

Draft Minutes of Northumberland Parent Carer Professional Forum (PCPF)

Venue: Stannington Village Hall

Date: Thursday 9 May 10.30-12.30

PRESENT:	Alison Bravey (Minutes), Claire Brown, Lesley Cole, Helen Cowens, Helen Elliott, Sarah Hanlon, Mary Johnson, Elizabeth Johnston (Chair), Julia Lyford, Janet Millington, Amanda Richardson, Eileen Robinson, Nicola Strachan
APOLOGIES:	Debbie Bakkali, Mark Bagott, Karen Carnaffin, Alan Carrick, Stephanie Cole, Kath Lennon, Dorothy Lewis, Doris Ross, Jacquie Simpson, Gill Turner

ITEM	DESCRIPTION OF DISCUSSION	ACTION BY
1.	Welcome and introductions	
2.	Minutes of Previous Meeting: Lesley Cole to be added to the apologies.	
3.	<p>Matters Arising:</p> <p>Invitations to future PCPF meetings: Lynn Bryden, Senior Manager for Commissioning, to attend PCPF meeting in October to provide information on Short Breaks and NE12.</p> <p>ER and CB to invite a representative from CYPS to the next Forum meeting.</p> <p>JL to email CB feedback re a recent careers event to be shared with the Adult Learning and Careers Guidance Teams.</p> <p>HE to forward email for Michele O'Brien from Carers Northumberland to ER to invite to future Forum meeting to provide clarification re carer's assessments, etc.</p> <p>Hub referrals: More information required by parents re locality Hubs; e.g. referral pathways and difference between Hub and LIST referrals Requested that this information is put on the Local Offer. If issue not clear cut it is 'triaged' through the Hub process. Clearly defined educational issues go straight to LISTs. ER to invite Christine Wilson, Early Help coordinator to next Forum meeting to explain Hub process.</p> <p>Changes from September 2016 with how LISTs are managed. There will still be multi-disciplinary teams working in localities, but strategic managers for Communication and Language; Behaviour and ASD; and Educational Psychologists will have oversight of these areas across the whole of the county.</p> <p>SFA (Skills Funding Agency) was discussed and the impact that Brexit and devolution of North East combined authorities may have on this funding. More information may be available through the NNPCF (National Network of Parent Carer Forums). ER to send information with minutes.</p> <p>SEND Transport: Mark Cusack has requested that any transport issues in different localities are raised with him through In It Together. He will attend a future Forum meeting to provide an update and answer any questions.</p> <p>Independent Travel Training: JL provided an update around some training for volunteers to provide travel training for young people. Had attended this with some young people from Splinter Group with a view to them supporting other young people. Could run training for schools and colleges. JL to provide a summary of what they can offer with costs.</p> <p>Driving is it for you? Event run by Splinter Group had been very successful. North East Mobility Centre in Newcastle is free and offers anyone an assessment of their driving capability.</p> <p>Discussion: Disability Bus passes: linked to inability to drive. Need supporting letter</p>	<p>ER/CB</p> <p>JL</p> <p>HE</p> <p>ER</p> <p>ER</p> <p>JL</p>

	<p>from health professionals. Scooter Scheme – Disability North can provide support. The driving theory test can be an issue for some young people with SEND. Need help with the way the questions are worded. List of approved driving instructors for people with SEND is available. Issue of how young people who live in rural Northumberland can access support with driving/travel; e.g. to access employment. Can go back to Job Centre with travel plan details showing that it is not possible for them to travel to a job.</p> <p>Short Breaks/holiday activities: Feedback from some parents is that most of these were based in south east/central Northumberland (e.g. Ability to Play) with no outreach to more rural areas. Not many were suitable for children with physical disabilities. Families not aware of other activities offered; e.g. through the Youth Service. Need clear eligibility criteria for access to short breaks. The revised Short Break Statement for the Local Authority will be available for consultation in the near future. The challenges associated with providing suitable short breaks were discussed; e.g. some contracts are for under 18's only; some providers won't put events on if they don't get enough take-up. Will be a work stream for the SEND strategic group. Need a Northumberland-wide offer which takes into account the geography of the county. Equal accessibility for families in rural areas.</p>	
4.	<p>Feedback from In It Together locality meetings:</p> <p>South East Central Northumberland: Information from meeting: Brightside Children's Services is now providing an adult enabling service. EDF Energy provides grants for white goods to their account holders who meet certain criteria – more details on their website.</p> <p>National Trust educational cards can cover groups of fewer than 50 people for £39 per year – can cover SEND organisations, but must go as a group. JL offered the loan of an Alnwick Garden group card which offers entrance to any number of people at any time – card expires at the end of August 2016. Card costs £400 per year.</p> <p>Data protection: Issue re wrongly addressed letter from an NHS Service lead to discussion about data protection. Concerns expressed about county council switch to g-mail. In It Together to email Alan Carrick for assurance re security around data for families of children/young people with SEND.</p> <p>North Northumberland: Sensory assessment: Parent had waited over a year for a sensory assessment only to be told that the child needs to have a physical disability to be considered for this. Would have helped to know this from the outset. Need clearer information about referral pathways and eligibility criteria. Alison Raine from the NHS is applying for funding for a post to cover sensory issues. Issues around Sensory Profiling have been raised at a strategic level.</p> <p>Social Care support: Parents contacting mainstream social services for support – situations sometimes regarded as a safeguarding issue because of a lack of understanding by the social worker about the child's disability. It was queried whether this was a work force development issue and whether social services have a code of conduct/protocols for how they work with families. Parents of children with SEND are often under a lot of stress and need the professionals who work with them to take into account their circumstances.</p> <p>Discussion: Need to know thresholds/eligibility criteria for accessing social care services, including the Disabled Children Team. Children with SEND are more vulnerable to safeguarding risks than other children. There needs to be good channels of communication between parents and professionals with regard to support arrangements in place for children and families. In It Together's SEND Mentors can</p>	ER

provide support and information.

CB noted that it is difficult to discuss individual cases without being able to unpick all of the circumstances. There are examples of excellent practice, but a mixed picture across Northumberland. Need to speak to parents early on to make sure their views are considered and to find out what would have worked better for them. Need to have a solution-focused approach with everyone working together in the best interests of the child/young person. CB has found a willingness among professionals to make things work better; need examples of things that make a practical difference for families.

PDA (Pathological Demand Avoidance): a number of parents have contacted In It Together who feel that their children have this condition. They have been told by CYPS professionals that if they go privately to get a diagnosis they will be discharged by CYPS. PDA has been a recognised condition for 30 years. It requires a particular approach with the child and with how situations are handled with them.

Discussion: It was noted that there is a team in Sunderland which deals with this condition. CYPS looking at services in Northumberland. Main contact Kate Brundell. HE noted that parents can speak to PALS (Patient Advice and Liaison Service) if they have on-going issues with the NHS. Specific cases dealt with on an individual basis.

West Northumberland: A much better turn-out at the meeting including parents, a grandparent and a representative from Action for Blind People. Issues raised:

Diagnosis of ASD: there seems to be a reluctance to diagnose ASD especially when there are other problems; e.g. ADHD and behavioural issues. The BAIT (Behavioural Assessment and Intervention Team) may become involved if there is low level and high level aggression.

Support for Families: Some parents need practical support from services; something that leads to action. Families may be afraid of involving social services. They may feel that if Children's Services, rather than the Disabled Children Team, get involved there may be the potential for children to be removed from the family home. There appears to be a policy of referring parents to parenting courses rather than offering bespoke support.

Discussion: CB noted that there are different threshold levels for involvement from social care teams. Special school heads share the concerns that parents are also expressing re social care support. Marion Moon, Operations Manager, for the Disabled Children Team is meeting with representative special school head teachers to discuss this. Thresholds and pathways for access to social care support to be reviewed and shared.

It was noted that while parenting courses can be very useful for some parents, they are not the only answer. Some parents face threatening behaviour from their children. Some young people can become very aggressive and confrontational when refusing to go to school. Need to look at what things are working, where things are going wrong and what needs to be done differently. In It Together are planning some training in the autumn term which will include reluctant school attenders and after school 'melt-downs'.

NE12: Some parents have raised concerns about the NE12 process (collaboration between the 12 north east authorities) with regard to their child's details being put on a website for providers to bid for them. One parent whose daughter was moving from school to college described it as making her feel like her daughter was a 'piece of meat'. Another parent had written to Northumberland to raise concerns and was told that her correspondence had been sent to Newcastle for a response. There were also concerns about the time frame for decisions being made and places not being

	<p>confirmed in good time for the transition to college. Discussion: CB noted that in a small number of cases college places had not yet been confirmed, but that the outstanding places would be sorted by the end of the week (by 7 July). In future transition arrangements will be completed much earlier in the year with the aim to have them sorted by Christmas. Alan Carrick to give an update at the next Forum meeting. Lynne Bryden will also be at the meeting and can answer questions on NE12.</p>	AC/LB
5.	<p>SEND Local Authority Update – Claire Brown, Senior Manager, Partnerships and Resources, Education and Skills</p> <p>Updates from the SEND strategic group and feedback from the SEND Parent Carer Survey April 2016 were circulated. CB noted that it was not possible to include every single individual comment from the Survey so the document is a summary of the responses. The main areas of work going forward as a result of the feedback from this and other sources are:</p> <p>Training: a bespoke programme for Northumberland SENCOs. Discussion: The cost to schools with regard to training their SENCOs was queried and what support schools can get with meeting this cost. The national SENCO qualification costs £1500 and there are no longer government subsidies for this. Schools have a spreadsheet of where to go for training. Many of the courses are on-line and not face to face, which keeps down costs. Schools keen for their staff to access training, but need to ensure that it is effective and of a high quality.</p> <p>Dyslexia: Work streams for particular SEND themes have been set up. The group for specific learning difficulties has met - with an initial focus on dyslexia. Group members have a lot of expertise in this area. Some have perspective of working in other authorities including North Yorkshire and North Tyneside. The way that information has been presented in Northumberland may give the impression that dyslexia is not recognised by the Local Authority, but this is not the case. The group is looking at diagnostic assessments and screening tools that schools can use themselves. Services also offered through LIST teams.</p> <p>Mental health and emotional difficulties: range of representatives including parents, primary mental health workers and CYPS staff. Looking at information and guidance. Need to review and update the Local Offer.</p> <p>Preparation for adulthood: summit sessions to bring services together will be held early next academic year (2016 – 2017)</p> <p>Mental health provision: nature and impact of different services offered by the CYPS (Children and Young People’s Service) being looked at with regard to outcomes for children and young people. For example, the current appointment system and waiting times may present a risk for some vulnerable children and young people. Changes to the current system won’t happen overnight and need to look at other ways of increasing provision and support around mental health. Discussion: support for children/young people who self-harm; e.g. waiting times to access services; issues around bullying and children who are socially isolated. School Councils need to look at how they find out if children are being bullied and what they have done to tackle bullying.</p>	
6.	<p>MAG (Multi-agency Group) Autism</p> <p>Looking to gather feedback from parents about services/support for children/young people with autism to take to Commissioners. This will be through a questionnaire which will focus on what is working well for families and what could be better. The next meeting will look at the aims and focus of the group.</p>	

7.	<p>Information Sharing/AOB</p> <p>CB: The Local Authority want to co-produce with a questionnaire for parents/carers as part of the EHC Plan process to look at the experience that parents and carers have with the process and provision. This will include both new EHC needs assessments and plans and transfer reviews.</p> <p>Another aim is to also produce a questionnaire for young people; possibly adapted from one for parents/carers. HE and JL expressed interest in helping to develop this. It was suggested that Paul Kirkpatrick Participation lead from the Youth Service might also assist with this.</p>	
8.	<p>Dates of future meetings:</p> <p>Thursday 6th October 2016</p> <p>Venue: Stannington Village Hall - all meetings 10.30 – 12.30</p>	

Agenda items for next meeting: Short Breaks, NE12, Carers Assessments, Early Help Hubs, SEND update

DISTRIBUTION LIST FOR MINUTES

Robert Arkless	County Councillor and Board Member for Children's Services
Mark Bagott	Consultant Paediatrician, Specialism in Autism, MAG Autism
Debbie Bakkali	Team Manager, Children's Services, Family Support Team
Paula Batsford	Designated Medical Officer
Alison Bravey	Parent Partnership Officer, SEND Information, Advice and Support Service
Ann Brown	Operational Manager, Involvement & Service Development Team, Northumbria Healthcare NHS Foundation Trust
Claire Brown	Senior Manager, Partnerships and Resources, Education and Skills
Kate Brundle	Head of Commissioning (Mental Health)
Lynne Bryden	Senior Manager, Commissioning
Karen Carnaffin	Team Leader, Families Information Service
Alan Carrick	SEND Commissioner
Lesley Cole	Autism Northumberland
Mary Connor	Senior Manager, Early Intervention and Prevention
Helen Cowens	Parent Representative, North Northumberland
Mark Cusack	Passenger Transport Operations Manager
Helen Elliott	Healthwatch
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 ^o e
Elizabeth Johnston	Parent Representative, North Northumberland; Chair of In It Together
Michael Kelcey	Northumberland Youth Service
Sarah Lee	Participation Adviser, Contact a Family
Daljit Lally	Deputy Chief Executive, Northumberland County Council
Kath Lennon	Specialist Teacher (ASD) Locality Inclusion Support Team (LIST) South East, MAG Autism
Dorothy Lewis	Children's Centre Coordinator - Seaton Valley Children's Centre, Team Manager - Community and Learning team, Volunteer Coordinator
Julia Lyford	Splinter Group representative
Carol Macdonald	Portage Lead, Portage Service
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
Joanne Nelson	Consultant Clinical Psychologist, CYPS, MAG Autism
Michele O'Brien	Carer's Lead, Involvement & Service Development, Northumbria Healthcare NHS Foundation Trust
Joanne Parry	NHS
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
Jacque Simpson	Parent Representative, North Northumberland
Jill Stewart	Community Clinical Manager for Northumberland, CYPS (Children and Young People's Service)
Gill Turner	Consultant Paediatrician, West Northumberland
Sue Welsh	Head of Therapies, Northumbria Healthcare, NHS