



Allied Health Professionals transforming health, care and wellbeing for autistic people and people with a learning disability

Case Studies

This quick guide showcases services that provide care to autistic people, people with learning disabilities, or both. We advise discretionary interpretation of the terminology to complement the service showcased.

Foreword

The NHS Long Term Plan¹ included a renewed commitment to drive improvements to the care received by people with a learning disability, autism or both. Significant progress is being made and yet there is more to do to transform services across England.

This document shines a light on our allied health profession (AHP) colleagues. They are a vital part of our workforce, formed of 14 different professions and 170,000 members of staff: the third largest clinical workforce. AHPs play an important part in the shaping of care and future health systems, contributing important skills and the scope to transform care across systems.

Care by AHPs is delivered through the lifespan and across organisational boundaries, including primary care, community services, secondary care, education and justice systems. They have a significant role in the future delivery of learning disability and autism services, and we are encouraged by the examples of best practice, which show AHP leadership at its best.

This document has a wide range of impactful practice, including improving people's access to mainstream services, the strengthening of specialist services such as reducing autism diagnostic waiting times and the designing of suitable housing so that people can stay living in their community with family and friends. The case studies are arranged according to their impacts: pages 3-15 showcasing AHPs supporting access to universal or mainstream services; and pages 16-29 shining a light on specialist AHP services.

We urge anyone looking to transform learning disability and autism services to consider our AHP workforce and use this document as a guide. The contribution of AHPs needs to be recognised and used if we want to achieve the ambitions in the NHS Long Term Plan to help this community reach their full potential and deliver high quality care across England.



Suzanne Rastrick,
Chief Allied Health Professions Officer (England)

Chapter 1: Supporting access to universal or mainstream services

Case study 1

Preparing for transition to adulthood – addressing the speech, language and communication needs of young people with autism

London North West University Healthcare NHS Trust

Young people with speech, language and communication needs (SLCN) are at greater risk of developing emotional, social and behavioural difficulties, mental health issues, lower academic achievement and school performance failure.

It is estimated that 10% of the school population have SLCN (2-3 children in each class) and only 3 % have been identified as having SLCN. While some young people's SLCN resolve, other pupils SLCN needs may only come to light in secondary school due to increasing social and academic demands. This includes young people with a diagnosis of autism. Speech and language therapy (SLT) services have a key role to play in supporting this population group

The SLT service at London North West University Healthcare NHS Trust (LNWH) addresses the communication needs of young people with autism throughout their education and in preparation for adulthood. They work with young people, their families and colleagues across education health and social care as part of an integrated whole system approach.

Schools and colleges are allocated a named Speech and Language Therapist whose input is determined by the number of young people with an Educational Health Care Plan (EHCP) who require SLT. Interventions may include:

- Guidance and training on the identification of young people with SLCN.
- Signposting young people and their families and schools to useful resources which support their SLCN.
- Education / information sessions for parents.
- Provision of training / information to upskills school staff to identify and support the SLCN needs of young people.
- Provision of specialist SLT Assessment, advice and therapy plans.
- Provision of evidence-based interventions to support the speech language and social communication skills of young people, their self-advocacy and independence as they transition to adulthood.
- Provision of transition plans and communication passports which support young people into further education and onto adult care.

- Working with the broader team around the young people, i.e. Schools staff, Child and Adolescent Mental Health Services, careers advisors, social care, youth offending teams etc. To increase awareness of their communication needs and providing strategies to support these needs.

Evaluation shows:

- 100% of parents provided positive feedback
- 100% of Special Educational needs Co-ordinators (SENCOs) rated the Speech and Language Therapy service by LNWH as either excellent or very good.
- 100% of SENCOs stated the support from SLT helped their school/college to work with and support students with SLCN.
- 97% of students identified that Speech and Language Therapy sessions help them at school, with over 85% of students rating the service as 7/10 or above.

100% of students identified that SLT support helps them to do some or all of the following:

- Understand their strengths and difficulties with communication
- Understand others (e.g. friends, teachers)
- Speak with teachers
- Have conversations with friends
- Take part in lessons
- Ask for help/support when needed
- Problem solve in difficult situations
- Feel supported and included in school
- Achieve their goals

84% of all targets were achieved by students by the end of the academic year 2018-2019 supporting young people to meet their long and short long-term outcomes from their EHCP.

SLTs have a range of highly specialist skills and knowledge which can be used to support young people and their families directly and also to train school staff to identify and support the communication needs of young people with autism.

For further information please contact: Joanna Hickey Principal Speech and language therapist joannahickey@nhs.net

Case study 2

Increasing diversity of professions providing leadership for Learning Disability and Autism in an Acute Hospital Trust.

Leeds Teaching Hospitals Trust

A Speech and Language Therapist holds the role of Lead Professional for Learning Disability and Autism. It is recognised that many barriers for Autistic people and people with Learning Disabilities, which prevented or limited access to hospital services, are due to communication difficulties.

The difficulties occur throughout the patient's journey and include arranging initial appointments, understanding care and treatment and ensuring safe discharges.

The Lead Professional offers direct support to people with communication difficulties. They also offer staff training, contribute to workstreams for the Accessible Information Standard, DeEscalation, Safeguarding and Patient Experience. They have developed resources which are now used locally and nationally: the leaflets produced were also adopted for use in the Nightingale Hospitals. The Lead professional is also supporting improvement work for many both clinical and non-clinical pathways, to ensure that Reasonable Adjustments are in place. Under the current post holder, the Learning Disability and Autism Team has expanded to include Registered Learning Disability Nurses and an Acute Liaison Physiotherapist. Further service development is ongoing with an imminent service expansion.

An example of where this input has made a difference to patient care is for a gentleman who has a mild learning disability. This gentleman is HIV positive, malnourished, with incurable bladder dysfunction and a high risk of infection from rotten teeth. His life was very difficult as he was frequently in urinary retention and his urine would leak from his old supra-pubic catheter site. He could not keep up with the washing of his urine-soaked clothes and towel and he could no longer sleep in his bed as it had become soaked with urine. He was socially isolated following a bereavement. He wished to begin a relationship but felt he could not, due to his health issues. This further reinforced his social isolation and affected his mental health, to the point where he would put himself in sexually and financially dangerous situations with strangers, to avert loneliness.

Although he called health services frequently, he did not retain information which was given to him and if he came to hospital, would often leave the ward and not return. He phoned the wards, GP or 111 multiple times per week to chat, or ask the staff to (e.g.) recommend a takeaway but did not engage on a deeper or effective level in his care and treatment. He would often become frightened when medical treatment was discussed and then disengage.

He believed that clinicians were negligent if they could/ would not 'fix' his bladder issues or felt that if he waited then a new medical solution would be found for a bladder transplant. His urinary retention was causing a threat to life.

With support from the Lead Professional, this gentleman is now successfully accessing HIV, Urology and Dental services in the Trust. He will soon begin to see psychology to help him to understand his altered body image with a catheter.

Information is provided to him in a way which meets his communication needs, including pictures, and he is given additional time to process and open access to call the Lead Professional with questions (these are shared to the relevant clinicians, then answers are presented in an appropriate format). He has a fixed pathway to come in for his catheter changes, with familiar staff who are aware of his communication needs.

Thankfully, he also has increased support from social care and now lives in supported accommodation. His staff work with the Lead Professional to repeat and reinforce key messages about health.

Having a Speech and Language Therapist as the Lead Professional for Learning Disability and Autism has invoked a change in approach with an increased focus on communication needs. It is believed that improved communication will lead to better outcomes for this population.

For further information please contact: alison.conyers@nhs.net or leedsth-tr.ldautism@nhs.net

[Or check the websites:](#)

<https://www.leedsth.nhs.uk/a-z-of-services/learning-disability/>

<https://www.leedsth.nhs.uk/a-z-of-services/autism/>

<https://www.leedsth.nhs.uk/patients-visitors/patient-and-visitor-information/patient-information-leaflets/easy-read>

Case Study 3

Paramedics overcoming communication barriers between staff and people with learning disabilities

North East Ambulance Service NHS Foundation Trust

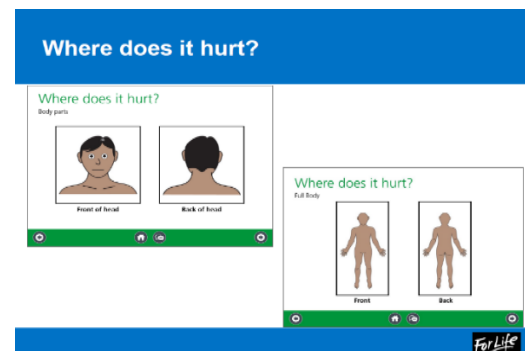
People with a learning disability can find long and complex questions difficult to understand. This may result in incomplete or inaccurate responses impacting on their assessment. Many people with a learning disability are living independently and paramedics need to be better able to overcome the communication barriers encountered. Accessible information, that includes simplified language, imagery and symbols can be helpful in aiding communication.

Community engagement with people with learning disabilities and their carers identified that the paramedic triage process was particularly difficult to engage with. A triage resource was developed using accessible information by the NHS programme Easy on the Eye, to support paramedics' communication with people requiring communication support. This resource enables people to be fully involved in decisions about their care. It allows more rapid and efficient assessment and treatment and reduces the confusion that occurs when communication breaks down.

Evaluation shows:

People, carers and stakeholders have reported that knowing the resource is available reassures them that, in the event of a health emergency, communication issues will be minimised.

The ability to communicate with people with learning disabilities and undertake a triage has been greatly improved.



Using images, especially ones that were developed for the sector and already in use and familiar in the learning disability communities, has helped paramedics and other front-line staff to have conversations about people's health needs.

It has been especially helpful for people who live independently and don't have family members, carers or advocates to support them when in a crisis situation.

Within 3 months of launch, over 65% of staff were aware of the resource, and 75% believe it will be a useful tool to support their communication with people with learning disability and/or autism.

A paramedic has said:

"The guide gives me another tool to use to improve how I communicate with people with various needs, this helps to improve how I care for patients"

For further information please contact: Mark Johns, Engagement, Diversity and Inclusion Manager, North East Ambulance Service mark.johns@neas.nhs.uk

Case Study 4

Dramatherapists reducing anxiety in children with autism

Shine A Light on Autism (SaLoA)), Roundabout

Anxiety affects many children with autism and can lead to depression, isolation and school refusal. A dramatherapy research project '**Shine a light on Autism**' (SaLoA) aims to reduce anxiety in primary aged children with autism who are in mainstream school settings.

Two 20 session dramatherapy groups were co-facilitated by dramatherapists in 2 schools. Sessions used therapeutic storytelling to try and reduce anxiety in children with autism. 10 children participated with 5 children in each school. Outcomes were measured using questionnaires at the start and end of the project and completed by the children, their parents and teachers. The questionnaires used were: the strengths and difficulties questionnaires (SDQ), the child self-reporting outcome measure Psychlops-Kids which identifies worries and impact on well-being and the anxiety scale for autistic children (ASC-ASD). Outcomes are summarised:

- Both children and adults reported that children felt less anxious at the end of the dramatherapy intervention.
- Parents and teachers had better insight and understanding of how children with autism communicate and express their feelings of anxiety.
- Overall children identified their worries were less post intervention.
- Anxiety scales revealed improvements for children in performance anxiety, anxious arousal and uncertainty
- Children's knowledge about themselves increased and parents/carers had gained better insights into their children's self-perceptions.

Feedback from the children

- *"It's like a lot of drama and everything. It's so much fun. You can show emotions."*
- *"It was good. A place where you calm."*
- *"DT is like fun and you get to dress up, act, narrate and draw at the end. Dramatherapy can help you calm down."*

Dramatherapists can be effective with reducing anxiety and supporting the communication of children with autism. It is important for dramatherapy to involve parents, carers and teachers to improve knowledge and understanding of the child's needs.

For further information please contact: Deborah Haythorne, Roundabout CEO, info@roundaboutdramatherapy.org.uk, www.roundaboutdramatherapy.org.uk

 **@ShineaLoAutism**

Case Study 5

Singing & signing for better communication & wellbeing

Include.org: The Include Choir

Include.org is a small charity working hard to break down barriers for people with communication needs, through speech and language therapy training across a range of health, social care and community settings. Training may be formal and accredited, or, in the case of The Include Choir, it is uniquely creative 'training by stealth'¹.

'I learned some sign language & how some people can struggle with communication in ways I didn't know'
Feedback from professionals

The Include Choir provides weekly, inclusive social and musical opportunities for people with a learning disability, autism or both. Led by speech and language therapists (SLTs), the choir brings together individuals, support staff and families and other community members through a shared love of singing. This reduces isolation, builds a supportive community and provides the additional health benefits conferred by singing together¹. The choir teaches inclusive communication skills including: Makaton signing, visual supports, objects of reference and Talking Mats, and raises awareness of widespread but hidden 'receptive language difficulties' (problems processing and understanding speech) as well as more widely recognised expressive difficulties.

Improving the communication skills of care staff can reduce behaviour that challenges, improve identification of medical conditions, and standard of care and increase quality of life². Limited ongoing access to SLT and lack of confidence are recognised barriers to staff sustaining inclusive communication techniques after initial training³; to address this, the Include Choir models inclusive communication, provides safe opportunities for staff to practice and makes SLT support more accessible long term. In addition, through performances song writing, The Include Choir raises awareness of the need for healthcare professionals to make 'reasonable adjustments' when assessing people with communication needs under the Mental Capacity Act – a principle which was 'lagging in its implementation'⁴ in 2019 and identified (along with lack of access to SLT services) as contributing to the disproportionate number of deaths of people with learning disabilities due to Covid in 2020².

Early data gathered through a range of inclusive communication methods, across several domains is very encouraging. A sample of 42 members and support staff provided the following results:

- 98% of members felt the choir helped them feel part of the community (*inclusion*)
- 95% of members had made new friends since joining the choir (*friendship*)
- 100% of members and staff felt more confident about communication (*confidence*)
- 100% of members and staff felt they had better awareness of communication need/inclusive communication (*knowledge*)
- 95% of members and staff said they had acquired communication skills since coming to the Include Choir (*communication skill*)
- 85% of members, staff and volunteers felt they had a better understanding of the Mental Capacity Act (*knowledge of MCA*)

'The song communicates the basic principles of the Act better than any professional training I have seen.' Feedback from professionals

This initiative demonstrates the power of partnership working and creativity, enabling over-stretched services to explore less conventional, yet effective training methods. The key messages are made more powerful and relevant as they come from the voices of the people themselves.

Even the pandemic couldn't silence The Include Choir. From before the first lockdown, Include rapidly pivoted to deliver all services remotely, tripling weekly sessions and more than quadrupling

membership online, demonstrating the need and appetite for inclusive communication support.

The pandemic has shone a spotlight on the importance of communication and community, as well as the systematic lack of support for people with cognitive communication needs. As we seek to 'build back better', speech and language therapy, and the services of Include.org, are needed more than ever.

For further information please contact: Alix Lewer, CEO Alix.Lewer@include.org

Case Study 6

“Seeing the Story” how to talk about offending experiences in Forensic CAMHS Services

Nottinghamshire Healthcare NHS Foundation Trust (Secure Children's Home)

The Youth Justice System can be challenging for people with Autism to navigate, the difficulties they experience are multifaceted, including speech, language and communication needs (SLCN)¹. They can find the demands of treatment programmes and talking therapies challenging, specifically identifying the emotional aspects of their offending behaviour, exploring the impact on their victims, and considering alternative means of achieving life goals, in the absence of offending¹. Speech and Language Therapists supporting people navigating the justice system have redesigned their service to support the reformation process. They have moved away from verbal approaches and use alternative ways to carefully support people with autism to “tell their story”.

The service uses a range of visual tools to work through a young person's offence in a structured manner. It avoids an over reliance on expressive language and narrative skills, which can be demanding and may not be robustly developed. Instead it uses “homemade” resources as well as communication tools, such as: diagrams, hand drawn images, maps, Carol Gray Comic Strip Conversations, visual timelines and accessible information. The tools simplify task demands, create a shared narrative and vocabulary, focus discussions and make abstract concepts more concrete.

“you can really see where it went wrong and then maybe put it right”
Feedback from young people

The visual approach to story telling has been positively received and, in some cases has proved an instant success. It has been used with over 35 young people in the last 3 years and everyone has been found to be more forthcoming with information, coherent & consistent with their story, which is important in the justice system and comfortable discussing difficult topics. This approach has enabled people to explore complex thoughts, feelings and decisions. It forms a positive foundation on which to build robust relapse prevention plans. In many cases it has been effective in supporting individuals to overcome the shame associated with “telling their story” through words.

*“there’s less stress... the pictures... talk for you.”
Feedback from young people*

This approach has seen non-attendance rates for offence specific sessions reduce, and people’s ability to recall information increase. In one example a young person who had declined to attend 50% of his 2 weekly sessions over a 6-week period, attended all but one session once the “seeing the story” approach was implemented.

Speech and language therapists are valuable members of the criminal justice system’s multi-disciplinary team, enabling reasonable adjustments to be made so that young people can meaningfully engage in services/treatment.

For further information please contact: Katie Hyde – Highly Specialist Speech & Language Therapist,
Katie.hyde@nottshc.nhs.uk

“the communication tools have revolutionised the way we talk about offending behaviours... in many cases a young person’s reluctance has been overcome in a single session,” Staff Feedback

Case Study 7

Integrated respiratory pathway for adults with complex learning disabilities – Improving access to specialist respiratory care

Guy’s and St Thomas’s NHS Foundation Trust (GSTT)

Adults with complex physical and learning disabilities are at high risk of developing respiratory problems without access to appropriate services, contributing to health inequalities^{1,2,3,4}. In response, an integrated respiratory pathway was developed between the community adults with learning disability multidisciplinary team (MDT) and Lane Fox respiratory service in 2015. The aim of the pathway is to:

- Optimise the management of respiratory risk factors;
- Reduce the number of chest infections and respiratory complications;
- Decrease access to primary and secondary healthcare;
- Improve quality of life and reduce burden on the network of care.

The integrated respiratory pathway is delivered across community and specialist services. People at risk of developing respiratory problems are identified based on the number of respiratory risk factors and symptoms of respiratory problems via referrals and screening during postural management reviews. They receive a comprehensive respiratory assessment; an individualised respiratory management

plan including an advance care plan and escalation of care discussions where indicated; and are allocated a review.

Prior to the implementation of the integrated pathway, the learning disability team would accept referrals to optimise the respiratory management in the community. However, proactive identification in this at-risk population did not occur and there was no access to specialist respiratory services to escalate care when required.

The pathway implementation has shown:

- 147 people with complex physical and learning disabilities receiving community level respiratory assessment
- 35 (24%) required specialist respiratory services
- 112 (76%) were managed effectively through the community MDT
- 100% of people have been allocated for an appropriate review either via in the community or specialist services.

Local evidence suggests that integrated community and specialist respiratory pathways are important for the management of respiratory health of people with complex physical and learning disabilities.

For further information please contact: Sarah Bruce, Lead Physiotherapist. Sarah.Bruce@gstt.nhs.uk and David Standley, Clinical Specialist Physiotherapist. david.standley@gstt.nhs.uk

Case study 8

Improving access to eye care for adults with learning disabilities, autism or both

Torbay and South Devon NHS Foundation Trust

People with a learning disability have a higher incidence of visual impairment which increases with the severity of the learning disability and age.¹⁰ Children are monitored in school by an orthoptist but those over the age of 19 years are at risk of dropping out of the eye care system. It is estimated that at least 14- 15% of adults with a learning disability have a severe visual impairment making them eligible for registration as blind or partially sighted^{11&12} It is suggested that people with severe learning disabilities should be considered visually impaired until proven otherwise.

Sight tests for people with learning disabilities is often overlooked, yet visual impairments can have a profound effect on a person's functional skills. Common misconceptions are that it is not possible to assess vision in a person with a severe learning disability and that people would not wear glasses. This contributes to health inequalities such as accessibility to diabetic screening programmes.

In Devon cross-referencing the learning disability register with that of blind and partially sighted people, found that of 1,866 people with a learning disability only 34 were registered as visually impaired, 1.82% of the population. It was clear that

improvements to eye care access were needed to identify those who were visually impaired or blind so that they could access the appropriate rehabilitation services.

Orthoptists have developed a service that ensures all adults with a learning disability can access eye tests. They carry out a baseline home functional vision assessment for those not able to access routine sight tests. The orthoptist has the co-ordinator role within a multi-disciplinary team of; primary care liaison nursing teams, the local optical committee, sensory teams, diabetic eye screening programme, consultant ophthalmologist, and nurses from eye outpatients and the eye surgery unit as well as commissioners.

Evaluation of over 100 visits involving 90 individuals over a 5-year period who were not able to access routine sight tests has shown:

- 54% showed high levels of strabismus (cross or turned eye)
- 43% showed refractive error (problems with focusing light)
- 33% were eligible for certification as visually impaired (increase from 1.82%)
- Diabetic screening increased from 45% to 93%

The orthoptic coordinator role highlights a unique skill set that bridges the gap between primary and secondary care. This service contributes to reducing the health inequalities experienced by this population including risk of falling.

For further information please contact: Kathy Diplock, Orthoptist. Eye Care Pathway Co Ordinator for Adults with Learning Disabilities in South Devon.

Kathy.diplock@nhs.net

Case Study 9

The Steps To Eating Programme (STEP) tackling selective eating in children with a learning disability and or Autism

Royal Cornwall Hospitals NHS Trust

Health Professionals report that the prevalence of children with restricted diets appears to be increasing, placing them at risk of malnutrition ¹. Selective eating, which can result in a restricted diet, is up to 30% more common in children with a learning disability and particularly autism ². It may also progress to Avoidance/Restricted Food Intake Disorder (ARFID) which is associated with nutritional deficiencies. Effective strategies to help parents and carers widen the food choice of their children are limited, yet the impact of selective eating includes:

- Faltering growth, hair loss, dental decay, obesity, diabetes and chronic constipation
- Financial costs of prescribed nutritional supplements, enteral tube feeding, medical investigations, treatments and specialist care
- Hidden costs such as social and educational exclusion, underachieving potential, reduced quality of life, impact on family life.

Steps To Eating Programme (STEP) is currently in development stage produced by the children's community dietitians and used within their caseload only. At present the proposed STEP plan provides a consistent and structured approach to tackling feeding problems, improve outcomes and reduce costs. Programme delivery can take place in settings such as nurseries and schools. The dietitians work with various organisations and in partnership with different health and social professionals for successful implementation. STEP empowers and educates family and carers to understand and respond to their child's feeding problems. The programme can be used at home and all childcare, play and educational venues. Assessment considers developmental, psychological, sensory and physical factors. It delivers a simple, structured therapy plan based on gradual change through child-focussed practical activities and supporting resources tailored to individual settings/home.

Outcomes include:

- Empowered workforce adopting STEP universally to those not known to dietetics
- Financial savings of prescribed oral nutritional supplements (ONS), for example one child reduced from 5 bottles of ONS to 3 bottles of ONS per day, resulting in £210.56 savings a month

STEP has become embedded into standard dietetic practise for children in Cornwall with selective eating. It is more effective than previous interventions because it tackles underlying feeding problems and is not focussed solely on nutritional issues. Early identification of selective eating is important to prevent it from becoming a feeding issue needing nutritional therapy. Collaboration with universal services prevents progression of nutritional issues and maintains a sustainable dietetic service.

For further information please contact: Julie Dutson/Sheila Kenney/Louise Tee, Dietitians, julie.dutson@nhs.net, sheila.kenney@nhs.net, louisettee@nhs.net

Case study 10

AHP and Carers co-produced training project

The Carer Health And Training (CHAT) project

Sussex Partnership NHS Foundation Trust and Carer Support West Sussex

Carers play a vital role in contributing to positive outcomes for people with a learning disability, autism or both. They often navigate the specialist and mainstream health services accessed by the people they care for, often providing essential support.

CHAT is a co-produced event that has taken place three times and has brought carers and health professionals together around the same table. It provides a safe space to openly share experiences and learn from each other. Events also include a wellbeing aspect such as a walk, relaxation exercises or mindfulness. Stakeholders include; family, friends and carers alongside speech and language therapists, occupational therapists, learning disability nurses, clinical psychologists, and physiotherapists.

The conversations are facilitated by a carer and clinician and led by a carer to encourage a sense of ownership and a feeling of equal partnership. The event identified that carers often found it difficult to find time for themselves and engage in peer support with other carers and that this was something they valued.

CHAT conversations focussed around four key areas of interest and concern by carers:

- Communication
- Sensory needs
- Mental health and behaviour
- Physical health

Outcomes have included:

- CHAT gives clinicians the time, space, and permission to listen and learn from carers gaining a more holistic view of the challenges and constraints that may affect need and the importance of language used
- Approximately 60 family or friend carers of people with a learning disability have attended events
- 100% of those attending the events rated the event 8/10 or above.
- Greater awareness of clinician roles

A reflection of the event from carers:

- *“My lived experience as a carer has, I feel, been very well-respected here and my contributions have been welcomed and valued and actually used”*
- *“It's been really positive, being listened to and even giving ideas and those ideas have been taken into action. You don't get that anywhere else. There's nowhere else in what I do where any of those things happen”*

A reflection from a clinician involved:

“Through this, professionals have been able to gain an understanding of a carers experience as a whole rather than just the answers through the lens of a healthcare assessment. Being involved in projects like this gives a fresh awareness to improve how we can work with carers in the future. I have learnt so much from planning with carers from the outset, from the language we use to the basic information on services that can be difficult to find. We can find more creative and suitable solutions if we can improve our mutual understanding. This project has raised innovative ways of doing this.”

For further information please contact: Viki Baker, Clinical Director and Professional Advisor for Speech and Language Therapy – Sussex Partnership NHS Trust Viki.Baker@sussexpartnership.nhs.uk

Chapter 2: AHPs delivering specialist services

Case study 11

Occupational Therapy-led adult autism service hits the triple aim by Making Every Contact Count

Cheshire and Wirral Partnership (CWP) NHS Foundation Trust

The adult autism service was developed in 2012 as there was no autism diagnostic pathway for adults who did not meet the threshold for learning disability services and the local health and social care workforce had limited awareness of autism.

Co-led by an Occupational Therapist the CWP pathway was developed to consider the whole person. As well as a diagnosis and identification of co-occurring conditions, it understands a person's needs and preferences and identifies any adjustments they may need to function at their best. It also identifies the person's strengths and aims to build on these to support them to meet their future aspirations and live a full life. The pathway offers 2 post diagnostic reviews which is beneficial to help people and their families understand their diagnosis, refine strategies used to improve functioning and explore barriers to accessing health and social care.

The pathway saw an increase in demand which resulted in Trust investment in a consultant occupational therapist post. Their role is to lead on assessments for functional needs and provide specialist advice and consultation to other health and local authority staff working with autistic people. Their leadership and cross organisation partnerships enables the provision of early intervention, to prevent the need for more specialist health or social support and has been key in developing co-produced and co-delivered Autism training packages (including for RCpsych & HEE).

Evaluation shows:

- People accessing the diagnostic pathway have increased from 18 in 2012/2013 to 410 in 2020/2021, (despite the Covid Pandemic) and a revision of the diagnostic pathway in 2016, including the development of the Consultant Occupational Therapist role ensured nearly twice the number of people could be seen for the same cost envelope, positively impacting on waiting times.
- Excellent feedback from people accessing the service, their supporters and referring professionals
- Improved partnership working with local authorities, third and voluntary sector organisations providing specialist formal and informal support to Autism Hubs
- Improved knowledge, skills and values captured in staff feedback and evaluation
- The team were highly commended at the [positive practice in mental health awards in 2018](#) and recently identified as a national exemplar by NHS England and Improvement.

Occupational therapists make every contact count and are well placed to identify the holistic needs of autistic people, support wider services and care providers to meet these needs and lead and develop autism services to reduce health inequalities.

For further information please contact: Clair Haydon, Consultant Occupational Therapist, Adult Neurodevelopmental Disorder Services, clair.haydon@nhs.net

Case study 12

AHPs as Advanced Clinical Practitioners reducing wait time for autism diagnosis

Cheshire and Wirral Partnership NHS Trust

Excellent clinical, teaching and leadership skills are essential to support people with autism and the health and social care workforce supporting them. AHP Advanced Clinical practitioner (ACP) roles have been adopted to enhance the multi-disciplinary community learning disability service, working alongside nursing and medical colleagues.

A speech and language therapist (SLT) and a physiotherapist were appointed as trainee ACPs in September 2018 and are now qualified as ACPs. They have supported their teams to provide earlier assessments and interventions in physical and mental health and have focused on reducing waiting times using “case management” and improving internal referral pathways.

Evaluation of current role shows:

- Waiting time for autism diagnostic assessments and treatment reduced from over a year to no wait, by redesigning neurodevelopmental pathways
- No waiting times for access to all specialist learning disability clinical services.
- Improved awareness of autism and its co-occurring conditions such as Attention Deficit Hyperactivity Disorder (ADHD) and Foetal Alcohol Spectrum Conditions (FASD) across the trust through staff training.
- Specialist Memory Clinics are multi-disciplinary and the Physiotherapist ACP is now able to prescribe and review medications to treat Dementia.
- ACPs provide Care Co-ordination for the patients with the most complex needs.
- New postural care and respiratory care clinics.

The SLT ACP is able to contribute towards clinical assessment for ADHD for people with a learning disability, reducing the waiting time to see a Psychiatrist for the initial assessments. Due to updated research into ASD and ADHD co-morbidity, all patients open to the teams with complex health needs with a single diagnosis will be screened for the other.

The ACPs can urgently refer directly to specialist secondary care services, including ENT and gastroenterology. Previously these referrals were GP initiated resulting in delays and unnecessary administration time for the GP surgery.

AHPs can grow, develop and inspire others in areas of work that were not traditionally an AHP's role, increasing the scope of career pathways and staff retention. AHP ACPs have been proactive and innovative in making people's journey through health care services more appropriate and effective.

For further information please contact: Natalie Hewitt (Trainee ACP and Advanced SALT) natalie.hewitt@nhs.net

Case Study 13

Improving diagnosis and pathway development using co-production for people with autism.

Mid Yorkshire NHS trust

In 2017 a CQC Ofsted inspection identified unacceptable waiting times of 2 years for an initial diagnostic appointment for people with autism. The systems autism strategy group has led to the co-production of an autism assessment pathway.

Within the strategy, a multi-agency professionals' group was developed which included speech and language therapists (SLT), occupational therapists, clinical psychologists, paediatricians, colleagues from the education sector and voluntary sector. The group is chaired by an allied health professional (AHP) in the role of designated clinical officer (DCO). The group aims to examine and challenge the multi-disciplinary team (MDT) involved with the assessment of autism. Shared learning from case studies, complaints, and incidents, as well as parent engagement, assisted in the development of the new pathway. The clinical professionals' group, led by the DCO, facilitated a co-produced new model of care that engages with parents who use the service.

An enhanced understanding of the nature of AHPs' contribution to the autism assessment has influenced radical changes to the pathway and increased the service capacity. An example of this change was the inclusion of Occupational Therapists in the latter stages of assessment, substituting appointments previously supported by community paediatricians. This allowed for Paediatrician capacity to be focused on the initial assessment, increasing capacity of the pathway as a whole. After the initial social communication appointment with a Paediatrician, SLT's and OT's are then core members of the team, which also includes clinical psychologists, to complete further assessment depending on the needs of the child. This change in approach took significant shared vision to ensure agreement from all professionals involved.

The service is now fully NICE compliant and includes all AHP's recommended within NICE guidance. The strong leadership and integration of AHPs has enabled waiting times to reduce. Utilising an occupational therapist after the initial appointment has enabled the paediatricians to offer 30 more assessment appointments a month. This has been vital for a service in which demand is consistently increasing.

The DCO attends regular strategy meetings which include members of the parent carer forum, commissioners, local authority and voluntary sector colleagues. This

collaborative approach has vastly improved relationships between health, parent forums and wider agencies in the area.

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Case Study 14

The Lifestyle, Energy, Activity and Nutrition (LEAN) Programme

Tees, Esk and Wear Valleys NHS Foundation Trust

The Lifestyle, Energy, Activity and Nutrition (LEAN) programme was developed by dietitians and aims to address the stark health inequalities experienced by adults with a learning disability. The most recent data on the prevalence of obesity in adults with learning disabilities showed that 31% of men and 45% of women with a learning disability were living with obesity compared to 24% of men and 27% of women without a learning disability¹. The Lifestyle, Energy, Activity and Nutrition (LEAN) programme was piloted in 2010 and has since been adopted as a weight management programme for adults with learning disabilities accessing the Trust.

The programme focuses on nutritional advice and behaviour change. It is delivered using accessible language, interactive learning and presentations. The 10-week programme consists of:

- Weekly sessions of interactive education and 30 minutes of physical activity.
- Exploration of different nutritional topics each week
- Goal setting, people are encouraged to set their own goals and dietary changes
- Weekly weight monitoring.
- An awards ceremony with certificates on completion of the programme.

The results from a 3-year pilot showed 181 people accessed LEAN:

- 162 (90%) completed the full 10-week programme.
- 132 (82%) lost or maintained weight post programme
- The average rating by service users (on a scale of 1-10) was 9.7.
- The average total weight loss achieved by participants post programme was 2.5Kg.

"I like trying healthy food like fruit" User feedback

The LEAN programme demonstrates a sustainable weight management programme led by dietitians. The programme has been recognised in "A Weight off Your Mind"² (the North East weight management plan for people with lived experience of mental health conditions and/or learning disabilities). It has also been published in the [Public Health England \(2016\)](#)¹ document for making reasonable

"I like talking about healthy eating" User feedback

adjustments to obesity and weight management services for people with learning disabilities.

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Case Study 15

Multi-Disciplinary Care Pathway for People with Profound and Multiple Learning Disabilities (PMLD)

Cornwall Partnership NHS Foundation Trust

The specialist health needs of people with profound and multiple learning disabilities (PMLD) in Cornwall were not always identified. Assessments and interventions were often carried out by clinicians in isolation and there was no consistent or robust review. Deterioration of health conditions can be missed in this population, due in part to the complex communication needs and the challenges with identifying symptoms and pain. This can result in health inequalities and premature death.

In 2014 there were 34 people identified with PMLD in East Cornwall. Less than 50% had received the recommended assessments or interventions / guidance, and then usually only by just one clinician. To address this gap, a PMLD pathway was developed by the Cornwall Adult Community Learning Disabilities Team, consisting of learning disability nurses, occupational therapists, physiotherapists, speech and language therapists, psychologists, support workers and a dietitian. The pathway helps compliance with the main national drivers for this population^{1,2,3}, together with the core and essential service standards for people with PMLD⁴.

There are currently 87 people with PMLD identified to the community team in Cornwall. Everyone is recommended to receive all assessments and guidance from the MDT. People are initially seen by 2 team members who complete an assessment and referrals are made to other MDT members depending on priority need and the individual / family / carer wishes. A personalised approach is taken in order not to overwhelm the individual and their support network. Input also varies depending on how needs are being met by their carers or families, or if care is received from other services.

The pathway offers specialist health assessments and interventions recommended by evidence-based practice. It also checks that people have current 'health support tools' in place such as health action plans, hospital passports, communication passports and pain profiles. It then reviews those needs on an annual basis. The review includes checking whether an 'annual health check' has been completed by the GP. Where there are gaps in specialist assessments and advice, these are completed by the MDT or there is liaison with other appropriate health services.

Since pathway implementation 100% of this population have access to evidence-based care and there have been improvements to holistic care plans. Before this work, there was no clear understanding of who this population were in Cornwall. The annual review empowers families, supporters, and health care professionals to identify and communicate changes and identify deterioration in health. The pathway has demonstrated the benefits of a multi-disciplinary team effort and collaborative approach to understanding and proactively meeting the complex biopsychosocial needs of people with PMLD.

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Case Study 16

AHPs supporting young people with learning disabilities (YPLD) in their transition from children's services to adult care.

London North West University Healthcare NHS trust

The children and young people's health outcomes forum (2012) report that a poor transition experience can lead to disastrous health outcomes for both physical and mental health. It can result in dropouts from medical care leading to unnecessary, costly and often distressing hospital admissions. The management of these young people falls upon their parents after transition to adult services. In order to better equip families and young people with a learning disability living in Harrow to cope with the transition, a pathway including a clinic involving professionals from health and social care both in adult and paediatric specialist teams has been established. Students with complex needs attending special schools have not previously had access to a similar pathway.

Occupational therapists, physiotherapists and speech and language therapists (SLT) work in partnership with Harrow Special Schools to prepare YPLD and their families for seamless transition to adult health, education and care services. The transition pathway ensures information is shared with relevant agencies and the transition plans are integrated within the education health and care plan (EHCP).

The pathway was collaboratively designed with the health care workforce (paediatrician, community children's nursing, and commissioners), education services, people with lived experience and social care.

The pathway is introduced to individuals aged 14, and their parents. Conversations focus on skills for independence, plans for further education and work and a plan is co-developed and reviewed annually. A meet and greet with adult services take place in year 12 for people with ongoing health needs. A further transition clinic is held for the formal transfer of young people to adult services. A transition passport is

developed and contains essential information about the individual, their needs, preferences, communication skills, equipment required and key information about family and friends. The transition passports are issued either in year 12 as they leave school for FE college or at year 14th when they go on to FE colleges or assisted work placements. A transition report is shared with individuals, their family, GP and adult providers to facilitate the sharing of information.

Evaluation shows:

- Over the past 3 years, 100% of 33 young people with severe or profound learning disability who have attended either the meet and greet clinic in year 12 or the transition to adult clinic in year 14 have had a transitions passport and transition plan, which is included in their Education Health and Care plan (EHCP)
- A further 30 young people with moderate learning disability have also had transition passports and transition plans as part of their EHCP, these students may not have significant medical needs but have AHP needs.
- All young people with a learning disability and their parents/carers have the opportunity to discuss transition planning at an early stage.
- Key information is shared with relevant agencies and transitions plans are integrated within Education health and care plan (EHCP).
- There is an opportunity to meet Adult health and social care practitioners before transition to discuss concerns or make enquiries regarding services.
- People have communication passports with their key information
- Parents and young people value the pathway, communication passports and transition clinics.

People can find the transition to the adult health care system challenging and difficult to navigate. This early intervention pathway is vital and AHPs have an important role to develop care plans advocate for people's care.

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Case Study 17

Improving access to eye care by the implementation of an Orthoptic-led Special School Eye Care Service.

Warrington and Halton NHS Foundation Trust

Children with a learning disability are 28 times more likely to have an eye problem than their non-disabled peers¹. Around one third of children attending special schools will require a glasses prescription, as well as other eye problems^{2,3}. However, up to 1500 (44%) children in special schools have not accessed any eye care⁴. Therefore, action is needed to ensure that assessments and diagnosis for visual impairments form part of every child Education Health and Care Plans (EHCP). There are 508 children attending 6 special schools in the area. To access eye care the options were the local optometrist on the high street for primary care and the hospital for secondary care, which includes Orthoptics. Up to 50% of eye care appointments in the hospital were missed, resulting in approximately 254 children not receiving eye care. This risks discharge and delayed treatment, which for children under 8 can lead to irreversible sight loss⁵.

To improve uptake of eye care appointments the orthoptists deliver assessments within the special schools. As a result, all children receive comprehensive eye care, including the 254 children who were unable to make their appointments. This also benefits the children's families, who have less hospital visits and time away from their school or home. This approach has also allowed the orthoptists to build improved relationships with the schools, as well as improved collaboration with the wider multi-disciplinary care team, teachers and supportive structure.

This service has made immeasurable impact to at least 254 children who are able to access important eye care each year as recommended. Service evaluation over 3 years satisfaction surveys by 624 parents have shown positive results;

- 99% wanted their child's eye care to be carried out in school
- 96% rated the service as good or excellent
- 71% said it reduced their child's stress / anxiety levels by having the eye care provided in the school setting

The service provides numerous benefits, including; children do not need to take time off school to attend multiple appointments as they can all be carried out in the school setting, the approach eliminates the stress and anxiety the child may experience due to waiting times at the hospital and unknown environment, it reduces parent stress levels and need to take time off work.

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"It was so stressful taking my child to the hospital for check-ups. It is much better that the eye care service see my child in school. In an environment they are used to. I am also not getting stressed as I know school will support my child during the check-up. Fantastic team"
Feedback from a parent

"This is such a valuable service to us my son does not cope at hospital at all. It's amazing he can be seen ...in school and we wish other services offered this." Feedback from a parent

Case Study 18

Dramatherapy groups supporting people with a learning disability and mental illness transition out of hospital

Cumbria Northumberland Tyne & Wear NHS Foundation Trust

Mental health problems affect approximately 40% of adults with a learning disability which is higher than the general population¹. Dramatherapists developed two dramatherapy 'Get Going' groups as a proactive approach to support people with a learning disability and mental ill health after a hospital admission. People were introduced to the groups when preparing for their discharge and then supported to attend once they moved into their local community. The approach allowed care to be monitored in the early stages of leaving hospital and concerns highlighted throughout their transition.

The Get Going Groups runs in 12-week blocks and has been running for over five years. The group has been used as part of an Assessment and Treatment Unit's (ATU) discharge pathway, offering people a chance to communicate, build friendships and improve their skills such as turn taking. It has also been provided to clients who live in the community and adapted to be an online group during the COVID-19 pandemic. The content and structure of the groups are based on play and story development using 'the six-part story' method. The stories produced offer insight into the difficulties a person may have had or are currently experiencing, which can offer opportunities for constructive dialogues and appropriate help to be identified.

The groups have been shown to support a person's successful discharge, offer an immediate link to healthcare practitioners, reduce the risk of unnecessary hospital re-admissions, and reduce social isolation for community clients during UK wide COVID-19 related 'lockdowns'. Data from our evaluation of clients attending the group during and following their ATU hospital admissions shows that out of 36 people who accessed the groups only two people required a re-admission to hospital.

The groups improved people's quality of life through friendships and skill building. Outcomes using the 'The Warwick-Edinburgh Emotional Wellbeing Scale' (WEMWBS) showed a whole group score increase of 7.1 post group and indicates self-reporting improvements in a person's mental well-being. A mean reduction on the Glasgow Anxiety Scale scores (GAS) with a lowering of fear and anxiety highlighted on the subsections of the tool, informing us that attending the intervention was beneficial overtime and reduced anxiety.

Twenty-two participants using the Rosenberg Self-esteem measure were analysed using a paired T-Test and results showed statistically significant improvements in all group members' self-esteem (mean scores at pre-intervention 21.35 and post intervention 24.75. resulting in a P value of $P < 0.01$).

During the COVID 19 pandemic online Get Going groups continued to show positive results for community clients with paired T-Test analysis of participants showing reduced anxiety levels (P value of $P < 0.002$).

People with a learning disability and mental ill health find it difficult to integrate into the community after psychiatric admissions and benefit from facilitated spaces and psychosocial interventions to meet people with shared experiences². Dramatherapy groups that use storytelling and drama methods to role play creatively and constructively personal challenges, can help people share their experiences and validate what they are going through. The group has won a Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust 'Staff Excellence' award for its mutual support approach where people who have attended have also become mentors for subsequent groups.

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Case Study 19

Supporting Independence for people with learning disabilities

East London Foundation NHS Trust

A lack of suitable local accommodation for people with learning disabilities and complex needs resulted in the use of out of area residential and supported living placements. This led to reduced family contact and many people would have preferred to live locally. There were also increasing numbers of older adults with learning disabilities and age-related co-morbidities, such as dementia and arthritis, who were living in accommodation no longer suitable for their needs and who wished to continue living with their friends. Out of area placements make it harder for the team to monitor the quality of placements as reviews are annual unless issues arise. The Community Learning Disability Service (CLDS) is an integrated health and social care service comprising occupational therapists, speech and language therapists, physiotherapists, an art therapist, social workers, community nurses, psychiatrists, clinical psychologists and an interpreter. To meet population needs, the team identified those living out of area who wished to return and those in supported living accommodation wanting to live more independently.

The occupational therapists worked collaboratively with the clinical commissioning group and a social housing provider to adapt and renovate a three-bedroom flat within a sheltered housing complex and a small block of flats. They advised on suitable layouts and fittings for bathrooms and kitchens and telecare options. 7 one-bedroom flats, including 1 for a wheelchair user, a shared communal flat for social activities, garden area and staff space were created. The occupational therapist also supported the development and implementation of a priority bidding process for independent social housing, for individuals who are ready to move on from supported living.

The CLDS AHPs and clinical psychologists also support people to develop the skills to live more independently. They work with people who are preparing to return to the borough, so that support staff know how best to support them. This includes assessments and support plans for behavioural, sensory and communication needs. Personal Health Budgets are used to fund bespoke solutions, such as sensory equipment, communication aids and gym memberships. This approach has so far enabled 5 people to move from supported living into their own flats, 1 from out of area. 3 friends, all older adults, moved together to an accessible property. The team has also prevented new out of area placements due to crisis through the supported living vacancies created and the 10 new supported living units within the borough. This allowed 4 people with very complex needs to return to the borough.

This project has supported individuals to have more contact with their families, often daily. People have reported positive experiences and excitement when gaining access to their properties, including decoration plans. New friendships have been formed, people are proud of their homes and 1 person has found part-time work. Supporting people in this way to have meaningful lives and live as independently as possible requires an integrated approach. AHPs have an important role in developing services, assessing individuals, developing skills and supporting a smooth transition process.

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Case Study 20

A Safe Home Is Still A Home - The Development of the Safe Home Environment Assessment (SHEA)

Sussex Partnership Foundation Trust

Designing a safe home for individuals who require a more bespoke design specification can be challenging¹. The Safe Home Environment Assessment (SHEA) tool was developed as a pragmatic response. Developed by occupational therapists, it aims to support clinical decision making in the transforming care transition process. It attempts to synthesise and risk rank complex sensory, communication, functional and behaviours that challenge to inform the design of an environment that meets the individual's needs and preferences.

The tool has been used in a small number of local transforming care cases, for example: Mr X is in his mid-20s with a diagnosis of moderate learning disabilities, autism, hearing impairment and a history of complex behaviours, had been in hospital for a number of years after many community placement breakdowns. The team supported the development of a home environment in line with his goal of increased independence, reduction episodes of destructive behaviours and use of restrictive interventions. The design also allowed for a communication environment as they used sign language to communicate. This intervention involved close multidisciplinary & multiagency working to develop a "capable environment" for the individual. The SHEA focused on elements of the physical environment that needed

to be in place as it could not be addressed solely by a positive behaviour support plan, staff intervention or risk assessment alone. The SHEA is divided into domains including; destructive behaviour, hygiene and difficulties with transitions.

The SHEA identifies and prioritises adaptation design. For Mr X, it was identified that robust fixtures and fittings would be needed and clear sight lines for communication. Mr X also required the "designing out" of known visual triggers such as staff shift changes, as they found this transition difficult. Adaptations included; adding a new separate staff entrance, a communication window so staff could withdraw but be able to still communicate with him during periods of high anxiety, robust furniture and window fixtures, graded access to the kitchen and food to take into account his food seeking behaviours. Mr X was also able to personalise his environment and he chose to have giant murals of his favourite animals and cityscapes. He also had a sensory room for relaxation and other sensory activities.

Strategies for property maintenance were also considered to reduce anxiety. This included supporting Mr X to leave the premises for a short time during maintenance works and having a 24 hour call out service for emergencies. These considerations are within the SHEA as environmental breakdown can be a leading cause of placement breakdown. Mr X has been living in his home for more than 5 years and he is proactively engaging in daily living routines, community activities, as well as having holidays abroad. The tool has been accepted as a [NICE shared learning case study²](#) and a future goal is to contribute case studies on co-production in the area of design for adults with a learning disability, autism or both.

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