



National Development Team **for inclusion**



Reviewing the Commissioning of Services for Children and Young People who Challenge

End of project report

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1. Introduction

Following the investigation into abuse at Winterbourne View, there has been a cross government commitment to transform care and support for people with learning disabilities and/or autism whose behaviour challenges services, including behaviour that can result in contact with the criminal justice system. Transforming care is about building community capacity as well as reducing inappropriate hospital admissions, and in October 2015 a service model was published describing what good services and support should look like¹. Services for children and young people are included in the model. In order to support the implementation of the model for children and young people, National Health Service England (NHSE) funded a number of projects, including a project by the National Development Team for Inclusion (NDTi) with In Control to develop a review of local commissioning arrangements for children and young people with learning disabilities and/or autism who challenge. This report briefly describes the project, pulls together key themes from the pilot sites and highlights good practice examples from the areas we worked with.

¹ Local Government Association, ADASS & NHSE (2015). Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition. See:

<https://www.england.nhs.uk/learningdisabilities/natplan/>



2. Developing the review

NDTi already have an evidence based review tool for adult services for people who challenge, developed from the commissioning guide written by NDTi for the Department of Health to support implementation of the Mansell report. For further information see: www.ndti.org.uk/publications/ndti-publications/commissioning-services-for-people-with-learning-disabilities-who-challenge- The review uses the seven broad areas of commissioning consideration set out in the guidance. These are:

- A clear vision and set of values
- Strong, Knowledgeable and empowered leadership
- Strong relationships and a 'no-blame' culture
- An evidence based service model
- Skilled providers and support staff
- Evidence based commissioning
- Other commissioning actions (such as up-front investment to ensure skills and resources are in place at an early stage; flexible contracting and shared financial risk between commissioners)

We used this tool as a basis for developing a draft review for children and young people's services.

2.1 To inform the review we consulted with a group of young people organised through KIDS and consulted with families through a series of six dedicated meetings plus two additional meetings where families were present. We also posted questions on a closed Facebook page (seven responses), and conducted four telephone interviews. We adapted the review based on their feedback (see below).

2.2 We identified five pilot sites to test out the review. One site subsequently dropped out. Due to the time restraints, we got agreement from NHSE to carry out the final review in April, once the pilot was complete. The four sites we worked with were:

- Newham
- Leeds
- Cheshire East
- Rutland

The fifth site we are working with in April is Rotherham. Each site receives a confidential report based on our findings and an easy read summary. We are very grateful to the sites for enabling us to pilot the review in the timescales given. Reviews such as this would normally have a two month lead in, so the effort required to collate information and arrange site meetings should not be underestimated.

At the end of the pilot we adapted the review tools based on feedback from the sites. As agreed with NHSE we will not publish these as the review needs to be carried out by independent reviewers. However we have included what we learnt in this report.



3. Feedback from young people

Below is a summary of feedback received from young people that helped inform the draft review:

3.1 The young people we talked to accessed a number of services including Physiotherapy, hydrotherapy, the GP, the hospital consultant, KIDS, short breaks, youth groups, college and residential college, work placements and both mainstream and special schools. Service flexibility is important, as is the ability of services to work together to improve outcomes. For example one young person talked about how having physiotherapy at college helped him relax, and another young person talked about how the combination of hydrotherapy and physiotherapy had helped strengthen their legs, and as a result they were able to go horse riding which is very important to them. Therefore, well planned services and supports enabled people to get better lives. The ability to access activities beyond traditional services was also crucial for improved quality of life.

3.2 It was important to really understand what people wanted to do with their lives and focus on these outcomes. One young man talked about how he enjoyed horticulture, but as a result he had been given a work placement in a florist. It hasn't helped him get a job. In contrast another young man was fulfilling his dream of doing a football coaching course at college and is going on to level two. He has personal assistants (PAs) and they ensure he has a chance to prepare for lessons, and put words into his word bank. He has an Education Health and Care Plan (EHCP) and his PAs are funded by education and social care. Although health funding is separate they were part of the EHCP discussion, and support was coordinated.

3.3 With regard to planning for the future, Circles of Support, college tutors and third sector organisations such as Riding for the Disabled were all mentioned. Having support to live on your own, despite parents' concerns was also mentioned, highlighting the importance of positive risk taking. However parents were also mentioned frequently as being a great source of support.

3.4 Thinking about what has worked well for young people, becoming more independent and learning responsibility was highlighted. KIDS had 'massively helped' with building independence, increasing social skills and helping to ease parents' concerns. Speaking up when things went wrong increased confidence. One young man had taken part in making a video to help public transport become more inclusive, after his brother (also a wheelchair user) had been left on the platform as only one wheelchair was allowed on the train.

Having appropriate health support – for example a back operation to increase mobility, was also important.

3.5 Things that didn't work well included a lack of accessible public transport, the job centre not meeting the young persons' needs and work placements that did not help people get jobs. There was still a lack of accessible information and some staff talked to parents rather than the young person. Support workers needed to be working in the young persons' best interests but this was not always the case.

3.6 With regard to what needs to change, young people were concerned that college courses were not always flexible enough to meet their needs or enable them to get jobs. Rather than having to fit into courses, young people said it would be better if they were asked about what they needed, and were able to be part of designing courses. They felt that sometimes they were sent on courses for the sake of going on a course, rather than as a route to get a job. Courses that improved confidence, helped people travel independently, manage money and cope with vulnerabilities were also mentioned. There was not enough work experience, and options were limited. For example working with children was offered rather than finding out what people really wanted to do. In work support also needed to cater for individual needs, including training on how to deal with different situations and people.

3.7 Young people wanted more opportunities to be listened to and involved. They felt they were often told what was happening rather than being asked for their opinions. People could also be rude, and lacked understanding about the issues young people faced. Creating a video to tell people what you want and how you cope with situations was thought to be a good idea.

3.8 Young people wanted information kept simple, with short statements and simple words. Information needed to be relevant to the situation and photographs could be helpful. Having a video meant it was possible to watch it again which was helpful, but the video should include young people the group could relate to. It was important to consider the pace of information giving and slow down.

3.9 None of the things outlined in the above paragraphs are unusual, and highlight the importance of ordinary life outcomes for young people with special education needs and disabilities, rather than the specialist 'challenging behaviour' service inputs that are sometimes offered.



4. Feedback from families

The feedback from parents below also helped inform the draft review framework:

4.1 The parents we talked to had little knowledge of any support services, resources or information that didn't require a diagnosis to enable access. This was frustrating as they felt it forced them to reach crisis point before services were offered, and without a diagnosis they fell through the gap. Professionals approached included Children's Autism Outreach Team (CAOT) key worker, the class teacher, the GP, the occupational therapist, Paediatrician and class teaching assistant. Worryingly social workers were avoided for fear of a judgement being made on their parenting skills or a safeguarding alert resulting in their child being taken away. One parent commented: *"often it goes a lot further than it needs to (if a social worker gets involved)"*.

4.2 Parents generally felt they shouldn't have to wait for a service because in their experience they had to be at crisis point to be eligible to get a diagnosis and thus a service. At crisis point waiting wasn't an option. If preventative intervention was offered to reduce and manage behaviours that challenge without a diagnosis, they felt they could stay out of specialist services longer. One parent said *"There is no system in place to reassure you, you haven't been forgotten, lost"*

4.3 It was really important to understand the family situation and giving parents tools and strategies to work with their children. Comments regarding what worked included:

"The CAOT worker doing a home visit and observing our family situation."

"Giving us hope and resilience to put boundaries in place for our daughter"

"We have a communication symbols to use at home now"

"I have activities and exercises to do at home, I don't feel so useless"

A good classroom environment was important along with short breaks. One parent observed of another: *"She came to support group with her two young children"*

(siblings), whilst her son was at home with a relative. She was so desperate for sleep she was curled up on a sofa whilst other mums and staff supervised her children. She is currently battling for respite and support for challenging behaviour at home especially through the night, but no energy to be assertive. Little knowledge of assistive technology to aid supervision”.

4.4 Staff were not always sufficiently skilled in working with children who challenged or children with autism. One parent said:

“I feel my son is managed and contained not receiving therapy”

Schools were not always flexible enough to meet young people’s needs. One parent described how her daughter was left at school while the class went out.

“The school tell me she is a danger to herself and others. I want my daughter to have the same opportunities as other girls of her age”.

For another parent, a change of personnel at the school was detrimental:

“My son was at mainstream for 8 years. Everything changed when a new headmaster arrived and he got a new TA. No one understood his sensory sensitivities which led to challenging behaviour. He was moved out of the classroom and worked in the corridor. He was also banned from school trips and frequently sent home from school. I often tried to let them know what would help, but they never took my strategies on board. I took my son out of the mainstream school in 2015 to a special school. He is now thriving”.

Children’s ‘reputations’ could become self-fulfilling:

“The New school read all the reports from professionals and expected the worse, so they got it!”

Another parent said:

“...Everyone expects him to behave badly and he does, he seems to like the attention. We are lost and can’t change things”

Parents said that professional support in the community was lacking, and that those on the front line needed to be given more information about what was available or at least know where to get it. They felt that there was a reluctance to refer on relating to a lack of understanding about how difficult things were at home:

“I feel that I tell people what behaviour is like at home, but if he does not display that with the professional it feels like they don’t believe me”

Waiting times were far too long, and referrals weren't always to the right service: *"I'm fed up with getting sent back and forth"*. Plans were sometimes changed without an appreciation of the impact on the family and professionals did not always turn up to meetings, which was particularly difficult when it was the annual review. Parents did not receive the information they needed: *"Most information I had to find myself on line or from other parents on Facebook"*. Information and support that would help included: Access to peer support, good stories, video and leaflet 'how to' guides.

The impact of service failures on parents was profound. One parent said they were:

"Scared witless that he'll be sent away like I read in the news"



5. Learning from the reviews

This is not a report on the review framework itself, whether it worked or not in process terms and helpfulness to local authorities, although this is touched on in section six, it is about the learning from the reviews. The sites we used to pilot the review were all very different in terms of geography, the way in which services were organised and the issues they were facing. With only four sites, this is also a very small sample, however some themes did emerge, which also chimed with the wider experience of the reviewers. Therefore the following section describes some of some of the key commissioning and service issues in relation to children and young people who challenge that were identified through the pilots including notes on positive practice that was identified (Section 7). We hope this will prove useful to NHSE as it raises some issues for national and local consideration that need to be addressed to improve commissioning for this group of people.

5.1 Terminology

The terminology used in the Local Government Authority (LGA), the Association of Directors of Adult Social Services (ADASS) and NHSE Service Model regarding people who display behaviour that challenges is generally not familiar to commissioners or staff in children and young people's services, and often had to be explained by giving examples. Children with behaviour that challenges were sometimes described as children with complex and additional needs or children with social, emotional and mental health needs, but these groups included a wider cohort of children and young people rather than just those with learning disabilities and or autism. The Service Model gives some helpful examples of the people it is for on pages nine and ten, but it isn't clear how well known the model is in children's services. It would be interesting to know if the other projects came across similar issues and whether further clarification at a national level could be sought.

5.2 The focus and purpose of Transforming Care

There was some confusion about the focus of the Transforming Care Programme and what it was aiming to achieve. For example, in one area there was evidence that the profile of Care and Treatment Reviews (CTRs), while important, had narrowed the focus of concern just to those individuals being admitted to health

commissioned beds. Thus, children and young people being sent to residential schools were not seen as an issue as they did not warrant a CTR, even though there is some evidence that this can lead to a life in institutional settings.

Transforming care is of course wider than CTRs but the focus on a specific group, rather than services for all people with learning disabilities and or autism, may make the programme seem less relevant to children and young people's services. This could be partly because of the terminology issue above, and related to this, children and young people's policies tended to be written for a wider group of children and young people with a focus on access to universal services and inclusion. In contrast, adult services tend to have specific policies on adults who challenge services.

There was a distinctly 'adult' focus to some (but not all) Transforming Care plans with children being included as an 'afterthought'. This is unfortunate as bad reputations often start young and are reinforced and magnified as the young person progresses through transition (as noted in the feedback from families above). A whole life perspective should address this issue, but in some cases children and young people's services hadn't been well engaged. Work had been done on returning children and young people back to county, and reducing the numbers going out, and was recognised as important, but it will be important to ensure that 'Transforming Care' is linked to wider local commissioning strategies for children and young people across agencies, including building community capacity and resilience so that mainstream services can play their part.

5.3 The role of education

The drive towards academies and the academically driven performance regime in schools, set against the climate of austerity, is a disincentive to inclusion in mainstream schools for some. We were presented with evidence of children who challenge being excluded from mainstream school for these reasons, and the range of options for them is narrowing. For children and young people, the role of education is of course very important, but it is missing from the national Transforming Care agenda. The role of OFSTED is also crucial within this debate, not least in including Equality duties within its inspection focus.

Linked to the above, we found a range of non-aversive techniques being used in areas, but no area had adopted a uniform approach, and it was thought that engagement of education in such an initiative would be difficult. There were examples of Positive Behaviour Support (PBS) implementation, but PBS was not widely known about across services.

Education Health and Care Plans (EHCPs) were in some areas 'education driven', and in other areas there was an absence of health. Thus currently many children and young people were not having their holistic needs addressed through EHCPs. Although one area in particular had used the implementation of EHCPs as an opportunity to embed person centred approaches, generally the approach was still process orientated, and could be quite bureaucratic. As noted by the young people from KIDS, a true person centred approach was important to get beyond a superficial understanding of needs.

5.4 Preparing for Adulthood (PFA)

There were some excellent examples of PFA planning, including the development of flexible college courses based on feedback from young people with an emphasis on gaining independence (highlighted as important by the young people from KIDS). However, generally there needed to be more focus on PFA from children's services, and this was particularly evident where there were generic social work teams with a focus on safeguarding, and a lack of in-depth understanding about children and young people with autism or behaviour that challenges.

Generally more work needed to be done to raise awareness of the Mental Capacity Act with families at an earlier age, to avoid the possibility of adversarial relationships between staff and families when the young person reaches 16. There seemed to be a particular issue with young people with autism who did not always understand the consequences of their actions, while technically having capacity, and the need for more skilled response.

Positive risk taking was in evidence in all pilot sites, but we didn't find positive risk taking strategies to support this practice. Having made a number of enquiries, we think that positive risk taking strategies are not common in children and young people's services, although there are plenty of examples in adult services. This is an interesting cultural difference, and is worth consideration particularly regarding transition, to develop a shared dialogue about positive risk.

5.5 Early intervention and prevention

We found some excellent examples of early intervention and prevention, and there was some good joint work with regard to early identification and flexible responses. Reducing the need for families to have to keep telling their stories was important, and some innovative attempts had been made to address this (see case study from Leeds below). However, generally more needed to be done with regard to early intervention/prevention. Working to a needs model, rather than waiting for a

diagnosis (as raised by the families we talked to when drafting the review documents), was an important step.

5.6 Support for families

As above, we found some good examples of support for families, but some big gaps too. The distrust of social workers voiced by the families in section 4 was also evident where there was a generic approach to social work and a safeguarding focus. Improved relationships were evident where there was a partnership approach to working with families including co-production.

Access to flexible short breaks was important. There are some good examples from Rutland and East Cheshire in the case studies below, but shortfalls in services within some pilot areas were also identified.

Sometimes parents did not know what support was available, and there was some evidence that this was particularly true of parents from more disadvantaged backgrounds with less resources and ability to speak up. Parents were often referenced as the best information source by other parents, highlighting the importance of a partnership approach and informed peer support. The Local Offer was work in progress, although some areas were further ahead than others. As well as including families in the development of the Local Offer, well informed staff, who could bring it to life for families was important.

5.7 Other service issues

Lack of access to Child and Adolescent Mental Health Services (CAMHS) in some areas was problematic, and symptomatic of a national shortfall, with long waiting lists and strict eligibility criteria, although some creative solutions had been found to address 'lower tier' mental health problems.

Personal Health Budgets were not generally used for children and young people who challenge, and the few examples we did come across were in relation to children and young people with significant physical health needs, where NHS Continuing Care Criteria were established.

A lack of skills in the wider workforce regarding children and young people who challenge, and autism was reported. This created barriers to accessing services and led to exclusion.



6. Changes made to the review framework following the pilot

As noted above, the review framework consists of a document for reviewers detailing what reviewers should look for and where, suggested questions and an outline review programme for local commissioners setting out what information and documents are required in advance. There is also an information sheet for participants. At the end of the two day review, there is a feedback meeting with commissioners where reviewers summarise their findings under the headings set out in 2.1. The report they receive is based on this feedback. At this session, we also asked commissioners about their experiences of the review process, whether we had missed anything out and whether we should change anything. Commissioners stated that they were generally happy with the review, and that only minor changes were required.

6.1 Changes made to the review documents based on feedback and reviewers experiences are as follows:

- Clarification on the information sheet regarding who the review is about (as per the issues made in 5.1)
- Inclusion of a question about links to the Health and Wellbeing Board, and an instruction to check the Joint Strategic Needs Assessment
- The addition of the Youth Offending team to the services included in the review
- The addition of a question about transport arrangements relating to children and young people with SEND



7. Good practice case studies

There were a number of examples of good practice from the pilot sites that we thought it would be helpful to share. They have been loosely grouped under commissioning, service delivery and support to parents for ease of reference, but often demonstrate a wider range of good practice.

7.1 Good practice examples relating to commissioning

Commissioning for Quality and Innovation payment (CQUIN)

In order to develop better coordinated care and support for families and children with complex needs, the CCGs in Leeds held consultation sessions with parents regarding their experiences and what needed to be different. Parents reported having to tell their stories repeatedly and didn't understand why different professionals didn't already know their situation. Breaking the news of their child's condition could also be much improved. As a result, a CQUIN (Commissioning for Quality and Innovation payment) was used in both the hospital and NHS community provider contracts in 2014/15 and 2015/16. The CQUIN focused on improving the areas the families had identified and delivery of more coordination of care, including the interface with Local Authority services.

Joint working by commissioned services

Cheshire East has developed a new joint commissioning unit, which operates on a 'virtual' premise, linking strategic commissioners to the commissioning responsibilities of individual teams and services.

This work is in its early stages, but a positive approach is emerging, such as the recent work on commissioning Speech and Language Therapy (SALT). Through the new partnership approach to commissioning, it is intended that pooled budgets will improve the services offered to children and young people, with improved personalisation and access to SALT as requested by the family or child/young person.

Flexible personalised commissioning

Rutland is able to make very personalised commissioning arrangements, due to several factors:

- The People's Directorate, which incorporates child and adult services, and which provides clear leadership and vision across the age range;
- The development of a formal structure- the Transitions Operational Group (TOG)- which identifies young people from Year 8 onwards, who may require adult social care engagement, or have social, emotional and mental health needs;
- The ability to network and engage very quickly with partners in schools, colleges and with families directly, due to geography and size.

7.2 Good practice examples relating to service delivery

The Best Practice Team

The Best Practice Team sits within the complex needs service in Leeds and develops local policy, provision and practice to meet the needs of children, young people and their families with special educational needs and disabilities. They are a small team but have a wide range of skills that goes far beyond project management, and have been in place for three years so they have had time to build networks and relationships across social care, health and education. This gives them credibility with the service. Projects they are involved in include:

- The Local Offer and wider SEND strategy
- Short breaks development
- Post 16 provision
- Education, Health and Care Plan development

South Cheshire College/Reaseheath and Manchester Met University with Springfield special school- developing curriculum offers for older students

Several FE providers have begun to develop interesting and innovative curriculum offers to young people with SEND, including behaviour that challenges.

Springfield special school has developed a link with Manchester Metropolitan University, which has a campus located alongside the school. Students complete work experience placements at the college, with aspirational Preparing for Adulthood outcomes, particularly linked to employment. Young people 'graduate' from the scheme, and are increasingly able to find work in the local area, following access to the scheme.

Both South Cheshire and Reaseheath colleges work positively with the LA to develop newly commissioned course options which are bespoke to the individual student, removing the need to place further from home at Independent Specialist Providers, as the course option is developed around the student and his/her needs.

Key success factors:

- Partnership commissioning and planning
- Person centred outcomes based upon the young person's views, interests and aspirations
- Increased readiness for work which should feed through to increased numbers who are employed in Cheshire East.

SCERTS (Social Communication Emotional Regulation Transactional Support)

SCERTS is based on research in child development; research that identifies the main challenges faced by children and young people with ASD; it aims to improve the life of children and young people with ASD and their families. Many of these children and young people display "challenging behaviour," associated with their autism.

The model says that the most meaningful learning experiences for children and young people happen in everyday activities at home, school or college. The most important goals are social communication (SC) and emotional regulation (ER) throughout a child's daily activities and with all the people they have contact with (TS).

The London Borough of Newham has been involved for the past three years in a project which has developed and embedded the SCERTS framework across schools and other

agencies. The project has provided:

- Training and development for school and other agencies, health , social care and the third sector across the borough
- Development of 'Lead schools' to become centre of excellence for supporting other schools
- Case studies showing pupil progression and impact of SCERTS
- Parent training workshops
- A borough-wide SCERTS conference scheduled for June 2016

SCERTS for Parents

120 parents have attended these workshops since summer 2014. All parents are welcome to request a place if they have a child aged 5-16 who has autism or social communication difficulties and they are willing to commit to the programme. They learn how to deal well with common areas of difficulty for their children including feelings of frustration, feelings of excitement and how to greet people appropriately.

The results have been very positive, with 80% of parents saying they have changed how they support their child and 90% saying that they are now more confident in supporting their child.

Some of the things parents have said after completing the course:

"My son said to me 'Mum, you really know me these days. You know me more than dad even.'"

"Now I'm more interested to ask him about his feelings, I see how important it is."

"I told his [3 siblings] what we have to do with the Now & Next board, and now they all do it too."

"The school were already doing whatever I learned so now we're all doing the same. It will make it easier to talk to them."

The Cluster model

Leeds is divided into 25 clusters based around groups of schools that have membership from Schools, Governors, the Children's Social Work Service, Police, Leeds City Council

youth service, Youth Offending Service, Children's Centres, Housing services, Third sector, Health, and local elected members. The Clusters:

- Enable local settings and services to work effectively together to improve outcomes for children, young people and their families
- Build capacity to improve the delivery of preventative and targeted services to meet local needs, with a particular emphasis on Early help and additional support
- Promote the Leeds Children and Young People Plan and the ambition of a child friendly city across the locality

The cluster geography enables data to be analysed and presented at the locality level which supports a better understanding of local need. Since 2012, cluster working has been supported by a 1% top slice of the DSG which has provided an annual £5.2m budget; this budget is allocated on a needs based formula.

The focus of cluster working is on targeted early intervention work and cluster budgets support a number of key areas including family support, social, emotional and mental health and attendance. Key to effective cluster working is local partnership and multi-agency working under the leadership of Targeted Services Leaders (TSLs). Schools gain access to cluster resources through regular guidance and support meetings chaired by the TSLs where cases are discussed and allocated to the different cluster services.

The CCGs are currently piloting joint funding of cluster support for early intervention emotional and mental health services.

The Ofsted report in March 2015 noted that "A well-coordinated locality and cluster approach results in early identification and extensive work with families according to need."

A Multi-disciplinary team attached to a special school

The special school in Newham has two sites, one at Stratford supporting children with medical health and communication needs aged 2-19 and one at Beckton supporting children and young people with very complex needs associated with autism, communication or behaviour difficulties aged 5-19 years of age.

Over the last year, initiated by the Head, a multidisciplinary team has been established attached to the school. The team is commissioned by the Local Authority and jointly

provided by the Local Authority and Health, funded via the Educational Guarantee Fund together with some health funding. The team comprises:

- A social worker – for two days across the two sites
- A CAMHS worker – one day a week mostly based at Beckton
- A Speech and Language Therapist – two days at Beckton and two days at Stratford
- An Occupational Therapist- FT with three days at Beckton and two days at Stratford
- A Paediatric nurse – full time but mostly based at Stratford as there are 45 students on care plans
- An Educational psychologist two days a week across both sites

They have supported a higher level of personalisation of curriculum access for children who are very cognitively impaired and present with very challenging needs.

The team members for each discipline provide both direct and indirect work to support the children, as well as skilling up staff expertise to meet their needs, eg implementing new strategies and developing better understanding of needs and approaches to meet those needs.

It has enabled a stronger emphasis on safeguarding of which 51% of our children and families are rag rated red.

Strength in parental engagement and reinforcing parental partnership has been vital in offering parent support. Many home visits have taken place supporting families in crisis. Members of the team also offer training to parents and undertake joint visits with school teaching staff to the home. Supervision is also provided to staffs who are working with such high needs students.

Staff describe many positive outcomes from this joint provision including a reduction in children's visits to A&E, and invaluable links to the clinic meaning specialist health staff are learning about children's needs at an earlier stage and there is direct contact with a person instead of a long referral system. Families are picked up earlier by social services and do not miss appointments. Professionals are also learning more about students when they see children in the classroom day to day and help them to understand and provide a better informed wrap around service.

7.3 Support for families

Specialist short breaks for children with a very personalised approach and support to the whole family

Children with very complex needs are able to participate in short breaks, due to the skill, dedication and commitment of several specialist foster carers, and the link commissioner for children's social care having good knowledge of individual children and young people.

In one case, a young person with significant health needs, with a life-limiting condition, is able to access four overnight breaks per month, which enables his family to be resilient and for him to enjoy his life with them.

Key to the success of these arrangements, which sound simple but are highly skilled, enabling families to live 'ordinary lives' are:

- Preparedness of foster workers to train in a range of complex health interventions
- The backing of social care leaders to develop and provide support to the foster carers
- The person-centred knowledge of the families needs, encompassing both the child/young person and parents/carers and siblings, by foster carers and Cheshire East social care staff
- A culture of 'what will it take' that the children's social care manager is developing across services to develop positive risk taking, to enable better lives lived closer to home.

Aiming high short breaks

Short breaks have continued to be known as 'Aiming High' in Rutland, which appears to free the offer from connotations which families assume relate to the need for social care involvement (for safeguarding purposes).

The neutral name descriptor is accompanied by locally driven commissioning, which is responsive to individual and group needs. For example, a group of young people with similar needs were able to access an appropriate local independent living/cookery course facilitated by the Transitions Operational Group, who knew of their age and needs. As an example of excellent partnership working, not only did the two 'arms' of social care- children's and adult services- work well together, but the LA then commissioned a highly

regarded local community organisation, Family Centre, to deliver the course at a time that was convenient to the young people.

Key elements of success:

- Liaison between children's and adult services within the local authority;
- Commissioning with anticipatory duties at the forefront of planning;
- Commissioning a local voluntary/community organisation to deliver directly to families where and when best for them.

Support to parents

Rutland is a small though geographically semi-rural locality, with some services, predominantly health, located in the nearby larger conurbations of Leicester and Leicestershire. Working with the 'social capital' within the area is an ambition of the County's Commissioning strategy, and links clearly to the commitment to inclusion within the locality. Parents and volunteers bring these strategies to life, particularly through the Sunflowers early years parents support group, and through Family Centre, which provides wide-ranging activities for young people with additional needs alongside mainstream peers.

Both Sunflowers and Family Centre benefit from volunteers with both professional expertise in the field of additional needs, and from members who have direct experience of a family member with additional needs. This creates a knowledgeable and committed local offer to families of highly effective and empathetic support.



Alongside these excellent voluntary providers, the LA commissions the local Citizens Advice Bureau (CAB) to run its SEND Information, Advice and Support Service, RIASS (SEND Information, Advice and Support Service). Here too, parents report great satisfaction with the support from RIASS- one parent who has benefited from support for 15 years, described RIASS and a particular officer, as 'being the one person at my side every step of the way'.

Sunflowers and Family Centre noted that there is more to be done- a culture of continued improvement- and wanted to be more visible in connecting to other parts of the area outside of the Oakham centre, for example, in the military base within the county.

Key elements of success:

- Commitment and knowledge of volunteers, and the social capital which they bring to support for parents, energised by their own knowledge and experience of additional needs;
- No judgement made of parents requiring support- particularly important for those children and young people whose behaviour challenges;
- LA commissioning of an independent, impartial service for IASS, which sits within the CAB, with its wider array of signposting for family support.

8. Conclusions and next steps

8.1 A two day review is inevitably designed to provide an overview of issues, rather than a detailed service review. It does not claim to be definitive or fully accurate in terms of all the detail. It is not a review of the quality of services. Its aim is simply to provide an external overview of key commissioning issues and challenges in order to offer a framework for action. In this, the framework we used seems to have been successful in identifying key issues for children and young

people's services relating to children and young people who challenge services and/or have autism, and we hope the process has been helpful for the sites with regard to progressing their plans. We plan to evaluate the review process with the sites in the next month, and ask for explicit feedback about whether it was helpful and also about the type of actions that they are instigating as a result. We will report on this in a few weeks' time.

8.2 Many of the themes identified above are not new, but some would benefit from further attention from the national team particularly regarding the messages to local areas on the importance of fully engaging with children and young people's services including education about Transforming Care, with a broad focus on the services and supports that are needed. We know that what happens in children and young people's services is crucial with regard to the future life course of individuals and their families, and thus a shared understanding about outcomes is needed.

8.3 As a result, we plan to develop a commissioning guide based on this work, which will follow a similar format to the commissioning guide NDTi wrote for the Department of Health, on which the adult review framework was based:

<http://www.ndti.org.uk/publications/ndti-publications/commissioning-services-for-people-with-learning-disabilities-who-challenge-> NDTi will do this at their own expense and will share it with NHSE CAMHS.

8.4 NDTi and In Control will promote the review, and use public speaking opportunities to talk about it. We will also host one or more webinars to promote its existence, as specified in our proposal.

8.5 We are particularly grateful to all the sites for allowing us to access their services, and for opening themselves to scrutiny by ourselves. We are grateful to the professionals who spoke to us and most especially to the parents we met and who shared what were sometimes some very difficult personal experiences. We are also very grateful to the families and young people from KIDS we consulted with when developing the pilot. Many of the themes they raised had resonance in the pilot sites.