

Draft Minutes of Northumberland Parent Carer Professional Forum (PCPF)

Venue: Stannington Village Hall

Date: Thursday 8 October 10.30-12.30

PRESENT:	Alison Bravey (Minutes), Karen Carnaffin, Alan Carrick, Lesley Cole (guest speaker), Mary Johnson, Kath Lennon, Elizabeth Richardson (Chair), Eileen Robinson, Doris Ross, Nicola Strachan
APOLOGIES:	Mark Bagott, Debbie Bakkali, Ann Brown, Michael Kelcey, Helen Cowens, Helen Elliott, Jean Hedley, Ann Jolley, Julia Lyford, Marian Moon, Amanda Richardson, Ben Sanderson, Jacquie Simpson, Gill Turner,

ITEM	DESCRIPTION OF DISCUSSION	ACTION BY
1.	<p>Welcome and introductions</p> <p>Alan Carrick was welcomed to the meeting. Alan commented that he had been impressed by the breadth and detail of items covered by the Forum when reading the minutes.</p>	
2.	<p>Minutes of Previous Meeting: The minutes of the previous meeting were agreed.</p> <p>Matters Arising (not covered by the agenda)</p> <ul style="list-style-type: none"> • Childcare suitable for disabled children: continues to be an issue – item to be carried forward to future Forum meetings to ‘keep it on the radar’. • The A-Z of pre-school services for children with disabilities: link to be put on In It Together website – still awaiting final version. • Parent Carer Forums – funding 2016-2017: No decision to be made until after spending review in November. It is expected that funding will continue, but may not be at the same level per annum (currently £15,000). Roles within Contact a Family (who support the Forums) have been re-jigged. • Membership of the Parent Carer Professional Forum: discussion around the core membership of the Forum. Need to ensure broad representation of services and parent/carers, while keeping membership at a manageable level. Guest speakers can be invited to specific meetings to update the Forum on their roles/the service they provide. • Query from Gill Turner re cuts in adult services: need to clarify which services Gill is referring to. Need to know the criteria/threshold levels for access to different services. • Explanation of FE (Further Education) funding: exercise undertaken by Local Authorities to account to Education Funding Agency. Covers 16 – 18 year olds and 19 -25 year olds. High needs/i.e. not low or moderate. Information from each Local Authority published as a summary. • Low and middle level SEN: school staff and SENCO cater for a child/young person’s needs within the school’s SEND funding. Young person can stay in education as long as they like - college gets funding directly from the government. • High level needs – ‘Raising the Participation Age’: school age covers until 16 and from 16 – 18 years a young person needs to be in Education, Employment or Training. It is illegal for them to be NEET (Not in Education, Employment or Training). Young person can be prosecuted. Stops in the year the young person turns 18, but can roll over to 19. Local Authority not making enough provision. 	<p>Elizabeth Richardson</p>

The SEND Code makes this a bit misleading and raised expectations re provision up the age of **25** years. SEND Funding is all about preparing the young person for adulthood. Two chapters in the SEND Code are dedicated to explaining Further Education and Preparing for Adulthood from the earliest years. The Skills Funding Agency provides funding once the young person becomes an adult except for those with EHCPs (Education, Health and Care Plans). Focus on what do from 13 – 16, 17 or 18 years in preparing for adulthood. Need evidence of progression to take the young person forward to adulthood and next steps for their life. May be exceptions with regard to funding; e.g. for young people who have missed a lot of education due to illness and not had the opportunities that others have had because of medical needs.

- **Makaton training** – contact with Shona Chambers from Cerebra. Makaton training in south east. Training is free, but the accompanying book costs £27.
- **Splinter Group: From the Horse's Mouth conference** – looking for support for Kirsty Trimming who is running a workshop covering ASD (Autistic Spectrum Disorder). Kath Lennon is not available, but is looking at capacity within the LIST (Locality Inclusion Support Team) to see if anyone else is available. The driving event was cancelled because the firm providing the driving simulator has gone into liquidation. The event will be rescheduled for February or March 2016. The importance of young people learning to drive, where they are able to acquire this skill, was emphasised in terms of employment and social/leisure opportunities.
- **Dyslexia/dyspraxia referral system.** The following response had been received from Gill Turner, Community Paediatrician:
'Assessments and services for dyspraxia and dyslexia are quite different, so it's useful for people not to think of the two together. Dyspraxia (proper name Developmental Co-ordination Disorder DCD) is assessed by Occupational Therapists and Physiotherapists, but the actual diagnosis needs to go through a paediatrician to ensure nothing else neurological is being missed. Dyslexia is never diagnosed by "health". Educational Psychologists in Northumberland do not tend to use this label and therefore parents often find themselves paying for private assessments. However I'm never sure how education responds to a private report. It would be good to get clarity from both schools, LIST and the SEN team about which reports they find helpful and which they simply ignore. In the new EHCP system it would be great for parents and professionals to have guidance about what is the best route for assessing CYP presenting with literacy learning issues.'

Discussion: The Local Authority is looking to provide a series of quick guides for parent which contain helpful information, what makes a difference and where parents can go for further information and support; these could include dyslexia, which is covered in the SEND Code of Practice under the category 'Cognition and Learning'. It was noted that there is no specific dyslexia category in the census that is sent to schools 3 – 4 times a year. It is covered by the category 'specific learning difficulty' which would include specific literacy difficulties. Provision would usually be through SEN Support in school, with input from the LIST teams, and the school's SEND funding. Access to SEN provision should be based on the needs of the child and this does not require a diagnosis of dyslexia. The same would apply to children with social and/or communication needs.

Need an early assessment of specific learning difficulties and support through the model: **Assess – Plan – Do – Review**. The LISTs can screen for dyslexia at a basic level and some Northumberland high schools can also do this. More detailed assessment and formal diagnosis have a cost in money and time; i.e. private assessments. It was emphasised that it is the **need** and not the label that is the important factor. Any identified needs should be met through appropriate support.

<p>3.</p>	<p>Feedback from In It Together locality meetings:</p> <p>West Northumberland – Eileen Robinson: Quite low attendance at the last few meetings. Looking at reaching more parents; e.g. by linking in with parents from Priory School. Proposal to move the meeting to Hexham. The parents identified a training need around ‘puberty and growing up’. A previous training event (trainer: Lynn Moxon) was described as ‘invaluable’. It was felt that it was never too early to start preparing a child for adolescence and adulthood.</p> <p>Alan Carrick had requested parental involvement in the following areas:</p> <ul style="list-style-type: none"> • Meeting the Department for Education with him for their next update conversation; • Reviewing other Local Authority Local Offer websites, to identify good information/practice; • To be part of an ‘editing group’ to check new SEND guidance documents the Local Authority has written and make sure they are clear and helpful; • Parents with particular SEND interests – such as autism or hearing impairment or physical disability – to look at new ideas for Northumberland and to reach out to other parents who are harder to reach. <p>The response to Alan’s request was that the parents are willing to become involved but want to know the impact of their involvement; e.g. through meaningful feedback communicated to them. Parents should not be out of pocket for agreeing to participate. They need to be paid travel expenses, or alternatively documents could be sent to them electronically for feedback and comments. Most parents have lots of other commitments and their children’s needs must come first.</p> <p>Discussion: Alan agreed that expenses could be paid when events involved work/feedback for the council, but not for information sharing events.</p> <p>South East/Central Northumberland – Elizabeth Richardson on behalf of Amanda Richardson: A CYPS (Children and Young People’s Service – mental health) representative attended the meeting. It was reported that the service provided by CYPS has improved and the waiting times have been greatly reduced. There was interest in getting involved with providing feedback and information re Alan Carrick’s request. A grandparent who attends the meeting also works for Health Watch and provides regular updates.</p> <p>North Northumberland – Elizabeth Richardson: Alan Carrick had attended the meeting to outline how he would like to involve parents/carers. Some parents present at the meeting were willing to be part of editorial groups for reviewing documents, providing feedback, etc.</p> <p>Transition – the lack of provision/opportunities in north of the county for Post-16 and Post-18, even with an EHCP, continues to be an issue. Even if needs are identified there is not the provision to meet those needs close to where the young person lives. There seems to be a group of young people, who don’t need to be in the Berwick special school (the Grove), but who are not managing in mainstream provision.</p>	
<p>4.</p>	<p>Alan Carrick, SEND Commissioner – update</p> <p>The new national OFSTED inspection process for Local Authorities will start from May 2016. Want to involve parents/carers in reviewing progress with the SEND Reforms, the Northumberland Local Offer and the documents relating to the EHCP (Education, Health and Care Plan) process.</p>	

	<p>Need to make sure information and practice conforms to the law. Need representative groups and voices: children, young people, their families and schools to provide feedback on whether information/services are accessible and effective to ensure that the Local Authority and NHS provide the right service information and support. Need to get up to date and relevant information out to schools and families. Want to publish what is happening in Northumberland on the Local Offer website.</p> <p>Northumberland needs to have an SEND Strategy that contains data and facts about what is happening, as well parental comments about impact. May require a different response to SEND issues in different localities. The SEND data provides a pattern of what has been happening from 2010 to 2015 for children and young people, but there is not a lot of adult data. Data collated and used as an indicator to predict what may happen in the future – used to plan services.</p> <p>Discussion: How many EHCPs have been completed in Northumberland? Alan to check exact figures (he approximated 50 – 60 Plans). Checks are done monthly. The annual target for the next two years is 600 – 700 Plans per year. Progress with transferring Statements of SEN into EHCPs had been delayed because of staffing levels. If the SEND Team had been fully staffed from the outset of the reforms the process would have been much further forward by now. Two new members of staff started with the SEND Team on Monday 5 October and all posts were now filled.</p> <p>How many requests for an EHC needs assessment had been refused and how many assessments had not gone ahead to Plans? Alan will check figures – mentioned that it is rare for Plans to be turned down.</p> <p>What are the criteria to get a plan for a child in school? Would look at how a child/young person is progressing and whether they meet the threshold for high needs funding; i.e. when the resources normally available to a school are not sufficient to meet a child’s special educational needs. Funding is divided into Element 1 and Element 2 funding (this equates to approximately £10,000) that a school/college would already have in their budget and Element 3, or higher needs funding, that is held by the Local Authority for children/young people with the highest levels of need. Would need to look at whether a Plan would be of benefit – it is a legal document. Evidence-based process, looks at which services, including LIST (Locality Inclusion Support Team) have provided support and advice. How do the child/young person’s special educational needs affect their ability to learn? Schools can apply for higher needs funding (also known as top-up funding) – a two week process meaning that funding can be accessed much faster than through the EHCP process which takes up to 20 weeks. The bar for an EHCP is set high, and may seem a very bureaucratic process, because it should only be the pupils with the highest level of need who require a plan. Need to keep an eye on whether children’s needs continue to be met as they progress through the education system. Educational settings should have arrangements in place for facilitating a child/young person’s transition through the different phases of their education.</p>	
5.	<p>Autism Northumberland – Lesley Cole</p> <p>Lesley outlined the work of the Autism Northumberland and distributed information leaflets. The charity was set up as a result of her own experience of the lack of support available to parents once their child had been diagnosed with Autism/ASD. Some services were really good; e.g. Portage for pre-school children, but others could not offer support post-diagnosis. The charity has grown from starting as a parents group in October 2014 to having a parents-only group on Facebook and a centre at Manor Walks, Cramlington.</p>	

	<p>The charity provides training for parents on DLA (Disability Living Allowance), Makaton, EHCPs and interventions (including PECS); guest speakers; communication/social skills provision for children/young people, including Saturday and Sunday clubs, Circus skills and Theatre. Provides help for sensory needs, including Lego therapy, Wii's, and i-pads, and fine motor skills, including eating. Help parents who struggle to play with their child with encouraging play and other skills. Developing a football club tailored for the children's needs, and brownies, guides and scout groups. Have an after-school club and also cater for the siblings of children with autism. A girl's group (10 – 13 years) has been set up to encourage friendships and develop social skills. Looking to set up something similar for teenagers (13 – 19 years). Want to cater for the whole family. Events are also held during the holidays. A child doesn't need a diagnosis to be able to access Autism Northumberland events and provision. There is no cost or membership fee, but the charity asks for voluntary donations. Have 300 members from all over Northumberland. Sign up for events is on a 'first-come, first served' basis. Parents group meets every four weeks on a Thursday evening – anyone is welcome to go along to the centre to have a look around. Details of events are advertised on Facebook and e-mailed out to members. Have applied for funding for paid positions within the charity.</p> <p>Discussion: It was queried how the charity differs from the Toby Henderson Trust. Toby Henderson Trust employs an occupational therapist and can also offer support for adults with autism and their families</p>							
6.	<p>MAG (Multi-Agency Group) Autism: feedback Discussion about the future viability of the MAG Autism was deferred until the next Forum meeting when Dr Mark Bagott will be present.</p>							
7.	<p>Information Sharing/AOB</p> <p>SEND Mentor project - Elizabeth Richardson: trained SEND mentors can meet with parents/carers to offer information and support around the SEND 'system'. For further details contact Elizabeth Richardson on 07729192909.</p> <p>Daslne – Mary Johnson: very successful conference attended by 90 families – speaker Dean Beadle (who has Asperger's Syndrome) and workshops. Covered helping teachers with supporting children with ASD in mainstream education, helping children with ASD to make sense of their world, sleep and improving sleep patterns, and social skills. The Daslne Facebook page was mentioned.</p> <p>Disabled Children Team – Doris Ross: Sharon Willey has retired and Marian Moon now line manages the team. Awaiting report setting out how the Disabled Children Team will look in the future.</p> <p>LIST: Kath Lennon: data analysis showed an increase of children with ASD and speech and language difficulties at infant level. Process of preparing the children for transition to school begins at Easter through to the summer. Early Year's 'Talk Boost' used. LIST work with pilot schools using Autism Education Standards Trust materials to raise awareness through accredited training. Autism Awareness Training offered to five schools to build capacity of staff and inform good teaching practice. Resources available on-line with option of gaining accreditation. Mixed response: two schools not interested, but the other three very enthusiastic. It was noted that there is a lot of pressure on schools to provide data/grades and for some schools the training is not a priority. Benefits are that teaching strategies for autistic children work for any child.</p>							
8.	<p>Dates of future meetings:</p> <table data-bbox="165 1850 903 1951"> <tr> <td>Thursday 8th October 2015</td> <td>Thursday 5th May 2016</td> </tr> <tr> <td>Thursday 3rd December 2015</td> <td>Thursday 7th July 2016</td> </tr> <tr> <td>Thursday 4th February 2016</td> <td>Thursday 6th October 2016</td> </tr> </table> <p>Venue: Stannington Village Hall - all meetings 10.30 – 12.30</p> <p>❖ (Pre-meeting for MAG Autism Group members from 10.00 – 10.30)</p>	Thursday 8th October 2015	Thursday 5th May 2016	Thursday 3rd December 2015	Thursday 7th July 2016	Thursday 4th February 2016	Thursday 6th October 2016	
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DISTRIBUTION LIST FOR MINUTES

Robert Arckless	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
Alison Bravey	Parent Partnership Officer
Ann Brown	Operational Manager, Involvement & Service Development Team, Northumbria Healthcare NHS Foundation Trust
Siobhan Brown	Clinical Commissioning Group
Lynne Bryden	Senior Manager, Commissioning
Karen Carnaffin	Team Leader, Families Information Service
Alan Carrick	SEND Commissioner
Mary Connor	Senior Manager, Early Intervention and Prevention
Mark Cusack	Passenger Transport Operations Manager
Helen Elliott	Healthwatch representative
Jean Hedley	Blyth Valley Children's Centre Locality Manager
Ann Jolley	SEN Lead Officer
Andrew Johnson	Director of Education and Skills
Mary Johnson	Co-ordinator of Dasl ^o e
Michael Kelcey	Northumberland Youth Service
Sarah Lee	Participation Adviser, Contact a Family
Daljit Lally	Executive Director, Wellbeing and Community Health
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
Carol Macdonald	Portage Lead, Portage Service
Janet Millington	Clinical Lead, Speech and Language Therapy, MAG Autism
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
Amanda Richardson	Parent Representative, Central/South East Northumberland
Elizabeth Richardson	Parent Representative, North Northumberland
Eileen Robinson	Parent Representative, West Northumberland
Doris Ross	Team Manager, Disabled Children Team
Joy Rutter	Parent Representative, Central/South East Northumberland
Ben Sanderson	Youth Participation Worker, Northumberland Youth Service
Jacque Simpson	Parent Representative, North Northumberland
Katharine Taylor	Clinical Managers, Children and Families, Northumbria Healthcare Trust
Carys Thomas	Parent Representative, MAG Autism group
Gill Turner	Consultant Paediatrician, West Northumberland
Judith Turner	Community Clinical Manager for Northumberland, CYPS (Children and Young People's Service)
Sue Welsh	Head of Therapies, Northumbria Healthcare, NHS