

There were repeated examples of children putting up barriers to being close and rejecting some parents verbally in public. Most adoptive parents were not usually embarrassed by these outbursts but the nature of the insult was a cause for concern. One mother was called a paedophile, one child screamed that his adoptive mother had stolen him, another told a teacher his mother had locked him in cupboards and not fed him. The nature of lies told by younger children were often so exaggerated that parents were confident they would not be taken seriously by the authorities. For example, one child told their teacher their parent had killed them *several times.* Parents did worry about what they would say about them next. “*My children come up with all sorts of elaborate stories...it's a worry for the parent. What they are going to say next?*”

There were often threats about going to the police: “*she would often say, “I am going to report you.”*” However, in two cases teenagers did make allegations about parents which were subsequently investigated by the police. The allegations made about one parent meant they had to spend the night in a police cell and another parent was not allowed to return to the family home pending an investigation. Both allegations were found to be untrue.
Adoptive parents told us that their children also rejected their carer by persistently seeking to control the relationship. Children as young as 4 years old wanted to be in totally in charge. They talked about stealing car keys and driving off where they wanted to and buying their own house. They were resistant to their carer washing and dressing them and would “always have to be the first one through the door.”

There were examples of how children “put down” their mothers in an attempt to dilute their caring role. One adoptive mother told us that her son would go to the fridge and deliberately eat the food that she liked (as opposed to her husband’s favourite foods); another explained how her 4 year old asked her nonsensical questions that she couldn’t possibly know the answer to in order to make her look “stupid”.

“He deliberately asked me questions that I could not possibly know the answer to and when I got it wrong he would say that I was a thick little woman and kick me…”

Being independent and not being able to receive care was commented upon by one adoptive parent who felt the baby she adopted appeared to be already street wise with no naivety:

“I remember being really struck by the way he looked at me as a baby…he really looked at me intently, he was already more in the world…almost aware of being a separate being which made it harder for him to receive and just be himself.”

It was not only attachments to the primary carer that were often volatile. Thirteen out of the 39 adoptive parents in our sample had adopted siblings. Eleven out of the thirteen families described an unhealthy bond between them:

“I have to prepare for them when they come out of school because they fight all the time. They can’t be together… I have to anticipate what will happen every evening.”

“The relationship between them was difficult. He hated his brother, I mean really hated him. He saw him as the cause of all his problems. He was the one who had been particularly abused in his birth family.”

Adoptive parents continued to find themselves de-skilled and unable to feel they had any control particularly in teenage years. They described their children as “defiant, oppositional and unmanageable.”

“He wouldn’t do anything for me…telling me to ‘f*** off.’ You know, going off on his bike, couldn’t find him…resisting everything. So in your face…”

“He was out on the streets. He was taking drugs. He would just disappear. We didn’t know where he was a lot of the time…there’d be all sorts of things going on…”
Children who have been adopted do not only struggle to make healthy attachments with their primary carer. Not having experienced love in the caring sense, adoptive parents of both teenage boys and girls worried about the sorts of relationships they would form beyond the family home and school. One adoptive mother told us of her concerns about her daughter using social media sites to meet people:

“She can’t...(interact) with her peer group...so she has these virtual friends who she Skypes and people in other countries who she contacts, just slight acquaintances who she’s on Facebook with...it’s like a fantasy...it’s upsetting…”

“They have just started using Facebook…it’s very difficult...she’s impulsive. I have been particularly concerned about pornography and stuff on the internet. we have strict rules about it but it’s difficult.”

One of our parents told us that her adoptive daughter now had her own baby:

“She’s just a kid herself...it’s so hard to protect them in their life choices...they don’t think things through or even understand the relationships they are in are not really about love but the need to take risks, to get attention even if it isn’t the right sort…”

Relationships are difficult for adopted children and follow them into their teenage and adult lives. Not only did adoptive children tell lies about their adoptive parents, there were two examples of teenagers making allegations against strangers of the opposite sex. “She made an allegation against a young man, which she fortunately acknowledged before it went too far because it wasn’t the truth.”

Other behaviour that adoptive parents spoke of was stealing. One family said they no longer keep money in the house, another parent had money stolen from her jacket pocket and one child had used details from a credit card:

“Money had been taken...he rung up a £2,000 bill on a card on X box games that we knew nothing about. He had memorised the card number.”

3.3.2 The Emotional Needs of the Adopted Child.

Children who have suffered neglect have not had their emotions and feelings validated. In our sample, adoptive parents mentioned birth mothers who were completely absent and unable to meet the emotional needs of their baby due to addiction or living in a situation which did not enable them to be a responsive parent. Emotionally, adopted children are not able to deal with stress in the same way as other children who have experienced stability as an infant; they have not been shown how to relax and are described by parents as remaining in a state of “hypervigilance”.
Adoptive parents told us about resilience and that adopted children find it very difficult to regulate emotions.

An inability to regulate their emotions means adoptive children will often over-react to situations. One adoptive parent explained how the impact of trauma has not allowed the “thinking part” of the brain to develop. Children who have been in care are not always able to rationalise, or understand cause and effect.

Adoptive parents of younger children described how their children could have tantrums which were “explosive”. They used words which expressed the intensity of the anger the children displayed and the relentless nature of the outbursts:

“It started the moment we got up until half past 11 at night, with very little let up.”

“You can’t leave X in a room alone. He’ll be in the cupboard, taking stuff out, taking things apart…there’s the tantrums, the screaming, the shouting…”

Adoptive parents of teenagers described how they would take their anger out on property, rooms were trashed and cars damaged.

“The fridge had been knocked in, the dishwasher kicked in…these chairs are up against here because they’ve all been broken…”

“I don’t know if you noticed the hole in the wall out there, and the broken doors and stuff…it gets really, really difficult.”

“There was stuff being thrown down the stairs…her room was trashed…at one point she smashed a double glazed window with a hairdryer…there was glass smashing that’s an achievement in itself…we’d had the police in three times in one week…”

Adoptive parents described the emotional outbursts of their children as unpredictable across all ages. Parents found it difficult if not impossible to understand what triggered the behavior.

“He’s very unpredictable. He can come in looking happy and before you know where you are you get punched…you never know what will happen next.”

“You’d never know what’s around the corner. It’s ongoing…it’s like walking on egg-shells.”

“The hardest part is that she becomes cross, frustrated, excited and it’s very unpredictable. X can fly off and it isn’t gradual. It just suddenly escalates and X becomes quite aggressive. Her arms and limbs are just flying around…I got hit in the face…she’s very strong.”
Adopted children experience trauma and neglect during a time when the development of the brain is critical. The world they have absorbed physically and mentally is one in which danger and chaos are normal. Even if the world they now live in is safe with their new families, adopted children will often continue to be drawn to chaos and danger because it feels like home. In other words, children who have suffered trauma might feel that calm and loving environments are very difficult so they look for “what they know”. Adoptive parents told us how even children as young as 5 years old were drawn to taking risks:

“He’s perpetually thrill seeking, physically very danger loving.”

“He was a boy that took enormous risks from a very early age. He would bomb up a climbing frame.”

Parents told us that risk taking increased in teenage years. Examples included taking drugs, gambling, committing crimes and running away.

“He chose to live with another family we didn’t know. He came back in a terrible state. He had got nine good GCSEs. He should have gone into engineering or something like that...but he took skunk and did his brain in. We don’t know if he will be functional again.”

Consistently, adoptive parents explained to us that underneath the front of spontaneous risk taking, dislike for authority and intense anger, these young people are emotionally vulnerable and immature in their emotional development. One father told us of how his son is often defiant and aggressive but at the same time will make a den and sit in it with his teddy.

“He gets the sofa and puts the sofa right up against the TV in a little triangle so you can’t really get in...he’ll be there with his teddy swearing at Grand Theft Auto...he’s got his bizarre teenage way but he’s reverting to being a little boy and he flips between one and the other...”

“As young as 5 years old he would say things to shock, like I’m going to have sex with lots of people when I’m older and kill all the policeman...he would be so street wise...but then he would watch TV programmes for toddlers...”

3.3.3 The developmental needs of the adopted child

Adoptive parents told us that not only had their children not reached developmental milestones in terms of their emotional health but they were experiencing some form of physiological developmental problems. Five children in the sample are considered to have sensory processing disorder (SPD). This is when the child experiences difficulty in interpreting sounds, sights, tastes, smells, movement, balance and body position. The brain has not learned or is not wired to make sense of stimuli and cannot organise it into an appropriate response. Adoptive parents suggested
that a lack of interaction and opportunity to explore their environment as an infant impairs development.

“She wasn’t used to being held. So all the nurturing skills that parents pass onto children, you know when they are young; just all that, the handling, the bathing, the talking the touching, toys. She never experienced. So her early days were very poor.”

“She obviously hadn’t been comforted. She couldn’t even put her head on my shoulder.”

There were examples of children holding their hands over their ears when the vacuum cleaner was used, reacting to certain clothing material or seatbelts in cars.

“He gets distracted very easily and he’s very sensitive to loud noises so going out in public is challenging.”

“She can’t touch very well...any sort of pressure or anything on her arms when you’re sitting with her she doesn’t like...she couldn’t regulate her body. Her arms were all over the place like her body was in space or something.”

Children in our sample struggled with both fine motor skills such as; handwriting, getting dressed and tying shoe laces, as well as gross motor skills.

“In his first year at school he found it difficult just to hold a pen, so he had really poor fine motor skills.”

“When he was walking, it was like his balance, it looked like he was trying to trip himself up with his feet.”

“Her reception teacher noted that she found pedalling and steering a bike very challenging.”

A small proportion of the children in our sample were identified as having specific learning needs such as dyslexia or were slower in terms of developing speech.

“We noticed that he had no language at all, and he was three years old...he’s a year delayed with his language...”

“His speech development was very slow...even now his speech is delayed...he’s got a lot of sensory issues.”
3.3.4 The Learning Needs of Adopted Children

Adoptive parents told us that learning was affected by the wider emotional and physiological needs of adopted children previously described. These developmental needs are exacerbated in a school setting in which classes are structured by chronological age. Children and young people are measured against social and learning targets which assume they have followed a normal developmental pathway. “If you’ve got complex developmental trauma, you ain’t going to be able to concentrate on school work.”

For adopted children the school environment is a difficult place for them to thrive and achieve. The fact the children are anxious and frightened in a school setting is illustrated in the language they used to tell their adoptive mothers what the school day had been like. One child told his mother the headteacher had “run him over in her car twice and shot him three times and then everyone in assembly had stamped on his head.”

The mother of a teenager explained:

“Her view of the world and her experience of the world and the people in it is not your average one...she reacted extremely to what were relatively small things at school.”

Adoptive mothers described children across all ages as being in a constant state of “hypervigilance or arousal” and that without the emotional intelligence to make sense of their environment, their default coping mechanism is flight, fight or freeze. There were examples of children running off the school site, hitting support staff or crawling under tables to hide. Parents had observed how exhausted their children were at the end of the school day.

“Her nervous system really takes a drumming going to school every day.”

“He gets really, really tired quickly, it’s quite a lot to take on social environments.”

Children reacted to changes of structure in the school day. Non-uniform days and school sports day were difficult. They tended to be noisy and over stimulating which might also suggest these children were experiencing some difficulty in processing sensory information.

“School sports day was too much for him...he just looked over-whelmed by it all...the race started and he ran in the opposite direction. He wasn’t being naughty...he just couldn’t cope and was so disorientated...”

“She was so frightened at the summer fete. She really struggled to play the recorder and do the little dance they had planned.”

Not only do the adopted children in our sample struggle with their emotions and anxieties in a school environment they struggle to fit in with their own peers. Parents told us they didn’t really have any true friends:
Adoptive parents told us that their children were often bullied at school both physically and verbally. One adoptive parent told us her daughter had “got marks where the other girl had dragged her around the playground by her tie” and several parents told us that socially at school “they do not do well.” They find it very difficult to make friends and are drawn like “magnets” to other children with behavioral difficulties so they sort of “feed off each other.” Parents concluded that their children just seem to prefer disregulation and chaos.

The most common type of Special Educational Need (SEN) in our sample of adoptive children were “behavioral, emotional and social difficulties” which significantly impacts on the ability to learn. School requires organisation, logic and the ability to socialise, a level of resilience that some adopted children do not have. Adoptive parents felt that the school system does not take into account the fact their children are emotionally and cognitively younger than their peers. We received several comments which demonstrated how this inevitably affects the self-esteem of their children.

In older children this lack of self-worth added to by the pressure of school continues. One adoptive parent said her son locked himself in a room at school, another said her teenage daughter told her “when the children tease me at school, it makes me want to hurt myself.” One parent told us her son frequently talked about ending his life because he kept getting into trouble at school.

The evidence above shows that the learning needs of adopted children are great. Children who have been in care are in survival mode; the environment, the people in it and relationships are of paramount importance. Section 3.3.4 looks at what works in schools to meet these needs.
3.4 Meeting the needs of adopted children

The interviews with adoptive parents indicated that the needs of adopted children are complex and multi-layered and this is reflected in what is often a multi-agency response. This section of the report explores the services and support adoptive parents accessed so the needs of their children could be met. The services accessed include universal services (GPs, schools, health visitors, paediatricians) through to specialist mental health services (CAMHS) and play therapy provided by the NAS.

3.4.1 The Norfolk Adoption Service (NAS)

Children’s Services has a team of social workers with specialist expertise in providing post adoption support. There are currently 90 cases open (May 2015). The social worker allocated to the adopted child is in essence, the corporate parent. In order to meet the needs of the child and the adoptive family they network with health and education professionals to achieve an individually tailored package of support. This section of the report focuses on what adoptive parents told us about the “in-house” support they received from social workers to include play therapy, life story work and consultation with Family Futures.

3.4.2 Play therapy and life Story work

Adoptive parents talked about play therapy they had accessed with their child. These sessions were led and facilitated by a specialist social worker from the NAS. Play therapy is an attachment-based approach using play to understand the children’s needs. The sessions nurture positive interactions between the parent and the child and promote positive emotional development. Parents described how sessions are designed to explore the child’s feelings through play with figures, dressing up and expression through artwork. There is also an area to relax and enable the parent to practise their nurturing skills and intimacy that most adopted children have not experienced in their early years.

In our sample, only five adoptive parents talked about play therapy in any detail but overall comments were positive. One adoptive parent told us that play therapy “seemed to help quite a lot” and another adoptive parent said that “everything would have broken down without it.”

One parent described how it taught her to understand her child’s inner emotions:

“I painted a picture with a big sun, flowers and trees with bright colours. X painted a picture, which was black and then painted black over mine. It was the first time I understood more about the world he came from and how dark things were for him inside.”

“We went to the Steiner school for theraplay. So lots of modelling, using creatures to set up different scenarios or art...she’s got lots of tools and strategies and has bonded very well with the lady she’s working with.”

“It made all the difference...I found it really helpful and supportive.”

Adoptive parents did indicate there were two areas for possible improvement. One was the availability of the social worker. There was recognition that it was not their fault, but was nonetheless an inconvenience, particularly when children are so sensitive to change in routine.
“The social workers are not all full time. So probably as many sessions we’ve had we’ve had cancelled because of emergency cases, training courses, or annual leave...because the dates are on the calendar, she likes to know in advance to prepare herself and then we have to tell her its cancelled.”

The other comments were concerning clarity. Two adoptive parents commented that in the effort of the social worker to make the session child-led and go at the child’s pace, they felt too unclear about what the purpose of the session was themselves.

“I said ‘can you tell me what our action plan is? Where are we heading? What is it that you’re looking for?’ She said ‘we have no plan. It’s all child-led. We just come back and play every week.’ She didn’t give me any answers to my questions…”

Some adoptive parents told us that life story work had been incorporated into the sessions in order to give the children a stronger sense of identity, to link past to present and make sense of their experiences. Life story work helps the child or young person to make sense of their experiences and dispel fantasies and fears about birth family. Overall, adoptive parents were very positive about the life story work that they experienced.

“I felt very supported by the social worker with regard to life story work…my child had experienced multiple moves and multiple carers and I found it difficult to know how to explain it all, particularly as he was not attached to me...he did not trust me…”

Life story work equally received positive comments from adoptive parents with teenagers:

“Life story work was good. We did different colours for different feelings. At the beginning there was so much anger…it was scary to see…it seemed that for a while, anyway he grew up and didn’t get as angry as he had done before…”

“When they did remembrance things at school about the war, he was able to say he would remember his dad because he was in the war. Well, he was actually in the army. But it gave him a means of making a connection to his real dad which I think is important.”

Life story work by its very nature is emotional and intensive. Two adoptive parents commented on “information overload” which they indicated had possibly affected the quality of the life story work. Their children were aged between 5 and 7 years.

“He looked traumatised...he had to draw his life story on a big piece of paper and it involved writing down lots of stuff about his birth parents.”
“I did find the session too intensive...too much information in one session. It would have been better to have broken everything down...we did consecutive sessions in the same week which I sort of understood in terms of keeping the momentum going. On the other hand it was very intensive...I think X was then filled with thoughts about his birth family and then didn’t really know what to do or how to process this information.”

Interestingly, when we asked a young person in care what might have made the health and well-being support he had received better, he told us that he remembered doing life story work when he was little and thought he was too young.

“I was only 6 years old or something. I didn’t want to do stuff like that. I just wanted to leave, I think it should be done when you are older like when you are 13 years old or something. You should know you why you are in care but not in loads of detail.”

There was some debate over the language used in life story work with regard to “forever mummy and daddy.” For three adoptive mothers they felt the term “forever mummy” put unprecedented pressure on the child and may have heightened behaviours to reject them. In other words, rather than reassure the child of a secure future it might actually antagonise them.

“The first time I saw them they called me mummy and daddy which I would now change completely. You know it’s their choice. They should have decided because with mum, this label mum, comes everything. All of their stuff comes with it, so you’re the one that gets it, full on.”

“It was so hard. He had been taught to call me mum form the start but would scream at me ‘you’re not my mum...I will kill you...lots of times...’ and you felt like saying, ‘Well you’ve got a point. You must be really angry with me. You’ve had no choice in this.'”

One adoptive family told us they had experienced secure attachments with both their children. When we asked them what the most important advice they could give new adoptive parents would be, they told us the following:

“Listen, listen, listen to what the children want to tell you...really know what they would like...tread carefully. If they want to talk about it; their past, talk about it-don’t avoid it but don’t ram it down their throats. Let them tell you where they want to be...I was desperate for them to call me mummy and they did...but in their own time. It took about 6 months. It has to be natural. It’s not natural for these children to come into a home and call someone Mummy and Daddy when they don’t know if these people are even worse than anything else they have already experienced.”

A young adopted person pointed out that nothing is forever, even adoptive families change and people get divorced. “My adoptive dad left. I thought ‘you were my forever family. How could you do this to me?’”
3.4.3 Family Futures

Family Futures are a London based adoption support agency. Norfolk social workers have referred adoptive families to Family Futures either for a one off consultation or direct therapeutic family work. Only a small percentage of our sample mentioned Family Futures. The service, which comprises of a holistic package of support for families with psychologists, therapists and nutritionists working in the same team, was described by parents as very good and excellent but not easily accessible which caused a great deal of stress for the families and this had an impact on how much they actually benefitted from the sessions.

“The children in the car were a nightmare but we tried it and it did something...the appointments were on days I was working.”

For some families, the initial consultation was not followed up by further work which parents were told was due to funding: “they decided not to fund it” and in one case, funding was stopped after a few sessions “because they said it was too expensive.” This caused confusion and frustration for some families as they were not offered a full service.

Also, families felt it was important that when sessions finished, they required further support particularly as techniques such as life story work can trigger strong emotional responses.

“We did some therapeutic work with family futures which was based around life story. It went well and we were warned that although it went well at the time it might blow-up later and it did.”

“Family futures decided intensive support was needed. We needed respite and the kids needed a big body of work done. I came back to Norfolk and mentioned the respite. They (NCC) laughed and said ‘we don’t have anything like that’ I mean you’re at these meetings, people are writing things down and you think thank goodness something’s going to happen now and it doesn’t. It was the fact for me that you have a key organisation like Family Futures saying this needs to happen.”

The psychotherapeutic approaches outlined above which enable the child to explore trauma and builds on the attachment between the parent and the child, are arguably the most important in terms of supporting a child’s needs. That said, one approach is often not enough. Adoptive parents talked to us about the other services social workers have made referrals to, in particular CAMHS.
3.4.4 CAMHS: Child and adolescent mental health services

CAMHS is an umbrella term for all mental health support available to children and young people including universal services such as schools, GPs and paediatricians through to more specialised teams. When adoptive parents spoke about CAMHS this was with reference to professionals who had a designated role to provide a consultation service to foster carers, adoptive parents and professionals working with looked after and adopted children. The team includes psychologists and clinical psychiatrists who are employed by the Norfolk and Suffolk Foundation Trust.

Our understanding is that an adoptive family or child might be referred to the CAMHS team if it is thought that the child has a diagnosable mental health problem or perhaps requires medication, which only a clinical psychiatrist is authorised to prescribe. One adoptive parent told us that her child had been prescribed medication to help them sleep, another so that they were calmer and could then access therapy more easily.

The adoptive parents we spoke to who had experienced the CAMHS service raised two concerns. The first was about referrals (eligibility and waiting times) and the second, was with regard to the service the young person in their care had received.

Adoptive parents were confused about what makes someone eligible for referral. Without doubt specialist teams within CAMHS will be forced to prioritise and make difficult decisions given pressures on resources, but the perception of parents is that the service is there to be accessed. Consequently they find it frustrating to be turned down with little explanation and told us that “accessing CAMHS was a nightmare or impossible.”

It was the opinion of some adoptive parents that the needs of children and young people are not deemed to be “severe enough” and that “attachment issues” that impact on daily life do not require intervention from a specialist clinician.

“We can’t access help for adopted children because they are not ill enough...they didn’t have the right behavioural problems…”

“If you’ve got a child who’s got early difficulties you won’t get them near. You won’t get anything until they have gone over the edge.”

Three of our adoptive parents spoke about the transition to adult mental health services. The comments indicated two areas of concern, firstly, that it is too soon for their child to move to adult services and secondly, that the professionals do not always effectively support the young person:

“Once you hit 18 it’s goodbye to all services as far as I’m concerned. She has a counsellor at college that she really liked so when that ended I took her to the doctors. The doctor gave her 6 phone calls. Her stress levels were assessed as fine. Because it was half term and she was lying on her bed. Of course she is more relaxed. Of course the person on the other end of the phone doesn’t know the background. Not a useful service.”

Two adoptive families reflected on their situations which had required more intensive support. They told us that the young people in their care had experienced psychotic episodes. Both were arrested and sectioned before any real help was given.
“Teenage years, the transition to adulthood needs to be supported. It is really hard for these young people. We’re talking about outcomes, a functional relatively happy and content adult. Resources should be concentrated around 15-30 years as well.”

One parent felt the service for 18-24 year olds did not meet the needs of the young person in their care and that the professionals in the team did not have an understanding of the complexities of children, who have been in care and suffered trauma:

“The key worker told us he needed clear boundaries, like we were bad parents and he was just a defiant child...even when he was psychotic we couldn’t get them to do a mental health assessment. His roots into mental health services came by the police.”

There were other examples from parents whose overriding opinion was that professionals within specialist CAMHS teams did not appear to understand the needs of adopted children and their families. They told us “the knowledge of CAMHS workers needs to be increased.” This resonates with the opinion of the young people in care who completed our survey (see Part 1 findings). Two adoptive parents felt so let down they had made formal complaints about the service they had received.

“We are stuck with a psychiatrist who doesn’t have a clue about the complexities of X...I mean I was explaining it all to her. She didn’t know. So we don’t go. I have lost the psychiatry support because they don’t understand.”

“Regrettably I have significant reservations about CAMHS. My experience of the team is that I’m not convinced they have the expertise to fully understand the issues that adoptive families deal with...they don’t look at the situation holistically. They tended to concentrate on pathology, if you like, on the presenting difficulties. But these difficulties happen within a context and understanding that context is crucial. It felt patronising. Like they were not an open service.”

One adoptive parent told us that long gaps between sessions is unhelpful when trying to build a relationship with the client, particularly because the work that had already been done had “triggered the re-emergence of her early trauma.”

“There were long gaps between appointments and I suppose if one is trying to encourage a young person, leaving long gaps isn’t usually the most effective way of engaging the young person...as a family you need to talk things through. It needs to be available.”

What comes across from the evidence is that relationships and trust are crucial to adopted children and young people and long gaps between sessions may have a detrimental effect.

“He absolutely hated it...he just wouldn’t talk or open up to the psychiatrist, he absolutely refused to talk to them.”
One adoptive mother expressed how it was difficult to get an appointment and she did not agree with the way they worked:

“Every time I phone up the psychiatrist’s secretary I couldn’t make the appointment because she manages her open book...yes, we have a difficult relationship with CAMHS.”

Adoptive parents drew comparisons to their social workers, who despite their enormous caseload parents say are both understanding and accessible (in outreach and receptiveness).

“I mean, our daughter has been incredibly cross with our social worker on so many occasions but she’s kept coming to see her. You know, they don’t get put off...she will see our daughter in whatever location, not a clinical setting...she has demonstrated an ability to hang in there...they understand the level of distress...I can ring when I want to...she’s non-judgmental in her work.”

The comments of adoptive parents suggested they were impressed with the outreach work of social workers from the NAS but had not had the same experience in a clinical setting. More than one parent had experienced a time where a consultant psychiatrist had a strong link to the adoption service. The comments about this professional were overwhelmingly positive. They described the consultant as “very good, “excellent”, a “godsend” and “attuned to the needs of adopted children.”

“The psychiatrist was brilliant with him. She agreed I could sit in the corner and watch. I learned more in that hour about my son, about his inner workings than I’d learnt in the previous 12 years. It was absolutely staggering to me. She knew the signs and what was going on...”

“Brilliant, she helped me to manage my daughter’s worries. She also organised psychometric testing. She’s got an array of cognitive difficulties, it’s no wonder she’s struggling.”

The voice of the adoptive parent raises two questions. Firstly, is the criteria of the CAMHS service clear enough to both social workers who make referrals and to families who have expectations to be helped? Secondly, is the service accessible and flexible enough for looked after and adopted children?

The nature of our sample meant that most adoptive parents talked about CAMHS. However, we did have adoptive parents who made brief comments about access to other specialist services such as occupational speech and language therapy.
3.4.5 Occupational, Speech and language Therapy

Thirty two out of the thirty nine adoptive parents we listened to identified specific needs their children had. Eight out of our thirty two adoptive parents described their children as having sensory processing difficulties and or gross/fine motor skills and had sought the help of an occupational therapist.

Although our sample is relatively small, it was clear that adoptive parents perceived occupational therapy to be very important in supporting the child’s developmental need, particularly in their readiness for school. The occupational therapist provides artificial situations through play and exploration in which children can re-visit developmental milestones, that they did not achieve due to their neglectful start.

“This holistic package of support including occupational therapy is a must. How can they manage at school if they can’t hold a pen or if they can’t deal with sounds or process all the visual things they have to take in?”

It had also helped them to understand the needs of their children better, “it was a real eye-opener.”

Our comments showed that one parent had received funding for occupational therapy and two had not. It is reasonable to assume from these comments that the NAS have to prioritise need which explains why some families might receive funding and others do not. That said, adoptive parents are uncertain of where to access services so they at least have the choice to privately fund support (or not). They spoke about wanting to have a list of services available from the start so they are not forced to “dig around” for information.

“I don’t think that sensory occupational therapy is available on the NHS so I started looking around and found my own therapist…it’s expensive and he’s had several sessions...”

Only two of our parents were accessing or had accessed speech therapy for their children. The comments suggested that there was a long referral procedure but once they received the support it was helpful. “It helped him to come along nicely…we discovered he was a whole year behind with his speech.”

3.4.6 General practice and health visiting service

Adoptive parents told us that they felt there was a need for training for those professionals who have direct contact with their children because the vast majority did not seem to understand the complex needs of looked after and/or adopted children. “If health professionals don’t get it, where are you supposed to get help from?” Adoptive parents spoke about the more universal aspects of health and education (tier 1&2) not having enough insight.

Where adoptive parents had seen a GP about their child, there was a lack of understanding around the needs of looked after children. One adoptive mother was told “You adopted at 6 weeks so the adoption won’t have any bearing on this (behaviour).” Another mother asked the GP to complete a form in order for her daughter to be accommodated on campus at university.
Another adoptive mother stated she went to see her GP who said “attachment disorder? What’s that? You’ll have to fill me in.” The mother went on to say that when you are exhausted and seeking help from a professional person, if they do not understand, “your heart sinks and you feel very alone with it all.” One adoptive mother told us that the GP referred her to parenting classes that were completely inappropriate for adopted children; another GP did not understand the idea that a child would deliberately not defecate but hold it in as a means of control. “The GP said have you heard of a high fibre diet? Are you feeding her a good diet?”

Two adoptive mothers spoke of health visitors. Once adopted from the care system children no longer undergo health assessments with a designated LAC nurse. When the adoptive mother raised a concern about her child’s habitual urinating over clothes and the bed, the health visitor responded that “no child would want to deliberately wet the bed and lay in it” meaning it was an accident. Another adoptive mother told us she was advised on how to play with her child and read stories:

“It was all rather patronising. I know how to play, I have a child of my own already. It was more than that…”

“I was advised by the health visitor to read a book called Toddler Taming. It was all about using the time out step. With hindsight that’s the worst thing I could have done”

When GPs or social workers referred adoptive families to paediatricians, three parents were concerned by the accuracy of the diagnosis their child received. All three children had been diagnosed with ADHD and or ADD which parents conceded may well have been true, but felt a single diagnosis simply did not represent the complexities of the adopted child:

“The GP said ‘this child has not got ADHD and yet, he’s been diagnosed twice with it.’ Where does that get you? It’s a worry. When you see ADHD on a diagnosis everyone seems to think they know what it is but it’s much more complex than that.”

“The paediatrician was simply looking from a medical point of view…my daughter was diagnosed with ADD and she didn’t link any other issues to adoption…which if they are specialising in the care of children that should be holistically included in their wellbeing, that there are issues linked to adoption?”

“When I challenged the diagnosis, I was told not to worry and that it’s just a way of flagging up to schools my child has emotional and social difficulties? I felt very frustrated. ADHD does not describe all the behaviours my child presents with. I then got a leaflet about parenting and putting boundaries in place. My child does not get consequences. How will that help?”
Three parents who had been to the paediatrician also commented on the waiting room which they did not think was an appropriate environment for their children:

“The children’s waiting area is awful. It doesn’t work. It’s noisy and you wait for ages...he just wanted to run...there are toys everywhere.”

“There is a waiting room with lots of toys...I could see he wanted the best and the biggest toy in order to be in control of the situation and feel safe….he called a child a f****** idiot which didn't go down too well and then ran out of the room. I think an over stimulating environment for a room full of children who predominantly have ADHD is probably not good. Maybe there could be a darker, calmer area sectioned off?”

“The waiting room, my daughter hated it because there were rocking chairs and toddlers screaming.”

3.4.7 Schools

“Without addressing the underlying causes of emotional and mental health issues and offering the young person the skills to regulate behaviours, educational outcomes for children in care will continue to fall short” (Department of Education, 2014, p11)

Recent statistics provided by the Department for Education in ‘Outcomes for Children Looked After by Local Authorities (March 2014)’ tell us that attainment levels for those children who have been continuously looked after for at least 12 months (up to and including March 2014) are far lower than those children who have not. Looked after children were also identified as having more needs:

- 48% of looked after children achieved the expected level in reading, writing and mathematics combined in 2014 compared with 79% of non-looked after children.
- 12% of looked after children achieved 5 or more A*-C GCSEs or equivalent including English and Mathematics.
- 66.6% of looked after children had SEN which consist of 29% with a statement and 37.6% without a statement.17% of all children (looked after and non-looked after) had SEN which consisted of 2.8% with a statement and 15.1% without a statement.

Of our 39 adoptive parents, 28 parents spoke about school and education. Some parents had more than one adopted child at school which means overall, we learnt about the educational experiences of 37 children, though the depth of comments varied. Our snapshot tells us that:

- 14 out of our 37 children were of an age (post-16) where they would have possibly taken GCSEs: four had achieved five A*-C passes, 5 achieved “a couple or a few low grade GCSE” (E grades) and four young people did not take any exams at all.
- Of the four young people who achieved five A*-C passes, two went on to college and then university, whilst the other two young people left college. For both young people who did not stay in education, life outcomes included substance misuse, criminal records and time in prison.
The educational outcomes above are strongly influenced by the child’s emotional and mental health. Part 1 of the report describes how the needs of adopted children are often exacerbated in a school environment, which demands the sort of resilience that adopted children do not have. Our adoptive parents talked extensively about school life and how when schools are not forthcoming, the learning needs of adopted children are not met.

Overall, adoptive parents spoke warmly of the nurturing approach of pre-schools and infant schools and felt the emotional needs of their children were met, even if this was by default. In other words, the nurturing approach of staff is gentle and far more therapeutic than that of staff (typically) in middle and high schools. In most cases, adoptive parents said that whilst there were problems, their children sort of muddled through their younger years in education.

“We managed to keep things together-ish, while they were at primary but they’d all been excluded at some point or other…”

“First school was very good...It doesn’t work the same at high school.”

Sadly, the experience of adopted children was not as good at secondary school and all adopted children who were currently at high school were experiencing problems. Adoptive parents spoke about the general lack of understanding in recognizing the complex needs of adopted children and then responding in an appropriate manner.

Several parents empathised with the school (to a degree), after all, they said that aggression and defiance may remain hidden at school. Adopted children see most situations as more threatening than they actually are due to early experiences of trauma and default to a freeze, flight or fight coping mechanism. They often appear compliant at school (freeze) and save the fight for when they are at home.

“At primary school she was an elective mute...she never speaks. She was incredibly busy but never spoke to anyone...when she got in the car, she’d never stop talking.”

“At school she blends into the wallpaper, she doesn’t kick off in class. She doesn’t scream or shout. She does all that at home...so she stays under the radar at school. We thought she was learning to read but she had memorised the stories, she knew them off by heart.”

“She appears co-ordinated and organised but she’s anxiety driven to be organised and to have the right things in her school bag.”

That said, parents did not feel believed despite telling staff what was going on at home. One adoptive mother, although she acknowledged she wanted her child to do well at school, was receiving such a level of aggression at home that she admitted feeling relieved that the behaviour started to spill over into school life. “It was the only way the school staff could possibly understand what was going on and it resulted in the educational psychologist coming in and supporting us.” Another adoptive parent videoed an outburst at home and showed it to the school:
“It was only when we videoed him at the end of one of his outbursts and took it into the school that they actually said, ‘Ok we need to do something.’ Because he’s a little angel at school. Holds it all together at school and lets it go when he comes home. They stood there with their mouths open. It was like, that’s what we live with and that’s when they did stuff.”

“It was hard communicating to the school. Teachers haven’t got a clue how to deal with children that have been adopted. When the teacher found out I had adopted at 6 months she said ‘Oh well, she’s been with you long enough, she’ll be fine.’ No idea of trauma and the effect on the brain.”

Parents told us they did not feel listened to by all school professionals. One parent said she had specifically asked the school to put her daughter in a class with the teacher she preferred and this did not happen. “They’d given her the less-nurturing teacher which shows they had not been listening.” Another parent said the school didn’t seem to believe they were struggling with their work, possibly because they were withdrawn and quiet. “The school were telling us he would catch up but that didn’t happen and it was obvious that he wasn’t doing well.

“...You’ve got many teachers who are not really used to dealing with children who can have challenging behaviors and don’t understand and use very, very punitive methods of dealing with children...”

“You set the child up to fail. He or she fails, then you get loads of support. That’s not how it should work...it should be there is a problem, ok, we need to wrap around this straight away...”

“She’s in water out of her depth...she’s already got low self-esteem...school is pushing it lower and lower.”

Not only does the punitive nature of some schools set adopted children up to fail through the eyes of the adoptive parent, parents felt some of the staff did not always understand:

“There was no understanding about attachment or early childhood trauma...you always got...he’s immature, he’s this that and the other.”

Just as many un-prepared adoptive parents did not know how to assess the behaviours of their children there were examples of school staff misinterpreting the needs of adopted children which was frustrating for parents. One example was a teaching assistant who had chosen to carry out the ‘Thrive Assessment’ on a child and came to the inaccurate conclusion that the child was deprived of spending time with the parent. “She didn’t have a clue I had been sharing a den for the last two nights with my son and was getting punched for trying...”
Another adoptive parent was told that she needed to practice reading at home with her daughter which she found very patronising. “She was making the assumption that I was a parent who did not get involved with my child’s learning and that I didn’t do any at home.”

Since adopted children may present so differently in different environments, it was not uncommon for our adoptive parents to be told that their child was “fine” which may to some extent explain why some adoptive parents have felt the need to fight for a statement of SEN (now an education, health and care plan).

“*The teacher would tell me how good he had been...it was difficult because it was hell at home.*”

Children in trauma do not always act the same in different environments which further isolates the adoptive mother.

“He was wonderful at school...they almost couldn’t believe how compliant he was...as soon as he got home it was hell. It was like a personality split.”

That said, we also received several comments where the behaviour had spilled over into the school setting and it had still been difficult to get proper recognition of special educational needs. We should highlight that there were more positive comments about individual teachers than negative ones. SENDCOs were understanding and bent over backwards to try to accommodate their children. However, even a helpful SENDCO could not make much difference within high schools which had a punitive rather than nurturing approach. Adoptive parents felt it was unfair that they could not get their child into a school that best suited their needs as with looked after children. They pointed out that just because they had been adopted does not “erase the massively disadvantaged start they have already had.” Where parents have looked for schools out the area, they felt they should like foster carers have a petrol allowance.

The punitive set up of high schools in particular has led to escalated exclusions. Adopted children have not learnt cause and affect thinking.

“The problem we had with the school is their red slips. You could give him a million red slips. It’s not going to work.”

“He should have got five A-C grade GCSEs but he just couldn’t cope.”

It is no surprise that adoptive parents look for alternatives to educate their children in an attempt to prevent the inevitable. Four families had chosen private schools, not that they found this financially easy:

“We’re having to find £9,000 a year to pay for his private education. But there is no way he could access state school...the primary school he was in refused to statement him because they said his needs weren’t grave enough...”
Other adoptive families have turned to the Steiner School in Norwich whose vision and ethos is one which allows the child to engage and learn in his or her own way; the child is *not pushed towards a particular attainment level or set of targets*. (www.norwichsteinerschool.co.uk)

“*I felt X was so unhappy, so anxious, so over-whelmed we had to try a new school and a whole new system and that’s why we chose the Steiner.*”

What adoptive parents have found to be successful is the therapeutic approach provided in short-stay schools or learning resource bases. This adopts the sort of therapeutic approach that children suffering from trauma need. On site education is not separated from therapy, learning is flexible and embedded in a nurturing approach. One adoptive parent said that the move to a short stay school with a plan to always try to return to mainstream worked for her little boy:

“*He could not manage at Infant School and moved to a student resource base with a high ratio of staff to children. It gave him a chance to settle and experience positive feelings in a school setting...mainstream schools should use more of these approaches and strategies.***”

“We arranged for him to go to a short stay school but we could only get 5 hours a week but it was so helpful...he managed to get three GCSEs. Low grades but it was something and it helped him get into college and his attendance is very good.”

One parent told us that when her son went to a behavioural specialist school he was finally able to experience something more positive and achieve something other than being excluded and being in isolation:

“He achieved his Duke of Edinburgh bronze and silver award, to France and to Morocco to repair a school, he climbed the Atlas Mountains. It was just a completely different mindset environment. And he did do stuff wrong. He did get caught smoking but fundamentally he knew he was liked and that is so important. In mainstream school this was a child that behaved so badly he wasn’t allowed to go to the school disco.”

Another adoptive parent described how her son who now attends college has the space to take responsibility for regulating his emotions, to the extent that he is now able to meditate somewhere quiet provided by the college:

“There is a room...specialist provision for young people on the autistic spectrum...it’s got little sort of alcoves that are darkened where you can go and sit...it’s got a living room area...and its staffed all the time...it’s not there for punishment it’s there as a safe place...it’s not about what you’ve done wrong...”
Parents emphasised that what works for children who have suffered trauma is a therapeutic approach and small class sizes. One parent suggested that she asked her daughter what school should be like:

“She wants a private tutor who can come here. The dog would be with her because she feels safe and soothed. She said she wouldn’t have a uniform but some kind of work clothes which denoted that it wasn’t play time.”

Only four young people in our sample went to college as parents highlighted, their children preferred the structure of high school and routine.

“Whoa, free periods. What are they? What do I do in a free period? He just couldn’t make that transition.”

One young person had left college and told us that she wasn’t ready to make decisions for herself:

“Well, after school I obviously went to college for a year and did my course but at college they sort of expect you to know what you’re doing and I needed some kind of structure. I found it hard…”

Parents are understandably worried about the future: “You want for your child to be independent so they can leave home etc. Get a job and a flat...but at the moment, I can't see that.”

It did seem the case that those young people who left the education system early did not experience good life outcomes. That said, one adoptive mother told us that her son had responded well to the staff at the residential home he was in. Whilst leaving the adoptive home prematurely may be viewed by many as a poor outcome, one mother felt it had aided her son’s transition from a teenager to adulthood. She felt the package of support he got was better than what she could have provided if he had remained at home in her care:

“He’s more sorted than before because of the package of support they have put around him...he did some work experience...they’ve given him an apprenticeship. They seem to get him, know how to work with him and are providing him with opportunities. He’s got a nice place to live and he’s supported there...he’s got mentoring that is going on alongside and people helping him. They’re nurturing him through his work experience. He needed an adult other than us.”

Three adoptive parents spoke about the benefits of a support worker from the youth team, which provided respite. This seemed to particularly alleviate pressure on adoptive mothers who found the relationship with their son intensive.
“I think he was a youth worker? He was sort of my son’s buddy for a while...my relationship with my son was difficult...my son did seem very happy when he was with him...”

“A few times when he has been taken out of school a youth worker used to take him out and I found that support really successful. You know, he was a cool bloke. He was really nice and would take him off and have a game of football. He would also take him to McDonalds and have a chat.”

3.4.8 Integrated Provision

As noted in the introduction to this report, the move away from a national focus on embedding multi-agency working through Children’s Trust arrangements, (since 2010) has been seen by some as holding back the move to more integrated models of service delivery. Whatever the cause, our interviewees made a clear case for integrated services, structured around the often complex needs of their children.

One adoptive parent told us their social worker felt a centre with integrated joint professionals working together was the best way forward, as well as more staff resources and better training regarding the latest neuro-developmental research. Post-adoption support, whilst coordinated by the social worker at the NAS, taps into other specialist services such as child paediatricians, psychotherapists, occupational and speech therapists, CAMHS, schools, GPs and youth workers. Those practitioners who work very closely with the NAS are thought highly of by adoptive parents. “The team work together, they communicate.” However, adoptive parents are not always sure that psychiatrists understand the needs of their families and they do not understand the assessment criteria for CAMHS. A definite sense emerged from our interviews that CAMHS and therapeutic provision is not sufficiently joined up.

“There was one unusual psychiatrist within CAMHS...unusual because she’d had a relationship with the adoption unit over a long period of time...she was key because she understood. They have not replaced her.”

Adoptive parents have picked up a tension between professionals “the practitioner said they had not received all the information they needed from the other service, it was their fault they should have done it” and “the social worker said they were sorry the referral had been made and for now, it was out their hands.”

There were instances of contradictory advice which was confusing for the adoptive parent and whilst they recognised that there is not a one size fits all approach to parenting particularly with children with complex needs, it is not “reassuring” when the professionals appear to disagree.

“The mental health worker suggested different parenting with my daughter...keep your tone low, talk to her about what you are doing, try to distract her...but then you’ve got a contradictory social worker’s advice saying that you need to raise your voice if hers is raised, tell her no...”
In the eyes of adoptive parents and foster carers who are trying to access services in both social and health care, there is a lack of accountability and clarity of roles in health and social care.

“Social services and health don’t work closely...they both think his needs are being met and because sensory processing disorder is not recognised by the NHS it’s all financed privately by the adoption agency...even the therapist who deals with attachment is funded separately.”

“We went to the paediatrician and they said ‘have some tablets’ and I thought, what about addressing the behaviour? She told us to contact Point one. I phoned Point one and they said you need CAMHS. Got an appointment. CAMHS said, you didn’t need to see us. Your GP could have just phoned. Got GP to call CAMHS. Three months later haven’t heard anything. I decided to chase it myself. I phoned CAMHS. I spoke to the same person and they said ‘Oh, did you expect me to do something? But you say you’ve got tablets?’ I thought yes, but it’s just a plaster on a haemorrhage. We’ve tried endlessly to get help. It’s just rubbish.”

Adoptive parents expressed confusion around what a diagnosable mental health condition is. What is a moderate-severe mental health condition? If referrals made by GPs and social workers are being turned down, does this suggest they too are unsure of what the criteria is?

Literature needs to be available that is up front and clarifies the services that exist. There is a sense amongst adoptive parents that services are too discreet. The “Adoption passport: a support guide for adopters” says that “social workers will mediate with health professionals” but adoptive parents in our sample have signalled they would like to know examples of who these professionals might be.

One parent commented that having the psychiatrist and the therapist both present at an appointment gave a reassurance that there was a “Total support network in place for her child. They not only assess for ADHD but look at development and developmental trauma.”

Specialist services need to help universal services to understand. Schools do not always seem to understand the complex needs of adopted children and those in the care system and behavioural policies may not be flexible enough.

“A child with a broken leg is not expected to do PE. A child who lacks organisation and executive cognitive functioning should not be punished every five minutes for not having a tie done up.”

Are we asking for the expertise of the voluntary sector enough? Parents have told us that their teenagers enjoyed talking to youth workers. How strong the links between the adoption support service and the youth service and are they being used to their full potential?

A holistic package of support that integrates psychiatrists, educationalists, nutritionists, occupational therapists, psychotherapists and youth workers that wraps around the whole family should not be seen as ideal but vital.
3.5 The needs of adoptive parents and how they are met

“I really hope someone out there listens to us...I hope other people have said something similar to me, so that people do listen and then they will see there is a need for this, that and the other.”

This section of the report looks at the support needs of adoptive parents and the extent to which current service provision in Norfolk adequately prepares them for their parenting role and supports them through it.

3.5.1 Information and preparation - Understanding adoption

The comments we collected from our foster carers tell us that the needs of looked after children are complex, in addition to this our comments from adoptive parents explain that these needs do not suddenly disappear once a looked after child is legally adopted.

“You can’t expect looked after and adopted children to drop their defences and ditch the strategies of survival they had developed in the context of abusive, rejecting and abusive birth parenting.” (Howe, 1998)

If an adoptive parent is to improve the outcomes of the child in their care, it is perhaps reasonable to assume that they will need to understand the needs of children who have suffered trauma and abuse. A significant number of adoptive parents in our sample stated that this was not the case. They had expected that the child would settle after a while and things would be straightforward:

“I thought adoption might be a little hard at the beginning but then the child would settle in and it would be smooth sailing like having any other child...”

With a lack of knowledge about the true implications of attachment issues and the impact of trauma on development, it is understandable that parents described themselves as feeling mystified and perplexed by the behaviours they were facing:

“We didn’t know how to handle it...we were just muddling through...you’d put him to bed and as soon as you’d go downstairs he would be standing at the stairgate screaming his head off.”

“There were some real points where we didn’t think we could manage her anymore. Extremely difficult. Extremely violent.”

Behaviours relating to underlying attachment issues were particularly difficult for parents to understand and the child’s constant rejection of affection led to adoptive mothers feeling anxious, stressed and incompetent.
"Why was he cuddling all the other mums in the playground but not me? Worse still, why was he pinching me and spitting at me and asking other mums if he could live with them instead? I felt like a complete failure. A rubbish mum."

"I never thought that years later I would be staring at a child thinking, My God, how do I try to get you to trust me?"

It was clear from our interviews that adoptive parents, unless they already had a personal connection to the world of adoption they did not understand the meaning of attachment.

"I googled it. I was at my computer on my own when I finally realised what attachment disorder was. It was a complete shock."

"I did some research. At that point I was depressed form it all. At one point I was on anti-depressants...I was just getting by day by day."

Parents could not read their child’s emotions or understand their behaviours; they could not understand why their children were not playing with toys. Toys and possessions were often destroyed and parents did not understand that this was an expression of the traumatic world their children had come from.

In addition to not being able to interpret the needs of their children, parents were not responding to the needs of their children in the therapeutic approaches advocated by adoption professionals such as Dan Hughes (founder of dyadic developmental psychotherapy).

Adoptive parents told us they were using traditional parenting methods and “muddling along”. Their comments indicate that they only discovered therapeutic parenting when they had finally asked for help, often at crisis point. Indeed some had “hung in there for years” using timeout steps and sticker charts in ignorance of alternative approaches:

"We were in a desperate state...we didn’t know what to do...we didn’t know how to help him."

"We could have avoided so much stress and heartache if we’d started the stuff we are doing now with him...we feel that many problems could have been avoided...now we are dealing with a teenager it’s hard. It’s really hard."

"We’ve needed support all the way through-except that we didn’t realise that at the time...I’ve looked back and realised it was attachment disorder and it’s not a normal childhood thing."

"They said (Family Futures) ‘why are you trying normal parenting methods? You weren’t using any of the parenting methods that people use with adopted children?’ I said no, I don’t know there’s anything different.”
Parents were frustrated that they had been using traditional parenting methods which assumed the child understood cause and effect or consequences. Not only were these methods ineffective, one adoptive mother questioned if she had made things worse. “I’m thinking to myself as a parent, am I doing more damage?”

A lack of information and education on children’s needs did not only limit the adoptive parent’s understanding of behavioural needs. Out of our parents who described their children as being over sensitive to noise or finding it difficult to co-ordinate their bodies, only three parents looked to an occupational therapist for support. It is reasonable to assume that this option of support had not been sown as a seed; that adoptive parents, particularly those who had not had children previously or foster care experience would not be able to compare their child’s developmental journey to that of a healthy child’s development. It is therefore a missed opportunity to improve the outcomes of adopted children. It might be reasonable to suggest that some adoptive parents did not know what the milestones of a healthy child looks like that generally, a three year old can ride a tricycle and use safety scissors, and a five year old can colour in-between the lines.

These gaps in the knowledge of our adoptive parents strongly suggests that in order to understand and meet the behavioural, emotional and physiological needs of their children, they need information at the beginning of their adoption journey.

There may be some truth in the view that adoptive parents are reluctant to ask for help once they have adopted - the assessment process is lengthy and intense. Prospective adopters undergo several visits by social workers to their home and as a new parent, may feel threatened in case they appear to be incompetent. However, the comments we received strongly suggested that parents did not ask for help because they didn’t really know what help they would be asking for. It seems, that adoptive parents had as one parents described: “to fall down a hole and climb back out of it before they realised they needed help.”

“I wish I had known about theraplay...we could have...I don’t know, got the cotton wool out and tickled each other’s noses on the prep course!”

Even those who already had their own birth children said they only had a “feeling something was wrong”. In other words, they had not been trained to identify behavioural and developmental issues common to children who have suffered trauma. Those who had previously been foster carers seemed better prepared:

“Because I have had experience in learning difficulties I knew that he might not develop properly so that’s something I decided to take on. So I did therapy. I did physio. I could deal with him projectile vomiting several times a day.”

This delay in using correct parenting techniques may also affect the quality of intervention and support when parents did receive it. When adoptive parents reached the point in their stories where they had actively sought help, some described themselves as feeling “exhausted”, “low” and “depressed”. These are not emotions which lend themselves well to the playfulness, acceptance, curiosity and empathy that underlies attachment based/therapeutic parenting. So not only are adoptive parents learning about therapeutic parenting later than they would like, they have far less energy to tap into the support provided and benefit from it.
I ached all over...pretending to be a jumping bean and having fun was the total opposite to what I was feeling.”

“I was on anti-depressants...the thought of doing therapeutic parenting, it just exhausted me. I just thought I don’t think I can and it’s too late anyway.”

The experiences that adoptive parents shared with us suggest that there are deficiencies in adoption preparation and home assessments. When adoptive parents reflected upon initial home visits and the questions asked they struggled to see the relevance other than it being an enhanced background check in addition to a DSB. Do the questions that prospective adopters get asked, and their answers inform recruitment and matching effectively?

“We were looked at. Our finances were looked at. Our home was looked at. Our relationships was looked at. What girlfriends and boyfriends we had in the past was looked at...everything you can imagine was looked at.”

Another adoptive parent spoke about the focus on the fact she was adopting a child of mixed race. The question raised by the social worker about cooking may have been a sensible one but was perceived by the adoptive parent, in the scheme of things, as patronising:

“And there’s all sorts of hoops. I remember because the child we were adopting was mixed race, the social worker asked us if we needed information about Caribbean cooking...I said, I think we’ll be alright. Do I need to stop cooking Shepard’s pie...its nonsense.”

“During our home visit the social worker wanted us to fence off part of the garden...I think it was to make the children feel like that this little space was theirs. Totally unneeded. We kind of made this temporary fence, but we did point out it was an invitation to be climbed over. It seemed odd.”

Two adoptive parents told us they were asked to spend time with other children because they were first time parents:

“I had to help out at a local nursery and baby-sit for my friends. I did it because I felt I had to jump through hoops for the social worker but it was over-kill and looking back, time with children who have not been adopted does not prepare you, it’s not useful...”

The voice of the adoptive parents we listened to strongly suggested preparation needs to “move on” so that the realities of adoption are presented with honesty. Adoptive parents told us that “it’s no good being soft with preparation” and we need “to cancel naivety” and manage the expectations of adoptive parents more effectively. Adoptive parents understand that social workers do not have a crystal ball and do not always know the specific trauma a child might have suffered, such as sexual abuse. It is however, reasonable to assume that all children who have been removed
from their family of origin have suffered trauma and adoptive parents have the right to information on how trauma impacts on the behavioural, social and emotional needs of children and the support they might need to access.

“They need to hammer home at preparation that it is likely you will need support and help and that is normal…”

“It was talked about as if we would go back to work…”

“Nobody talks to you about behaviour, what they might do to your home. You’re going all through this and haven’t got at this point any specific intervention. You’re just going through it yourself.”

“Parenting in the world of adoption is not the same as parenting a child who has not experienced abuse, loss and insecure attachments. You think you can love them into the perfect human being they could be and you can’t.”

An empathetic adoptive parent who had previously fostered commented that:

“Adoptive parents don’t often know that when it goes wrong, it’s not their fault. You’re taking on children with a troubled past. Whether they’re removed at birth or not, the damage is done in the womb before it starts, and that needs to be made clear.”

More than one adoptive parent had a vague memory of being told that post adoption support existed but did not know what that actually looked like:

“Post adoption support was never mentioned in specific terms…I mean, there are groups where you can go to a lecture. That’s not support though in relation to children specifically because of course no one seems willing to say ‘we will offer you this. We will offer you that’...it is not [support] discussed from the outset and you can be way down before you realise ‘Actually, this isn’t right.’

“No adoption should go forward without concrete information about what post adoption support is available...adoption support should be an integral part of the package. Not an add on. Not a bolt on.”

There are examples where families did recognise their child has needs and they need parenting support but the first port of call has not been NCC or AFFU because the post adoption support seed has not been sown strongly enough:

“Things had become very, very difficult for my husband and I...we didn’t know what we were dealing with...we didn’t know what on earth to do with him...I rang up the author of a book I’d read about the development of the brain in infancy and asked her what she would recommend. She told us that intervention was essential. But nobody in Social Services had offered us that...that was never mentioned before...the adoption had gone through and nobody at that point said you could have any kind of support.”
Adoption is an enormous role. When there are couples that have children placed with them who in some cases is going to destroy their lives and take over entirely. I just don’t think that’s fair. I find that really ugly...people are just not clued-up.”

“I'd like to talk to prospective adopters. The problem with adoption literature is that it’s like some kind of sub romantic fiction. There needs to be more information...a bank of stories online. You need to be honest about it.”

“I just feel like if they'd started it when he was two and a half when we battled all those years...it might have been different.”

Not only did adoptive parents feel there was not adequate preparation for the realities of adopting, they also told us the child’s social worker had often painted an inaccurate picture. Two adoptive parents were told by social workers that “you will have a normal parenting experience” and “they will be a little shy at first and then it will be fine.” More than one adoptive parent was specifically told that the child had “formed a good attachment to the foster carer” insinuating that there were no attachment issues.

“We were told he had a good and secure attachment to his foster carer...it was clear from the beginning that this was not true.”

Adoptive parents were also confused about how transparent foster carers are allowed to be at hand over; “When he first came to us our foster carers told us he was a little angel. They must have known things weren’t right?”

It is perhaps the responsibility of all practitioners who work directly with the child to ensure adoptive parents have a good understanding of the needs of the child they are going to care for. Foster carers and the child’s social workers should not be tokenistic during the matching or introduction process. Our foster carer interviews revealed that the bridging process, the transition from foster care to adoption was not always smooth. A foster carer said that they suspected that adoptive parents were not trained in attachment difficulties which they felt had led to disruption. The foster carer recounted two recent episodes of children who had been returned one after only two days during the bridging process because the adoptive parent was unable to cope. More than one foster carer expressed concern that adoptive parents have unrealistic expectations.

“Don’t have this illusion....it might be lovely but at the end of the day, these children have been through really negative abusive relationships and you’ll probably have behavioural problems...it’s probably going to be a real rocky road...”

Adoptive parents thought that in addition to being better informed about the needs of looked after children and how to recognise behaviours, a play therapy taster session of how to respond to needs practically would be a good idea:
“This would not only provide a more honest preparation but it makes therapeutic parenting the norm...it is a double shock...first you find out you will need support and then you sort of have a crash course in what the support looks like.”

One adoptive parent felt that clarifying post adoption support during preparation would also be useful:

“This finding out your child needs a psychiatrist or speech therapist should not come as a shock...invite the professionals to preparation. Allow us to meet them and understand the sorts of services and people we might need to help our children.”

“If you are going to take on a car that needs a lot of work, you need to know you’ve got a massive team of mechanics to help you.”

Adoptive parents expressed that whilst they felt preparation needed to be improved, the social events and workshops that were provided and on-going training was very good. Although two families felt there needed to be a greater focus on outreach therapists for teenagers. Someone who could go to your home and trouble-shoot. This would free up the social worker to oversee the case properly.

3.5.2 Emotional needs of adoptive parents

“What do I do? I’m at the point now where I can’t take any more.”

The adoptive parents we spoke to clearly demonstrated that parenting a child who has suffered trauma on a daily basis can be extremely stressful. Parents explained how adoption had made an impact on daily routine, socialising, their mental and physical health, martial, family relationships and their birth children.

One adoptive parent described the upheaval in her home:

“Your whole world is turned right upside down...you’re in a nice little place at the moment but in a minute,...it’s something very different...It’s like a hand grenade going off in your house.”

They talked about how they felt “low”, “depressed”, “despairing”, “numb’ and “unable to manage the situation”:

“It’s like being stuck in one of those glass domes with all the snow around you...it’s such an intensive surreal experience you sort of get used to that rather than the regulated world you are trying to pull your child towards...you just can’t see beyond it.”
“You’re in a constant state of stress because you don’t know what’s coming. You could be sitting here all day enjoying some peace and quiet but you can’t because you’re terrified of what’s going to happen later.”

“Parents were at times scared of their children. “It’s very frightening. It’s really, really scary.”

Two adoptive mothers spoke of clinical mental health issues such as developing secondary trauma. Two mothers had been driven to extreme desperation.

“During a period of respite my body just shut down...I had nothing left...I frequently wished I was dead. I didn’t want to be here...It was a very low time. I felt that I was in an impossible situation and I wanted to die.”

“Horrendous. Absolutely horrendous. One day I went upstairs, I got into bed, I locked the door and I thought I just want to die...please let me die.”

Others described how stress had affected them physically. They spoke of their body constantly aching, chest pains, palpitations, panic attacks and insomnia.

“It had a big impact on my health. I ended up with irritable bowel syndrome, styes, cysts in my eyes and it all lasted for a whole year. I was really run down. I ended up anaemic...”

Adoptive mothers found themselves unable to regulate their own feelings due to the constant rejection they were experiencing:

“It’s agony...you think, I’ve got to keep loving you, but you’ve just hit me with a chair and so all my instincts tell me to get away from you...It’s so hard.”

A lack of understanding of the extreme behaviours presented by children exacerbated the strain on the mother who blamed themselves for being a bad parent.

“Gosh she’s so tiny. How can someone so small be so challenging? I thought it was me struggling with things. It took about four months before my husband said, things aren’t quite right.”

The constant verbal and physical rejection of a child they so badly want to care for, affected the adopted mothers we spoke to and had eroded their confidence.

“All I wanted to do was to love him...he would not let me attach. It was heartbreaking.”
The relentless physical and verbal rejection meant adoptive mothers struggled to keep well and re-energise. Two adoptive mothers mentioned they had been off work with stress and another spoke of how they are unable to do anything else other than look after their child “I am just too tired.”

Relationships and social lives were affected too. Parents were not able to meet up with friends or other children because “they would not cope”, “we didn’t go anywhere”. Three adoptive mothers spoke of taking their children out at unsociable hours.

“I used to take him for a walk on the beach in the summer holidays at 10pm at night when there was nobody there...because I knew there was no one else there.”

Adoptive mothers felt isolated in the school playground. Whilst they acknowledged that the public could not be expected to understand the issues surrounding adoption, adoptive mothers found it difficult to mix with other mums. One mother told us “I couldn’t stand being told ‘poor you...but all children do that.’”

Other comments that revealed this gap in understanding included:

“What football team are they playing for? They should be in one by now”...and I’m thinking. ‘Please leave’ and ‘we’re having a coffee morning’ and I thought. ‘Shut up. I can’t even get them to school.’”

Personal relationships were affected, three adoptive mothers who were divorced talked about the notion of adopted children with attachment difficulties “splitting mother against father. Pulling one person close to them and condemning the other.” At the time, the intense efforts of the child to divide, created huge hurt and upset. Adoptive parents also talked about the emotional impact on birth children:

“She doesn’t have any friends. I cannot remember the last time she got invited to a sleepover or had friends for tea. She doesn’t invite them here...because you know X struggles with boundaries...it’s had a profound effect on her.”

One family regretted they had not spent more time with their birth children as all their energies were diverted to their adopted child to the extent they felt they missed some of his needs.

“He didn’t do as well as he could have done at school and we feel bad about that. He’s been assessed and should have had extra time for exams but I didn’t see that.”

“There’s nothing for our birth children. My daughter has suffered terribly...we feel as though we have let her down. She under performs in exams due we think, to her anxiety and living in a disruptive household. Services need to be more accessible and in one place.”
One adoptive mother described how you can’t carry out the role of loving your children and cosy home life because:

“You live in an awful atmosphere because these children struggle with being within a family unit as we know it...It’s like trying to put an animal that was in the jungle in a zoo enclosure...”

Adoptive parents spoke about the difficulty of explaining their situation to their wider family or friends who having shared the positivity of the adoption process are left perplexed as to why parents so desperate to have children are now not finding things easy or enjoyable. Often there is no formal diagnosis; attachment issues are not well known:

“Her coping mechanism was to have to paint and invent a persona for the outside world and it was convincing to people that if you started saying to people, Oh gosh, we’ve had such an awful night, ‘they don’t, they really don’t believe you’...I mean, you almost felt like you wanted CCTV so people could see what was going on.”

“My children haven’t got a label, they have not been diagnosed as ADHD or autistic, it’s about trauma and development and no-one gets that...there is probably damage to the brain due to her birth mother’s drug addiction but it’s not a formal diagnosis. I have found it immensely difficult to make people understand.”

3.5.3 Supporting the wellbeing of adoptive parents

The adoptive parents we spoke to did not only tell us they needed practical help but it was important to them to be supported by the social worker who is allocated to their child when support is required.

“The adoptive mother, usually the one at home trying to cope, ‘I hate you, you’re not my mum’ needs to be able to just go and say ‘Wow, what a week’ and not be judged, not be scrutinised.”

Overall, adoptive parents spoke warmly about their attached social worker and described them as committed, fantastic, supportive, understanding and nice. For some adoptive parents they were a life-line. There were some concerns about their availability. Adoptive parents perceived the workload of their social worker to be too great and three parents spoke of meetings being cancelled. They made it clear that this was not the fault of the social worker but since it is such a small team, when their social worker goes on leave or is called to deal with an emergency, they felt there should be someone else they can talk to who knows about their case.

We received three comments from adoptive parents about two things that didn’t work for them with regard to social worker support. The first was if the parent felt that the social worker had not taken their issues seriously and “trivialised them”. Secondly, if they felt the staff were not listening to them or treating them as equals.
When adoptive parents asked for help, usually at a point of crisis they wanted someone who would “sympathise” and meet them where they were emotionally.

“There were mixed messages about respite. One family told us that they begged and begged for respite but were told there was a funding issue, resulting in no respite. “We called the emergency duty team. Respite was offered the following week, but it was too late.” Another family were offered respite and then told it was not possible.

It is perhaps thought that the extended family of adoptive parents should be able to provide respite if required. However, for children who continue to display challenging behaviours, this is not always possible and should not be assumed. One family drew attention to the fact that because their lives were so focussed on their child’s needs everything else was crisis managed. They did not feel the family was anywhere near functioning.

“3.6 Supporting the wellbeing of adoptive parents

Whilst practical support was important to adoptive parents, comments indicated that feeling listened to and understood by professionals was of great importance to adoptive parents. Attachment issues and complex behaviours of looked after and adopted children remain hidden from the general public, which, as discussed previously, can cause the adoptive parent to feel isolated and lonely. Therefore often the lifeline of the adoptive parent, the only people that get it or should get it are professionals, such as social workers and GPs.

But GPs were not always able to support adoptive mothers:

“I went to the doctors to access counselling or something I was very, very worn down...I was just sent away with a list of options and I got home and thought there’s too much information here. I just needed someone to say you turn up on Thursday at 5pm. I rang the number, it was an answer phone. I left my details and no-one rang back. I rang again a week later and just got the answer phone and just thought I’ll just have to cope.”

“I was offered CBT for secondary trauma. I did a couple of sessions but I couldn’t see how it was going to help and I was too tired to carry on.”
Adoptive parents wanted a face-to-face chat with someone and a coffee when things were difficult, someone that understands. The counselling service adoptive parents accessed had mixed reactions. Just as parents might not have gained the most out of play therapy sessions due to timing, this could explain the discrepancy in the comments received about counselling. In other words, by the time an adoptive parent is able to access counselling they do not wish to be told how to parent or explore issues in their own childhood.

“I had counselling sessions which I found more harmful than helpful. You know, bringing up stuff from my childhood. Making me vulnerable emotionally wasn’t helping… I felt that they were looking at me and showing me where my faults are, showing me I wasn’t good enough and making me feel like I wasn’t a good parent.”

Adoptive parents spoke highly of the buddy system set up by the NAS where adoptive parents support each other. Although our adoptive parents had heard of the buddy system, it might be that they are unaware of how beneficial it can be, to be in touch with other adopters: “Just one evening meeting other parents could set you up for the next month...”
3.7 Conclusion and recommendations

The evidence from our engagement with adoptive parents paints a compelling picture of a group of caring and committed adults that are often struggling to respond effectively to the needs of their children. The recorded interviews which Healthwatch Norfolk conducted and which have shaped our findings and recommendations represent a valuable in-depth resource to inform future decisions about services. The interviews tell the story of a group of people who have frequently been let down both in terms of levels of preparation for the challenges of adoption and appropriate levels of post adoption support.

The gap is startling between the experience of the adoptive parents we spoke to and the popular perception of adoption as a universal happy ending to a child’s journey through the care system or the completion of a childless couple’s family. The interviews demonstrate that adoption needs to be considered more as a stage on the journey to achieve the best possible outcomes for children and families and that more attention needs to be given as to how to give ongoing support to adoptive families. Against a background of tightened public sector spending it should also be remembered that effective services are efficient services and that cost of ineffective services is counted in human outcomes and the need for ever more expensive service responses in the future.

Children who are adopted are most likely to have complex needs. The explanation given to one adoptive parent that social workers do not have a crystal ball is not fair. Our evidence tells us that it is highly likely that children who have been in care will have exceptional emotional, behavioural and developmental needs. Information to help the adoptive parent prepare adequately so they might recognise and treat the needs of the child in their care will increase positive outcomes for children. The types of needs adopted children might have should not come as a shock.

Secondly, once needs are honestly discussed, the services need to be in place to support those needs. Referral criteria needs to be transparent as to what the services offer and how they join together. The needs of looked after children and adopted children are the responsibility of many agencies and services not just the social worker who co-ordinates the service response.

Recommendations

The depth of our engagement with adoptive parents (over 70 hours of focused interviews), captured above has enabled us to identify the following recommendations around better understanding the needs of adoptive families, both for the children who are adopted and their new parents.

We recommend:

- That NCC reviews its preparation for adoptive parents and includes specific training on team parenting and examples of play therapy sessions and other techniques tailored to the likely needs of their adopted child.

- Continuing professional development for social workers and other professionals should be matched with an ongoing programme of support for adoptive families.

- That NCC adopts an evidence-led approach to post adoption support and shares information about what works and what does not. This should include meaningful opportunities for professionals to share what they do and learn from each other to inform service improvement.
• NAS and CAMHS providers should establish more robust and regular opportunities to learn from each other’s practice and explore the opportunities for more integrated provision which better addresses the needs of adoptive families.

• NAS and CAMHS should look at practical forms of integration to deliver a more joined up and effective service to meet the needs of adoptive families.

• That adoptive parents are actively involved in service design and throughout relevant commissioning processes.

• Healthwatch Norfolk should make representation through Healthwatch England and other national channels that the training for GPs/school staff/health visitors should include guidance on understanding the needs of adoptive families.
4. Overview and next steps

Our work so far in relation to looked after and adopted children paints a picture of children, young people and families struggling to cope with the difficulties which they have experienced in early life. We have also heard evidence of a system that sometimes struggles to respond to the needs of children and young people and, compellingly in the testimony of adoptive parents, those who want to give them a loving home.

Healthwatch Norfolk makes no pretence that we are the first to notice this. Commissioners and service providers (long before those were the words that were used to characterise choices about health and care provision) have long identified that there is more to do and have done their best to take steps to improve outcomes. This report provides a fresh pair of eyes on the situation from an organisation that holds a remit (and a responsibility) to give an enhanced voice to those with the greatest health and wellbeing needs. We believe we have an important contribution to make, particularly if we work constructively with partner organisations. The recommendations made above are well supported and evidenced from what we have already learnt but we acknowledge that there is more that we need to do.

This report is in no way intended to be a criticism of dedicated professionals throughout social care teams and the NHS, who strive to do their best for looked after and adopted children and young people. We appreciate that these people operate under real pressures, both from the high-levels of needs associated with these children and young people and the limitations on resources within the system. This is also an area where new therapeutic understanding is emerging and, in some cases, offering a new challenge to how things have been done in the past. We commend the professionals who continually strive to offer the best service that they can in these circumstances.

What is not good enough is for us, or indeed the health and social care system, to simply say that this is too difficult, the problems too entrenched and the solutions too far out of reach to attempt fundamental improvement. Yes, the needs of children and young people who come into our care system will always be high and this will have an impact on their life chances and outcomes. This requires a commitment to the view that services can always be better (rather than the deficit view that they can never do enough).

Reflecting on the findings from this mobilisation phase of work it is certainly our view that there is more that Healthwatch Norfolk needs to do to ensure that it is an effective and trusted champion for those who are looked after and adopted. With this in mind, and in addition to the recommendations made above, Healthwatch Norfolk has identified the following overarching priorities to extend and deepen our work in this area:

- Ongoing engagement with looked after and adopted young people (including those who have recently left the care system or the adoptive home) in such a way to widen the evidence base without over-consulting with a small number of individuals.
- Ensure that the views and experiences of looked after children and young people are effectively considered in all relevant strands of Healthwatch Norfolk’s work (e.g. ongoing work relating to CAMHS).
- Explore with commissioners and service leaders the potential added value of Healthwatch Norfolk conducting or facilitating a structured, confidential consultation with professionals which captures frontline insight into strengths and weaknesses of current service delivery arrangements. This should be across service boundaries and reflect the full range of professional involvement along the care/adoption pathway.
- Pursue all the recommendations made in this report and provide updates on progress through our normal communication channels and events.
Appendices

Appendix A: Survey questions for looked after children and young people

Q1. Have you been to the doctors, the dentist or to hospital in the last 2 years?
   If yes, please rate how good you think the service you received was (1 = excellent 5 = poor)
   Dentist
   Doctors
   Hospital

Q2. Is there anything that you think would make the service(s) you used, better or more accessible to young people? (Staff, venue, opening times)
   I think health services would be better if....

Q3. If you have had any personal experiences of health services that you would like to tell us about please use the box below:

Your Wellbeing

Q4. In your opinion, what do you think are the top two things that might affect the wellbeing (happiness) of somebody who is the same age as you?

Q5. 21% of young people felt that anxiety and stress might affect the wellbeing of young people the most and 10% felt family and friends might affect the wellbeing of a young person. Please help us to understand why these things might affect the wellbeing of a young person? Please write below: I think that a young person might feel stressed or anxious because...

Q6. If you have any personal experiences you would like to tell us about in terms of the things that affect your own wellbeing please do below.

Q7. The young people in our survey told us that they would like someone to talk to about the things that affect their wellbeing. Please tick the support services or people you have accessed/spoken to in the last two years to support your wellbeing needs?
   • Family member/Carer
   • Youth worker, Psychiatrist, School counsellor, Friend
   • Teacher
   • Doctor
   • Social worker, Mentor, Independent visitor, Therapy (art/music)
   • Other (please specify)

Q8. Of the support you have received, please tell us how helpful you think it was on a scale of 1-5? (1=excellent, 2=good, 3=average, 4=not good, 5=poor)
   • Family member
   • Carer
   • Youth worker
   • Psychiatrist
   • School counsellor
   • Friend
   • Teacher
   • Doctor
• Social worker
• Mentor
• Independent visitor
• Therapy (art/music)
• Other

Q9. Overall, do you think that services could be improved to support the mental and emotional wellbeing of young people? How do you think young people who are anxious or have emotional issues should be supported?

Q10. The NHS are responsible for planning health services and they would like you to tell them more about your experiences so they can understand how to improve the services they provide, particularly for looked after children. If you are interested in attending a meeting to tell us what young people need to feel happy and healthy, please tell us in which area of Norfolk you would prefer the meeting to take place?

• Great Yarmouth
• Thetford
• Sheringham
• Norwich
• Kings Lynn
• Downham Market
Appendix B: Thematic analysis of interview with adoptive parents

Over 70 hours of interviews with adoptive parents were recorded and transcribed. Initial analysis of these transcriptions was completed using the software package NVIVO which allowed us to code the extensive body of comments as shown in the graphic below. These classifications (codes) have informed the structure of Part 3 of this report.
Appendix C: Partner organisations and acknowledgements

Our thanks go to the following organisations and individuals whose participation and collaboration allowed us to write this report:

- The Norfolk In Care Council
- Looked after children and young people across Norfolk
- Adoptive parents
- Foster Carers
- Norfolk Adoption Service (NAS) (formerly AFFU)
- Healthwatch Norfolk Children and Young People’s steering group
Glossary of terms and abbreviations used in this report.

GLOSSARY

These are definitions for non-specialists. For more information, visit the Social Care Institute of Excellence (SCIE) website or the British Association for Fostering and Adoption website (www.baaf.org.uk).

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tr>
<td>Aspergers Syndrome (AS)</td>
<td>A developmental disorder related to autism and characterised by awkwardness in social interaction, and preoccupation with very narrow interests.</td>
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<tr>
<td>Attachment</td>
<td>A secure attachment with a main caregiver, usually a parent, allows the baby or child to develop physically, emotionally and intellectually. Babies and children who have not had their needs met can, this lead to behavioural, emotional or social difficulties. The child may reject the carer’s attempts to care for them as they have a deep rooted fear of adults.</td>
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<tr>
<td>Attention Deficit (Hyperactivity) disorder (ADD/ADHD)</td>
<td>A group of behavioural symptoms that include inattentiveness, hyperactivity and impulsiveness. People with ADHD may also have additional problems, such as sleep and anxiety disorders.</td>
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<tr>
<td>Autism</td>
<td>A neuro-developmental disorder characterised by impaired social interaction, verbal and non-verbal communication, and restricted and repetitive behaviour.</td>
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<tr>
<td>Birth Parents</td>
<td>Biological parents as opposed to adoptive parent.</td>
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<td>Care plan</td>
<td>A document that sets out the actions to be taken to meet the child’s needs and records the person responsible for taking each identified action.</td>
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<tr>
<td>Child and adolescent mental health services (CAMHS)</td>
<td>CAMHS is an umbrella term that covers a range of universal (GPs, health visitors) and specialist services (psychiatrists, psychologists) which support children and young people who are at risk of, or are experiencing, mental health problems. In order to support foster and adoptive families, there are specialist LAC teams.</td>
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<tr>
<td>Complex Needs</td>
<td>If a child has been diagnosed with an illness, disability or sensory impairment that needs a lot of additional support for them to live day to day, they might be described as having “complex needs”.</td>
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<tr>
<td>Dyadic Developmental Psychotherapy (DDP)</td>
<td>Dan Hughes, a Clinical Psychologist, created Dyadic Developmental Psychotherapy (DDP) as a treatment for families with adopted or fostered children who had experienced neglect and</td>
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abuse in their birth families and suffered from significant developmental trauma. DDP is based on attachment theory which promotes the bond between the caregiver and the child.

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<tr>
<th><strong>Independent Reviewing Officer (IRO)</strong></th>
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<td>Registered social workers who are independent from the local authority promote who the health and welfare of looked after children and young people. They ensure the care plan in place is accurate, reviewed and updated and that any physical, emotional health needs identified are met.</td>
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<th><strong>LAC nurse</strong></th>
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<td>A designated nurse who is dedicated to carrying out health assessments of looked after children.</td>
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<th><strong>Life-story work</strong></th>
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<td>This helps children in care or who have been adopted to understand their past and help them to achieve a sense of identity. Photos, letters or other information might be used to help to explain how they came into care.</td>
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<th><strong>Permanence</strong></th>
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<td>Achieving a legally permanent, nurturing family for a looked after child or young person.</td>
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<th><strong>Placement</strong></th>
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<td>The foster home where the child or young person is living.</td>
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<th><strong>Placement Stability</strong></th>
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<td>A phrase used to indicate that a child or young person is living somewhere that those responsible for their care are unlikely to move them out of and that the young person is unlikely to change or move away from.</td>
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<th><strong>Preparation Group</strong></th>
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<td>Training that prospective adoptive parents attend in order to prepare for adoption.</td>
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<th><strong>Residential Care</strong></th>
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<td>Care for children and young people living away from home in children's homes and residential special schools.</td>
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<th><strong>Sensory Processing disorder (SPD)</strong></th>
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<tr>
<td>SPD (or SID Sensory Integration disorder) is a neurological disorder that results from the brain’s inability to integrate certain information received from the body’s sensory systems. The individual reacts in an extreme way to normal things that he or she experiences. For example, the child may have a low tolerance of noise or feel overwhelmed by a visually busy environment.</td>
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<td><strong>Resilience</strong></td>
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<tr>
<td>A term used to describe a person’s positive ability to respond to stress despite challenging or threatening environments or circumstances. Looked after and adopted children have not got the same level of resilience as children who have remained with their family of origin which makes them very vulnerable.</td>
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<th><strong>Sensory Modulation Disorder</strong></th>
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<tr>
<td>A category of Sensory Processing Disorder (SPD) and the most commonly diagnosed form of SPD. When a child has poor modulation, his/her responses may be over reactive leading to sensory defensiveness, under reactive, sensory seeking or fluctuate between these.</td>
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<th><strong>Turner Syndrome (TS)</strong></th>
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<td>Females with Turner syndrome often have a wide range of symptoms and some distinctive characteristics. Almost all girls with Turner syndrome are shorter than average and have underdeveloped ovaries. Other medical problems are associated with the syndrome such as; a heart murmur and kidney infections.</td>
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<th><strong>William Syndrome (WS)</strong></th>
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<td>A non-hereditary syndrome which occurs at random and can effect brain development in varying degrees, combined with some physical effects or physical problems. These range from lack of co-ordination, slight muscle weakness, possible heart defects and occasional kidney damage. Hypercalcaemia - a high calcium level - is often discovered in infancy, and normal development is generally delayed.</td>
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