Working with local partners to provide whole-child care

The Association for Child and Adolescent Mental Health

5th November 2021

Sue North M.B.E.  
Head of Children and Young People  
Learning Disability & Autism  
NHS England and NHS Improvement
Children and Families: what does it mean in practice?

• Working with and for children and for families
• Codesign/coproduction (both strategic and individual): parents and carers as equal partners
• Personalisation: not about ‘services’ that families have to fit into but about tailored support that flexes as children and families develop
• Family centred (including siblings)
• Thinking about trauma- the impact it has on how children and young people experience their world including the services they access
• Recognising that children’s lives are not siloed between policies and so need to reflect on the family and CYP journey and making sure there is the right help and support at the right time
Children and Families pathways
Recognition of challenge – efforts to respond

- Children Act 1989, 2004
- Children and and Families Act 2014
- Mental Health Five Year Forward
- Autism Act 2009
- Transforming Care
- The NHS Long Term Plan
- SEND Review
- Building the Right Support Delivery Board
System wide challenge and response

- Pressure on services that support CYP for mental health / secure welfare / health and justice interventions and accommodation require a collective response, acutely illustrated by the COVID-19 pandemic. Working with local partners (CQC; LGA; DfE; DHSC) to support and care for CYP

- Covid-19 impacted on provision of mental health care: staffing, restrictions on admissions to mental health hospitals, increasing quality challenges.

- Covid-19 especially increased and continued anxiety and depression for autistic children and young people and families.

- The challenge for many of the restrictions, change in structure and lack of access to usual support especially school and college makes it more important than ever that health, social care and education work together locally, using dynamic support systems, to assertively address the particular and significant difficulties experienced by these families.
Changes in health architecture – Integrated Care Systems

• ICSs have four key purposes:
  • improving outcomes in population health and healthcare
  • tackling inequalities in outcomes, experience and access
  • enhancing productivity and value for money
  • supporting broader social and economic development

• ICSs comprise all the partners that make up the health and care system working together in the following ways.

• The statutory ICS arrangements (subject to legislation) will include:
  • an ICS NHS body - ICB (Statutory Body)
  • an ICS Partnership - ICP - formed by the NHS and local government as equal partners – it will be a committee, not a body.

• Other Important ICS features are:
  • place-based partnerships
  • provider collaboratives
Collaborating as ICSs will help health and care organisations tackle complex challenges including:

- Improving the health of children and young people
- Supporting people to stay well and independent
- Acting sooner to help those with preventable conditions
- Supporting those with long-term conditions or mental health issues
- Caring for those with multiple needs as populations age
- Getting the best from collective resources so people get care as quickly as possible.

Other key information:
- The ICS NHS bodies will take on all statutory functions of CCGs as well as any direct commissioning functions that NHS England may delegate.
Provider Collaboratives

- **Long Term Plan Commitment** that all appropriate specialised (only) mental health services (and learning disability and autism services, will be managed through NHS-led provider collaboratives by 2023/24.

- Provider Collaboratives are a new way of commissioning and providing specialised services:
  - **Always** led by an NHS provider
  - Based on local clinical leadership and co-production with experts by experience driving which services are available for local people (absolutely allied to direction of travel for Integrated Care Systems).
  - NHS lead Provider has responsibility for the commissioning budget for specialised services for the local area as well as responsibility for quality oversight of the services commissioned and pathway management including when provided by the independent sector.

- The Lead NHS Provider remains accountable to NHSE/I for the commissioning of high-quality specialised services.
  - Opportunity to drive up quality
  - Includes independent sector providers within the collaboratives- because it is important all patients in specialised services are included

Provider Collaboratives are responsible for:

- Children and Young People’s inpatient mental health, learning disability and autism services (often referred to as Tier 4 services)
- Adult Low and Medium secure services (often referred to as forensic services)
- Adult Eating Disorder inpatient services
Building the Right Support Delivery Board

Department of Health and Social Care Minister led board (Gillian Keegan, Minister of State for Care)

Brings together Government Departments, Arms Length Bodies and key stakeholders

5 priorities are:

- Improving the provision and suitability of community-based preventative support, including crisis support.
- Improving transitions into adulthood, especially for autistic young people.
- Improving our understanding of best practice models in the community, including principles for bespoke support.
- Reducing the number of people in inpatient care under Ministry of Justice restrictions, including those on MM/PJ judgements.
- Addressing issues with funding flows, including financial disincentives across systems.
# Building the Right Support priorities

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<thead>
<tr>
<th>Priority 1</th>
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Building the Right Support Children and Young People’s Steering Group

Anne Longfield CBE – Independent Chair

Members include:
• Department for Education (DfE)
• Department for Health and Social Care (DHSC)
  Council for Disabled Children (CDC)
• Challenging Behaviour Foundation (CBF)
• National Network of Parent Carer Forums (NNPCF)
• Family carer
• Ofsted
• Care Quality Commission (CQC)
• Health Education England (HEE)
Steering Group priorities

Supporting identification of autism
Aligns with:
- Autism Strategy
- Autism Diagnostic Work
- SEND Review
- Born in Bradford
- Early Support / Family Hubs

Responding positively to children in school
Aligns with:
- SEND Review
- NCNE accelerator site
- Restrictive interventions

Targeted Intensive Support
Aligns with:
- LTP Intensive Support commitment and funding
- Admission Avoidance
- Keyworking
- Crisis response / shortbreak

Highly Specialist Provision
Aligns with:
- Specialist Mental Health Provision (e.g. ARFID)
- Highly specialist support for those with most complex needs - Social care / Secure welfare / Youth Justice / Mental Health / QT

Transition
Aligns with:
- BTRIS Board Priority
- LTP IS priority
- SEND review
NHS Long term plan commitments

- Reduction in the number of children, young people and adults with a learning disability and autism in mental health inpatient care
- Keyworkers for children and young people with the most complex needs – focus on those at risk of admission or in hospital
- Increase in annual health checks for those aged 14+ with a learning disability and testing an autism specific health check
- Testing new approaches to autism diagnosis
- Improving the quality of Inpatient Care
- Continued commitment to STOMP - STAMP
Key policy documents

The 9 principles of the Service Model

- My family and paid staff get the help they need to support me in my community
- I have a choice about where I live and who I live with
- I get good care and support from every team involved
- I get expert health and social care support in the community if I need it
- I get help to stay out of trouble with the law if I need it
- I can stay in hospital because they need me in a health context
- I have an enjoyable and meaningful life
- My care and support is well planned
- I have choice and control about my care and support

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“Golden threads”

- Children, young people and families are supported to have a good quality of life. They are treated with respect and have an expectation of a home in their local community
- Children and young people should be kept safe but at the same time supported to take positive risks
- Children and young people should have choice and control over their lives
- Children and young people’s support should be provided in the least restrictive way
- Children and young people should get equal health outcomes to the rest of the population

Dynamic Risk Stratification Process

- A local register and process for identifying people with learning disabilities at risk of care or health issues
- People receiving support for behaviours that challenge from other specialist teams (e.g. CAMHS and Forensic Services)
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- People known to be at risk of violence (e.g. youth offending teams, police, health visitors, school nurses, GP, mental health teams)
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### Learning Disability and Autism Children and Young People’s Team

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<td>CYP2 - Improving Quality</td>
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<td>CYP3 - Development of Keyworkers and participation</td>
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<td>Hannah Mann – Senior Programme Manager, Children and Young People</td>
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<td>Kate Sutton - Senior Programme Manager, Children and Young People</td>
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**SEND**
- Autism Team
  - Leading on work regarding diagnosis for children and health inequalities and quality for autistic adults

**Kate Naish**
- Specialist Advisor for Primary Care
Collective responses for CYP mental health and autism

Anxiety:
Anxiety disorders are substantially more common in autism than in the general population. Whilst around 10-15% of the general population have an anxiety disorder at some point in their life (most commonly a specific phobia; Kessler et al., 2012), around 40% of autistic children, adolescents and adults are thought to have at least one and often more anxiety disorders (van Steensel et al., 2011), with specific phobias and social anxiety among the most common forms. It is important to appreciate that anxiety disorder is not simply a part of autism but an independently co-occurring disorder that can be addressed and treated in its own right.

Eating disorder, disordered eating and ARFID:

• Recent work undertaken as part of the ARFID pilots with Autistica has demonstrated:

• Autistic children and young people (CYP) and autistic adults appear to be at higher risk of ARFID than those without autism³.

• We have worked with colleagues in the Eating Disorder team and in particular in relation to ARFID. Following feedback from the ARFID pilots, we commissioned specific training in relation to ARFID and autism rolled out in 2020.
Whole-child care for children and young people with a learning disability or autism

• Through the CYP IAPT service transformation programme, a curriculum and training programme was developed to train therapists to adapt mental health treatment for those with a learning disability or autism.

• A ‘whole team training’ programme was also developed and all community eating disorder teams for children and young people participated in the programme over a 12 month period in 2017.

• The training highlighted the need for staff to be skilled at adapting communication and clinical interventions for those with a learning disability or autism.
Examples of joint working

Accelerator projects:

• In 2019/20 NHS England rolled out a CYP accelerator programme.

• A particularly impactful project was seen in North Cumbria and North East where an innovative approach working between the CCG, Local Authority, Parent Carer Forums and Young People led to a collaborative approach to support understanding of the needs of this group in schools leading to a significant reduction in exclusions.

• In 2021/22 with £4m Spending Review money we will roll out the accelerator programme across systems in each region.
Eyesight, hearing and dental checks for CYP

• We are also working on the commitment to work with others to make sure that children and young people with a learning disability, autism or both in residential special schools have access to eyesight, hearing and dental checks.

• Starting last month, the service is delivered in the safe and familiar environment of the school premises by clinicians who have received additional training, including the dispensing of glasses for every child who needs them.

• Each child will also receive a report written in plain English to help parents, carers, teachers and other health professionals understand what the child can see, and offer strategies to help improve engagement with their immediate environment - in the classroom and at home.
Long Term Plan - Community Services Development
£25m (21/22), £40m (22/23), £80m (23/24)

• To achieve the Long-Term Plan commitment of reducing inappropriate hospital admissions, each local area has received additional funding in 2021/2022 to improve their local community-based support and services, this is crucial to achieve this ambition. Funding has been sent to TCPs/ICSs under the funding line of Community Capacity on a fair share basis.

• We have asked local areas to use this additional funding to develop support and services particularly for autistic children and young people aged 14-25 in 2021/2022; to improve intensive/enhanced and crisis support in community settings, delivering care closer to home. This includes community teams, overnight crisis care, and personalised responses.

• NHSE&I hosted a series of six webinars to support local areas in their delivery. A summary webinar is planned for early November which will then develop into a community of practice starting in December. If you are interested in joining this Community of Practice, please contact scarlett.milward1@nhs.net
Health and Justice

- Following the Long Term Plan (LTP) commitment to provide additional support for children and young people (CYP) with complex unmet needs who are high risk, high harm, high vulnerability, additional funding has been allocated to FCAMHS teams to focus on Children and Young People who present with Learning Disability or Autism or both. Some CYP may not yet be diagnosed with a Learning Disability/Autism or both but could benefit from assessment/support.

- Some Children and Young People may not yet be diagnosed with LD/ASD or both. This funding (£350k) is for FCAMHS to identify CYP eligible for their service, with LD/ASD or both needs and support them to access the right help and support to meet their needs and prevent avoidable admissions into hospital/residential/secure estate settings.

- FCAMHS Teams have been asked to consider development of Autism champions – this role to include ability to complete either a full Autism assessments or screening tools to identify CYP who may have autism and refer them onto an assessment service

- FCAMHS to Access specific training to identifying how to support and meet the needs of autistic CYP and people with LD – this training could include overview of the local area Dynamic Support offers (for example, The North Cumbria and the North East Dynamic Support Register Training 2021-2022)
Long Term Plan - Keyworking

By 2023/24 children and young people with a learning disability, autism or both with the most complex needs will have a designated keyworker, implementing the recommendation made by Dame Christine Lenehan. Initially, keyworker support will be provided to children and young people who are inpatients or at risk of being admitted to hospital.

• 2021/2022 £15m 13 Pilot Sites, 14 Early Adopters – test and refine; What is it? Who is it for? What does it do? Work towards full geographic coverage

• 2022/2023 £30m Mobilise to full coverage; Every area will have a keyworker site

• 2023/2024 £44m Extend scope to include 18-25 year olds and other vulnerable groups at risk of institutional care

• Development of Senior Childrens Intervenors for those most ‘stuck’ in hospital
Autism in Schools – Mental Health Recovery

- The **£4m** Project is based on the children and young people’s accelerator work with North Cumbria North East aimed to prevent crisis and escalation in school which often leads to exclusion.

- The aim is to support the development of autism friendly school environments, school-linked Parent Carer Forums and reasonable adjustments for autistic children and young people

- The original project was developed in co-production with the Parent Carer Forum and led to significant cultural change which saw a reduction in exclusions from schools.

- There are 15 Projects working across 7 NHS England Regions

- Key Deliverables:
  1) Establishing Mini Parent Carer Forums – Co-Production
  2) [Parent Led] Training offer – some in partnership with AET
  3) Improved CAMHS offer
  4) Reasonable adjustments including whole-school behaviour policies
Identifying Children and Young People at Risk of Admission £3.5m Spending Review

• Local partners across health, education and social care have been asked to work together to identify children and young people waiting for autism assessment (pre-diagnosis) and autistic children on Mental Health waiting lists, who are at risk of admission or who would become at risk of admission without immediate intervention.

• This one-year investment is intended to support Integrated Care Systems review waiting lists and identify those Children and Young People (pre and post autism diagnosis) at risk of admission to hospital. This should be aligned as far as possible with the local Dynamic Support Register arrangements/processes.

• Partner agencies should cross reference autism diagnostic waiting lists with those children and young people close to exclusion, known to social care or waiting for CYP Mental Health treatment. There should be a strong focus on those at risk of crisis and/or self-harm.

• The ambition is to support earlier identification of children and young people who may reach crisis point and enable earlier support to avoid CAMHS inpatient hospital admission.
Health Funded Respite – Mental Health Recovery

• To deliver health funded community respite care (short breaks) for those at risk of admission and/or mental health crisis; linked with Dynamic Support Register

• Funding (£3m) should be used to prevent avoidable hospital admissions for autistic children and young people or those with a learning disability or both by addressing and managing crisis in community settings through the use of health funded community respite.

• This is aimed at supporting local areas to jointly commission and work in partnership across CCGs and local authorities to enhance short break provision to prevent avoidable hospital admissions. Local area could use their dynamic support registers and processes (as well as waiting list triage work) to identify children and young people and their families who could benefit from health funded respite.

• Funding must align with your area’s Long Term Plan admission avoidance work for children and young people with a learning disability, autism or both, and where there is an immediate risk of admission a community Care, Education and Treatment Review (CETR) should be convened and health funded respite could be considered as part of the review to prevent admission.

• This funding MUST be used to provide additionality and not fund existing capacity/assessed provision or similar.

• Respite/short breaks MUST provide a break from caring for the parent/carer and a positive experience for the child or young person.
Additional Spending Review funding 2021/22

- Advocacy pilots and review
- Specific focus on those in long-term segregation – including pilot of Senior Intervenors
- Increased resource for testing of autism diagnosis for children and adults
- “Champion” for Learning Disability and Autism in each Integrated Care System
- Funding to support environmental changes in inpatient mental health settings
- Funding for VCS partners to respond to the impact of Covid on individuals and families