

# Shropshire PACC

Developing pathways for  
Neurodevelopmental conditions & learning  
disabilities within the Shropshire  
Emotional Health & Wellbeing Service

## Participation Report

### 'Thinking Back Looking Forward'

in partnership  
with

  
Shropshire  
Clinical Commissioning Group

  
South Staffordshire and  
Shropshire Healthcare  
NHS Foundation Trust



SHROPSHIRE  
Parent  
And  
Carer  
Council

Charity No. 1150180

# Report on Workshops to Facilitate Parent Carer Participation in the Development of Neurodevelopmental and Learning Disability Pathways for the Shropshire Emotional Health and Wellbeing Service.

## Background:

This service was commissioned by Shropshire Clinical Commissioning Group;

## The vision

**For children and young people to be resilient and have good emotional and mental health.**

*Children, young people and the adults around them will be better equipped with tools, techniques and networks to cope with everyday life/life transitions and support their peers. Those who know children and young people or work with them will feel confident and able to promote emotional wellbeing with the children and young people they know. They will be able to identify and support children and young people who have emotional issues. Where assistance for mental health issues is required from more specialist mental health workers, help and support will be provided quickly and easily.*

The following SEND specific elements were included in the contract;

## Specialist element for learning disabilities

- *Holistic assessment including observation in school settings (where applicable) and consideration of input from teachers*
- *Deliver a specialist service supporting mental health and challenging behaviour of learning disabled children and young people*
- *Provision of a range of multi-disciplinary intervention including assistance of young people and families to model behaviour (including home support intervention practitioners)*
- *Delivery of service in outreach settings, including clinics in special schools and assessment at school/home*

## Autism and ADHD pathways

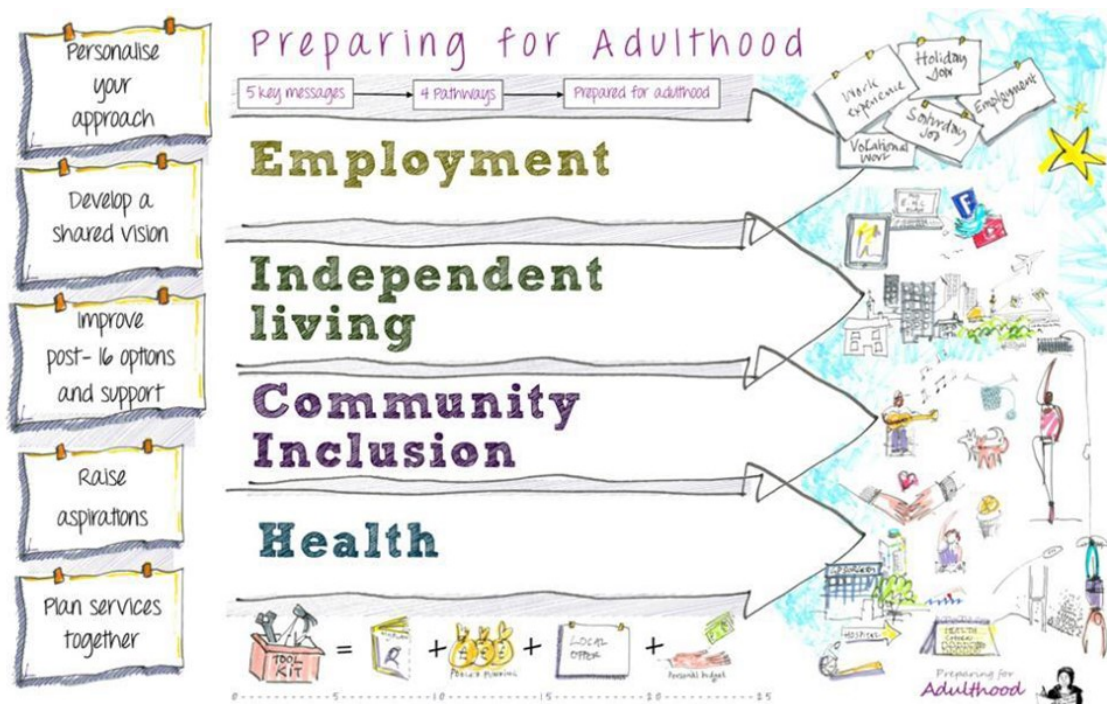
- *Delivery of support for children and young people who may have ADHD and autism. This includes provision of support and then efficient assessment/diagnosis for families who wish to pursue diagnosis.*



## Transition

The service shall ensure that any known transition points in a child/young person's life are planned for well in advance in order to ensure minimum disruption to the care and support the child/young person needs in relation to their mental health and emotional wellbeing.

In relation to transition to adult mental health services, those already receiving support from the Emotional Health and Wellbeing Service up to their 18th birthday will be given the option to continue to receive support through the emotional health and wellbeing service up to a maximum age of 25 years. In addition, care leavers will have access to the service until they are 25 regardless of when they first access the service. Transition to adult services, if required, shall be planned in line with the young person's needs and shall take place before their 25th birthday (individuals may be able to continue beyond the age of 25 years in exceptional circumstances, subject to commissioner approval).



The service started on **1<sup>st</sup> May 2017** and while significant developments have been seen in some areas there has been worrying little visible progress on developing and implementing pathways for those children and young people with neurodevelopmental conditions (e.g. Autism and ADHD) and for those who have a learning disability. This is despite parent carers repeatedly highlighting the urgency of the need for these pathways to be implemented in both the period leading up to the contract being issued and in the early months of the contract.

This lack of progress resulted in representations being made by PACC in partnership with PODs (the Telford PCF), to the service Commissioner. Following these discussions, it was agreed that two workshops would be held in Shropshire to provide an opportunity for parent carers to share their experiences and thoughts about the Service and how it should be developed. The workshops would specifically consider the neurodevelopmental (ASD/ADHD etc) pathway and the Learning Disability pathway.

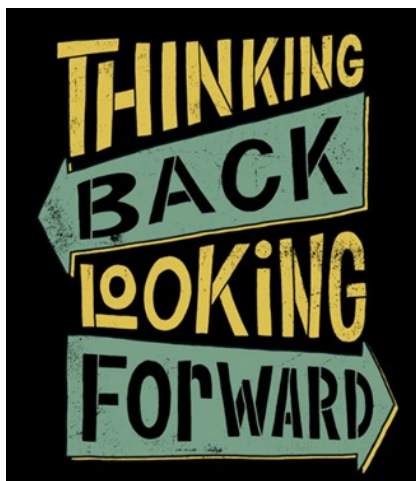
Both workshops would follow the same format:

	AGENDA		
9.30-10.00	Coffee		
10.00-10.05	Introductions/housekeeping		
10.10- 10.15	Why are we here and what are we aiming to achieve?	Sarah Thomas	PACC
10.15-10.30	Setting the scene- what have been and still are the challenges?	Frances Sutherland	Telford & Wrekin CCG
10.30 – 10.45	Service Update	SSSFT	
10.45	Discussion – What is your vision and what needs to happen to achieve this		
10.45-11.10	Referral		
11.05-11.30	Waiting for assessment		
11.30-12.00	Assessment		
12.00-12.30	Post assessment support		
12.30- 1.15	LUNCH		
1.15-1.45	Feedback from the tables		BY facilitators
1.45-2.15	Questions and answer session		
2.15- 2.30	Next steps		

At both workshop attendees were asked to consider each stage of the pathway; referral, assessment, diagnosis and post assessment support and consider the following questions;

- What words currently describe your experience at each stage?
- What words do you want to be able to use for each stage of the pathway?
- What outcome do you expect at this stage?
- Suggestions for what needs to happen to next

The ethos of the workshops was ‘working together’ and using the previous experiences of those who use the service to create an improved and more effective service



## Neurodevelopmental Pathway Workshop – 22<sup>nd</sup> January 2018

39 attendees – parent carers and SEND practitioners across education, health and social care.

### Table Discussions

The groups at each table were mixed and included both parent carers and SEND practitioners.

- **Referral Process**

How the existing referral process was described:



### **Other comments;**

“Early Years – Positive Experience. Multi referral via SALT + CDC. Child nurtured”

“Confusing process, and knowledge of the referral route has deteriorated through transition process”

“Process seems unknown to school and other professionals”

“Difficulties co-ordinating home and school experience”

“GPs not informed of ASC behaviours and how they present differently”

### **What attendees would like to see happening in the future:**

- **Clarity** - Publish a flow chart/time line to show complete process. Should show what happens at each point of process, and what assessments/information gathering needed. Complaints process? Leaflet, Q&A on Local Offer to address this. How are young people who move into Shropshire cases managed?
- **Facts** – Who can refer/who cannot. Address self-referral question.
- **Responding to shared experiences** – Use information from young people/parents of their experience of process to make improvements – you said we did approach
- **Transparency** – Knowing what to expect, service providers being clear and honest about why they are asking for information and what information they will want to look at, as part of the diagnostic process.
- **Setting the scene and supporting the understanding of about what will happen and when and what outcomes to expect** - everyone involved in process should understand ASD and associated

conditions and how it presents (professionals response to behaviours, parental concerns, challenges to child/school). Knowing when to refer (professionals/schools). Discussion at point of referral – why you are having a referral, what outcomes you might expect and what support you might need. Explore cause and effect of young person’s behaviours/challenges. Flexible referral route – changes to suit need. Write to families updating them on progress/stage they are at on waiting list, with a clear point of contact if they feel they need more information. Referral form – let families know how much detail is needed and who will complete it – All about me/us.

- **Pre-assessment drop in for families** – access to support/therapy whilst on waiting list. Crisis support available if needed. Competent and experienced staff. ‘I would like to feel confident in the process’. Timely process – information gathering/observations etc. Young people treated as individuals not numbers. Guidelines for process (could be visual/diagram)
- **Easy access, clear pathways, user friendly, with relevant information given at relevant part of process** – diagram of pathways, provision and support services, including what is available for those who do not meet diagnostic criteria.
- **Understanding how the service fit / work with other services** – look at gaps, overlaps, replication of system/provision. A ‘Who’s Who’ guide to teams and their role. Positive self- actions signposted at each stage of journey, Early Help support, Parenting courses, AWM, to help give structure and purpose to waiting period.
- **An overview map of system**
- **Core and ‘traded’ services staffing review** – are there enough in post and are they at the right point of process/ do they sit within right team?

- **Assessment Process**

The existing assessment process was described as:



**Other comments;**

“When you are in the system, the procedure is robust. It’s getting into the system and navigating it, that is problematic”

“CDC MDA (health led process) nurturing, clear point of contact, home visits, regular contact, good understanding of process e.g. who, what, when”

“No idea what happens next”

## What attendees would like to see happening in the future:

- **All those involved with the assessment understand process** – e.g. schools. There should be some flexibility so additional information provided by all professionals/services/settings involved with young person be considered and contribute to assessment process. Assessment needs to include time spent observing the young person in a range of environments, on a first-hand basis by professional assessing.
- **Outcome based assessments** - Reassurance that assessment and findings will be of practical use across other areas of young person's life e.g. school. How might diagnosis/findings impact on Preparing For Adulthood plan, how will the findings be used to inform an Education, Health and Care Plan or support plan? Ensure that decisions are detailed, informative and clear – move away from 'traits'.
- **Clarification of assessment protocol** – setting, evidence, models/diagnostic tools used. Practical strategies to support behaviours. How are aspirations and views of young person taken into account, and how this is supported. Does a diagnosis help/hinder these aspirations? Identify and manage access to support services young person's needs dictate. Joined up approach – not fragmented and person centred.
- **Seek views of family/young person to find out what changes they may want from having an assessment** - CAMHS to create leaflet 'Why a diagnosis?' dispelling myths and supporting service users to know what to expect e.g. access to services, supporting parents/school's understanding of young person.
- **Schools and Early Years settings more informed about the assessment process** - provide suitable training. Enabling/supporting conversations between setting and parents during referral and assessment.
- **Named person as point of contact** - who co-ordinates activity throughout assessment process and initially post assessment
- **Pathological Demand Avoidance** – how is this diagnosed and referred for?
- **Clearer post 16 support/pathway needed**



How attendees would like to be able to describe the assessment process in the future:



#### Other Comments;

“Include social questionnaire for everyone who interacts with child/young person on a regular basis”

“Need a checklist for Parents”

“Don’t discount those children who ‘cope’ in school – swan effect. Come out of the dark ages”

- **Diagnosis Process**

The existing diagnosis process was described as;



#### Other Comments;

“Need a Multi-Disciplinary Assessment meeting and feedback”

“Currently feels like the process is that you are diagnosed and dumped”

#### What attendees would like to see happening in the future:

This feedback mainly revolved around improved post diagnosis support that includes;

- Information, advice and support on how to manage behaviours, and impact on family/siblings.
- Help to support with social barriers, a buddy system to join in with social activities.
- Support for young people to attend AWM/All In social activities – in many cases there are activities being offered for young people with ASD and associated conditions but anxiety is a barrier to them accessing these.
- Support for high end anxiety
- Specialist provision at school identified as part of the diagnosis
- ASD nursing support - similar to LD nursing team.



- Support with sensory issues
- Strategies for home and school
- Risk assessments advice
- Sign posting to other services
- Training for schools on ASD needs and strategies.
- Information about how to access to crisis team/intervention if required.
- Post assessment referrals process – who has responsibility/accountability for this process, and checking on outcomes. Being clear about what support from other services might be needed
- Diagnosis accepted by all (professionals/school/family/peers). Everyone diagnosed referred to Enhance for 1 to 1 work.
- A supportive pathway for those without a conclusive diagnosis – ability to gather more information/observations and go back at a later date?
- Consideration for stress on mental health of young person – assessment process is stressful.
- Signposting to family support groups/organisations – PACC, AWM, Jigsaw
- Advocacy service for family and child – to support the participation in decision making
- Access to post diagnosis courses – SALT /Early Bird courses / Managing challenging behaviour (Lee Burden Course)
- Closer working with schools – SENCO briefs all staff who have contact with child with guidance on how best to support that child
- Access to talking therapies where appropriate
- Kooth for parents – supporting parent carers resilience and wellbeing
- Multi agency support to meet families and young person’s needs.
- Clear signposting process at end of assessment.
- Care plan for young person and family, drawing together all areas of need following diagnosis – to link to EHCPs / SEN Support / Care plans
- Family and siblings access young carers support, short breaks, crisis support and respite.
- Follow up support from a team of professionals; OT, school, paediatrician, outreach support, psychiatrist, SALT, dietician, GP, physio, social worker, diagnosing professional and EWO.

**“Diagnosis should be the start of things not the end”**

## Learning Disability Pathway Workshop – 22nd January 2018

31 attendees – parent carers and SEND practitioners across education, health and social care.

### Table Discussions

The groups at each table were mixed and included both parent carers and SEND practitioners.

These discussions were held in the context of a number of current issues;

#### **1. The need to be clear about who is included in this group and how learning disability is defined.**

The NHS definition of Learning disability was shared with the workshop (see below).

*Individuals with a learning disability (internationally referred to as individuals with an intellectual disability) are those who have:*

- *a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;*
- *a significantly reduced ability to cope independently (impaired adaptive and/or social functioning), and;*
- *which is apparent before adulthood is reached and has a lasting effect on development.*

*Each of these three criteria must be met before someone can be said to have a learning disability; Intelligence Quotient (IQ) alone should not be used to determine presence of a learning disability. In terms of intellectual functioning, learning disability is conventionally defined as an IQ score in the region of 70 or below. However, it is not appropriate to use a 'cut off' figure of 70, as the results of a recognised IQ test require skilled interpretation. There should also be significant difficulties in adaptive and/or social functioning, for example in relation to conceptual, social and practical skills (such as language, interpersonal skills and activities of daily living).*

*Learning disability is different from a specific learning difficulty, such as dyslexia, or a mental health condition.*

#### **2. The available data about the health inequalities that exist within the LD community that tells us that those with learning disabilities have;**

*A shorter life expectancy*

*More sensory & physical impairments*

*Poorer physical health*

*Poorer mental health*

*Little or no effective monitoring in health information systems (generally)*

Factors that lead to poorer health outcomes are;

- *Issues with Communication and Health Literacy including;*
  - Poor bodily awareness*
  - Limited communication skills*
  - Difficulties with recognition of pain and discomfort*
- *Issues with access to Services including;*
  - Scarcity of appropriate services*
  - Physical barriers to access*
  - Inappropriate eligibility criteria*
  - Failure to make reasonable adjustments*
  - Diagnostic overshadowing – dismissing symptoms as ‘just’ part of the learning disability*

### 3. **The Transforming Care Programme that aims to ensure;**

*‘Children, young people and adults with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition\* have the right to the same opportunities as anyone else to live satisfying and valued lives and, to be treated with the same dignity and respect. They should have a home within their community, be able to develop and maintain relationships and get the support they need to live a healthy, safe and fulfilling life.’*

## Table Discussions

The groups at each table were mixed and included both parent carers and SEND practitioners.

### • **Referral Process**

How the existing referral process was described;



### **Other comments;**

“Portage referral made early was really helped”

“Health visitors vital. Close contact with family, listen/see child regularly”

“Early intervention crucial – bring back Health Visitors visiting families”

“Experienced rude/unhelpful comments – ‘he’s a boy’, ‘they all develop differently’ ‘you’re being neurotic’”

“Need to be aware of impact on Parents of not knowing”

“Who can refer?”

“No understanding and not enough training amongst wider professionals (awareness)”

### **What attendees would like to see happening in the future;**

- It should be clear when you have been referred
- The criteria for referral should be openly shared
- Provide clarity around which/who is CAMHS, and which/who LD CAMHS
- See the Parent as the expert – LISTEN
- Be clear what is out there to support LD families
- To be listened too – by that somebody understands
- Be supported with empathy
- Provide a clear outcome for YP/family/school from the referral process – what happens next
- Training for all Practitioners (Schools especially) about learning disabilities
- Better collaboration/joint working/up to date info provided
- Address the cultural fear of transparency within services
- Overcome people’s embarrassment about LD
- Provide more opportunities for practitioners to learn about what it is like to be a Parent Carer
- Provide support during waiting – talk about expectations – ‘assessment will fix things/provide all the answers’ is unrealistic – provide support for families to adjust to parenting a child with a learning disability
- Share more positive images and stories about living with a learning disability
- Address parental fears/guilt
- Clear criteria, openly shared – especially under 5s.

- **Assessment Process**

How the existing assessment process was described;



**Other comments and what attendees would like to see happen in the future;**

- CDC – Positive, amazing and experienced staff, but what happens Post 5 years
- Poor continuity of care – psychiatric support specialists
- All comes down to lack of people
- If there are difficulties identified at school age it is difficult to get an assessment
- Early Intervention is needed – not when Parent in crisis on knees!
- There should be monitoring of support given, a process to ensure that it's effective – a plan, do review approach
- Portage/Play Pals Post Assessment support should be more readily available
- Individual therapy sessions vital, as well as small group
- Local specialist clinics are needed – everything is in Shrewsbury
- Ed Psych – service varies so much
- CDC – positive/supportive meeting other parents but it can be an overwhelming experience.
- More moderate development issues often get overlooked
- We need a speedy/responsive/clear service – with practical strategies suggested.
- The assessment should be outcomes based and supportive – professionals who listen with honesty and openness.
- Booklet of what to expect would be helpful - process and outcomes for families/YP. Include who does what – assessment/support/evidence collecting.

- **Diagnosis Process**

How the existing diagnosis process was described;

So-what  
Cliff-edge  
Not-conclusive  
Mixed-messages  
**What-next**  
Unproductive  
**Unclear**

**Other comments and what attendees would like to see happen in the future;**

- Need a clear pathway for child that doesn't get a diagnosis? (Monitoring process – begun through CDC)
- No signposting for support given – I have a diagnosis but now what do I do?
- What is Plan B if Plan A isn't effective – monitoring pathway required.
- Leaflets given are often not sufficient or unhelpful; only support given for some concerns/ behaviours.
- No counselling support for parents
- Signposting family to Local Offer
- Giving Family information about what to expect, who to go to for support and how to access it
- Need the next steps explained
- Simple clear diagram of what now, who, where would help
- CAMHS Drs to have experience of sensory issues and how to tackle them.
- Cliff edge – has felt like a diagnose and dump process
- What happens when the diagnosis isn't conclusive – what happens next?
- Diagnosis is the reason and that is important, but what do you do practically, do you want to tell people about the diagnosis? All things that families need support with.
- People not understanding the value of diagnosis – helps understanding, not about labelling or an excuse for poor behaviour
- Health Visitor get a copy of CDC report, which is good – sharing diagnosis with other services or practitioners involved is important
- There seems to be concerns diagnosis could be used as an excuse for poor behaviour.

- Global Development Delay – grey area which can often lead parents to believe child could catch up eventually – should this diagnosis be reviewed post 5 years
- Pathological Demand Avoidance – not recognised in Shropshire why not?

**In this workshop there was extensive discussion about what should happen post diagnosis with a particular focus on it needing to be outcome focused.**

**Other comments;**

- Follow up after diagnosis is essential – what should be put in place in view of the diagnosis should be clearly identified
- The need for respite care given/overnight care should be considered
- How does the diagnosis inform what happens in schools – specialist and mainstream
- Involvement in EHCP reviews by the diagnosing clinician is essential – this is a process that enables a joined-up approach to support
- What happens to those families who don't get a diagnosis – where do they go?
- Not being signposted to relevant support post diagnosis – this needs to be part of the process
- Address issues around shared care arrangements with GP's to help with medication management and reviews
- Parents finding best support from each other – how can the service support this to happen?
- Amazing behaviour therapist from CAMHS LD – but we need more
- Education, Health, Social Care should all work together
- Current support seems to be reactive – crisis oriented – need to change this

**What those who attended the workshop would like to see happen in the future;**

- Key outcomes are identified for each young person, to inform all the service that are providing support to work towards – what has worked and what hasn't
- Parent carers are able to speak honestly without fear of misinterpretation – 'can't cope' etc.
- Parents are seen as experts in terms of their child
- Post assessment/diagnosis – Parents and YP feel informed, supported, listened to, know what's ahead. A visual route and timescales. Have a Plan B.
- Schools and clinicians to work together
- Good post diagnosis information provided – courses, leaflets, web, IASS. Not just medication offered, menu of support including opportunities for peer support and developing parent carer resilience
- Our YP's are individual. Tailor interventions individually and implement a person centred-approach
- Improved information sharing and continuity of care – not having to tell story AGAIN.

- A holistic approach is implemented
- Give schools the skills to manage behaviour – look at SALT model
- Multi-Disciplinary Team approach to bring core package together – pro-active approach to address issue that we know young people are at risk of developing – e.g. behaviour that challenges, inability to effectively communicate. Try to stop things before they go wrong
- Schools understand how LD and/or mental health needs present.
- Opportunities for practitioners to shadow other practitioners/services e.g. attending CDC, EHCP Panels to increase their knowledge and understanding of wider system
- Improved parental support – Portage, Parenting Practitioner, Key Worker – someone for the whole family to talk to and listen, who is experienced in and understands Learning disability and how it impacts on a family – including siblings
- Make it clear to everyone what is happening – in writing and explain purpose of meetings/ assessment.
- Work with schools and family pro-actively – this is what this diagnosis might mean.
- Follow up work – identify key areas of work – implement plan, do, review approach
- Enable young person to communicate how they feel – develop self-awareness as a key outcome
- Help with Parents understanding of issues, and other family members
- improved information sharing between services/teams
- Clear information about what services are available
- Moderate Learning Disabilities – need more support with mental health and social needs, as gap widens at Secondary age.
- Offer sufficient behavioural/Sensory Outreach Support
- Social Care need to support LD not just expect health and education to shoulder the load for service delivery
- Support needs, not diagnosis – be person centred
- Offer lifelong support for a lifelong disability

**Post diagnosis support for those with learning disabilities should be;**

person-centred  
 Supportive  
 Aspirational Clear  
 Holistic Multi-disciplinary  
 Life-long  
**Collaborative**  
**Proactive Informed**  
 Family-focused  
 Empathetic



## Summary

### Neurodevelopmental workshop.

#### Key messages;

1. There was a significant level of agreement between parent carers and SEND practitioners across education health and social care about areas of concern and what needs to happen.
2. Communication and clarity was a major area identified for improvement – every discussion group identified this as an issue. There needs to be a much better understanding of what the pathway is, who does what, how pathways work together etc There is a huge training /raising awareness need amongst SEND practitioners to improve their understanding of the big picture and how services fit together.
3. The importance of supporting parent carers – addressing the wider impact on families and enabling families to lead positive lives.

#### Some key questions;

- What triggers a referral?
- Who can refer?
- What information is needed for a referral?
- What is the intended outcome of an assessment? – This should be more than just providing a diagnosis – need to result in support plan for the young person and their family. The plan will need to be multi agency and so there needs to be a shared language across services.
- How does the service link with schools and SEND processes in education?
- How does the service prevent people falling to the black hole that is created by a diagnosis of ‘autistic traits’?

### Learning Disability workshop

#### Key messages;

1. Again: There was a significant level of agreement between parent carers and SEND practitioners across education health and social care, about areas of concern and what needs to happen.
2. Communication and clarity was a major area identified for improvement – every discussion group identified this as an issue. There needs to be a much better understanding of what the pathway is, who does what, how pathways work together etc. There is a huge training /raising awareness need amongst SEND practitioners to improve their understanding of the big picture and how services fit together.
3. There is a need to clarify who we are talking about with regard to this service and have a shared language across the system to reduce barriers to accessing services i.e. an agreed and shared definition of learning disability.

4. “A life-long service for a life-long disability” – we know a significant amount about the possible challenges that individuals with LD will face in the future as they become older the service needs to be working to address these from the earliest point in a young person’s life – health inequalities, challenging behaviour, isolation etc – need to be aspirational.
5. A collaborative approach is essential – LD services cannot work in isolation – there needs to be a partnership approach to supporting the development of young people with learning disabilities across clinicians, school and home, with a constant eye on the long-term future of these young people.
6. Supporting parent carers and wider families is key – need to understand the role of social care in this, need to give parent carers the tools, ability and confidence to plan for the future.

### Some key questions;

- How does the service define a learning disability?
- What information is required for an LD assessment?
- How does the service work with other services following an assessment?
- If Global Developmental Delay is diagnosed what action is taken to review this diagnosis as the child gets older?
- How is the effectiveness of interventions reviewed?
- Should the Learning Disability Service be delivered by a multi-disciplinary team?
- How does the service work to reduce health inequalities for people with learning disabilities?
- How does the service contribute to the Transforming Care Programme?



## Recommendations

1. The service leads and commissioners provide a written response to the feedback provided in this report, which can be shared by PACC with the Shropshire SEND Community and through other local SEND networks.
2. The service provider, service commissioners, SEND Leads, children social care leads, school representatives and family representatives create a task and finish group to discuss the findings of these workshops and produce an action plan to address the issues identified. These actions should come together to create an effective service pathway for diagnosing and supporting young people with neurodevelopmental conditions and learning disabilities in Shropshire.
3. The same multi-agency SEND group should meet twice a year to review the pathway and consider and respond to feedback from those who use the service. This SEND group would report to the EHWS Stakeholder Forum on the development and delivery of the SEND specific part of the wider Emotional Health and Wellbeing Service as required.

**PACC would like to thank all the parent carers and practitioners who supported these workshops and gave their time to work together to improve services and outcomes for SEND families in Shropshire**

# Appendix 1—Feedback

## Neurodevelopmental Pathway Workshop – 22<sup>nd</sup> January 2018

### Parent Carer Feedback;

**Has attending the event increased your knowledge of services and SEND systems?**

Yes (12 of 14)      No change (2 of 14)

**Has attending the event made you feel more able to participate in decisions that affect your family?**

Yes (11 of 14)      No change (2 of 14)      No (1 of 14)

**Has attending the event provided you with an opportunity to influence the design of services?**

Yes (9 of 14)      No change (3 of 14)      No (2 of 14)

**Has this event helped you to feel more connected to other parent carers?**

Yes (12 of 14)      No change (2 of 14)

**Has attending this event helped you to feel more supported?**

Yes (9 of 14)      No change (4 of 14)      No (1 of 14)

**Rating of venue**

Good (5 of 14)      Very Good (9 of 14)

**Rating of refreshments**

Good (5 of 14)      Very good (9 of 14)

**Rating of organisation of the event**

Good (6 of 14)      Very good (8 of 14)

### **Suggestions for improving the day?**

More detailed feedback on next meeting.

Very disappointed the professionals have gone before we had an opportunity to ask questions. Maybe they need to stay until the end, or questions need to be asked at start of session.

Could we have time programmed in to the session to complete the feedback forms?

Asking questions of, and getting a reply from the professionals. Parents seem to come to these meetings, say the same thing and no change!! CAMHS professionals need to stay to hear our feedback, how else will they take our opinions and experiences back?!

Having more information from CAMHS themselves re procedures and policies.

Would have been good to hear from GPs, from their perspective on child mental health needs. How do they see themselves fitting in the process?

Listen more to parents. Professionals to take on board more of what is said from parents. More support after diagnosis. Professionals to stay back to listen to feedback.

No, was brilliant.

### **Additional comments about development of ASD/ADHD/neurological pathway.**

Often feel I attend these meetings and always the promise that in future lots of things going to be done, but I worry about the long timescales involved to improve things. What happens to children NOW?

Keep it simple, so people know where to go. Consistent approach, more support, therapies, more follow up.

We need active change, a louder voice, as it feels that talking to us, is just a box ticking activity. Serious near miss and now a death of a member of our ASD community, means we cannot wait.

GPs need more awareness regarding ASD, ADHD, and all other neurodevelopmental conditions. Clear pathways for all areas e.g. diagnosis, assessment and post assessment.

Needs to be more support in place for children post diagnosis – ‘no worries’, social skills, life skills. CBT help to boost self-esteem and increase confidence.

Support for re-referral. Post diagnosis support especially if no diagnosis, but still presenting with difficulties.

Still feel there isn't going to be the progress that is needed to support every child and their family, because of lack of funding, resources and understanding. Fed up of different professionals passing back and forth, i.e. school and GP.

More help, therapies. Need OT involved. Multi-agency meetings needed – especially at school. More follow up after diagnosis. More support for families – parents/siblings. More support for schools.

I think it's really important that at the end of the workshop, none of the professionals were here to answer questions. I thought it was very sad.

## Practitioner Feedback;

	<i>Strongly Agree</i>	<i>Agree</i>	<i>Neutral</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
The aims of the workshop were clearly defined	3 of 6	3 of 6			
Participation and interaction were encouraged	3 of 6	3 of 6			
The topics covered were relevant to me	3 of 6	3 of 6			
This workshop experience will be useful in my work	3 of 6	3 of 6			
The speakers were knowledgeable about the workshop topics	4 of 6	2 of 6			

### Rating of Venue

**Very Good (5 of 6) Good (1 of 6)**

### Rating of Refreshments

**Very Good (6 of 6)**

### Rating of organisation of the event

**Very Good (6 of 6)**

### Suggestions for improving workshop

Sharing more details in advance – agenda, names of speakers etc to allow thoughts and preparation.

Q&A sessions – Practitioners/agencies to be made available to answer questions.

### Additional comments/feedback for ASD/ADHD Pathways Development

Understanding CAMHS long term action term and milestone dates – in terms of who, what, where and when are services being delivered – May 2017 was a date of change, but what the changes were, hasn't been communicated.

Document/leaflet updating C/YP, families, professionals of the service currently available now, pending the anticipated changes.

Communicate next steps.

A mission/vision statement such like 'achieving clarity and support for all living with social communication needs in Shropshire',

## Learning Disability Pathway Workshop – 22nd January 2018

### Parent Carer Feedback;

**Has attending the event increased your knowledge of services and SEND systems?**

Yes (9 of 9)

**Has attending the event made you feel more able to participate in decisions that affect your family?**

Yes (9 of 9)

**Has attending the event provided you with an opportunity to influence the design of services?**

Yes (6 of 9)                  No change (3 of 9)

**Has this event helped you to feel more connected to other parent carers?**

Yes (9 of 9)

**Has attending this event helped you to feel more supported?**

Yes (8 of 9)                  No change (1 of 9)

#### **Rating of venue**

Good (4 of 9)                  Very Good (5 of 9)

#### **Rating of refreshments**

Good (3 of 9)                  Very good (6 of 9)

#### **Rating of organisation of the event**

Good (3 of 9)                  Very good (6 of 9)

#### **Suggestions for improving the day?**

Venue was a little cold.

More time to talk to professionals.

No. A fantastic day all round.

It would have been interesting to hear from people like; Woodlands, Havenbrook, and other services that can help.

#### **Additional comments about development of learning disability pathway.**

Needs more definition as in bits and pieces at the moment.

Feel young adults 18+ need to know more about services that are out there, and also where to go if things go wrong.

Need to reduce waiting list time. Benefit advice re fitness to work for LD/mental health would have been useful.

Needs to be clearer (system) and schools more aware of it.

## Practitioner feedback;

	<i>Strongly Agree</i>	<i>Agree</i>	<i>Neutral</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
The aims of the workshop were clearly defined	3 of 5	2 of 5			
Participation and interaction were encouraged	3 of 5	2 of 5			
The topics covered were relevant to me	5 of 5				
This workshop experience will be useful in my work	4 of 5	1 of 5			
The speakers were knowledgeable about the workshop topics	4 of 5	1 of 5			

### Rating of Venue

Very Good (5 of 5)

### Rating of Refreshments

Very Good (5 of 5)

### Rating of organisation of the event

Very Good (5 of 5)

### Suggestions for improving workshop

I think it would have been really useful for staff from DCT Social Services to have been here. Maybe some representation from mainstream school, as lots of children/young people with LD attend mainstream education. Practical strategies.

### Additional comments/feedback for LD Pathway Development

Excellent training very useful for future use.

Really useful and good to meet with other parents and professionals.

Maybe looking at grouping people in cross sector groups for a wider holistic look i.e. health, social care, education, parent carers and other. Excellent having a chance to speak to the range of families and sector reps. Thank you.