

## Talking Points: Engagement and co-production with Health

We continue to work with our colleagues in the NHS to build strong relationships that will allow us to co-produce with them in a truly productive way.

Many areas have seen improvement in health engagement since our first Talking Point (2017) through an increased focus on parent carer forums from NHS England and the SEND local area inspections. At a regional and national level, we have seen good engagement in the Learning Disability and Autism programme. However, some forums and regions still report that engagement with CCGs, NHSE transformation projects and providers remains sporadic and sometimes ineffective.

**This is the latest version of the Health Engagement Talking Point.**

### Individual co-production

Parent Carer Forums (PCFs) up and down the country are reporting widely varying levels of personalised care plans being developed with families, Clinical Commissioning Groups (CCGs) and providers. Often families report that staffs remain very provision focussed, rather than outcome focussed.

The NNPCF would like to see person centred planning and an outcome focus fully embedded in all interactions by health staff with families.

Parent Carer Forums across the country continue to report the ability of health professionals to support the SEND reforms is limited by their capacity and financial prioritisation, and the quality of health advice to Education Health and Care Plans is still cause for concern.

A review of recent Ofsted/CQC Local Area SEND Inspection letters found the contributions from health are frequently mentioned as issues. These key messages are reflected in Ofsted/CQC Local Area SEND Inspection findings. For example:

*“Children with SEND are not easily identifiable in health records at an individual, service or trust level. This makes it harder for health professionals to be aware of children’s needs in a holistic manner and negatively impacts on the tell-it-once approach for parents and carers. This also reduces the effectiveness of leaders’ oversight because they cannot easily identify the outcomes achieved by the health care received.” Kent (March 2019)<sup>1</sup>*

*“The clinical commissioning groups do not have effective oversight of the health provision specified in EHC plans. Too great a reliance has been placed on contract monitoring of services, which lacks specificity and limits assurance that children’s needs will be met. The quality of the health information on EHC plans is inconsistent and poor in places. In the absence of effective oversight, opportunities for improvement are impeded and may impact on children achieving better outcomes” (Inspection letter Q1 2019)*

*“Although more recent EHC plans are of a better quality, there are still many occasions when health contributions are not included in the final EHC plan. Health practitioners still do not routinely receive the draft EHC plan for review”.<sup>2</sup> (Local area SEND inspection Norfolk June 2020).*

The health contribution to EHC Needs Assessments and Annual Reviews and the rising number of referrals is a real area of concern for the NNPCF. We continue to raise these issues with the DfE and NHSE.

## Strategic co-production

The NHS constitution and the Five Year Forward View enshrine public involvement.<sup>3</sup> This document also sets out the NHS and Local Government’s vision for greater collaboration.

We have seen a vast improvement in national and regional strategic co-production from Health agencies since the introduction of the LA SEND inspection framework and following the work done by the Children’s

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<sup>1</sup> <https://files.ofsted.gov.uk/v1/file/50066616>

<sup>2</sup> <https://files.ofsted.gov.uk/v1/file/50151804>

<sup>3</sup> <https://www.england.nhs.uk/publication/patient-and-public-participation-in-commissioning-health-and-care-statutory-guidance-for-ccgs-and-nhs-england/>

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and Young People team at NHS England. Despite this progress, some Parent Carer Forums still report that local engagement is patchy, with health services in some areas still not working with forums and remaining detached from the SEND agenda.

We have seen an increase in concerns from forums that their local areas cannot deliver the health services required with constrained resources. The demand and scope of health services for SEND is increasing at a time when local authority and health finances are under ever increasing pressure.

Forums need to make sure that Integrated Care System (ICS)/local areas have a really good, shared understanding of local needs through a SEND Joint Strategic Needs Analysis (JSNA) to ensure they can jointly prioritise, commission, and deliver services that meet these needs.

The NNPCF would like to see strategic co-production more consistently embedded with Health Partners at every level across governance and delivery groups.

This is reflected in the fact that relatively few Parent Carer Forums at a local or regional level are funded by health bodies.

We would like to see clear guidance around the systemic funding of Parent Carer Forums by health bodies - either nationally (from NHS England / Department of Health), regionally or locally once ICSs are established. The NNPCF continues to raise this issue with NHSE and DHSC as a significant proportion of local and regional activity is now within the health arena

The NNPCF is a member of the Complex Needs Board and is actively involved in the implementation of the NHSE Long Term plan which relates to SEND.

We will continue to work with NHS England to help inform and develop more consistent models of co-production across the NHS, and more consistent use of the language of co-production and participation. This would enable the NHS to work with a range of partners including the NNPCF in a way that recognises and leverages their different strengths and specialisms.

## Changing landscape across health

The landscape for health is rapidly changing. All changes are based upon the triple aim duty on health bodies<sup>4</sup>:

- better health and wellbeing for everyone (including CYP with SEND)
- better quality of health services for all individuals
- sustainable use of NHS resources

The NNPCF welcome in principle the plans for ICS Boards to have decision-making responsibility for arranging healthcare services.

However, forums have told the NNPCF that SEND is not a high priority for many clinical commissioning groups and that ICS boards do recognise Parent Carer Forums as strategic partners representing a key community within the system. This means that many health commissioners have not focused on the requirements of the SEND reforms and families report shortages of key services (e.g. long waits for ASD diagnosis and services, speech and language therapy). Going forward forums will need to support & challenge how any SEND proposals will deliver these three aims and where forums are able to participate at board level, should be welcomed.

There are five main things that forums need to be aware of:

- Long Term Plan (LTP) 2019
- Sustainability & Transformation partnerships (STP)
- Integrated Care Systems (ICS)
- Primary Care Networks (PCN)
- Provider Collaboratives

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<sup>4</sup> [NHS England » Integrating care: Next steps to building strong and effective integrated care systems across England](#)

## NHS England Long Term Plan (LTP)<sup>5</sup>

What does the LTP say about Children and Young People with SEND?

The LTP sets out a number of overarching principles including:

1. Put children and young people and their families at the centre of care
2. Involve children, young people and families in the design and delivery of health work.
3. Target action at reducing health inequalities, including addressing the needs of vulnerable children and those with complex needs.

The NNPCF have partnered with NHSE/I to produce some webinars on the NHS Long Term Plan. You can find them under the “Improving Health Services” section of the [Contact website](#).

There are a number of named SEND related areas in the LTP. These include:

### Learning Disability and/or Autism (LD/A)<sup>6</sup>

The LTP recognises that all SEND children and young people, including those with learning disabilities and / or autism (LD/A), have the right to lead fulfilling lives in the community. The focus is on “homes not hospitals”<sup>7</sup> with young people receiving the support they need to live at home with their family or locally in the community. A number of initiatives are needed to deliver this including

- Designated Key Worker. The role of the key worker is to work with children and young people with LD/A. Initially, keyworker support will be provided to children and young people who are inpatients or at risk of being admitted to mental health inpatient beds, and will be extended to other vulnerable groups, including adopted and looked after children, by 2023/24.
- Wider use of Personal Health Budgets.

<sup>5</sup> <https://www.longtermplan.nhs.uk>

<sup>6</sup> <https://www.longtermplan.nhs.uk/areas-of-work/learning-disability-autism/>

<sup>7</sup> <https://www.england.nhs.uk/learning-disabilities/care/>

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- Development of Dynamic Support Registers<sup>8</sup>.
- NHS Quality checking of services by young people with LD/A<sup>9</sup>.
- Mental Health **Provider Collaboratives**.

The introduction of NHS-led Provider Collaboratives<sup>10</sup> creates a shift in the approach to commissioning specialised mental health, learning disability and autism services. The collective focus of the NHS will be on the health of local populations, understood through outcomes, experience and the delivery of transformation in pathways of care. NHS-led Provider Collaboratives aim to ensure that people with specialised mental health, learning disability and autism needs experience high quality, specialist care, as close to home as appropriately possible, which is connected with local teams and support networks. Provider Collaboratives are seeking to enable specialist care to be provided in the community, to prevent people being in hospital if they don't need to be, and to enable people to leave hospital when they are ready.

## Mental Health

The LTP describes greater funding for children and young people's mental health services. Investment in expanding access across community based mental health services (NHS-funded mental health services and school or college-based Mental Health Support Teams)<sup>11</sup>

The NNPCF believe there needs to be a focus on earlier intervention and prevention, especially within and linked to schools and colleges. We welcome the government's work to provide earlier mental health support for all children and young people including those with SEND through new Mental Health Support teams however this rollout has been slower than planned and only a third of pupils will be reached by April 2023.<sup>12</sup> There also needs to be greater support for local areas to explore their system wide approach to CAMHS and Neurodevelopmental pathways, taking early intervention offers into consideration and looking at the connectivity across universal, targeted,

<sup>8</sup> <https://www.england.nhs.uk/learning-disabilities/dynamic-registers-and-dynamic-systems/>

<sup>9</sup> <https://www.england.nhs.uk/learning-disabilities/projects/>

<sup>10</sup> <https://www.england.nhs.uk/mental-health/nhs-led-provider-collaboratives/>

<sup>11</sup> <https://www.annafreud.org/schools-and-colleges/research-and-practice/the-link-programme-new/>

<sup>12</sup> <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/07/nhs-mental-health-implementation-plan-2019-20-2023-24.pdf>

and specialist offers to provide an improved graduated response. Many families have significant concerns about the long-term impact of the Covid 19 Pandemic on their child's mental health and wellbeing and the capacity of services to meet needs.

**The NNPCF continues to raise these issues at a national, regional and local level.**

### Reducing Health Inequalities for those with LD/A.

The LTP recognises the health and life expectancy is lower for those with LD/A. A number of steps address this:

- Annual Health checks have been introduced for those aged 14 and above.
- Hearing, sight, and dental checks will be delivered for children and young people with a learning disability and/or autism in special residential schools.
- The STOMP/STAMP programmes<sup>13</sup> (Stopping the Over-medication Programme for children and young people with LD/A and the Supporting Treatment and Appropriate Medication in Paediatrics Programme.)

Covid vaccination roll outs have highlighted the challenges across many areas in respect of the LD registers held by primary care networks. Forums have reported discrepancies in the numbers known to an area through their allocation of an EHCP or their access to social care support versus the numbers of young people aged 14-25 held on GP LD registers. The NNPCF are pleased to see an increased local and regional focus in some areas on how best to support this cohort to be better known to the primary care networks, but also feel there can be greater exploration of using more than just health records and notifications to identify and refer young people to LD registers locally. We would encourage local systems to explore this with their Parent Carer Forums as to how best to inform the process and make these young people known to the appropriate GPs.

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<sup>13</sup> <https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>

Forums are strongly encouraged to help to promote the 14 plus health checks for Learning Disabled young people. See the Preparing for Adulthood Talking Point.

### Support during the autism diagnostic process

The aim is to reduce waiting times for specialist services and to get earlier intervention to help those diagnosed with autistic spectrum disorder. Forums report ongoing difficulties with connectivity across the wider support pathway. As the move to ICS happens in a local area, this could be a good opportunity to revisit the way pathways are described locally to support families and practitioners to understand the support available locally. The NNPCF are also concerned by reports from forums about other services pausing or not engaging with families when they are awaiting autism assessments. This is clearly a risk for escalation of need and could be detrimental to the wellbeing of the family and child/young person.

### Children and Young People's Transformation

The LTP sets out the creation of a Children and Young People's Transformation Programme to oversee the delivery of the Plan's commitments to care for children and young people.

### Improving children's transition to adult care services

Extending services to cover 18-25 to support transition to adult services in line with the Children and Families Act 2014. There are many concerns raised about the pressures on the system to transition a child to adult services at the age of 18, the role of this transition period is welcomed, but also needs to be quality assured and monitored for positive impact and outcomes. There are still risks that if local systems do not use this time to address commissioning needs in an area they may face the same problems but further into the system for these young people.

### Sustainability & Transformation partnerships (STP)

In 2016, NHS organisations and local councils joined forces in every part of England to develop proposals for improved health and care. They formed new partnerships – known as sustainability and transformation



partnerships (STPs) – to run services in a more coordinated way, to agree system-wide priorities, and to plan collectively how to improve residents' day-to-day health.

Sustainability and Transformation Partnerships (STPs) were asked to feedback to NHS England with their response on how they would implement the LTP for their area. From 2018 some STPs began to take on more responsibility by becoming Integrated Care Systems (ICS).

With some specific parts of the LTP work already underway, it is important forums link into their local STP to develop ways to engage especially as they move to Integrated Care Systems.

### Integrated Care Systems

The NHS Long Term Plan confirmed that all parts of England would be served by an integrated care system from April 2021, building on the lessons of the earliest pilot schemes and the achievements of earlier work through sustainability and transformation partnerships. STPs and ICSs – groups of local NHS organisations working together with each other, local councils and other partners – were responsible for developing and publishing their own five-year Local Plan by Autumn 2019. The development of these services has been included in NHS commissioning contracts from 2019/20 and it is hoped that these services will be in place by 2023/24.

Local forums should make sure they are aware of the details of the Five Year forward plan for their area and that the services being developed to meet this Plan are co-produced to best meet the needs of children and young people with SEND. Understanding local governance structures will help forums to inform these discussions.

As each part of the country nears readiness to function as an ICS, NHS England and NHS Improvement (NHSE/I) has asked Government and Parliament to establish ICSs in law and to remove legal barriers to integrated care for patients and communities. Decisions on legislation will now be for Government and Parliament to make.<sup>14</sup>

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[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/960549/integration-and-innovation-working-together-to-improve-health-and-social-care-for-all-print-version.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/960549/integration-and-innovation-working-together-to-improve-health-and-social-care-for-all-print-version.pdf)

## The structure of ICSs

The key to the vision for the new ICSs is that *decisions about how services are arranged* should be made as closely as possible to *those who use them*. For most people, their day-to-day health and care needs will be met locally in the town or district where they live or work. This leads to the 'place' or neighbourhood structure of ICSs. Partnership in these local 'places' is an important building block of integration. Social care, parent carer forums and local democracy are set up around long-established local authority boundaries, and for the majority of ICSs this should translate into the 'place' for the ICS structure. These place-based partnerships would be supported by a statutory NHS ICS body to oversee NHS functions across the whole system, and a statutory health and care partnership made up of a wider group of organisations would bring together a wider group of partners to develop overarching plans across health, social care and public health.

In a small minority of areas though, it may not always be feasible to have 1:1 mapping to the local authority area and not every ICS has made the decision yet that 'place' equals local authority area; one of the strengths of the system is that arrangements can be adapted to reflect what makes sense locally. The NNPCF are concerned that a lack of consistency in how 'place' is applied across the ICS structures will lead to additional barriers and complications in delivering outcomes and coproducing solution across a whole system that meet local needs.

**The structure of ICSs is still emerging and there will be more on this in the NNPCF webinar.**

## Primary Care Networks

All patients in England are now covered by a primary care network (PCN) – the most significant reform to general practice in England in a generation was completed in July 2019. PCNs should help to integrate primary care with secondary and community services and bridge a gap between general practice and emerging Integrated Care Systems.

Since January 2019, practices have been organising themselves into local networks to provide care at greater scale by sharing staff and some of their funding. GP practices have begun working together and with community, mental health, social care, pharmacy, hospital, and voluntary services in their local areas in primary care networks. There is concern that while PCNs offer huge potential to integrate care and improve services, there is a risk the speed of implementation will undermine the best intentions of the policy. As we have seen PCNs are being developed within a context of wider changes in NHS structures. Sustainability and Transformation Partnerships (STPs), themselves relatively new, are rapidly evolving into ICSs, and the wider architecture of the NHS is shifting quickly. These overlapping initiatives, which must eventually work seamlessly together if their ambition is to be realised, add to the complexity of implementation.<sup>15</sup>

### Participation and the NHS

The NHS traditionally looks to their Public & Patient Advisory Groups for engagement. These may not have parents of SEND children and young people involved. It may help forge links if some forum members joined their local Patient Advisory Group (PAG) or develop links with their local Healthwatch for engagement. It is crucial that participation pathways are well described on local offers and within local governance structures to ensure that SEND community representatives can use the most appropriate pathway to achieve successful coproduction. Many of the pathways that exist in health are not suitable for parent carers due to their design (when and how they meet) and their adult services focus. Systems need to support coproduction by ensuring their participation pathways are both fit for purpose and accessible to the whole community.

The NNPCF would like to see NHS England outline expected engagement of parent carers and parent carer forums to inform the LTP, STPs and ICSs from 2021. We feel this is imperative as traditional Public and Patient engagement does not always ensure SEND communities are represented.

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<sup>15</sup> <https://www.health.org.uk/publications/reports/understanding-primary-care-networks>

The Children and Young People's Transformation Programme Board will, in conjunction with the Maternity Transformation Programme, oversee the delivery of the children and young people's commitments in the LTP.

The NNPCF are represented on the SEND and Learning Disability and Autism work streams which report to the Children and Young People's Transformation Programme Board and are well placed to support the implementation of the LTP at a national, regional, and local level.

### What does this all mean for SEND and PCFs?

The rapidly changing landscape within Health will bring both challenges and opportunities. The NNPCF will continue to work with NHS England, and Parent Carer Forums with local NHS organisations and their partners, to turn the ambitions in the Long Term Plan into improvements in services for children and young people with SEND in England.

### Mental Health Act review

The independent review into the Mental Health Act (MHA) has found that the MHA does not always work as well as it should for patients, their families and their carers.

The Department of Health and Social Care (DH&SC) is now proposing a wide range of changes to rebalance the MHA, to put patients at the centre of decisions about their own care and ensure everyone is treated equally.

The changes are based on 4 principles which have been developed with people with lived experience of the MHA. They are:

- choice and autonomy – ensuring service users' views and choices are respected
- least restriction – ensuring the MHA's powers are used in the least restrictive way
- therapeutic benefit – ensuring patients are supported to get better, so they can be discharged from the MHA

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National Network of Parent Carer Forums

'Our Strength Is Our Shared Experience'

- the person as an individual – ensuring patients are viewed and treated as individuals

The NNPCF welcomes this review and has responded to the recent consultation.<sup>16</sup>

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<sup>16</sup> <https://www.gov.uk/government/consultations/reforming-the-mental-health-act>

## Appendix A: Covid Impact on Health and wellbeing of children and young people with SEND and their families.

The Covid pandemic has had an enormous impact on the health and wellbeing of children and young people with SEND. The most significant of these are:

- Lack of access to therapies during the pandemic.
- A much wider attainment gap than prior to the pandemic.
- Lack of College work experience and internships.
- The return to school, SEN Support and reasonable adjustments
- Behaviour and exclusions
- Impact on mental health of children, young people and parent carers.

As the country is slowly reopened after the second wave, we will be left with a legacy of medium- and long-term adverse impacts on the health and wellbeing of children and young people with SEND caused by these impacts.

The NNPCF is asking local forums to jointly collate these longer-term impacts, so together we can start to address them at national, regional, and local levels. In addition, positives will be logged and translated into general practice in the future.

## Appendix B: Ofsted SEND Inspections

Ofsted suspended Inspection visits during the pandemic.<sup>17</sup> In their place Ofsted and the Care Quality Commission (CQC) are carrying out a series of 'interim visits' to local areas to hear about the experiences of children and young people with special educational needs and disabilities (SEND), their families and the practitioners and leaders who are supporting them during the COVID-19 (coronavirus) pandemic.

Ofsted used a case-study approach speaking to the parents and carers of 28 children and young people, along with the education, health and social care practitioners who work with them.

### Ofsted findings - positives

Multi-agency working continued and improved for some. Families and practitioners generally described the move online as a positive change and said they felt they had been able to stay in contact more effectively,

Most practitioners felt that meeting virtually was easier and health workers such as paediatricians, GPs and psychiatrists said that moving meetings online had meant that they had been able to attend more meetings than previously. This was vital for ensuring that families were supported.

### Ofsted findings - negatives

A small number of parents did report that their child had received no contact from health services.

In several local areas, access and waiting lists for CAMHS were a particular concern. Practitioners and leaders felt this was partly due a greater demand from families for face-to-face appointments, which were not possible.

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[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/933499/SEND\\_COVID-19\\_briefing\\_October\\_2020.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/933499/SEND_COVID-19_briefing_October_2020.pdf)

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Some parent carers found it challenging to implement some therapies in a home setting without professional guidance or found they were unable to understand the material supplied by practitioners.

In some local areas, some support was reduced or absent because families had varying access to IT equipment and technology as well as time to spend supporting their child.

Practitioners noted that extended family members who might previously have provided informal interpretation were unable to do so using the new methods of contact

A small number of the case-study families described turning to charities for therapeutic services, which they felt had been able to resume face-to-face interventions more swiftly than NHS providers.

During the pandemic, specific guidance on important topics was shared by the NNPCF. For completeness these are recorded here:

- Aerosol generating procedures – see guidance in footnote<sup>18</sup>
- Vaccinations – see guidance in footnote<sup>19</sup>

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<sup>18</sup> <https://nnpcf.org.uk/2020/11/15/aerosol-generating-procedures-guidance-update/>

<sup>19</sup> <https://nnpcf.org.uk/2021/02/08/covid-19-vaccinations-and-send/>



## Appendix C: Children and Families Act requirements for Health Service Providers

### Principles

1. All services should be based upon the principles of co-production: a. Individual co-production with young people, parents-carers and families to ensure a person centred and outcome focus for individual service delivery
- b. Strategic co-production with representative groups for children and young people and their families to ensure that service design reflects the changing needs of patients and their families.

### Joint working

2. Providers to contribute data and information for the Joint Strategic Needs Assessment.
3. Providers should share information as necessary between different agencies and services to ensure a joined up approach and reduce the need for the duplication of information requests on children, young people and families.
4. Providers should work in an integrated way with other agencies and services to ensure a seamless transition between children's and adult services
5. Where a child or young person's primary need is a health condition, providers should be prepared to identify and act as a key worker.

### Education Health and Care Plans

6. Provider must supply EHCP advice in the agreed format (suggest we use the June 2017 formats published by the Council for Disabled Children) with the 6 week required timescale. This advice should be produced in a person centred and outcome focussed way.
7. Providers should attend multi-agency meetings for EHCPs where required.

## Local offer / Information Advice and Support (IAS)

8. Providers are required to update the local offer of significant service changes and to respond to feedback on services from the local offer. At a minimum the local offer should be formally reviewed and signed off once a year.

9. Providers should supply information as required by IAS services to support their work

## Workforce development

10. All staff is required to attend the following training as a part of their induction:

- Introduction to the Children and Families Act 2014
- Person centred planning and outcome focus which includes (co-production with families and young people, creative use of personal budgets)

## Personal budgets

11. There must be some provision in the new contracts to enable personal budgets to be expanded beyond continuing care. There is a requirement in the Children and Families Act that “demand from parents and young people for funds that cannot, at present, be disaggregated should inform joint commissioning arrangements for greater choice and control” (code of practice section 9.106)

## Appendix D: Glossary

APG	Aerosol generating procedures
CCG	Clinical commissioning groups
CQC	Care Quality Commission
DHSC	Department for Health and Social Care
ICS	Integrated Care Systems
JSNA	Joint Strategic Needs Assessment
LD/A	Learning Disability and/or Autism
LD	Learning Disability
LTP	Long Term Plan
NHSE/NHSEI	NHS England/NHS Improvement
PCN	Primary Care Networks
STAMP	Supporting Treatment and Appropriate Medication in Paediatrics Programme
STOMP	Stopping the Over-medication Programme for children and young people with Learning Disability and/or Autism
STP	Sustainability & Transformation partnerships