

# Minutes of Northumberland Parent Carer Professional Forum (PCPF)

Venue: Stannington Village Hall

Date: Thursday 13 July 2017 10.30-12.30

<b>PRESENT:</b>	Sam Barron, Alison Bravey (Minutes), Helen Cowens, Julie Anne Curtis, Hayley Fawcett, Elizabeth Johnston, Julia Lyford, Scott Millican, Heather Pringle, Amanda Richardson. Eileen Robinson (Chair), Doris Ross, Jacque Simpson, Nicola Strachan, Fiona Tarn, Gill Turner
<b>APOLOGIES:</b>	Paula Batsford, Alan Carrick, Sarah Hanlon

ITEM	DESCRIPTION OF DISCUSSION	ACTION BY
1.	<b>Welcome and introductions</b>	
2.	<b>Minutes of Previous Meeting:</b> amendments noted.	
3.	<p><b>Matters Arising:</b></p> <ul style="list-style-type: none"> <li>● <b>Short Breaks:</b> information not getting through to parents - seems to be an ongoing issue. Patrick Love currently covering for Debbie Bakkali - to be invited to PCPF meetings. Northumberland funds places with Ability to Play, but the organisation is not exclusively for children/young people from Northumberland.</li> </ul>	<b>EJ</b>
4.	<p><b>Healthwatch - Heather Pringle</b></p> <p>Healthwatch works alongside support groups, individuals and organisations to listen to the experiences of health and social care at service user level. Attended In It Together locality meetings to share information and get feedback from parents re any issues.</p> <p>Northumbria Healthcare have commissioned Healthwatch to do a survey to obtain feedback about urgent care units overnight closure (midnight to 8am). Have been closed for the past 3 months and it is proposed they remain closed for the next 3 months.</p> <p><b>Definitions:</b></p> <p><b>Urgent care</b> includes minor injuries or ailments which require medical attention - included sprains, minor breaks, nose bleeds, minor cuts.</p> <p><b>Emergency care</b> includes chest pain and strokes</p> <p><b>Discussion:</b> The public need to know about the alternatives to urgent care, other options available when someone needs treatment. Travelling distance and need for own transport are among the factors to be considered. It was queried whether the proposal to keep the units closed for another 3 months means they are earmarked for permanent closure.</p>	
5.	<p><b>SEND Update - Sam Barron</b></p> <p>Sam has been appointed as Partnership Development Manager for SEND. Her background is in speech and language therapy. Currently completing the latest Local Area SEND SEF (Self Evaluation Framework). This covers how well Northumberland is doing in terms of the SEND Reforms as part of the inspection framework.</p> <p>One of the areas an inspection will look at is how well the Local Area engages and co-produces with children and young people and their parents/carers. Need to look at these areas separately. Engagement with parents and carers seems to have improved over the past 2 years. Children and young people seem happy to engage, but are not asked. There are examples of good consultation with them as service users, but this is not the same as co-production. Currently no mechanism for wider engagement, consultation and co-production with children and young people. Looking at options for how to take this forward.</p> <p>The process of co-production includes having an impact on and/or changing services. Need to be able to demonstrate that children/young people have been listened to and the difference that this has made.</p> <p>The SEF describes the situation at the moment across the Local Area and includes an action plan about what future steps need to be taken and how to support this process.</p> <p><b>Discussion:</b> There is a group for young people with SEND, facilitated by Ben</p>	

	<p>Sanderson, which is called REC (Respect Equals Change), but it was felt that this was not getting the breadth of representation needed. It was noted that there is less resource within the Local Authority for child/young person participation. Need to look at how to involve partners from other sectors in this process.</p> <p>It was noted that most often children/young people are not asking for a resource, they are asking for a voice. Need to look at the what happens between the ages of 18 and 25 years. No mechanism for the co-production conversation to happen. It was noted that arrangements for children/young people seem to ride on the coattails of those for parents and carers. Need to have parallel arrangements specifically for children/young people, which includes strategic representation, including service users/participation groups.</p> <p>Suggestions to take this area of work forward included: establishing links with student councils; having young people trained to look at the quality and accessibility of services; speaking to young people who have recently experienced the transition to adulthood process.</p> <p>IIT representatives to meet with Sam Barron to discuss this further. Sam to attend locality meetings.</p> <p>It was noted that the DfE (Department for Education) SEND Survey includes questions about how well the Local Area is doing. Parent Carer Forums are a mechanism for parental engagement with the Local Authority and receive funding to support this process. Having the same resource for a Young People's Forum would provide a better mechanism for engagement with them.</p>	<b>SB/IIT reps</b>
6.	<p><b>Locality Round Up: In it Together representatives</b></p> <p><b>West Northumberland:</b></p> <ul style="list-style-type: none"> <li>● <b>CYPS</b> - concerns about the length of waiting times for appointments and children not being accepted into the service at the end of the wait. One family had waited 24 weeks to access the service. Continuity of staff can also be an issue. Diagnostic route for ASD. Lack of OT (occupational therapy) for sensory needs. Toby Henderson Trust do sensory profiling privately at a cost of £380 - why is this not available on the NHS?</li> <li>● <b>EHC paperwork</b> - not enough time given to work with families. Paperwork filled out and lost.</li> <li>● <b>SEND Mentor Service</b> - no longer available to families because funding no longer there.</li> </ul> <p><b>Discussion:</b> Scott Millican responded to the issues raised re CYPS - was surprised it had taken 24 weeks to access the service because waiting times generally have greatly improved. Might be because of specific circumstances or might be a historic case when waiting times were much longer. Usually about 13 weeks to Choice appointment. Waiting times depend on the treatment pathway.</p> <p>OT sensory profiling - some parents have had the assessment done - arranged by the Care Coordinator. CYPS is not commissioned to do sensory assessments - no longer offering this through Toby Henderson Trust. It was felt that this was a gap in provision for identified needs.</p> <p>It was mentioned that the name CYPS also causes confusion with it being confused with SIPS. In most other authorities it is known as CAMHS. The name was changed to CYPS following a consultation with service users</p> <p>The process of assessment for ASD through the Neurological team (who cover ASD and ADHD) was explained. The first appointment (Choice Appointment) is with a Care Coordinator and this is followed by school observations and ADOS assessment. This has been identified as a training need and some staff are undertaking training to deliver this assessment. CYPS are looking at the alignment of treatment pathways. Some of the Learning Disability staff are undertaking training in PBS (Positive</p>	



	Need to look at whether other strategic groups are meeting the requirements of the NICE guidelines and how different groups can work together; need to establish links between strategic and operational boards, including Health and Wellbeing Board. Coordination of services and provision. It was queried whether the group should link in with the Adult Autism Group chaired by Alan Curry.	
8.	<b>Short Break Provision Countywide</b> The Short Break Statement and the lack of short break provision were raised. Patrick Love to be invited to the next Forum meeting.	<b>Elizabeth Johnston</b>
9.	<b>SEND Consultation Events and Road Shows</b> Uptake for consultation events very poor. Parents had not received letters from school. Feedback from events: some interesting discussions and parents who attended found them very positive. A letter to be sent in September to families of children/young people with SEND from the Local Authority and In It Together inviting them to the Roadshows.  <b>Discussion:</b> concerns raised about getting communications out to families of specific groups of children/young people, including Looked After Children, EOTAS, educated outside of Northumberland, pre-school children and 18-25's. This was raised at the PCPF last year and had been raised at the SEND Strategic group. Looking at the way data is collected and held. Ideas shared for how to get information out; including through Children's Centres, community and charitable organisations (CVA bulletin, Contact a Family newsletter, Carers Northumberland).	
10.	<b>Information Sharing/AOB</b> <b>Eileen Robinson:</b> raised concerns about delays in naming colleges in EHCPs. Last year this was left as late as July. The statutory deadline is 31 March to give enough time to organise transition arrangements for the young person and their family. The same delays have happened with some EHCPs this year. Preparation for Adulthood should start in Year 9. The Northumberland Local Authority interpretation of DfE guidance published in February that all young people should exit education at 18 is not the law. <b>Julia Lyford:</b> mentioned work of new RAP (Rural Access Project) Splinter group in Alnwick. Graffiti project over the summer for young people with learning differences. Event on 5 September: 'Driving is it for me' with simulator. At a previous event out of 6 young people assessed at the driver mobility centre, 4 were told that there would be no problem with them driving. Offer driving theory support. Networking: 2 young people are now workers - looking to reach more 18 -25 year olds. 'Train the trainer' - offer training for staff working with young people with learning differences. Safe Places - designated places where vulnerable people can go to if they need help. SpLinter commissioned to roll this scheme out across Northumberland. Have an App encouraging people to use these places. Training members of SpLinter to do presentations to groups of young people with learning differences and other vulnerabilities. On-going mentoring.  <b>Heather Pringle:</b> Healthwatch would like to be involved with co-production activities with service users as much as possible. <b>Jacquie Simpson:</b> mentioned accessibility of public toilets in Northumberland for people with disabilities. Jacquie and Elizabeth Johnston has met with two representatives from Newcastle University to discuss research and plans for this. Accessible toilets and changing beds in some venues in Northumberland; e.g. Alnwick Gardens and Ashington Leisure Centre. Money invested through the Aiming High for Disabled Children programme. It was suggested that a map of accessible toilets be included on the Local Offer. There is an App which tells you where they are.	

	<p>Shops with “You’re Welcome” signs.</p> <p><b>Doris Ross:</b> Disabled Children Team update. From 1 April the team has been responsible for Child Protection cases involving disabled children/young people. Pilot in West Northumberland for transition 18-25 years. Michael Nelson, Transition Social Worker, is now based over in Hexham. Team being disseminated to different locations in Berwick, Bedlington, Blyth, Alnwick and Hexham. Doris will travel between the offices.</p> <p>Kirstine Gagie will no longer be the Enquiry and Referral Coordinator. From 1 August all referral will now be through first contact.</p> <p>It was noted that eligibility criteria for accessing social care services need to be set out clearly on the Local Offer website - difficulties with navigating the website were flagged up.</p> <p><b>Fiona Tarn:</b> SEND Support Services are now working with schools on a traded model through SLAs (Service Level Agreements). Schools buy into different packages of support. Most schools have bought in, but may have opted for basic packages of support. May have an impact on staffing. Services had previously been funded through a centralised budget retained by the Local Authority - budget now delegated to schools - so schools may have been under the impression that they were getting them for free. It was noted that there are so many demands on the High Needs Block funding - need to prioritise how the money is spent.</p>	
<p><b>10.</b></p>	<p><b>Dates of future meetings:</b></p> <p>Thursday 5 October 2017 Monday 11 December 2017</p> <p><b>Venue:</b> Stannington Village Hall - all meetings 10.30 – 12.30</p>	

## DISTRIBUTION LIST FOR MINUTES

Debbie Bakkali	Team Manager, Children's Services, Family Support Team
Sam Barron	Partnership Development Manager for SEND
Paula Batsford	Designated Medical Officer
Alison Bravey	Parent Partnership Officer, SEND Information, Advice and Support Service
Kate Brundle	Head of Commissioning (Mental Health)
Lynne Bryden	Senior Manager, Commissioning
Karen Carnaffin	Team Leader, Families Information Service
Lesley Cole	Autism Northumberland
Mary Connor	Senior Manager, Early Intervention and Prevention
Helen Cowens	Parent Representative, North Northumberland
Julie Anne Curtis	Team Manager, Neurodevelopmental pathway, Northumberland CYPS
Mark Cusack	Passenger Transport Operations Manager
Wayne Daly	County Councillor and Board Member for Children's Services
Jean Hedley	Blyth Valley Children's Centre Locality Manager
Sarah Hanlon	Parent Representative, West Northumberland
Andrew Johnson	Director of Education and Skills
Mary Johnson	Co-ordinator of Dasl'e
Elizabeth Johnston	Parent Representative, North Northumberland; Chair of In It Together
Sarah Lee	Participation Adviser, Contact a Family
Patrick Love	Acting Team Manager, Children's Services, Family Support Team
Daljit Lally	Deputy Chief Executive, Northumberland County Council
Dorothy Lewis	Children's Centre Coordinator - Seaton Valley Children's Centre, T
Julia Lyford	Splinter Group representative
Janet Millington	Clinical Lead, Speech and Language Therapy, MAG Autism
Rachel Mitcheson	Head of Commissioning (Children)
Marian Moon	Line Manager, Disabled Children Team, Northumberland Healthcare, NHS
Michele O'Brien	Carer's Lead, Involvement & Service Development, Northumbria Healthcare NHS Foundation Trust
Katie Paul	Team Manager, Complex Mental Health Pathway, Northumberland CYPS
Russell Pickering	SEND Manager
Amanda Richardson	Parent Representative, Central/South East Northumberland
Eileen Robinson	Parent Representative, West Northumberland
Doris Ross	Team Manager, Disabled Children Team
Ben Sanderson	Youth Participation Worker, Northumberland Youth Service
Jacqui Simpson	Parent Representative, North Northumberland
Fiona Tarn	SEND Support Service Manager for ASD, Behaviour
Gill Turner	Consultant Paediatrician, West Northumberland
Sue Welsh	Head of Therapies, Northumbria Healthcare, NHS