

WORKING TOGETHER TO SUPPORT CHILDREN AND YOUNG PEOPLE WITH AUTISM

AUTISM LEARNING PROGRAMME, NORTH CUMBRIA AND NORTH
EAST ACCELERATOR PROJECT: PHASE 1 EVALUATION REPORT



contact

For families with disabled children



Contact, the charity for families with disabled children, support Parent Carer Forums (PCFs) in localities around the UK. These are led and made up of parent carers and families of disabled children and young people. PCFs exist in most localities and vary in how much capacity they have, due to their voluntary nature. Not all children with autism spectrum conditions (ASCs) have a diagnosis. Because PCFs welcome families of children with a range of disabilities and needs, in most cases the PCFs work focused on a wider group than only those with an autism diagnosis. As a result, the project and this evaluation covers the experiences, policies and approaches towards children with SEND more broadly, not only in relation to ASC.

This report was commissioned by the Transforming Care Partnership to evaluate Phase 1 of the Accelerator project, to demonstrate the successes and challenges of the programme and to provide rapid learning input to Phase 2 of the programme, running from September 2019 to March 2020. The report was prepared by Contact, the charity for families with disabled children.

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Executive Summary

This evaluation report was commissioned to identify outcomes of the Transforming Care Accelerator project (Phase 1) in North Cumbria and the North East. Phase 1 began in October 2018 and completed in April 2019 and included 13 mainstream secondary and 5 specialist educational environments.

AIMS OF THE PROJECT

The Accelerator project aims to reduce inappropriate educational exclusions and hospital admissions for children and young people with learning disabilities, autism spectrum conditions (ASCs) and/or challenging behaviour.

WHY THIS WORK WAS NEEDED

The North Cumbria and North East region has one of the highest rates of under-18s in inpatient hospital care where the child's learning disability, autism and/or challenging behaviour is a reason for the admission. Children with autism only, are now the biggest group using inpatient child and adolescent mental health (CAMHS) provision. Availability of autism-specific services is a gap in the region's provision, despite pockets of good practice. Evidence suggests better planning, joint action and more capacity in local services would prevent many hospital admissions. Ofsted's recent Written Statements of Action have required several areas in the region to improve joint working between services.

WHO WAS INVOLVED

Parent Carer Forums, supported by Contact, have played a key role in developing and delivering this programme, alongside statutory services. The forums offer a route for families of children and young people with special educational needs to have their voice heard. Throughout this project, forums have helped design the right support, recognise the young peoples' strengths and capabilities, and identify ways to intervene to avoid a crisis. Core to the approach has been an attempt to listen and respond to families at each stage of the project.

This evaluation reviews the project's activities and outcomes through data gathered in interviews and surveys. Contributors include parent carers, schools, and specialist services.

POSITIVE CHANGE FOR PARENTS, CHILDREN AND YOUNG PEOPLE

The combination of approaches outlined in this project has led to positive change for many of the children and young people. For some participating schools, a culture change is evident. Example activities and outcomes include:

- Parent carers said they were better informed and noticed positive changes at home. They felt less isolated and reported improved mental health.
- Schools were provided with bespoke training, including support with policy development, such as behavioural policies. This led to increased knowledge and resilience for some SENCOs, teachers and senior staff.

- Feedback suggests schools were making fewer and more appropriate onward referrals, for example to CAMHS.
- Improved concentration in class was seen by introducing practical tools to support sensory needs and improve childrens' environments. Teaching adjustments meant children experienced less anxiety about day-to-day learning.
- A peer network for parents and professionals working with SEND children and young people was developed. Many said this was invaluable and key to sustaining progress.
- Structured reflective time was used by teachers to share learning each time incidents occurred for SEND students. Collectively teachers planned how they would approach such situations in future. This school experienced a significant drop in fixed term exclusions.
- Appropriate cross-agency support, and working with families at a time of crisis, prevented at least three children from having to be admitted to inpatient care.

CHALLENGES

Despite the many examples of progress, a lack of quantitative data for Phase 1 means that it is not possible to know the extent to which these outcomes have impacted on all schools. Parent carers in some forums experienced frustration that some schools did not make them feel welcome. Some participants felt the process went too quickly and would have liked longer to embed the programme.

RECOMMENDATIONS

A number of recommendations are made to inform Phase 2 of the programme and to support future work, including the Mental Health Trailblazer sites.

It is recommended that:

- A two-year project is established with dedicated schools and resources to provide wider quantitative and qualitative results, linked to a research project to improve data analysis.
- Consideration is given to the capacity and skills of forums to engage with schools, with options for appropriate professional input so all forums feel supported to tackle challenges.
- Schools consider seniority of staff attending training, so staff have responsibility to influence and implement proposed reasonable adjustments.
- Schools are encouraged to share data on key indicators, and resources are made available for follow up data collection, for example six months and a year after the outset of Phase 2.
- Mental Health Trailblazer university modules include awareness of autism, impact of sensory processing, foundations of positive behaviour support, and reasonable adjustments in schools.
- Links are explored between the activities of the Accelerator project and the reduction in CAMHS Tier 4 hospital beds in Phase 2 and going forward, to ensure sustainable reductions in inpatient services.

The second Phase of the Autism Learning Programme completes in March 2020. Its outcomes will be the subject of a follow up evaluation.



Rationale for the Accelerator project

The North Cumbria and North East (NCNE) region has a high use of CAMHS inpatient services ('Tier 4'). It also has one of the highest rates of under-18s in inpatient hospital care with learning disability, autism and/or challenging behaviour as the contributing factors. This includes children and young people with a diagnosis of autism only using the majority of inpatient provision. The availability of autism spectrum condition (ASC) specific services is currently a gap in the region's provision, despite pockets of good practice, and evidence suggests better planning, joint agency action, and more capacity in local services would help to avoid many hospital admissions. For this reason, we chose to concentrate the Accelerator project on children with autism, although other groups of children with SEND also benefited.

In October 2018, the NCNE region was selected to be one of six Accelerator sites. From the start, the project aimed to listen and respond to what families in the region had shared through the regional Parent Carer Forum. The work was coproduced with parent carers of children with special educational needs and disabilities (SEND), including children with autism, throughout.

AIMS OF THE PROJECT

The project aimed to raise awareness of the needs of young people with autism, to listen to the voice of young people and their families, and to model and implement practical ways schools could improve the experience for young people with autism. This involved bringing together health and

education expertise to take steps to support children who were finding school a challenge due to their disability. The work included 13 mainstream secondary and 5 specialist educational environments. It aimed to reduce inappropriate educational exclusions and hospital admissions.

WHO WAS INVOLVED

The Accelerator site comprised two projects:

- the development of a peer network for parents and professionals caring and working with children and young people; and
- a schools' project, developed and delivered with parent carers and schools.

The foundations of the programme were based on supporting families and schools in innovative ways. The national Transforming Care team provided approximately £350,000 funding as part of NHS England's commitment to support more children and young people with autism to receive personalised care in the community, closer to home, and reduce preventable admissions to inpatient services¹.

Evidence and background to the project

The NHS Long Term Plan (2019) commits to increase access to support for children and young people with an autism diagnosis and to invest in intensive support approaches to prevent children being admitted into institutional care². It says that by 2023/24 children and young people with a learning disability, autism or both with the most complex needs will have a designated Keyworker. And that by March 2023/24, inpatient provision will have reduced to less than half of 2015 levels.

Previously, *Building the Right Support* (2015) had set out plans for people with a learning disability and/or autism to be supported closer to home. However, there are many challenges in delivering these aims. National figures show the number of young autistic people (without a learning disability) in inpatient care is increasing³. The figures also show that autistic girls are now disproportionately identified in inpatient care.

NEED FOR THE PROJECT

Sadly, figures from autism research charity Autistica, suggest that autistic children are more likely to experience bullying and mental health problems and to be left out of activities⁴. And for young autistic people with mental health needs, accessing the right support can be a challenge⁵.

The NCNE region has highlighted the need to understand the needs of their population and ensure appropriate provision of support for young people with autism and behaviours that challenge. In addition, whilst swift action was taken to

close Whorlton Hall hospital in 2019 and to safeguard the people living there, these events have focussed public attention to the issue of supporting young people with complex needs closer to home.

The Council for Disabled Children's report *The Tip of the Iceberg*, about the SEND Information Advice and Support programme, notes the challenges families face, including '*the impact of 'zero tolerance' behaviour policies on rising school exclusions*' and '*increases in fixed terms and unlawful exclusions*'⁶. It notes trends observed over time such as the impact of undiagnosed SEND and social and emotional and mental health needs (SEMH), the encouragement of elective home education and the exclusion of younger children.

This recognition of the need to improve support has driven a system-wide approach and the momentum for change demonstrated in this project has begun to make many small but significant changes for children and young people with autism and their families.

HOW WERE PARENTS AND CHILDREN AND YOUNG PEOPLE INVOLVED?

The Parent Carer Forums, supported by Contact, offered a route for families who were keen to collaborate with agencies to have their voice heard and to help design the right support for young people with complex needs, to recognise their strengths and capabilities, and to intervene with support before they reach a crisis.

Guiding principles

Working with parent carers from the outset helped to embed certain important principles into the Accelerator project.

The Accelerator's approach included:

- Coproduction: listening and responding at every stage with families, young people, educators and experts.
- Person-centred: the young person, not the service, is at the centre.
- Joining things up: peer support networks collaborating across education, health and care.
- Early intervention: getting it right before challenges become embedded and lead to crisis.
- Building resilience: for young people, parent carers and teachers.
- Autism positive: using constructive language and approaches to neurodiversity.

Co-production was a key feature of the Accelerator programme. The ambition was for all the schools and families (via the PCFs) to collaborate with each other and with outside agencies to develop strategies for more personalised child-centred support. From the outset, families

and schools collaborated to develop the learning modules.

Strong local leadership was vital in supporting cross-agency working:

- Martin Gray, Director of Children's Services at Stockton-on-Tees Local Authority, chaired the Accelerator Steering Group.
- Deanne Taylor, Head of Service, Early Help at Redcar and Cleveland Local Authority provided leadership and oversight of the Transforming Care children and young people's agenda.
- Christine Brown, Deputy Director of Quality, NHS England and NHS Improvement, with responsibility for oversight of Transforming Care and SEND.
- The Steering Group comprised a core team (below) with additional contributors: Julie Bates, NHSE; Jill Anderson, Local Authority; Maureen Morris, PCF; Sarah Thomas, Contact; Trish Churchill, Transforming Care project manager.

The combination of key skills and multi-agency approach is unique and important. The group led the project oversight and participated in the Community of Practice, set up by NHS England to bring together the NCNE Accelerator Site with the five other regions. This ensured progress and communication and engaged the right representatives.

Programme activity

AUTISM SCHOOL PROGRAMME

The Learning Programme delivered in the South region (Durham, Darlington and South Tees) aimed to create sustainable networks across schools and enhance knowledge, skills and behaviours.

The modules comprised:

- Understanding the impact of sensory processing on the child and family.
- Self-awareness and Positive Behavioural Support.
- Effective communication and its impact on setting boundaries and reducing anxieties.
- Reasonable adjustments and equality: working with families to manage inclusivity in the classroom.
- Engaging parent carers in effective person-centred planning.

Using Action Learning Sets during training helped develop a professional peer network and enabled a safe space for participants to discuss progress and challenges during the project to help tailor the plans (a list of schools involved in the programme can be found in Annex A).

PARENT CARER FORUMS (PCFS)

Each forum was allocated schools to partner with and received £1,000 funding per school (some PCFs partnered with one, others with two). In each locality, PCFs:

- Completed surveys with schools and families.

- Worked with schools to develop action plans and support schools in creating a more welcoming approach and reasonable adjustments
- Set up mini-school networks to support delivery and bring together families from the schools.

INTENSIVE SUPPORT WITH SCHOOLS AND FAMILIES

This was developed with a small number of families and gave the opportunity for:

- Children and families to access family support programmes provided by charity experts, Autism and Mind, and Daisy Chain.
- ‘All About Me’: an autism self-awareness course, tailored to children and young people and their families, delivered by experts by experience
- CAMHS additional support to schools: targeted action plans and work programmes.

NEW INNOVATIVE, SPECIALIST SUPPORT

CAMHS, positive behaviour and autism expert support. This was an additional offer to support schools to develop their:

- Workforce.
- Support environment.
- Cultural change.

Bespoke, targeted action plans and work programmes were designed around the schools’ own needs.

CHILDREN AND YOUNG PEOPLES' (CYP) PEER NETWORK: ALIGNING PROCESSES

This strand aimed to support further development and embedding of processes such as the Dynamic Support Registers (DSR), Care Education and Treatment Reviews (CETR), Education Health Care Plans (EHCP), and Annual Health Checks (AHC).

The CYP Peer Network provided project steering, led by the PCF for NCNE region.

Overall, this work:

- Raised awareness of the Transforming Care Programme.
- Listened to parent carers to understand 'what good looks like'.
- Developed shared understanding and language across agencies and families, to enable a joined-up response.
- Brought interested parties from all agencies to share practice and work collaboratively to align Transforming Care and SEND agendas, including links between EHCPs and CETR.

The work also shared information and developed understanding on:

- The 'Local Offer', for example, the availability of input from the 'intensive positive behaviour support team'.
- Annual health checks 14+.
- Legal requirements for reasonable adjustments.
- How to reduce discrimination.

PARENT CARER FORUMS

In the south of the NE region, six PCFs were each linked with two local mainstream schools to develop peer-to-peer support for parent carers of children and young people with SEND.

When developing the project, PCFs heard families repeatedly say they felt isolated and uninformed. Forums were linked into schools, aiming to:

- Bring parent carers together to reduce isolation.
- Link parent carers into the forum information networks.
- Facilitate a positive environment for carers to raise concerns around school activity and collaborate on solutions.
- Strengthen and grow PCFs.

PCFs ran coffee mornings, training workshops and provided materials. They planned meetings and events carefully to ensure parent carers felt welcomed, informed and supported.

For one forum, running a stall at a school event helped to 'normalise' their involvement and inform parents who might not otherwise know about them.

Programme developments

The aim was for the project to be co-produced at each stage, from design and planning to implementation. To support this, the programme used the 'Plan, Do, Study, Act' model to build in flexibility by trying out a change, evaluating it, and improving it⁷. During the course of the project, the team listened to participants and altered elements to respond to what was needed.

'ALL ABOUT ME'

Early on, it became clear that some families whose child did not have a diagnosis would benefit from ASC self-awareness training. The existing course only included those with a diagnosis and could not be changed at this point, so the team commissioned additional support via a learning disability and autism specialist CAMHS practitioner. In Phase 2 the 'Understanding Myself' course has been developed by autism charity Daisy Chain for all children with neurodevelopmental needs.

AUTISM IN SCHOOLS FILM

We wanted to hear and understand young autistic people's views more directly. Families involved wanted a way to show the day-to-day experience for children in mainstream schools. The team commissioned North Cumbria CCG and autism charity Triple A to co-produce a film and eBook. The film was launched in May 2019 and has been shared widely across schools:

www.youtube.com/watch?v=YKnmIEMxkhs

ANNUAL HEALTH CHECKS

Catcote school in Hartlepool delivered a project on learning disability Annual Health Checks 14+, including merchandise and film encouraging young people who have special educational needs, to access their annual health check.

<https://nhsjoinourjourney.org.uk/what-we-are-doing/priorities/learning-disabilities/>

EQUALITY SEMINAR

Arranged by PCFs for schools and families: development work identified a need for awareness on equality law, discrimination and rights.

LOCAL VOLUNTARY RESOURCES

Elements of courses were delivered via local organisations, such as the autism charity Daisy Chain, who ran continuing professional development (CPD) programmes supporting local sustainability and development of relationships between the voluntary sector and education, health and care services. The project also paid for a license to the Autism Education Trust, a programme set up by the DfE to improve educational access, experience and outcomes for children and young people with autism.



Outputs from the programme

Between December 2018 and October 2019, a range of positive outputs were achieved:

Type of output: Schools and Families	Number
Reach of the forums in Cumbria and North East	5,765 parent carers
3 PCF sessions attended	approximately 32 participants
Families and schools: mini-forums established regular meetings	around 20 additional parent contacts for each school
Initial CETR awareness training: train the trainer session	10 PCF reps
CAMHS intervention support for schools	247 contacts with professionals in schools 14+ sessions; action plans with all mainstream schools
Schools learning modules (schools and PCFs)	13 mainstream and 5 special schools; 5 modules, 2 learning sets, approximately 70 participants
The charity Daisy Chain delivered Myth Buster training	attended by 193 school staff

Young People directly involved	Number
'All about Me' course	2 courses, each with 15 young people and parents
Children and young people's film production	1 film, showing what it is like for children in school, what schools can do differently
Improving uptake of Annual Health Checks (AHC)	Young people from 1 School (Catcote) designed promotional merchandise, presented at a Children and Young Peoples' peer network and completed a film.

Type of output: Culture and Awareness	Number
Children and young people professional peer network membership	4 meetings held, up to 200 attendees over the year, from PCFs, health, social care and education
CETR training for professionals, including DSR and TC awareness-raising (majority of CAMHS services reported no understanding of CETR prior to training sessions)	5 awareness sessions held for practitioners: first event 92 attendees; repeated for 80 attendees
'Local Offer' awareness	PCFs working with 13 local authorities to improve accessibility and information
Equality training	100 people attended from schools, PCFs, health and social care.

SPECIALIST CAMHS SUPPORT FOR SCHOOLS

The specialist CAMHS support to schools was delivered by Stephanie Carr, Clinical Lead for the Positive Behavioural Support, Teesside CAMHS, from Tees, Esk and Wear Valleys NHS Foundation Trust.

Stephanie used a bespoke approach, adjusting the scope of training for each school to meet their needs. Her input provided CPD and school policy development, such as behavioural policies. She met with SENCOs and senior members of staff at different times of day, including early and late, to suit the school.

Some occasional individual pupil meetings were held using a coaching method, so schools could see the type of advice appropriate to specific students. Specialist advice included observations with pupils, behaviour clinics for staff to share common issues, walk-round environments to understand what adjustments could support learners, whole school training, workshops, masterclasses and SENCO coaching. Training activities included 'Social Stories', 'My Incredible 5 point scale', and emotional regulation training.

Approach to Phase 1 evaluation

Most of the evaluation process has been captured in the qualitative information described below. This was provided during the evaluation event in June 2019, attended by many of the participants of the Accelerator project in one-to-one interviews with Contact, and in one-to-one semi-structured interviews led by Contact's evaluation team.

Learning modules outcomes were tracked at the start and end of the course, when schools and parent carers were asked to provide confidence ratings about how much they had learned. Surveys were carried out by PCFs of families and schools to understand how they felt at the beginning and end of the programme.

Schools were asked about data on absence rates and exclusion rates. Unfortunately, given the short time period of the programme and lag-time for data publication, this data was not collected consistently. However, examples of the type of data schools may hold are provided below.

A list of those who contributed through telephone interviews to this evaluation, as well as contributors to previous presentations, feedback and evaluation processes during Phase 1 is provided at Annex A. A list of documents provided to the evaluation can be found at Annex B.

A case study provided by the Council for Disabled Children on the voluntary sector Key Worker role is provided at Annex C.



Outcome measures

MEASURE 1: NUMBER OF SCHOOLS WHO CAN EVIDENCE NEW WAYS OF POSITIVELY WORKING WITH THE CHILD OR FAMILY. EXAMPLES INCLUDE POLICY/PROTOCOL CHANGE AND IMPLEMENTATION

OUTCOME: All schools attended the modules and the equality session. All reported they will review their policies and protocols, for many these changes are underway or already in place.

For example, schools have made adjustments such as;

- Late cards: If a child's transport is late, but the child does not explain, the teacher does not know the reason for lateness and may give a detention. This way, a pupil can pick up a 'late card' at the school office and hand it to the teacher to explain. The pupil is not then singled out in front of their peers, which causes real anxiety.
 - Environmental adjustments: One school created a small 'chill out area' for pupils struggling during the day, which the children could use if they chose to. Located close to the SENCOs, staff would attend to check on the child. This has also been beneficial for non-SEND pupils, to give them a quiet space to calm down.
 - Parents report: schools are more welcoming; sharing of information is more family friendly.
 - Including information from the Effective Communication session into the school's Communication Policy.
- Staff training in communication and social stories⁸.
 - Purchase of sensory equipment.
 - Discussion in assembly about needs of pupils with autism, taking a whole school approach.
 - Training for key support staff in person-centred planning and communication.
 - Links were made with post-16 education for ASD students, support was given to the students around opportunities and applications.
 - One school put in place a new autism 'pathway' for teaching and support staff in relation to applying interventions for a child with autism who flags as vulnerable. This includes a clear list of strategies that can be trialled and implemented to support the child.
 - One school implemented simple steps to support proprioception, based on OT-led sensory training. This included practical measures such as sitting on cushions or coats, suggesting solutions to issues around clothing, for example wearing tights under trousers to avoid seams rubbing and trying out tight vests to mimic a proprioception vest.
 - Reflective time: In one school, a group of teachers would meet to share learning each time incidents occurred for SEND students and reflect on what had happened, what calmed the situation, how they should all approach this type of situation in future.

- In one school, parents suggested the behaviour policy ‘SLANT’, (Sit up, Listen, Answer, No interruptions and Track what the teacher is doing) was causing some pupils real anxiety, because it is not always as easy for children with SEND to make eye contact, to look to the front, and so on. During the Accelerator project, the Trust made adjustments to relax the rules for those with SEND. Parent carers described the behaviour policy had caused anxiety. Children were assessed as having anxiety and a CAMHS referral was proposed. Whereas often, the children needed measures in school to support them, which once in place enabled them to remain in the classroom.

MEASURE 2: REDUCTION OF DAYS LOST THROUGH ABSENCE (TOTAL NUMBERS PER SCHOOL) – TO BE MEASURED OVER A FULL SCHOOL YEAR.

OUTCOME: Data on this indicator was not available from schools involved for Phase 1 during the time frame of the Phase 1 evaluation.

MEASURE 3: A REDUCTION IN EXCLUSION RATES (TOTAL NUMBERS PER SCHOOL) – TO BE MEASURED OVER A FULL SCHOOL YEAR.

OUTCOME:

- One mainstream school in Redcar achieved zero pupil exclusions for their SEND cohort from the beginning of the new programme up until summer term. In this period the school had expected between 7 and 14 pupils to have had multiple fixed-term exclusions (for

example, these are often a half day or a full day).

- In the period of the programme Northshore Academy school would normally have had at least one exclusion, but recorded no exclusions.

MEASURE 4: NUMBER OF AVOIDABLE ADMISSIONS TO HOSPITAL INFORMED BY LOCAL AREAS DYNAMIC SUPPORT REGISTER.

OUTCOME: It has been highlighted since the start of the project, that there has been a reduction in the number of children in CAMHS hospital Tier 4 beds in the region.

The current number in hospital is 12-15 children and young people under 18 years. This remains within the agreed target at present, however by March 2021 the target is 8-9 children. Dynamic Support Registers (DSRs) have developed in most areas and local audits show progression, with awareness of Care Education and Treatment Reviews (CETRs) improving.

- One school described three CETRs developed for three children, two of whom had previously been sectioned under the Mental Health Act within the same year resulting in hospital stays. Because of the Accelerator training and the improved cross-agency working, CETRs were successfully carried out, support was implemented, and inpatient stays were avoided (see case studies below).
- However, there is still work to be done. One teacher did not understand the DSR process and felt more explanation would

be welcome. And one forum expressed concern that for a young person for whom a CETR should be a priority, 'no one seems to know how to arrange one'. The forum Chair planned to raise this at the next SEND Strategic Leads meeting.

MEASURE 5: PERCENTAGE OF PARTICIPANTS WITH INCREASED RESILIENCE AND CONFIDENCE LEVELS

Unfortunately, data issues with the baseline survey taken at the start of the project and end of programme meant the quantitative survey data for schools and PCFs was not available.

OUTCOME: Families who participate in the project reported a range of benefits, they told us that the opportunity to be part of a school-based forum meant;

- They were better informed and there had been positive changes at home from what they have learnt.
- They feel less isolated and there had been improvements in their own mental health.
- They are learning more about what their children are entitled to.
- The school-based forum provided an official platform to raise worries and work together to find solutions, breaking down barriers between school and parents.
- Their sons and daughters appreciated them getting involved and could see they valued their education.

For school modules, quantitative evaluation showed:

- Overall average scores for the quality of learning recorded as 4.5 (4 being very good and 5 excellent).
- The highest scoring related to effective person-centred planning (PCP).
- Overall scores for the impact and usefulness, to be taken back to workplace recorded as 4.3 (1 being not useful at all to 5 being very useful).
- In terms of usefulness the highest scores evaluated on the modules for Effective PCP.
- Post-course knowledge/confidence levels have gone up by an average score of 1.4.
- The 'Increase in confidence' score (post training) by module was highest for the modules on Sensory Awareness and Effective PCP.

The CAMHS specialist noted that the schools she worked with are now more confident with managing young people with autism and have changed the way they refer students to other services, for example, not always referring to CAMHS unless diagnostic or mental health services are required. She noted improved awareness in schools, with people considering different, more enlightened approaches.

The school training covered specifics around the needs of girls with autism, who may effectively mask their symptoms and can develop eating disorders, anxiety and depression. It encouraged teachers to consider a girl's patterns of behaviour, for example relationships with close friends and how they interact.

MEASURE 6: CHANGE IN CULTURE EVIDENCED THROUGH APPLICATION OF TIMELY AND SPECIFIC INTERVENTIONS AND USE OF BEST PRACTICE RESOURCES

OUTCOME: There have been a number of examples from schools and reflections from parent carer forums (PCFs), including:

- Use of One Page Profiles, which the pupil can share with their teacher to help them understand their needs, strengths and practical adjustments to support learning, sensory awareness and adapted approaches.
- Development of ASC Champions in schools, to build awareness and upskill other staff and students. Schools reported having a toolkit of strategies for all staff to access.
- One PCF had been facing a difficult local situation for some time, and now felt rejuvenated by the project as it provided an opportunity to do something positive and proactive.

One school used 'Pupil Voice' training, which supports schools to listen to the voices and views of their autistic pupils, and put in place a sensory questionnaire for autistic students to understand their likes and dislikes including noise, textures and tastes. As a result:

- i. more sensory equipment was put into the reception level classroom and this was made easier to access (for example, signs for pupils to say what they want)
- ii. more choice was offered on the school menu

- iii. one pupil who couldn't stand the sound of her pencil now happily writes in pen.

Abbey Hill school adjusted their timetable for one child struggling with the transition from primary, whose morning routine meant he needed extra time to get ready for school. It was agreed he would start the day at 10am and he now comes in calmer and ready to learn.

- Adjustments to teaching: Parents noted the difference made by teachers allowing extra time to answer questions in class. A child may have heightened anxiety at being asked questions, because autistic children can have difficulty processing what is being asked. In some cases, the child now has a card on their desk: 'Come back to me, I need time to think of the answer'. Also, the teacher now makes sure to clearly say the pupil's name when asking them a question.
- Acknowledging sensory difficulties: teacher asking the child, what is the best place for you to sit in the classroom? Child benefited from avoiding off-putting light and reflections, also liked the structure of knowing where they would sit in the class, and found it reassuring to have their own chair.

MEASURE 7: PERCENTAGE OF PARTICIPANTS ABLE TO IMPROVE THEIR ACCESS TO OPPORTUNITIES IN SCHOOL AND THEIR COMMUNITY.

OUTCOME:

- The PCFs reported in some cases that the discussions with parent carers, enabled by their activity, resulted in changes in the way schools operated. In one school this included changes to their behavioural policy and the introduction of reasonable adjustments for SEND pupils.
- Two schools have participated in 'All About Me', improving the young people's opportunity to access and be more part of the school life. The project also benefited the PCFs themselves. Forums reported an increased understanding of the Transforming Care agenda and especially of the journey that might lead to a young person entering a residential or inpatient setting. They have developed stronger local relationships that have extended their reach in their own communities.
- Heads/Executive Heads of schools reported sharing good practice across academy trusts.
- Voluntary sector capacity building within local areas has created a legacy effect: a 'train the trainer' approach is now being explored for the 'Understanding Myself' course.



Documented outcomes and impact

WHAT PARENT CARER FORUMS SAID

Maureen Morris, regional Chair for the PCFs highlighted the positive impact that the project has had on the PCF regional network as a whole.

“We can’t underestimate the positive impact the Accelerator Schools Project has had on the PCF regional network. It has provided a focus and energy, that has brought the region together. I have seen the confidence of forums grow as they establish new relationships and develop their understanding.”

STOCKTON FORUM

“As a forum, we have found that the Transforming Care project has developed and strengthened our relationships with schools.”

“We have seen an increase in membership directly resulting from the schools promoting our service and parents have attended our events outside of the project”.

REDCAR AND CLEVELAND PCF

“For our forum, the most successful part has been the links we have made with other Forums in our region. As a new Chair, the other Forums provided much needed support, a sounding board, and allowed the sharing of contacts and training opportunities.”

FORUMS SAID

“We talked to local parents who had made complaints because their child was experiencing problems at school. We said ‘lets work through it together with the school to try to show how we can find solutions’. We encouraged the parents not to just complain about the issue but try to think of an idea to solve the issue together.

“The project created ‘chatter’ with the other schools in our area and doors that were renowned for being closed, are starting to open as SENCOs realise the benefits of open and honest dialogue with parent carers.”

The project also benefited the PCFs themselves. Forums reported:

- Increased understanding of the Transforming Care Agenda and especially of the journey that might lead to a young person entering a residential or inpatient setting.
- Stronger local relationships that have extended their reach in their own communities.
- Increased membership for some forums.

WHAT FAMILIES SAID

Families who participated in the project reported a range of benefits. They said that the opportunity to be part of a school-based forum meant:

- They were better informed and noticed positive changes at home from what they have learnt.

- They felt less isolated and experienced improvements in their own mental health.
- They learned more about what their children are entitled to.
- The school-based forum provided an official platform to raise worries and work together to find solutions, breaking down barriers between school and parents.
- Their sons and daughters appreciated them getting involved and could see they valued their education.

WHAT CHILDREN AND YOUNG PEOPLE SAID

The children involved in 'All about Me' say they feel listened to, and have gained better understanding of themselves and autism.

WHAT SCHOOLS SAID

"The training we have received and the opportunity to meet with professionals across the whole of the region has increased our knowledge and broadened our links with services."

"Our biggest success as a result of this project is that we now have a group of parents willing to take forward a school parent carer forum, which we will support to develop their skills in working with the school to improve the setting and the experience that their children have."

"If child is struggling, we make a bespoke timetable to ensure the young person is in school. We've learnt to be structured but flexible around timetable, as children

respond better to structure, but it's done in negotiation with them. So for example, if the noise in the DT room is too much, what could we give them instead?"

NORTH SHORE ACADEMY

"The project immediately opened doors to a range of support networks and CPD development solely centred around autism. This has allowed for a bespoke package that can meet the needs of children and parents in our academy."

FEEDBACK FROM HEAD OF SCHOOL RYE HILLS ACADEMY

"The academy has benefited from the training and it has strengthened our good practice around supporting ASC students. We especially found the support provided by Stephanie Carr (CAMHS) invaluable... her observation feedback of ASC students has provided additional strategies to support struggling learners and the training she gave on emotional regulation has been used for whole-staff CPD. The 'All About Me' sessions for our Year 11 ASC cohort have been extremely well received by students and has increased their level of self-acceptance. Through the project we have developed links with the Redcar and Cleveland Parent Carer Forum, which we hope... will... improve how we work alongside our parents to support SEND children. The training... has strengthened our policy around reasonable adjustments and our knowledge of sensory processing."

ABBAY HILL ACADEMY (SPECIALIST EDUCATION):

“We’ve had the opportunity to offer staff extra training. We were offered sensory training and a trainer came into school for the day, so 10 staff were able to attend. Many of the staff said it was the best training they’d ever had.”

LONGER-TERM IMPACT OF THE WORK FOR CHILDREN AND YOUNG PEOPLE, FAMILIES AND SCHOOLS

Here are three examples of the young people whose lives have been changed by the Accelerator project. The project improved cross-agency working and person-centred support to enable this to happen.



CASE STUDY: A

‘A’ is a young man whose needs had reached a crisis point. Teachers had noticed behaviours consistent with ASC, however a diagnosis took time and during this period ‘A’s needs had intensified. Through the Autism Learning Programme training, the school found out about the CETR process and then worked with other agencies to put in place a CETR. ‘A’ now has funding for one-to-one support and has a bespoke school timetable in agreement with the local authority, who now fund his transport. ‘A’ also has regular counselling sessions and the correct medication. Fortunately, the mental health needs of ‘A’s family have now been recognised and the whole family approach includes respite support. Regular meetings keep the different agencies in touch.

As a result, ‘A’ has now increased the amount of time he’s in school and in the classroom, whilst getting support he needs. The staff are better equipped to understand ‘A’s autism needs and are feeding this into the CETR process. They now feel confident to prevent ‘A’s mental health needs exacerbating.

CASE STUDY: L

'L' is a young teenage girl whose cognitive ability is much younger than others of her age. Because she can communicate well verbally and appears to be quite grown up, she is particularly vulnerable in the community. 'L' had been turned down several times for social care support but she was experiencing problems at home and in the community, including forming inappropriate relationships. Through the CETR process, the panel could see the school was already taking the right steps but her needs outside school were not being met. As a result, the appropriate support was put in place to prevent 'L' from reaching a crisis and a likely inpatient stay, and 'L's family was better supported to understand her needs.

CASE STUDY: P

One parent whose son has SEND had struggled to get extra time for him in exams. He was not predicted to do well. As a result of the learning in the programme, the school reassessed 'P's' learning needs and he was allowed extra time. He moved up 2 grades because he had had time to respond to questions appropriately. This has had a significant impact on 'P's confidence and future options.



Reflections and learning from Phase 1

To understand what factors might affect how successful schools have been in implementing the various elements of the programme, we can consider some specific challenges highlighted during the evaluation process, and the possible lessons that could be learned:

PARENT CARER FORUMS

Each forum developed their relationship with the schools at a different rate, depending on the individual circumstances at each school and the capacity of the forums. Some forums were actively involved in other key local pieces of work and this inevitably impacted on the school project.

RECOMMENDATION: In future projects of this type, consideration should be given to the capacity and skills of the forums to engage with schools. This would help their effectiveness, for example offering the option of a professional to attend an initial meeting with the school.

A small number of schools were not as welcoming of forums as expected. Perhaps they did not recognise the importance of the school in facilitating the role of the forum across parent networks. For example, one forum was not allowed to put up information on a display board. As a result, this forum only had a few attendees and found interactions with schools were not as effective. In such cases:

RECOMMENDATION: Greater Local Authority or SEND team input would help to make contact with other school parents.

Forums asked that consideration be given to involving them in discussions about the choice of schools selected for the project. Whilst this may be difficult in practice to achieve in a short project mobilisation timeframe, it is worth noting that the choice of school is likely to have an impact on the effectiveness of PCF activities. In one experience, a forum was paired with an academy trust whose policies run through multi academy schools. The forum found this school more rigid in its response and policies have been more difficult to change than the other school it worked with.

RECOMMENDATION: Consideration is given to involving forums in discussions about the choice of schools selected for the project.

TRAINING AND CAMHS SUPPORT

It was noted that where the support worked well, this was often due to the seniority of the staff involved or championing the work. If a junior staff (for example, teaching assistant) attended several training sessions without involvement of more senior staff, the required adjustments to school policies and timetabling, for example, would be impossible and other changes would have a reduced impact. Nor was it possible, in these cases, to gain insight as to why certain interventions tried in the past had not worked.

RECOMMENDATION: Schools consider the seniority of staff attending training in light of this finding.

YOUTH OFFENDING TEAMS

RECOMMENDATION: In future, it is recommended that opportunities are identified to link in with youth offender teams, due to evidence of the growing number children and young people in this group diagnosed with ASC and other neurodevelopmental needs.

FOCUS OF SCHOOL LEADERSHIP

During the Accelerator project it was noted that one or two of the schools involved in the project were under substantial pressure from elsewhere due to action by the regulator or other significant events. This understandably meant they were less able to engage in the programme due to capacity and availability of leadership focus.

QUANTITATIVE DATA COLLECTION AND ANALYSIS

The Accelerator project asked about data in schools on exclusions and absences, and asked PCFs to carry out a survey on schools and families. However, for Phase 1, data was not a main focus of the programme and the extent to which schools contributed and PCFs were able to share survey findings has been varied. As a result, the evaluation of Phase 1 is light on quantitative impact assessment. However, it is anticipated that the baseline and follow up survey for Phase 2 will be improved to enable analysis and some level of impact assessment, although this will be of limited use given the short timeframe.

RECOMMENDATION: Funding should be made available for follow up data

collection, for example six months and a year after the outset of Phase 2:

- A follow up survey by PCFs of schools and families.
- A request to willing schools to share their own data on relevant indicators – to track data from January 2020, April 2020, July 2020, and December 2020.

In addition to school absences and exclusions, consideration of indicators could also include: number of reasonable adjustments made, use of internal isolation, number of sanctions, referrals to CAMHS or other possible indicators, where data is collected.

TIMEFRAMES

Several contributors noted the short timeframes of the programme and the difficulties in achieving changes in the short period. One asked if the training programme could be spaced over a longer period than three months, which would make attendance less of a pressure on staff diaries. Improved communication, such as a newsletter, was also suggested, to enable a sense of community over a longer timeframe and provide updates on what had been learned, examples of reasonable adjustments, and details of the programme to follow.

RECOMMENDATION: A longer project over two years with dedicated schools and resources could provide wider quantitative and qualitative results. Linking this to a research project would further improve data analysis.

COMMUNITY OF PRACTICE

Being part of the Children and Young People National Community of Practice has been key to the progress and delivery of this phase. The group helped to explore new ways of working and provided constructive challenge as the project developed. The NCNE team particularly acknowledge the role of Sue North and Phil Brayshaw in this process.



Sustainability and future work

Phase 2 of the Accelerator programme began in September 2019 and will complete at the end of March 2020. In this period, it is anticipated that rapid learning work will take place through the PDSA model to share these and any other lessons learned from Phase 1, and where possible to positively influence the implementation outcomes and evaluation for Phase 2.

Since the start of the project it has been highlighted that there has been a reduction in the number of children in CAMHS hospital Tier 4 beds in the region.

RECOMMENDATION: Any link between the activities and outcomes of the Accelerator and the reduction in inpatients should be explored further in Phase 2 and beyond.

MENTAL HEALTH TRAILBLAZER PROJECTS

In addition, it is hoped the lessons learned from the NCNE Accelerator project will be useful to those developing Mental Health Trailblazer projects with schools and communities in relevant localities. The two projects have several commonalities, including their early, low level intervention approach to support in schools. Both projects focus on children and young peoples' self-awareness and coping mechanisms, mental health and wellbeing. In addition, both projects work to increase skills of the workforce with the aim of improving outcomes for children and young people. There are many opportunities for learning between projects, for example to improve wellbeing approaches in Wave 3 and 4 of the trailblazers.

RECOMMENDATION: That Mental Health Trailblazer university modules include awareness of autism, impact of sensory processing, foundations of positive behaviour support, and how to make reasonable adjustments in schools. These two projects both offer an alternative model to traditional CAMHS support through the Learning Disability and Autism School Liaison roles, Wellbeing workers as well as ASC champion 'Understanding Myself' training the trainer opportunity.

CHANGING CULTURE

A key driving force, but also a challenge for the Accelerator project, has been the desire to see a change in attitudes and culture within a short amount of time. Many are keen to see these changes have an impact in reducing numbers of institutional placements. This report highlights some of the early indicators of such culture change, such as reasonable adjustments and positive approaches.

Phase 1 of the Accelerator programme has challenged the schools and families involved to focus on how they, as communities, work together to tolerate difference and listen to one another to support the young people's learning and lives. We have seen the importance of how schools use the right language with families to approach conversations, how families are empowered with information, and how teachers and others in the system respond to individual children.

The combination of tiered approaches in this project has led to real and positive change for many of the children and young people. Increasingly, participants have understood that behaviours stemming from neurodiversity are not always the child’s choice. With this understanding, we have seen many schools respond with greater tolerance. This report captures just some of the considerable efforts of individuals across the system to enable real and lasting positive adjustments.

RECOMMENDATION: The project is funded over a longer period to explore cultural change, and explore the significant reduction in hospital admissions over the last year.

By continuing the national Children and Young Peoples’ Community of Practice, sharing the learning across England, working with NHS England and other national team colleagues, the Council for Disabled Children and Contact will support the project to be sustainable and to emphasise the unique opportunity for health and education to work differently with families.



Annex A: List of contributors

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Organisations

Autism and Mind	autisminmind.com
Daisy Chain	daisychainproject.co.uk
Triple A	tripleaproject.org.uk
Autism Education Trust	autismeducationtrust.org.uk

Annex B: List of documents used to support this evaluation

Document Title	Author / Commissioner	Date
2c. NCNE Part 2 End of Year Project Evaluation Report 2018/19	Bates, J.	March 2019
Parent Carer Forum Accelerator Site Evaluation	Parent Carer Participation	March 2019
Take Time to Allow aTime. Tripleproject.org.uk/media	Triple A, NHS England	February 2019
Evaluation learning programme – Autism School Learning Programme & Support	White, R.	May 2019
Appendix B: Role of the School Champion in Implementation	White, R.	May 2019
Transforming Care webinar recording	Thomas, S. Morris, M.	4 June 2019
Transforming Care Accelerator Site C&NE region, ‘Schools, Families & Supporting Children & YP with Autism’. Sharing the Learning	Thomas, S. Bates, J	15 March 2019
Developments for supporting students with ASD at Abbey Hill Academy	O’Donnell, S.	22 January 2020 (date shared)
Autistica Altering Trajectories	Autistica	Nov 2019



Annex C: Case Study

KEY WORKER FROM THE VOLUNTARY SECTOR PROVIDING FLEXIBLE SUPPORT & HELP FOR FAMILIES, NORTH CUMBRIA & NORTH EAST REGION

OVERVIEW

A pilot scheme in place since July 2019 which introduced a key worker (also known in this context as a **Family Support Worker** or a peer worker) across the North patch of North Cumbria and North East.

Personalised, flexible support

The key worker works with children and young people with autism and/or learning disabilities who are at crisis point and provides **personalised, flexible support** for their families. This support includes help with applying for benefits, housing and carer support, improving access to leisure facilities, and direct face-to-face work on education or sleep habits.

The service includes **out-of-hours support** as required and has significant flexibility in line with family's needs. The expected case load is up to 4 'active' cases plus two cases of young people who are leaving the pathway. Currently, the case load is four and the role is part-time.

Where does the role sit?

The role is currently attached to the **Intensive Positive Behavioural Support Team**: a service that provides an alternative to hospital admission for young people with very complex needs who otherwise would be **Tier 4 inpatients**.

Future aspirations include testing out other ways of providing family/keyworker support, with additional key workers in different teams, for example to link to the CETR process and dynamic risk registers, if the service is able to expand.

Uniquely, this role is provided in **partnership between the local NHS trust and voluntary sector organisation**, CNTW and Skills for People, who host the role and employ the key worker.

Service goals

The service goals are to:

- Prevent hospital admission.
- Prevent home breakdown.
- Maintain community school placement.
- Maintain respite and social care support.

“The broad aim is to support parents and the family in whichever way they feel is useful, across the system. This role is not limited to health, social care or education, but can work with the family on anything, anything at all, that they feel is important.”

ROLE FUNCTIONS

- **Referring and signposting** to further support and services, including peer support groups and respite provision.
- Supporting the family with **panels and applications**, including the EHCP process, care giver grants etc.
- **Carer and sibling support.**
- Housing and benefit **advice.**
- **Direct help** with education, skills for independence, and sleep counselling.
- Support to **access leisure facilities**, accessing peer support and support groups.
- Supporting the family at **multi-agency meetings** by attending with them and for them.
- **Evaluating current working and provision.**
- Engaging in **consultations with the wider children's services team** to prevent the escalation of other young people to the IPBS team.

PERSON SPECIFICATION AND BANDING

In this model, the role holder comes from the third sector and has lived experience as a parent carer of a young person with a learning disability, as well as a number of relevant qualifications.

The three interviewees from this area felt that having a **parent carer in this role worked extremely well**, and this peer approach was highly valued by families. The area envisions future roles continuing to be

held by parent carers as this is what families have told them is most useful, but may test different approaches. However, for this peer worker model to be rolled out more widely, the area expressed the need for a training and development package, focusing on the law and the needs of families which such complex situations, to ensure other key workers had the same level of knowledge. This could be developed in line with guidance / testing of the keyworker roles in the forthcoming year.

Required skills and experience:

- Strong knowledge and experience of the system, of how it maps together and of different teams and services .
- Empathy/ understanding of how difficult it can be to navigate.
- Understanding of positive behavioural support.
- Understanding of relevant rules and legislation.
- Ability to challenge and hold to account.
- Independence from health and social care
- Flexibility.
- Lived experience (strongly valued by the families themselves).
- Other skills like Makaton; being IPSEA trained in SEND; a sleep counsellor etc. is valuable however not essential.

“Fundamentally, this is about having the skills to be able to react to whatever it is the family require.”

TEAM STRUCTURE AND MANAGEMENT

In this model, the key worker is employed by a specialist local charity and undertakes the key worker role through a service level agreement with the local NHS Trust.

The role sits within the Intensive Positive Behaviour Support (IPBS) team for children and young people. This IPBS team was developed as an alternative to hospital admission, was funded by the closure of a children's ward, and provides a multidisciplinary team for the same complex group of children and young people who would otherwise be inpatients.

However, because the key worker is employed by the third sector organisation, they are also seen as independent from health, social care or education by the families they work with and can externally evaluate services, ask difficult questions and hold teams to account.

While the current key worker role sits within an IPBS team, there is scope to develop and test out additional key worker roles in different teams so they can work with young people before the point of crisis. Ideally this service would expand to put an equivalent key worker in the ICS/P level, to support children and young people and families who regularly use inpatient services and link to the CETR process and the dynamic support registers as in this context they could engage in more preventative work as well as crucial family support work post-discharge where there is another gap in current provision.

REFERRALS/ELIGIBILITY

Young people who are known to the Children and Young People's Community Services for People with a Learning Disability and Autism (CYPS/ CAMHS) Team and who are **at risk of hospital admission** based on risk registers will be invited to a consultation with the Intensive Positive Behavioural Support Team.

At this consultation it will be decided whether the young person and their family are suitable for key worker support and if they want to engage with this type of intervention. The family support/key worker role is regarded as an intensive piece of work that requires buy-in from the family and which is also primarily aimed at supporting the most complex and challenging young people, so it is an **opt-in service**.

INTERACTION WITH REGISTERS

Currently, the key worker only works with young people involved with the IPBS team. This cohort are red on the risk register and are involved with the IPBS service as an alternative to imminently being admitted to hospital.

Attending panels and register meetings is managed through senior members of the IPBS team, with the key worker sitting on panels where the family want them to.

HANDOVER

Unlike the IPBS team in which they sit, the key worker does not have a time-limited pathway of work with the young person and their family, and can support them for as long as needed, with a much longer discharge process. **The length of the intervention is entirely flexible**, based neither on time nor achieving particular

goals, but this can be reassessed if case load becomes an issue. The key worker is expected to continuously facilitate access to existing services in the community to ensure support is ongoing, but there is not the same focus on discharge from the key worker as there is in other areas.

RESPONDING TO LOCAL CONTEXT

This role was developed by the IPBS service and the charity jointly as both felt they were seeing children, young people and their families at the moment of crisis and that more could be done in the local community and to support families. A survey evaluation commissioned as part of children and young people Accelerator Project explored what families need, They consulted with families to find out what would be most beneficial to them.

“What parents told us they most struggled with was having so many professionals involved in their life and their child’s life that did not have the experience they had. They wanted a peer worker, somebody with lived experience of their situation who understood what they were going through.”

Based on this and after engagement with a Children and Young People’s Peer Network, they developed the idea of a family support/ key worker role **in direct response to the feedback from families**. What was most needed was a key worker who could come alongside the family, who would have empathy and face-to-face contact with them.

“We did not feel any need for just another coordinator role.”

Broader or strategic oversight of the system and coordinator roles were held elsewhere in the system, and the area covered would be too large for the key worker to take on some of this function.

Each of the twelve local areas and eleven CCGs covered in NCNE has a commissioner who has responsibility for overseeing the dynamic risk register and the young people on it.

Most of the areas also have complex case panels which have oversight of the system and a good understanding of the complex cases and CETR process.

The biggest gap was felt to be help and support for families and for young people in crisis who were remaining at home, whilst continuing to be at risk of admission so the service developed in response to that.

SYSTEM REQUIREMENTS AND WHAT WORKS WELL

- **Independence** from health, social care and education teams was highly valued – sitting outside of existing services was felt to work well.
- **Lived experience** of the key workers
- High-levels of **flexibility** in the design of the service, type of intervention and in attitude of the key worker.
- The key worker role has to be **aligned with an existing care pathway**, in this case the IPBS pathway, so it links to the wider system of support, is narrowly focused on supporting the most complex young people, and so it is linked to pre-existing escalation processes.

- Being **hosted by the voluntary sector** was seen as very useful, as it has enabled the role to be solution focused; to link people with wider networks and other families; and to work in a more imaginative way as they are not bound by particular organisation rules. They also don't have the same perception among families so there is no feeling of being spied on or judged.

If working across services or with a service-level agreement, it is important to set out the governance, a Memorandum of Understanding etc. ahead of time, and to work out the practical details of data sharing, and so on.

IMPACT

This area are in the process of evaluating their service but this information will not be available until end of February. However, the key worker role is regarded positively by the families involved.

FEEDBACK FROM PARENTS

"I felt like an equal in the sessions, like we were really doing it together"

"Although there are tough days I now feel there is light at the end of the tunnel."

"I finally have a voice I didn't have before."

Key outcomes to measure against going forward include:

- That the families feel supported.
- Families understand links to other services.
- They receive benefits and services they previously did not have access to e.g. access to respite care, leisure facilities, carer support.
- There is a reduction in avoidable admissions and readmissions.

NCNE aspires to build on what parents have told them and works with the regional and local Parent Carer Forums to continue this, and hopes to be able to test out further models/ functions of the Keyworker.

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- 7 NHS (2018). *Plan, Do, Study, Act (PDSA) cycles and the model for improvement*. improvement.nhs.uk/resources/pdsa-cycles.
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