

Minutes of Northumberland Parent Carer Professional Forum (PCPF)

Venue: Stannington Village Hall

Date: Thursday 6 December 2018 10.30 - 12.30

PRESENT:	Lisa Anderson (guest), Sam Barron, Alison Bravey (Minutes), Helen Cowens, Hayley Fawcett, Kate O'Brien, Amanda Richardson, Eileen Robinson (Chair), Doris Ross, Jenni Wade (guest)
APOLOGIES:	Judith Dodds, Sarah Hanlon, Elizabeth Johnston, Naomi Jones, Lynne McKillup, Isabel Russell, Jacquie Simpson, Nicola Strachan, Fiona Tarn, Nicola Taylor, Gill Turner, Lesley Tweddell

ITEM	DESCRIPTION OF DISCUSSION	ACTION BY
1.	Welcome and introductions	
2.	Minutes of Previous Meeting: agreed	
3.	<p>Matters Arising:</p> <ul style="list-style-type: none"> • Short Breaks - it was queried whether Jackie McCormick is the right contact and who would be the best person to speak to the Forum about what is available and the eligibility criteria for the Disabled Children Team. Doris Ross to provide briefing next meeting. • SEMH (Social Emotional and Mental Health) Suzanne Barton is the CCG commissioner and has been doing some work re access to CYPS. Waiting times have never been better. Only 3 children waited more than 12 weeks. May be that waiting times in other parts of the system is causing confusion. It was noted that an issue is how a child gets back into the 'system' when there is an emergency. 	DR
4.	<p>Smile Through Sport Project - Jenni Wade</p> <p>Smile Through Sport is a north east disability sports organisation, founded by the paralympian Stephen Miller. It covers the 5+ age range and all special educational needs and disabilities, including mental health. Have received 4 years of funding from Sport England for a project called Smile Together. It aims to encourage families to become active together and develop the confidence and skills to take up different sports. Will be running activity days and courses to promote ideas and skills for doing activities and sports at home and other places. Resource pack available. Also have a library of equipment that can be borrowed for a set period of time.</p> <p>Had a launch event in Ashington in October attended by 7 families (25 individuals). Will be setting future dates for sessions and activity days. Want to spread the word to families. Events will be fun and relaxed within a loose structure. Want these to be family-led so families provide the ideas for how they want the project to go.</p> <p>Data required by funders to give details of participants age/disability/current level of activity. Some criteria required by the funders will need to be modified for individual situations; e.g. one of the questions is about walking to school, which would not apply to children/young people who travel by bus or taxi.</p> <p>Discussion: centred around ways to reach families. Suggestions included In It Together locality groups and Facebook, local support organisations, special school head teacher meetings, Portage, Info-link, Adult Social Care services and Disabled Children Team. It was mentioned that to make the project sustainable for the future, families would need to pay to attend, but perhaps taster sessions could be offered for free so families could see which activities would be suitable for them.</p>	

5. Continuing Care, CHC (Continuing Health Care) and Personal Health Budgets - Kate O'Brien

Kate explained that her role covers health provision for people with mental health needs, learning disabilities and other disabilities. There are currently 447 people in Northumberland accessing personal health budgets, 103 of which are through direct payments where the person takes responsibility for arranging the provision themselves. There is a growing number of children with personal health budgets in Northumberland. Data benchmarked against other authorities.

The eligibility criteria for children for CHC (Continuing Health Care) or who are covered by the Mental Health Act Section 117 after care is different to those for adults. CHC for children is based on unmet health needs. If a child's health needs are already being met they would not be eligible, even if their health is severely affected by the condition they have.

There are different ways of triggering eligibility for CHC. Transition to full CHC (Continuing Health Care) happens when a young person turns 18. They are referred through the checklist for CHC. Their specific needs are assessed against set criteria to establish the quantum of needs; e.g. the frequency or unpredictability of needs to be met.

Suzanne Barton, Health Commissioner, is leading on redesigning services to address the gaps so that children can get the right service at the right time; e.g. for mental health. Eligibility might be through CHC or Section 117 after care.

Personal health budgets - parents receive money to directly commission a service. Can use an agency to manage the administration of the budget. Can be requested where a child has an unmet health need and needs a service to access education. An example would be where a very specialist service is required; e.g. specialist sensory therapy or mobility equipment. If the need is over and above what specialist school nurses can provide a budget might cover interventions on a more frequent basis. It can't be used to pay a resident parent or the partner of an adult service user. Section 117 after care when a child or young person has been detained under the Mental Health Act. Need to look at support for parents and carers and whether support is needed through a Personal Health Budget. There is a statutory duty to review the situation on an annual basis. Continued support into adult life may be jointly funded through health and social care. There is no charge for this service.

Discussion: Some families feel that they are being fobbed off when they are told that their young person doesn't meet the criteria for CHC. The process for determining whether someone is eligible is robust and aims to be fair and transparent. A national assessment framework is followed, all parties contribute to the assessment process and there is a right to appeal against panel decisions.

The assessment process should start well ahead of the child's 18th birthday. The change in funding begins when they turn 18. If a child has an EHCP it should be part of the annual review process. The systems for Continuing Care and CHC need to be aligned. It is important that clear and easy to understand information about the processes is published on the Northumberland Local Offer.

Jo Price is the Personal Health Budget regional lead for NHS England.

6.

Adult Social Care - Simon Murray

Simon explained that his background is in learning disabilities and mental health. A focus of his current role is transitions and SEND. Transformation in the last 2 years with social care teams with a focus on how to deliver on the SEND agenda. Establishing a clear transition protocol and policy, looking at the key stages of a child or young person's educational journey, increasing contact as a young person approaches 18 to look at what they will need for their adult life. Need to ensure that there is good quality, joined up information from different services to give a clear picture of need to inform future pathways. Adult social work practitioners are linked with SEND champions and Children's Transition Champions.

Looking at social work contribution to EHCP and ensuring that the format and language is standardised. Resourcing issues have been considered and the caseloads of social workers have been reduced. Expanding their transition work to cover Year 9 onwards.

Discussion: It was noted that the Council for Disabled Children are running some training on transition. Doris Ross noted that the Disabled Children Team used a specific model for transition a few years ago. Linked in with locality adult care managers. Cath McEvoy-Carr is now the Director of both Children's and Adult services. Focus on additional needs from birth. Need services to work collectively together for the good of the individual. Need a seamless transition process - avoidance of the 'cliff edge' described by some families.

Questions covered and discussed:

1. *How long does it take to access supported living or housing? Is there capacity in current provision to meet needs?* This depends on individual circumstances and their complexity. Need to start conversations early so there is enough of a timescale. There is a vulnerable person's housing list, but it is difficult to put a timescale on this because it depends on where the person lives and what availability there is. The issue was raised of children/young people who attend residential schools because of their needs. There is an assumption that they will just go home when they leave school which may not be the best option. There seems to be a gap in what happens next after school/college. Planning needs to happen in a timely way. Pathways to ensure the right services are available at the right time. Person centred planning process is not used for every children with an EHCP. Need to look at different models for providing person centred planning.
2. *Could Adult Provision for Day Care be put on the Local Offer?* This is being discussed with Jane Falconer who is leading on the Local Offer. It was noted that there are huge gaps in the Local Offer and a dependency on social care managers knowing what is available in each local area. It was noted that the Transitions and SEND Champions have local knowledge.
3. *What percentage of short break provision is taken up through day care?* Will need to come back to this question - not sure of the answer. It was raised that some parents feel coerced into accepting daycare places rather than their child continuing with education because they are worried about their child being left with nothing. Some day care services are more geared towards the interest and abilities of older people and may not be suitable for an 18 year old. Families need to know what is out there if the EHCP doesn't continue to 25. Provision is not just building-based day care, it can be community based services, support to access the community, community activities or a blended approach to community inclusion. The parents of adults with learning disabilities have the right to work and this is part of the assessment process to identify the needs of the individual and their carers and family. Parents can request a Carers Needs Assessment. Use a

	<p>person centred approach to identify what is needed to meet identified outcomes. Looking at the use of direct payments (e.g. for enabling and personal assistant support) and a move away from the more traditional types of services; how existing leisure facilities can be used more effectively.</p>	
<p>7.</p>	<p>Northumberland Joint Local Area SEND inspection - Cath McEvoy-Carr, Director of Children’s and Adult Services</p> <p>The findings of the inspection by OFSTED and the CQC (Care Quality Commission) were summarised. The inspection was to judge the effectiveness of the Northumberland local area in implementing the SEND reforms as set out in the Children and Families Act 2014. Following the inspection an outcome letter is produced. The Local Authority is sent a draft copy and can advise the inspectors of any inaccuracies in the letter. The letter is not finalised and shared until the amendments are agreed. The final letter for Northumberland was received on Friday 30 November and published on the Northumberland Local Offer website on 6 December. It will be published on the OFSTED website on 7 December. The Local Authority has produced a press statement which acknowledges that the local area is nowhere near where it needs to be. The message coming through from the inspection was that education services were run ragged with little support from partner agencies. The letter was felt to be a fair reflection of the current situation. It crystallised the thoughts of families about co-production with them during the years since the reforms were introduced - a mixed experience.</p> <p>The Local Authority was informed about the inspection on Monday 24 September and the inspection took place the following week. There were three inspectors in the team; two from OFSTED and one from the CQC, and one inspector shadowing the process. Sam Barron coordinated the inspection process on behalf of the Local Authority. The inspection covered the length and breadth of the county.</p> <p>There were a few issues with accessing the webinar used to gather feedback from parents, but there was the opportunity for parents to attend focus groups with the inspectors in four localities. Keeping in Touch sessions were held with the inspectors and key parties on a daily basis to provide briefings and additional information. The Self Assessment Report produced by the Local Authority was open and transparent about the current situation and was described by the Lead Inspector as ‘disarmingly honest’. It acknowledged that the focus historically has been on identifying shortcomings with regard to implementing the SEND reforms, but not how to address these.</p> <p>Although the inspection recognised the pace of change in the last year, it concluded there has been too little progress since the reforms were introduced and determined that a Written Statement of Action is required because of significant areas of weakness in the local area’s practice. Children and young people with SEND in Northumberland don’t do well enough in mainstream schools and too many are being excluded from school. The letter lists strengths, which includes the strengthening partnership and co-production with In It Together and identifies areas for development, including the lack of a framework for measuring and evaluation outcomes for children and young people with SEND. There will be an improvement plan to address the issues identified. Need firm foundations for moving things forward in the future. There will be a revisit by an inspection team within 18 months to check progress with the action plan.</p> <p>Cath is happy to deliver a presentation to a wider group of parents if this would be beneficial. In It Together will check with their membership. The positive comments in the inspection report about the Northumberland SEND Information, Advice and Support Service were acknowledged.</p>	

10.	<p>Dates of future meetings:</p> <p>Monday 11th February 2019 Thursday 16th May 2019 Thursday 4th July 2019 Thursday 10th October 2019 Thursday 5th December 2019</p> <p>Venue: Stannington Village Hall - all meetings 10.30 – 12.30</p>	
-----	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	--

DISTRIBUTION LIST FOR MINUTES

Sam Barron	Head of SEND Strategy, DCO (Designated Clinical Officer) CCG
Suzanne Barton	Children's Commissioner, Northumberland CCG
Alison Bravey	Parent Partnership Officer, SEND Information, Advice and Support Service
Lynne Bryden	Senior Manager, Commissioning
Karen Carnaffin	Team Leader, Families Information Service
Mary Connor	Senior Manager, Early Intervention and Prevention
Helen Cowens	Parent Representative, North Northumberland
Julie Anne Curtis/Laura Burnage	Northumberland CYPS
Mark Cusack	Passenger Transport Operations Manager
Wayne Daly	Deputy Leader of Northumberland County Council and Board Member for Children's Services
Judith Dodds	SEND Support Service Manager, Speech, Language and Communication Service; Literacy Support Service (Dyslexia), EAL
Hayley Fawcett	Speech and Language Therapy
Gill Finch	School Equalities Support
Fenella Gowans	Special School Nursing
Jean Hedley	Manager, Barnardos
Sarah Hanlon	Parent Representative, West Northumberland
Dean Jackson	Director of Education
Elizabeth Johnston	Parent Representative, North Northumberland; Chair of In It Together
Sarah Lee	Participation Adviser, Contact a Family
Daljit Lally	Chief Executive Officer, Northumberland County Council
Dorothy Lewis	Children's Centre Coordinator - Seaton Valley Children's Centre
Patrick Love	Acting Team Manager, Children's Services, Family Support Team
Julia Lyford	Splinter Group representative
Lynn McKillup	Portage Lead
Scott Miilican	CYPS Manager
Rachel Mitcheson	Head of Commissioning (Children)
Simon Murray	Manager, Adult Social Care
Kate O'Brien	Commissioner, CCG
Katie Paul	Team Manager, Complex Mental Health Pathway, Northumberland CYPS
Russell Pickering	Senior SEND Manager
Amanda Richardson	Parent Representative, Central/South East Northumberland
Eileen Robinson	Parent Representative, West Northumberland
Doris Ross	Team Manager, Disabled Children Team
Isabel Russell	Acting Sensory Support Manager
Ben Sanderson	Youth Participation Worker, Northumberland Youth Service
Jacque Simpson	Parent Representative, North Northumberland
Nicola Strachan	Parent Representative, North Northumberland
Fiona Tarn	SEND Support Service Manager for ASD, Behaviour
Nicola Taylor	SEND Project Manager
Gill Turner	Consultant Paediatrician, West Northumberland
Lesley Tweddell	Healthwatch
Sue Welsh	Head of Therapies, Northumbria Healthcare, NHS
Adele Wright	Line Manager, Disabled Children Team, Northumberland Healthcare, NHS