WORKING TOGETHER TO SUPPORT CHILDREN AND YOUNG PEOPLE WITH AUTISM

AUTISM LEARNING PROGRAMME, NORTH CUMBRIA AND NORTH EAST ACCELERATOR PROJECT: PHASE 2 EVALUATION REPORT

Appendices

contact

For families
with disabled children

Appendix 1: Co-production of transition film *Talk to me! One size fits no-one*

INTERVIEW WITH HARRY HARRISON, NHS NORTH CUMBRIA CLINICAL COMMISSIONING GROUP

WHO WAS INVOLVED?

- Young people from schools in Netherhall, Maryport and Ullswater Community College in Penrith.
- Triple A..
- Haltwhistle Film Studios.
- NHS North Cumbria Clinical Commissioning Group.

WHAT'S THE BACKGROUND?

Two previous films had been made by young people with autism in North Cumbria. The first film was on health, and shared with GPs and health workers to help make reasonable adjustments in GP practices and A&E settings. The second film was about autism in schools. The transitions film was the third film.

The launch event of the film about schools took place on 3 May 2019, when the young people involved in making the film talked to an audience. They shared their experience of being involved in the work and how it had made a difference to them.

ABOUT THE TRANSITIONS FILM

For the transitions film, Triple A and the CCG hosted six focus groups (two schools, young adults from Carlisle Mencap, transition social workers, school teachers and college lecturers) in the selected schools. They used the citizenship model of disability as a visual tool for the discussions. This template covers all of aspects of life, including work, housing, exercise, love and sex, transport, and more.

Two schools were selected for involvement: Netherhall in Maryport, and Ullswater Community College in Penrith. Head teachers facilitated and SENCOs identified eight or nine young people to invite to each of the focus groups. At the end of the focus groups, they were asked if they wanted to be involved in the film. All of them said yes!

HOW WAS COPRODUCTION DEVELOPED TO INVOLVE THE YOUNG PEOPLE?

After the autism in schools film, the CCG and Triple A listened to the young people involved and noted the things they said could be done differently. This time, they chose Haltwhistle Film Studios because this company had done work involving young people with learning disabilities and autism in co-creating films.

The young people attended the focus groups to share their views. The key themes from those discussions were identified and a storyboard created by Haltwhistle Film Studios, from which the young people then made the props, got behind the camera to do some of the filming, and produced and edited parts of the film themselves. This meant the process was inclusive throughout and enabled an even more meaningful experience for the young people compared to the previous film.

WHAT WAS THE IMPACT OF THE TRANSITIONS FILM?

In the focus groups and on film the young people talk about their hopes and ambitions for a range of interesting careers. Because the jobs currently on offer to young people are often not so ambitious or creative, working on the film enabled them to see behind the scenes of the industry and gain new skills. One young man wanted to write comics, another person wanted to work in film, so this experience allowed them to see the opportunities they could aim for.

WILL THE FILM HAVE WIDER IMPACT?

It is hoped the film can also be taken to workplaces. As part of Cumbria's written statement of action (WSoA) a working group is looking at employment opportunities for young people with learning disabilities and autism. This film will support that work going forward. The film was completed earlier in 2020, but the release date has been rescheduled for a hybrid virtual/face-to-face launch event in the autumn.

HOW WILL FEEDBACK FROM THE TRANSITIONS FILM BE GATHERED?

Previously, following the launch of the other films, feedback was gained informally via conversations with school staff and young people who were involved in the focus groups and filming process. A more formal approach is to be taken following the launch of the latest film to garner feedback from all those involved plus the wider community.

WHAT WAS THE IMPACT OF THE PREVIOUS FILMS?

The CCG and Triple A received direct feedback about the previous film on autism and schools when they showed it in training with teachers at several schools. One watching, several teachers said:

> *"Oh, that's why that young person had a melt-down in the class!"*

On 3 May 2019 at the launch event one young woman describing her involvement talked about how she felt listened to and heard. She was happy that her voice is out there on the film and that she is making a difference for other young people with autism. She felt strongly that:

> *"The best way to teach people about autism is for people with autism to do the teaching."*

Appendix 2: Case study

CONNOR RICHARDSON: MY JOURNEY THROUGH LIFE, EDUCATION, AND EMPLOYMENT

Hello, my name is Connor Richardson. I have been asked by Daisy Chain to share my journey in my own words. I hope to summarise various aspects of my life, including my experiences of living and coping with autism, and my experiences of education, an Employability Skills Course which I undertook at Daisy Chain, and finally employment.

A little bit about me

I am 24 years old and I have a diagnosis of Asperger syndrome with moderate-severe OCD. I was diagnosed with my condition when I was in Year 6 (2006/2007). I am currently employed full time by Daisy Chain as a receptionist, starting with them in August 2018, working for one year prior to this as a sessional receptionist.

A lifeline of support

Daisy Chain has been a lifeline to me over the past eight and a half years and I believe that without them, I would not be in paid employment today. They have supported and encouraged me throughout: first as a service user, then a volunteer, and finally as a staff member. More than this, they have been extremely tolerant towards problems which I face as a result of my condition, (for example my time management skills), and have gone above and beyond to ensure that I am OK, both professionally and personally. Some staff members have acted as mentor figures to me and have continued to support me in spite of my difficulties.

MY EXPERIENCE OF EDUCATION: THE EARLY DAYS

I attended primary school from 2000 until 2007. Fortunately, although my parents did not yet know about my condition, they chose to send me to a primary school which supported children with mental and/or physical disabilities and the teachers there picked up on my condition.

Thinking differently

There were signs from a young age that there was something different about me: I did not think and behave in the same way as other children did. One example; I have difficulty dealing with multiple instructions. If I was asked by the teacher to walk across the classroom, put a piece of paper in the bin, pick up a pen from the table and then bring the pen back to him/her, I was unable to process this. I could only follow instructions if the task was broken down into individual steps. I was prone to daydreaming in my first few years at primary school; I often lost focus and switched off from the world. There is a video of my first day at Reception when the teacher can be seen taking the register and having to temporarily stop as I was singing to myself.

Help with physiotherapy

My condition didn't just affect me mentally, there were physical manifestations. I was born with low muscle tone. My hand-eye co-ordination was extremely poor, which had detrimental effects, including that I

used to walk down stairs slowly, moving one foot at a time. I was unable to catch a ball, and I was unable to clap my hands together.

My primary school assumed I had dyspraxia, however, they decided not to 'label' me and instead provided me with six years of physiotherapy sessions, in which I gradually increased my muscle tone and improved my hand-eye co-ordination. The activities undertaken in these sessions included throwing and catching a ball and guiding a small ball between cones using a plastic hockey stick. This physiotherapy paid off and my hand-eye coordination is at a level which allows me to function on a day to day basis.

MY STRENGTHS AND CHALLENGES

In Year 2, I began to become generally more focussed at school and as a result of this, I began to achieve a lot more academically and in addition, I displayed a talent for story writing.

Primary school

Throughout my life, I have struggled with time management, both in life and at school, which results in me spending too long completing individual tasks; feeling unable to move on to the next one until the current task has been completed to perfection. In a school setting, this resulted in me being unable to finish pieces of work in timed conditions, which presented a serious problem in Year 6 when I began to complete mock exam papers, because I spent too long on each question and hardly ever finished an exam paper in the allocated time. I was offered a CAMHS assessment and shortly afterwards I was diagnosed with Asperger syndrome with OCD. Once I had received my diagnosis, I was given 25% extra time in exams and significantly improved my scores for mock exams. By the time I was in Year 6, my time management wasn't perfect but I performed well in my SATs, and was put into high set classes for most of my subjects in Year 7 at secondary school.

Secondary school

I attended secondary school from 2007 until 2012 and although I liked it, in Years 7 and 8 I did not receive adequate support for my condition. For example, although I was allowed 25% extra time when we completed tests in the classroom, when larger mock exams were conducted outside of the classroom, I was placed with everyone else in the main hall for the exam with no extra time.

I believe the reason for this was that I looked 'normal' and that to those who didn't know me, I seemed to be like any other student in the class. Many of my teachers were uninformed about my condition and when the Year 7 school reports were being written, one of my teachers actually asked me to come up to the front of the class, in order to verify that the database which contained my details was correct in saying that I had Asperger syndrome with OCD. In Year 8, when my mam rang my head of year to discuss with him that I was struggling to cope with homework (due to spending too long on tasks and having to perform various rituals before I could start working), it was clear that he had no idea about my condition.

GETTING THE RIGHT SUPPORT

In September, 2009 (when I was in Year 9) I got a new tutor and in January of 2010 he helped push my case forward for special exam concessions in the Year 9 mock exams, which took place in that month. As a result of his support I was able to receive 25% extra time in these mock exams. However, I was not placed in a separate venue. I also often had to convey information between the SEN (special educational needs) department and my teachers (due to them not communicating with each other).

Telling fellow students about my condition

The other students in my classes would sometimes pester me, mockingly asking me whether I had OCD. Because I felt that I had to place all of my books and stationery in a straight line on the desk at the beginning of each lesson, this attracted their attention. When asked I denied it, as I wanted to keep my condition a secret.

However, my outlook changed in Year 9, when I experienced a very embarrassing situation, due to the carelessness of one of my teachers. He was using the interactive whiteboard at the front of the classroom to teach us a new topic. He set the class off on a task and then sat down at his computer at the back of the class, and began looking at a table containing information on each student in the class. Unfortunately, he did not switch off the overhead projector and as a result, my details were displayed on the screen in front of the whole class, including the fact that I had Asperger syndrome with OCD. People in the class read about my condition on the screen and then began to look at me, as if their suspicions had been confirmed. From then on, I did not try to hide my condition from the other students and when I was asked about whether I had OCD, I said I did in fact have it.

Help with transcribing in exams

In Years 10 and 11, school became much more positive for me because the new SENCO (special educational needs coordinator) ensured I received my special exam concessions. In addition to receiving 25% extra time, my exam papers had been for some time transcribed due to the poor quality of my hand writing. She also offered me the chance to have a prompt in exams, to aid me with my time management, however, I turned this opportunity down as I didn’t want to have someone watching over me whilst I completed my exams.

My grades from the two years averaged out to provide me with fairly strong GCSE grades. But I struggled to cope with my condition significantly during the summer holidays between Years 10 and 11, partly due to the lack of structure.

Support at sixth form college

I attended a sixth form college from 2012 until 2015 and I feel that I was supported very well there, even though I didn’t achieve as much academically as I would have liked to. At this college, I continued to receive my special exam concessions (25% extra time and a transcribe) and I also began to use a prompt, who helped me with my time management in exams. One of my biggest struggles at college was the lack of structure, as a result of the number of free periods that we were given and I found it very difficult to spend my time effectively.

MY EXPERIENCE OF THE EMPLOYABILITY SKILLS COURSE AT DAISY CHAIN

Between December 2014 and June 2015 I was a student on the first round of Daisy Chain’s Employability Skills Course, which allowed for four groups of adults with a diagnosis of autism to work towards gaining an ABC qualification in Employability Skills. Each group attended sessions once a week for five hours, spending the morning at the Daisy Chain Day Centre, where we learned about various topics such as manual handling in the workplace, food safety and hygiene, maintaining work standards, interview skills and how to conduct an enterprise project. In the afternoon, we worked in the ‘Daisy Chain Charity Superstore’, where we delivered different roles, including safe sorting bags of clothing, quality testing, labelling and pricing items of clothing, working behind the coffee shop and working behind the main till.

My first paid job!

I believe that being on this employability course played a major part in helping me to progress on to an administration apprenticeship, (my first paid job role), which lasted for one year and from which I gained an NVQ Level 2 Diploma in Business Administration. This is because through being on the course, I gained many skills which are essential in the workplace and which were therefore, desirable to my employer. These skills include team work, communication, time management and organisational skills.

Appendix 3: Accelerator CAMHS support: suggestions for future evaluation

CAMHS PRACTITIONERS PROVIDED THE FOLLOWING FEEDBACK TO THE EVALUATION

SCHOOL NEEDS FOR CAMHS SUPPORT

One mainstream secondary included a 20 place provision for children with learning disabilities and SEND. They requested CPD on SEND, positive behavioural support and sensory needs training. They wanted an explanation of how the system works:

> *"Including why a referral might or might not be accepted."*

They also wanted to know how to support the young person in school when they're waiting a service or a diagnosis. For example, how staff can manage this, where they might go to for support (for example to duty advisors) so the school can get advice and support in the interim. Referrals to local services can have large waiting lists so schools want to know what type of information to include.

INPUT TO PUPIL REFERRAL UNITS (PRUS)

In one PRU, the Nurture Unit, does not run a traditional curriculum. Instead staff use a Thrive approach focusing on social and emotional development. They showed readiness for the Accelerator programme and wanted support on diagnosis, referrals and sensory training and were particularly keen for the Nurture Unit staff to access advanced training. They requested advice on linking their activities to the curriculum, to explain why this approach benefits the young people's learning, and how their activities respond to the children's difficulties, which helped them with their Ofsted inspection.

In another PRU, whilst it was a specialist behaviour school, teaching staff had not appreciated the additional adjustments that could be made for learners with social communication needs. An additional focus group was planned to look at the difference between autism and reactive attachment needs. This school has a significant number of young people with disrupted lives for example who have experienced neglect or abuse. It can be difficult for staff to understand systemic behaviour needs which stem from attachment issues versus autism, which is rooted in social and emotional needs.

Generally, CAMHS practitioners suggested it is key for them to have knowledge of the provision in the area and to understand what services are available. Schools need a realistic picture of what support they can access from partner agencies. For example, knowing the learning disability services pathways in the different localities, particularly where pathways vary between local authorities. For special schools the CAMHS practitioner was able to signpost what services might be offered and she understands the assessment process for neurodevelopmental pathways.

EVALUATION OF IMPACT

CAMHS practitioners reflected on how the evaluation of this strand of work could be improved in future. This needs to link to the evaluation of outcomes for the rest of the programme, as many activities are contributing to the same outcomes. One way would be to create a more structured evaluation and discuss this with schools at the beginning, setting out what outcomes are being measured for each part of the Accelerator programme.

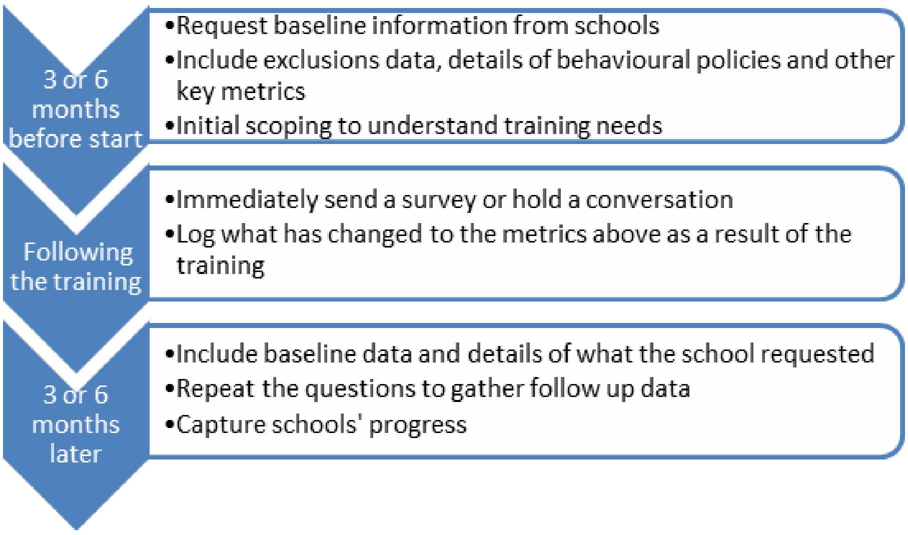
A scoping document which asked a series of questions to educators was used by CAMHS practitioners. This type of survey document could be re-run six months later to track progress been on outcomes. Following training, schools could be asked to review their previous position and asked if there has been a change in any of the outcomes. This could help to identify which are the most sustainable or successful interventions.

The existing scoping document asks about:

- level of autism awareness amongst staff
- understanding the link between behaviour and autism
- understanding communication and support needs
- understanding the effect of the physical environment
- how policies can reflect differentiation for this group
- level of staff aware of support that's available.

The schools have data which can help measure impact, including reducing exclusions and many other metrics, so the evaluation information could come from the schools themselves.

With a survey, baseline and follow up evaluation in relation to staff approach to managing behaviour, the evaluation would capture a sense of progress from the teachers.



3 or 6 months before start

- Request baseline information from schools
- Include exclusions data, details of behavioural policies and other key metrics
- Initial scoping to understand training needs

Following the training

- Immediately send a survey or hold a conversation
- Log what has changed to the metrics above as a result of the training

3 or 6 months later

- Include baseline data and details of what the school requested
- Repeat the questions to gather follow up data
- Capture schools' progress

Appendix 4: CYP peer network meetings

THE CYP PEER NETWORK MEETINGS

These meetings were well attended with a wide range of practitioners and parents and carers. Parents, carers, and professionals discussed what a good autism assessment and diagnosis experience and post diagnosis experience would look like.

The CYP network meetings also discussed support for families and expert professionals heard what good crisis support consists of from the point of view of the child and family who are experts by experience.

Families raised the importance of supporting their child's needs during the diagnosis period, how parents' views can be taken into account, how the assessment process can be explained at the start, and how young people are asked what will help them. They were also asked how to ensure that:

> *"Reasonable adjustments are noted and acted upon, not just seen as expensive and pandering."*

Parents and carers said people describe the challenges in terms of behaviour but don't always take the next step to understand what is causing the problem and then planning interventions to address this. Often, the demands being placed on a child can exceed their capacity to respond effectively. Parents and carers would like their children to have support to develop the skills and strategies that neurotypical children often master automatically as they develop and mature, including in:

- language processing and communication
- emotional regulation
- cognitive flexibility
- executive skills
- social skills.

In practice, this means getting to know the child's needs, identifying what skills are delayed and creating a proactive programme of interventions.

Appendix 5: Participant feedback

FROM PARENT CARER FORUMS

- One PCF was pleased to welcome a parent from the traveller community to the meeting, she was there as a representative for other parents and wanted to learn more about additional needs particularly autism, to better understand and support within their community. This mum has since become a member of the forum.
- Parents were positive about having the time to meet for an open conversation, without the time constraints of parents' evening.
- It was clear that previously, parents had lacked an opportunity to "be heard" within school so we decided to brand our initial meeting as a "listening morning". Energy went into contacting parents individually to open conversations ahead of the meeting:

"We planned it to make the experience as welcoming as possible." Parents reported huge progress in strengthening relationships with staff.

- Some said the role of the local authority in establishing the project with schools has been key to success. One PCF said:

"The local authority facilitated the initial meetings with all schools interested in the project and I really feel that this helped in getting things going this time."

- One school was disappointed that their local PCF had not engaged due to illness of a key volunteer and the issue of needing to drive to meetings up to 30 or 40 miles from home.
- One PCF reported poor engagement from the leadership team in two schools which prevented the PCF from taking work forward:

"Despite our numerous attempts to make contact with the leadership teams in both schools we have had no engagement at all from them."

FROM SCHOOLS

"It's given us confidence to actually make changes, to support children in school by tailoring to their needs from the way they enter school, what they do on arrival, arrangements for PE, assembly, break times, where to sit in the class, how their learning is approached. It has given us the confidence to put the child's needs first and defend our position if required." Educator's feedback from training.

"I'd just like to thank every single person who was involved in providing this training for us all as it has been extremely beneficial. The support from everyone involved has simply been incredible."

"This was an excellent course and it would have been good if even more staff could have attended. We are very keen for Marie [Jevons] to be able to pick up where she left off when we return to school in September. Thank you."

"It would be fantastic if we were able to finish it off in some way, especially with the CAMHS input directly into school."

"There was an extensive range of professionals who spoke about real life examples … There were several examples of strategies that could be trialed immediately on return to the classroom and the offer of visits from [practitioners] was a great benefit to our school."

When asked about the parent carer forum, one SENCO said:

"We've started something wonderful! Coffee mornings with parents haven't gone so well in the past. This time, the parent carer forum invited all parents of children with SEND and ran everything. 15 parents attended, which is a lot for our school."

It was an open meeting, and the SENCO decided to leave the parents to chat.

"The forum is neutral; the other parents have experience of what they're going through so they understand. Holding the coffee morning here, as an outreach for this community was great. I feel proud that as a trust we've got the link with the forum. Since then, some of our parents contacted the forum, which they wouldn't have done before. Now they're joining in with things, including a virtual bingo game recently, they're building a peer support network."

"I particularly found the sensory-related topics very interesting. Although this was aimed at improving provision of children with autism, the sensory related material could help a broad range of children within school."

When asked what topics could be added schools mentioned transitions (times in day and between settings), supporting children back to school, supporting with eating and toileting, and use of social stories.

"As open as we are, some teachers will say, 'Oh, they won't need that (sensory toy) they're just fidgeting.' So, it would be helpful to look at whether attitudes change later, once the tools are implemented." SENCO, discussing plans to roll out sensory processing training.

- One school was disappointed that they are no further ahead with establishing a working partnership with their PCF. Regional forum co-chairs reported to the evaluation, attempts to get this forum started have not yet worked partly due to parents and carers not having capacity, and due to long distances to travel to meetings. Regional forum co-chairs reported that they recognised the circumstances for this particular forum are challenging, and they are exploring ways to support schools in this locality in how they can engage with parents and carers.
- Regional forum co-chairs highlight the pressures on forums, many of whom are supporting authorities with written statements of action. This requires forum capacity to attend meetings but has not been supported with additional resources and has created a conflicting priority for some forums.

FROM PRACTITIONERS

"One of the students at the beginning found it difficult to talk in a group and communicated through nodding and shaking their head. As confidence grew and they began to feel more comfortable, they started to speak in the group." Trainer delivering the 'Understanding Myself' course.

"With the face-to-face training and questions, you get a sense of what the issues and anxieties are in the room. And there's something powerful about staff engaging with the same message at the same time, so the community is learning together, and it begins to embed the work into the school ethos. But with the webinars it has not been easy to organise to get enough staff online at the same time."

The Accelerator team and the authors of the report at Contact would like to thank all contributors for taking the time to give their input to the evaluation.

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