

2021 Contact & NNPCF Virtual Conference

What are the Health priorities for the NHSE/I SEND programme and how can we continue to work together Nationally, Regionally, and Locally with parent carers?

National Update

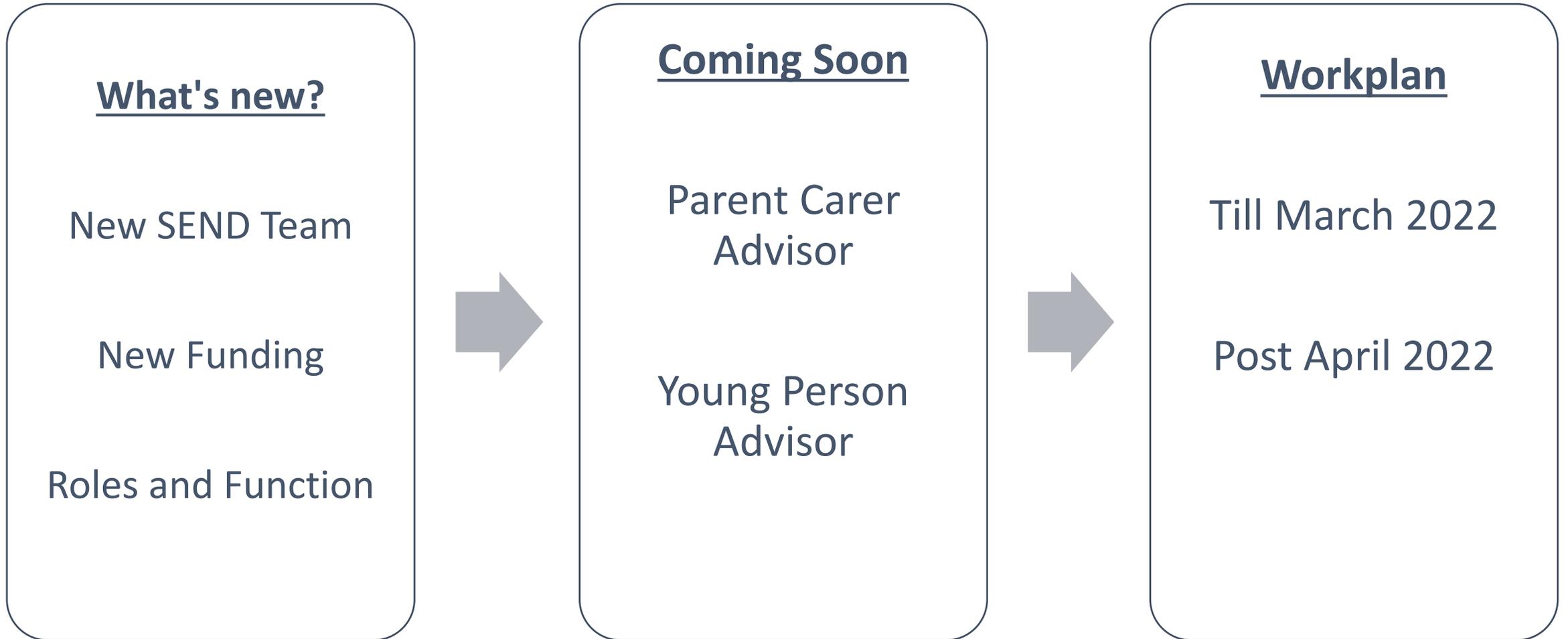
Special Educational Needs and Disabilities

What are the **health priorities** for the NHSE/I SEND programme?
and

How can we continue to work together
Nationally, Regionally, and Locally with parent carers?



Agenda - NHS England/Improvement - SEND



What are we focusing on nationally over the next 3 months?

Recruitment - Nationally and Regionally

Integrated Care System/Board heat map – focus stage 1 – leadership and governance

Recovery - Childrens Community Services with National community team

Continuing Care and Clinical Nursing in education settings with Nursing and continuing care team and jointly with DfE

Ongoing oversight and improvement- Inspections and revisits

Working with other CYP teams- Learning Disability, MH, Personalisation, Palliative and End of Life and Allied Health Professionals Team



Stage 2 – Heat map –3 out of 11 Key Lines of Enquiry are focused on

Partnerships	Can the CCG/ ICB demonstrate effective partnerships are in place (360degree survey or using place based survey /feedback from CYP, parents/carers).	Provide Evidence: Description at place, with overarching statement
Coproduction	Can the CCG/ICB describe the arrangements in place for effective coproduction , working with CYP and Parents/families	Provide Evidence: statement building on effective practice at place (Local Authority Level)
Experience	Can the CCG/ ICB describe the mechanisms in place to ensure ‘the voice of children/young people and parent/carers is heard’ ?	Provide evidence: statement building on effective practice at place.



Midlands Update

Midlands Region

November 2021

NNPCF conference

NHS England and NHS Improvement



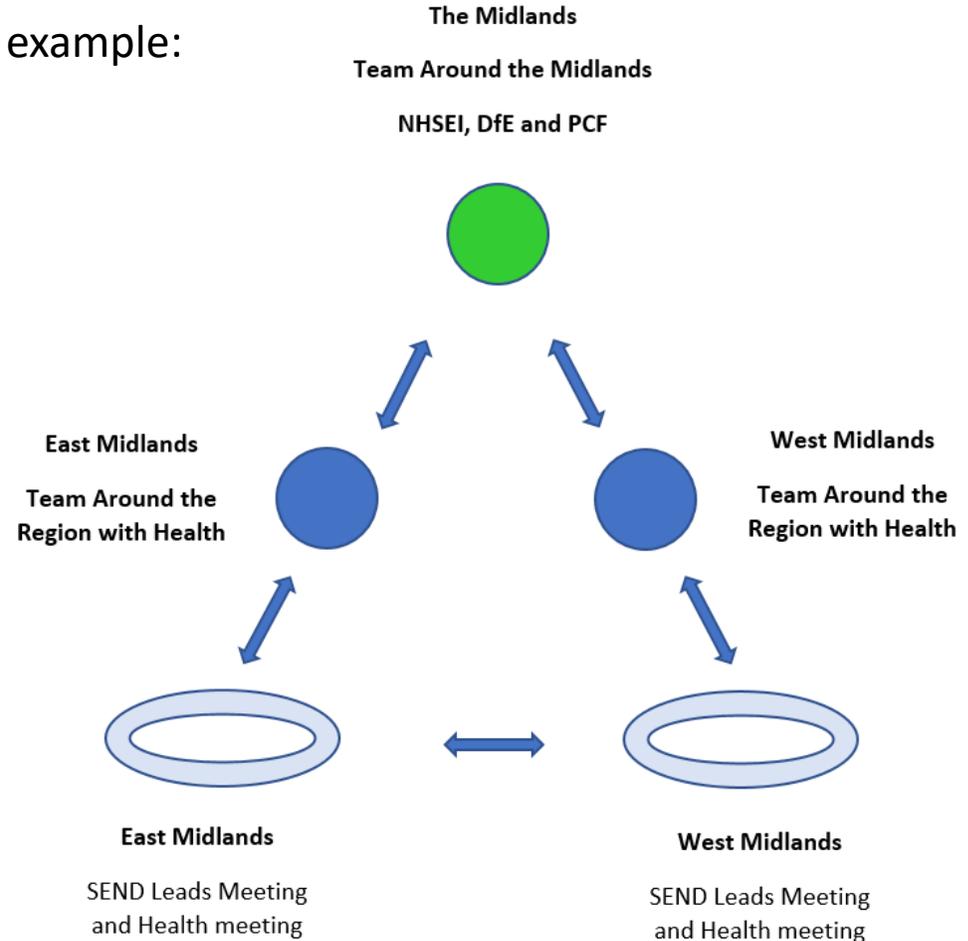
Midlands approach:



Set up an over arching strategic regional team
“The Midlands Combined SEND team around the region” with the key function:

- To share and exchange information, intelligence and data, in order to promote the best possible outcomes for children and young people experiencing SEND, at a strategic regional level.
- To operate as an early alert system to support inclusion and SEND within local areas.
- Sharing and finding excellence, leading edge practice and improving quality.
- Aligning the work across the midlands to ensure a consistent approach is maintained.

For example:



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Key as a result of these meeting:

- Selling the Message and building the resilience of PCF
- Midlands SEND Conference completed in June 2021
- Targeted work with Local Authorities and Health Partners around specific challenges
- Key work in relation to the Learning Disability and Autism Programme
- Exploring future planning of events/ training etc.
- Increased awareness of key working areas across regional systems.



Selling the Message



- In January 2021 NHSEI received funds to the Region to support the SEND agenda for 2020/21.
- Regional funds were allocated to support development of our SEND Parent Carer Forums (PCF)/ Parent Carer groups across the Midlands.
- NHSE/I commissioned an external provider to deliver workshops.
- To support the development and skills of SEND Parent Carer Forums (PCF).
- The modules were based on 4 key areas:
 1. Networking
 2. Impact and influence
 3. Presentation
 4. Building resilience



Selling the Message



- The sessions were fully co-produced with the Regional PCF Leads.
- To support flexibility and attendance (the sessions were completed online, using MS Teams, 3 times each at different times of the day (morning, afternoon and evening)).
- Session lasted approximately 90 minutes.
- Session was open to all PCF representatives and was promoted via the Regional PCF Leads and Designated Clinical and Medical Officers.
- In total 12 sessions were completed between end of February up to the end March 2021.
- Post event/ sessions evaluations forms were sent out along with attendance certificates.
- An additional website resource was created by the provider .



Selling the Message

Evaluation/ impact:

- 44 PCF representatives attended the sessions from across the midlands.
- The overall feedback received was very positive.
- A number of representatives stated that the sessions were useful in supporting them with how to present presentations and had given them clear, practical and useable advice.
- Some indicating that it had improved their confidence.

“Having some pointers on engagement around the forum and steering group, on how to interact on a more positive note”

“Useful to know the styles of different people to look at how to interact with them e.g. driver”

“The presentation session was perfect because it gave really clear, practical and useable advice. Especially when I have an upcoming presentation!”

“Talking about networking and designing a presentation Holistically the training allowed space and time to consider the aspects of, and be directed on, impact and influence which I don't think we'd make time for otherwise”

Further feedback obtained from the Regional Parent Carer Forum

NHS England and NHS Improvement



Learning Disability and Autism Regional Activities

- Admission Avoidance Learning Events and Parent Carer Forums
 - Upskilling forums to know how the SEND and LDA agendas can support these families in our local systems, where they fit within the work PCFs can do, and how we can utilise current work areas to understand and prioritise support for these families.
- Children and Young Peoples LDA Regional Program Board – co-chaired by regional PCFs representative
 - Opportunity for systems to share best practice and support each other to overcome challenges with a system wide approach – open to all partners to participate
- Annual Health Checks Forum
 - Covid Vaccination programs shone a light on the 14-25 year old AHC disparities and challenges in the system. Together we have shared ideas and seen systems respond to these challenges with some success. The workshop in October was well received.
- 3 Year Road Map Planning
 - Forums were engaged in this activity across the region at varying levels, but the message from regional teas was clear to ensure **all** coproduction partners (community representatives) are coproducing plans and delivery, whilst also being enabled to provide Quality Assurance of processes and ongoing developments.
 - Regional PCF representation facilitated a better understanding of what regional leads should be looking for regarding coproduction and quality engagement.
- Key Worker Regional Activity
 - Forums are all engaged in key working across the midlands. Some have been truly coproducing, while others have hit barriers. We have used the regional group to highlight best practice and challenge systems to think about where they may have weaknesses to address in their coproduction methodology or processes.
- Autism in Schools
 - Regional delivery follows a co leadership model that is echoed in pilot areas. This project has allowed forums to better connect with systems in a more effective and meaningful way due to the expectation of delivery via forums for some key elements. This approach has been helpful to support challenging discussions and enable reflections on effective coproduction practices across the systems.

Next Steps:

- Regional evaluation re engagement activity
- Future events planning (awaiting the outcome of the SEND review/ inspection framework)
- Further development and strengthening the support available to forums.





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South West Update

Special Educational Needs in the South West

Tina Emery

South West Regional Representative for the National Network of Parent Carer Forums CIC

Mark Tucker

SEND Lead, NHS England and NHS Improvement – South West

NHS England and NHS Improvement





National Network of Parent Carer Forums
'Our Strength is our Shared Experience'
www.nnpcf.org.uk



Co-production

South West NHSE & Parent Carer Forums

NHS England and NHS Improvement



Leadership & Co-production

- **Invest in developing collaborative relationships** - investing time, energy, capabilities and practices for shared work as collaborating partners will enable trust, openness and potential to grow.
- **Go where the energy is (under the radar)** - It is legitimate to 'go where the energy is' in your local system and work under the radar with your collaborative project until you have a compelling story to tell.
- **Don't underestimate Everyday leadership**





Co-production

Co-design

Engagement

Consultation

Informing

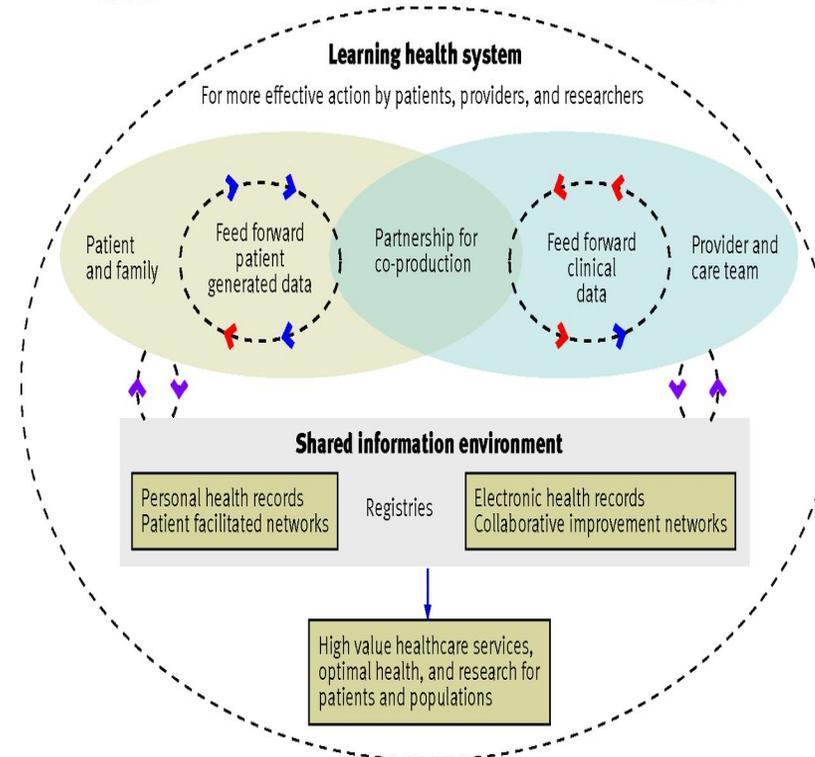
Educating

Coercion

Doing with
in an equal and
reciprocal partnership

Doing for
engaging and
involving people

Doing to
trying to fix people
who are passive
recipients of service



Making it happen in SEND



To support true coproduction requires time and resource

Local Systems

- Local health systems are now more actively coproducing with Children and Young People and Parent Carers
- This is placing more pressure on people's time and we have supported health systems to recognise the need to resource coproduction
- Children and Young People and Parent Carers are experts by experience and need support and infrastructure around them to participate
- We are seeing more and more Parent Carer Forums being financially supported by health systems

Local Funding

- NHSE regionally has been able to provide funding to support various projects run by the Parent Carer Forums

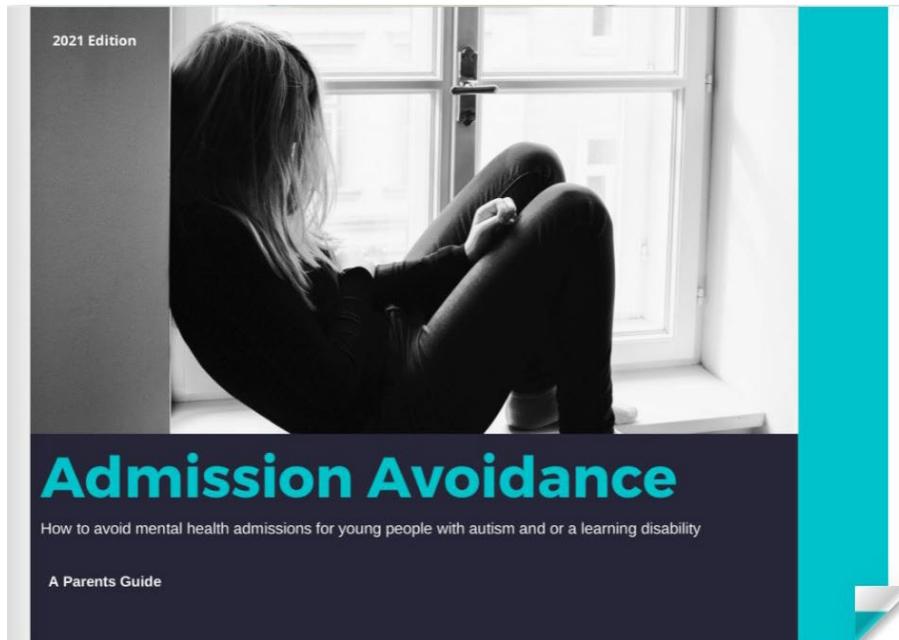
Regional Funding

- In recognition of the increasing regional work undertaken by the forums, we have funded regional time for the forums to support wider coproduction.

What we have achieved in the South West



- Admission Avoidance booklet
- Swindon Sensory Library
- North Somerset Sensory Processing video



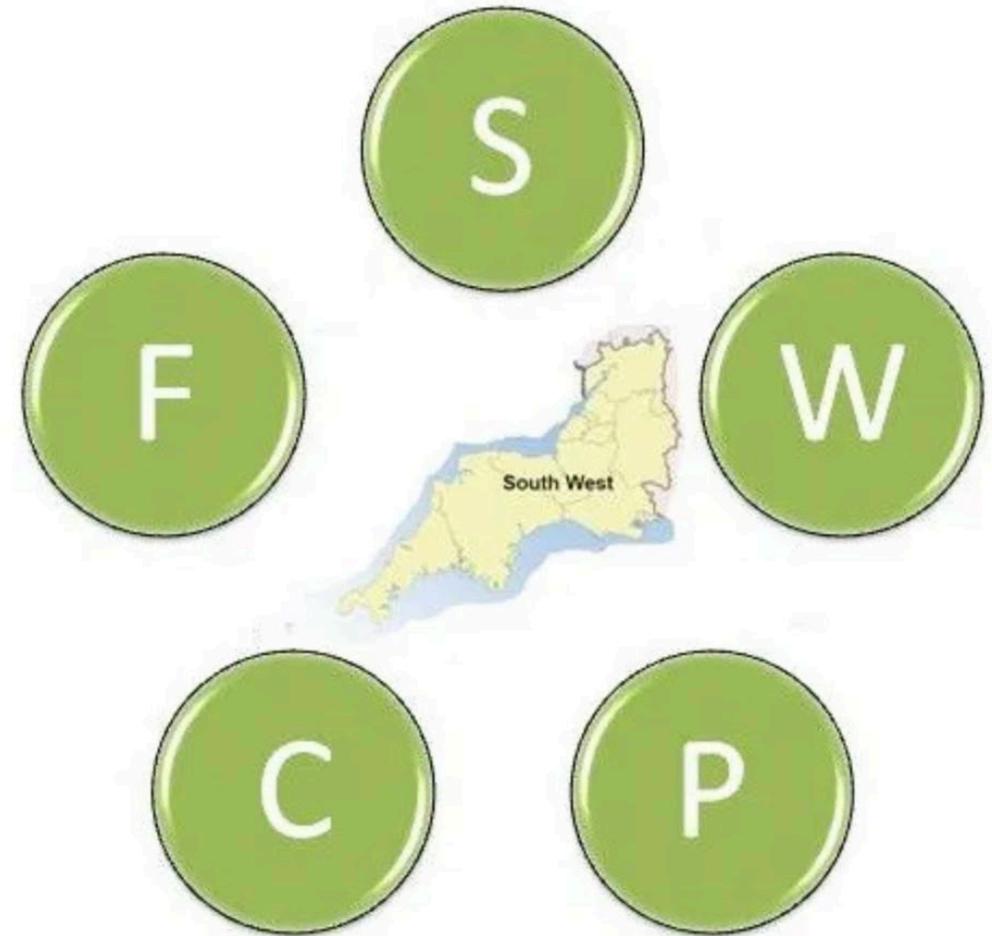
The key is to put principles into practice.



Note: Artist's representation of Graham, Mark and Tina

South West Parent Carer Forums

- South West is made up of 15 forums
- The regional representative is funded by SW NHSE/I
- Forums are given the opportunity to bid for monies.



How it works and comes together



Regional money is used so forums can bid on projects to deliver work at a local level



Regional money is used so we can coproduce work with those with lived experience



We converse weekly and this is fed between forums and NHSE regional leads, using the SW PCF rep as the conduit.

In **Torbay, Plymouth and Devon** (Devon STP) they were awarded £7,998. For this money, they are looking at building on engagement, co-producing the promotion of annual health checks, looking at ways to engage with users of the key worker pilot so they can see the impact of the programme.

In **Bristol, North Somerset and South Glos (BNSSG)** They were awarded £7,998. They decided to develop resources for parent carers to support pre and post ASD diagnosis. A video has been developed to talk about sensory needs. More videos are being developed.

In **Dorset STP(BCP and Dorset)**, they were awarded £5,332. They are developing training packs to families about post 16, in particular transitions into adult services from children's.

In **Somerset**, they were awarded £2,666. They are developing resources to help families to collect information which can be used as part of the diagnostic process. The resources will also look at strategies that families can use whilst waiting for the appointment.

In **Swindon**, they were awarded £2,666 to develop a specialist resource lending library. Similar to Somerset and the national picture we see, is that families need support and strategies whilst they wait for an appointment, these resources will do just that. Resources will also include sensory equipment.

We love it
when a
plan
comes
together...



North West Update

North West Co-production within the Children & Young People Transformation Programme with SEND as a priority area



Kelly Taylor, Head of Children & Young People Transformation Programme
North West, NHS England

Kath Bromfield, North West Network of Parent Carer Forums

NHS England and NHS Improvement



NHS Long Term Plan

www.longtermplan.nhs.uk

#NHSLongTermPlan



Obesity

- In 2016, 23% of 4-5 year olds and 34% of 10-11 year olds were overweight or obese and 4% of 10-11 year olds had severe obesity
- **2.5 million children in England are overweight or obese – with 1.22 million significantly obese** and eligible for treatment according to NICE guidance

Asthma

- The UK has one of the **highest prevalence, emergency admission and death rates for childhood asthma** in Europe, despite a slight fall in unplanned admission rates for asthma from 256 to 185 per 100,000 population between 2006/7 and 2016/17 in England

Hospital / ED admissions

- In England, children and young people make up **26% of all emergency department attendances** and are the most likely age-group to attend emergency inappropriately. We know around 30-50% of ED attendances **could be managed in integrated care services** linking primary and community care with paediatric expertise.

Epilepsy

- Epilepsy is the **most common significant neurological disorder** in children under the age of 19: more than one in 220 have epilepsy (approximately 63,400).
- The total costs of admissions attributable to paediatric epilepsy in 2016-17 was £18.4m.

Diabetes

- **31,500 children and young people under the age of 19 have diabetes** in the UK, with 95% having Type 1 diabetes.
- **Rise in obesity may result in more Type 2 diabetes** in the long term

Infant mortality

- **60% of child deaths occur during the first year of life**, and 70% of those are in the neonatal period (within the first month of life). **Without action, UK infant mortality rates could be 140% higher** than other comparable countries by 2030

First Year Priorities for the NW Children & Young People



Transformation Programme

- ✓ Asthma
- ✓ Complications Related to Excess Weight (CEW)
- ✓ Integration
- ✓ Diabetes
- ✓ Epilepsy



Department
of Health &
Social Care

**Integration and Innovation: working
together to improve health and
social care for all**

Published 11 February 2021

**The Department of Health and Social Care's legislative
proposals for a Health and Care Bill**



Working together

- Safeguarding
- Transition
- Mental Health
- Special Educational Needs (SEND)



North West Co-production

- Partnership working with Kath, NW NNPCF as a strategic paid partner and NW Board member
- System understanding of Strategic Partnership and team approach
- Representation and Youth Focus North West
- Hunter/gatherer approach
- Continuous conversation to influence and challenge
- Different ways: phone catch-ups, ad hoc or more formalised meetings, presentations, updates and events

First Year Priorities

Strategic Governance	NW Board Membership from NWNPCF and Youth Focus North West enabling strategic partnership for programme delivery. NWNPCF to take a strategic role in linking the best third sector partners to achieve the best possible co-production throughout the programme. This has including taking an advisory role across ICS areas. £10,000 has been made available to ICS areas to develop a <u>first year</u> co-production strategy
Asthma	Youth Focus North West will share existing work on developing asthma support with children and young <u>people</u> ; in particular sharing the asthma app. Liaising with the National Team to understand groups co-producing the Asthma Care Bundle. Working at Region and ICS level to understand how we can best co-produce local implementation of the Asthma Care Bundle
Complications Related to Excess Weight	Feedback from the NW CEW group on how pathways/services are being co-produced. Influencing/understanding of weight management pathways delivered across the patch and views/experience of families of the current position
Therapy Services	Sharing consultation recommendations from CDC and wider partners. Being part of the Deep Dive into therapy services as part of the SEND programme
Paediatric Sensory Wards	NW Network of Parent Carer Forums liaising with Contact and <u>NDTi</u> led a successful bid for £150,000 to; <ol style="list-style-type: none">1. 'Walk through' Alder Hey A&E and Paediatric Ward making recommendations for Sensory changes2. Gain feedback from NW wide PCFs and third sector groups around experiences of Wards meeting sensory needs
Information sharing with families	<u>Two way</u> communication on the CYP Transformation Programme priorities and progress through NWNPCF and wider family networks. This includes progress updates and opportunities to get involved and influence
Information sharing with young people	Exploring with Youth Focus North West mechanisms for sharing updates with young people. What would this look like? App/Social Media, can this be led by a young person?
National Consultations	Sharing information through the CYP Newsletter from national consultations such as the Children's Commissioner 'The Big Ask', Council for Disabled Children recommendations etc. This sharing should inform service commissioning and provision throughout sectors.

Examples of Leadership and Innovation

- ✓ Supporting ICS areas in Partnership working and a Co-production plan has been developed for the First Year of the Programme
- ✓ Engaging the right partners to Co-produce; *Where and who around Asthma?*
- ✓ North West Congenital Cardiac Network have asked for support
- ✓ NWPCF and Contact have drawn funding for NW and leading a bid around Sensory Friendly Paediatric Wards

Local lived experience

On the ground, real life experiences from more people.

Sharing thoughts, positive and less so. Individual co-production

Local lived experience groups

Mapping & supporting local community understanding of experience and identifying how we can link

Identifying and challenging strategic needs to improve local & regional delivery with more lived voices

Regional Collaboratives

Supporting regional understanding of processes and identifying needs/concerns and facilitating linking up. Critical challenge and intentionally disruptive

Identifying and challenging strategic systems to improve regional delivery, influencing local delivery and awareness. More people having a voice.

National Co-production Agenda

Regional and local operational support to lived experience voices as an individual and strategic level

Co-producing policy, direction and bringing on culture change

North East & North Cumbria Update

Working Together in North Cumbria & the North East



Chris Brown - Deputy Director of Quality and Safeguarding - Regional Safeguarding & SEND Lead - NHS England and NHS Improvement - North East and Yorkshire

Jo Gilliland – NNPCF Steering group member for North East & Cumbria

NHS England and NHS Improvement



Our Journey – Coproduction

NCNE Children & Young People (CYP) Peer Network – collaborative leadership model with Parent and Carer Forum (PCF) representatives to design and implement projects , plan includes CYP Network meetings, CYP Peer Network Newsletter, & training delivery for key priority subjects.

South Tees Keyworker Pilot

Regional Keyworker Early Adopter Steering Group

NCNE SEND monthly meeting

BUT Admissions Avoidance webinar – sharing regional good practice

Autism in Schools National roll out

NCNE SEND Regional Peer Network

SEND Regional Co-Ordinator Network

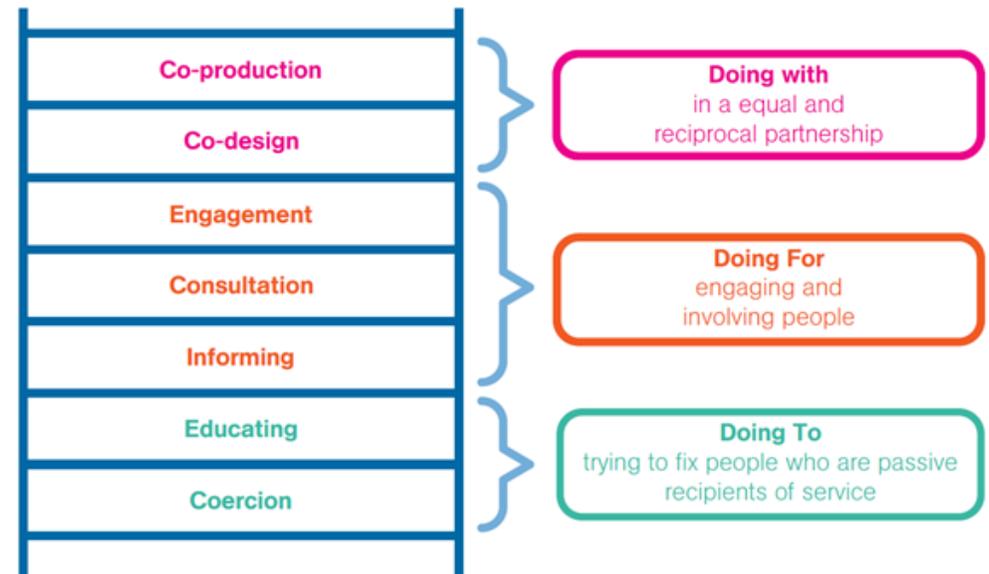
PBS Steering Group

Re-framing approaches to training for parent/carers

NE & Cumbria Learning Disability & Autism Network

South Tees Neurodevelopmental Pathway group

NENC Children & Young People’s Mental Health and Wellbeing Integrated Care System (ICS) Partnership, Parent reps represent the Learning Disability and Autism Workstream.



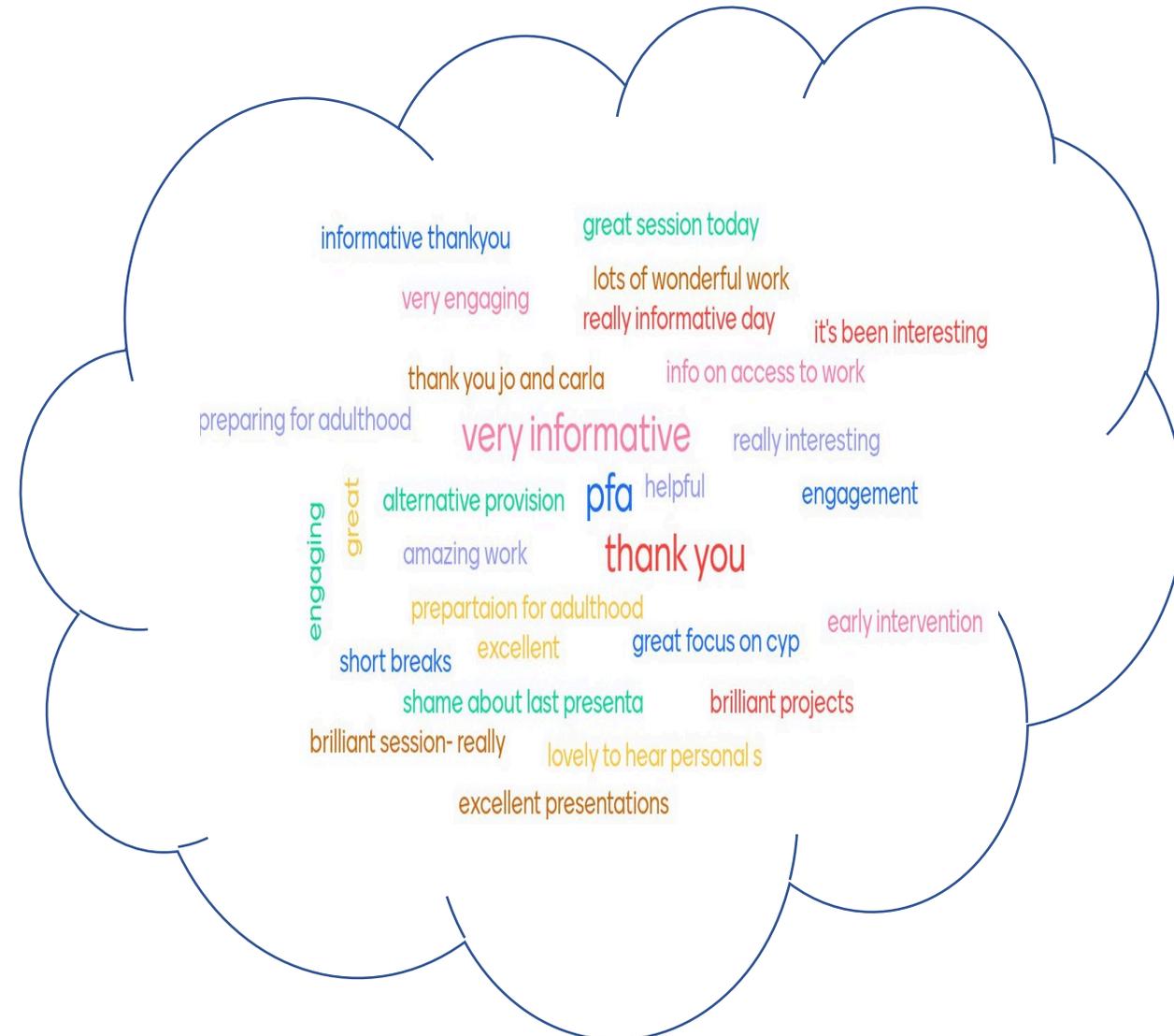
What we have learnt

- Language and narrative
- Recognising Leadership and development
- Equal Opportunities leading to employment roles
- Underpinned by values..... Listening, hearing and doing
- Evidence based – sharing what works well
- Collaboration - System approach

Reflection Leadership - embedded into the NCNE system - PCF

New roles

- Strategic Workforce Development Manager – Family Carers x 2 – Working across the ICS in NCNE
- Role ensures voice of families is heard and represented strategically
- Building the right support for families across the system
- Direct link to families working with our Parent Carer Forums
- PCF's leading and collaborating on project delivery
- ICS supporting PCF leadership & development programme for PCF's



Hearing the Voice of the Child & Young Person.....our journey



Building confidence.....

- Gateshead – SEND Youth Forum
- South Tyneside – leadership, and employment opportunities Champions, & Ambassadors
- Newcastle – Developing accessible resources (videos, blogs...)
- Children North East – Survey with children & young people , across the ICS on respite care (innovation) as a result of learning from COVID

What's next?

PCF NCNE and working within North East & Yorkshire & other regions



New Regional reps in PCF



Roll out the leadership & development training – involving regional reps in shaping the offer



Actively involving parent/carers in shaping services they use and embedding this good practice across the system



Cross regional working to be established as good practice for PCF's where NHS regions cross geographical regions

What's next? Regional Programme Priorities



Hearing the Voice of the Child & young person – Resources/Project initiatives



Supporting Leadership Development (Integrated Care Partnerships (ICSs))



Driving Quality improvement - Service Models & Provision , care pathways, collaborative commissioning



Deep Dive – Therapies



Raising the profile & establishment of Children & Young People (SEND) in the ICS – Self assessment Framework



Information – sharing key messages & effective practice