

# Minutes of Northumberland Parent Carer Professional Forum (PCPF)

Venue: Stannington Village Hall

Date: Friday 10 July 10.30-12.30

<b>PRESENT:</b>	Debbie Bakkali, Alison Bravey (Minutes), Karen Carnaffin, Helen Cowens, Helen Elliott (guest speaker, Healthwatch), Jean Hedley, Alison Hodges, Sarah Lee (guest speaker, Contact a Family), Kath Lennon, Julia Lyford, Janet Millington, Amanda Richardson, Elizabeth Richardson (Chair), Eileen Robinson, Doris Ross, Emma Shield, Jacque Simpson
<b>APOLOGIES:</b>	Mark Bagott, Ann Brown, Ann Jolley, Joy Rutter, Gill Turner,

ITEM	DESCRIPTION OF DISCUSSION	ACTION BY
1.	<b>Welcome and introductions</b>	
2.	<p><b>Minutes of Last Meeting:</b> The minutes of the previous meeting were agreed. It was noted that the meeting scheduled for 8 May 2015 had been cancelled because of the high number of apologies.</p> <p><b>Matters Arising</b> (not covered by the agenda)</p> <ul style="list-style-type: none"> <li>• <b>Childcare suitable for disabled children:</b> continues to be an issue – item to be carried forward to future Forum meetings.</li> <li>• <b>The A-Z of pre-school services for children with disabilities</b> has been updated and will be reprinted. Distributed through Children’s Centres, Health Visitors, etc. Link to be put on In It Together website.</li> <li>• <b>Short breaks:</b> as part of the Family Support Team evaluation of the current Play &amp; Activity short break opportunities across the county, a gap analysis exercise shall be carried out to look at where there are any potential gaps in services. Parent representation – need to involve parents to see where there are gaps in service delivery. Part of the funding for short breaks for children with disabilities is through the Play and Activity Scheme budget. It was noted that there were no cuts to the budget last year and that Northumberland County Council has continued to provide funding to support the previously funded Aiming High for Disabled Children programme. The only exception is that families no longer have access to log cabins through the Calvert Trust and caravans at Haggerston Castle.</li> </ul>	<b>Elizabeth Richardson</b>
3.	<p><b>Feedback from In It Together locality meetings:</b></p> <p><b>West Northumberland – Eileen Robinson:</b></p> <ul style="list-style-type: none"> <li>• The meeting focused on the Local Offer and getting feedback from parents/carers about how easy the website is to access and any gaps. The need for accurate information on the website was flagged up with the onus on the services and organisations registered on the Local Offer to ensure that it is accurate and kept up to date. E-mail prompts will be sent to remind them.</li> </ul> <p><b>South East/Central Northumberland – Amanda Richardson:</b></p> <ul style="list-style-type: none"> <li>• <b>Guest speakers:</b> A future aim for this meeting is to get speakers from different services to come to talk about what they do and answer questions.</li> <li>• <b>Dyslexia/dyspraxia diagnosis</b> – it was queried why parents have to pay to get a diagnosis for these conditions and why schools do not receive more training for working with children with dyslexia and dyspraxia.</li> </ul>	

**Discussion:** The position with the county council with regard to dyslexia is that it is regarded as a literacy difficulty and is covered by the specialist literacy staff from the LISTs (Locality Inclusion Support Teams). There is one literacy support teacher and one literacy support assistant per locality team. Access to this provision is through a referral to LIST – through the hubs for pupils in central and south east Northumberland, and directly from schools for pupils in north and west Northumberland. LIST staff use recognised assessments. It was queried what support would be available for young people who had left school (18 – 30 year olds). Support is available through colleges and community projects. Kath to check about this and feedback at next forum meeting.

**Kath Lennon**

Dyspraxia assessments are made through physiotherapy and occupational therapy services. An update will be sought on what is happening re dyspraxia assessments. Alison Bravey to check with Gill Turner.

**Alison Bravey**

- **CYPS staff changing or going on long term sick** – it was queried why someone else doesn't take over. Who can parents turn to after hours? Parents often don't know where to turn when they need timely help and support.

**Discussion:** Had been expecting someone from CYPS to attend the Forum meeting to answer questions on the service. Representatives from In It Together had met with Judith Turner from CYPS and the discussions indicate that the service is moving in a more positive direction. Waiting times are down from 18 months to 6 weeks for new referrals - the Choice (initial) appointment. Treatment appointment within 12 weeks for new referrals. It is first time for a significant period of time that CYPS has been fully staffed. Where children/young people have been on the waiting list for a long time parents are often advised to ask for a re-referral because it will be a quicker process. **NB: CYPS have confirmed this is not the case.**

- **Bullying:** Amanda mentioned a leaflet she had picked up at the RVI (Royal Victoria Infirmary) which covers the bullying of young people with additional needs. It includes tips for young person about dealing with bullying and gives useful websites.

**Discussion:** An App called Toot Toot was mentioned: <https://tootoot.co.uk/>. Its aim is to help children and young people to report bullying. The bullying of people with disabilities is covered by the Equalities Act under harassment and can also be regarded as a hate crime. Schools are required to have anti-bullying policies in place and publish their policy on the school website. Parents report that how schools deal with bullying issues can be quite variable. More information can be found on the Equality and Diversity webpage of the Local Authority website. A hate crime conference is taking place at County Hall on July 23 to raise awareness of the issue. A new phone App will be available to allow people to report hate crimes anonymously to the police.

- **Brightside Youth Service** – Ashington provision threatened with closure, because of issues around the availability of the venue, but the Saturday Club now able to continue.

**Discussion:** Brightside provided a Saturday Club and holiday provision in Ashington. The building used is leased by NCC (Northumberland County Council). Needed by Social Care services for family contacts and child protection conferences at times that clashed with Brightside provision. NCC wanted to support its continuation and suggested a number of potential other venues, but nowhere suitable could be identified by the provider. A compromise has been reached where Brightside can still use the building on Saturday at a different time and were also offered it on a Monday to cover the school holidays. Brightside have decided to continue with their Saturday provision, but not with their holiday provision.

## North Northumberland – Elizabeth Richardson:

- **Local Offer website** – well attended meeting. Local Offer – good feedback obtained, including about whether parents had heard about the website, where they had heard about it and whether they had used it.
- **Post-16 Provision** – LDAs (Learning Difficulties Assessments) – question about whether all LDAs will be converted to EHCPs. Availability of Education Post-19 to 20 year olds. It was queried how progression in college is measured – tend to look at movement through the levels of learning. Focus is on employability. 19/20/21 year olds may be targeted for being put on the Work Programme. May need support to get ESA (Employment and Support Allowance). Need to know where they sit within the benefits system and educational system. College or apprenticeship route. Young people may undergo repeat assessments of their basic skills (literacy and numeracy tests) by the time they reach their early 20s. A high percentage of young people with learning difficulties are told that they are not eligible for apprenticeships because their levels of literacy and numeracy are not high enough to get into an apprenticeship. ‘Mainstream’ diagnostic tests are used on those with specific learning difficulties and may not take into account their areas of strength. The apprenticeship route is quite a good one, but it may be best for some young people to not go down the route of a full apprenticeship because it may affect the benefits that they are entitled to.

Up in the North there is minimal provision. Border Links Community enterprise offers opportunities to support social and economic inclusion for people with learning disabilities. Dilston College has outreach in Berwick, but there can be problems when staff are off sick. Parents asked to keep their young person at home because nothing alternative can be provided for them. Northumbria Health Care Trust offer posts/apprenticeships matched to a young person’s learning needs. Looking to expand their working mentor scheme. Take on apprentices two times a year with the aim for all young people to get their choice of training opportunities. The mantra is “Grow our own” – want to get local young people on-board from an early age to ensure good progress into the future. Two levels of training offered: NTAC (Northumberland Trust Access Service) and Entry Level to Masters. Looking at changing job specifications and tailoring jobs to suit individuals.

Provision at Kirkley College was mentioned. Jay Casson has been doing a feasibility study for young people with complex learning needs, with a view to developing new provision there. Talent Match North East which had an £8 million fund was mentioned and that very little of this funding came to Northumberland. Not enough provision funded through Talent Match on a small group or 1-1 basis. Need providers of training, apprenticeship and employment opportunities to come together to look at how to be more creative with regard to the pool of provision for young people with SEND. Parents and young people need information about what is out there. Would be good to organise something around 18 – 25 provision and progression.

**Transitions to middle and high school.** Sometime a lack of information provided by the previous school about child’s needs. One parent reported that no information had been provided to the next school and this had affected the provision the child received. Mainstream school referral to CYPS hadn’t been done and the child became a non-attender. Problem created by move to two tier system in Ashington alongside the new build of the secondary provision. Rather than stagger the transitions, three year groups will be moving at the same time. Staff are acutely aware of the implications for children with additional needs. A three week summer school has been organised for children who need lots of support and preparation for the transition.

<p>4.</p>	<p><b>MAG (Multi-Agency Group) – Autism: feedback</b></p> <p><b>Future viability of the Group</b></p> <p><b>Discussion:</b> It is felt that the group has lost momentum since Carys Thomas (parent Chair), who was a driving force, has moved on because of other commitments. Dr Mark Bagott (community paediatrician), another key player, is also not currently available because he is covering for a colleague. It was queried whether the group should continue. Prior to the arrangement for meeting before the Parent Carer Forum, it had been felt that the group had lost its strategic influence and that there needed to be some mechanism for feeding information and issues raised at a strategic level. The group had become part of the wider Parent Carer Professional Forum to make it more efficient and effective, but recent meetings of the MAG Autism have been poorly attended.</p> <p>It was noted that the group is part of a huge wider group, not just locally, but nationally, at a time of massive change. It looks at the different issues that children with ASD might have; e.g. with school attendance, and provides a two way dialogue for parents and professionals. It was felt the group was very useful. It was identified in NICE (National Institute of Clinical Excellence) that every local authority should have an Autism MAG which feeds into commissioning processes. It was queried whether there was still a strategic autism group in the Local Authority and whether there was a group for children and young people. Need to find out if these groups still exist. Provision for children/young people on the Autistic Spectrum needs to be a priority. The frequency of referrals for provision is highest for pupils with ASD, then Speech and Language difficulties, emotional social and mental health issues, and then general learning difficulties. Alan Carrick, SEND Commissioner to be asked for his views on who should lead on the MAG Autism group.</p>	<p><b>Alison Bravey</b></p>
<p>5.</p>	<p><b>Parent Participation – Sarah Lee, Contact A Family Participation Adviser</b></p> <p>Sarah covers North East England and North West London. She circulated a series of hand-outs on participation, explained her remit and asked Forum members to consider where Northumberland was with regard to the participation ladder. There are 151 Parent Carer Forums throughout England which were initially funded through the Aiming High for Disabled Children programme. The government has continued to fund Forums. The grant started off at £10,000 per year and is now £15,000. Participation is all about building partnerships between parents and the services they use. Parents should be involved from the start with planning for the design and delivery of services. Services should fit comfortably with the needs of families; if they don't fit right this can lead to problems. The usual model is of a team of parent representatives meeting with key commissioners and directors. Mentioned good practice in other areas; e.g. at the beginning of each school year, North Yorkshire has what is known as a Big Calendar planning group involving parents and professionals. Forums from different areas may be run differently. Can be constituted groups and just operate as a voice for parents or can also run services. There are different ways for parents to have a voice and some parents want to be more involved than others. Social media has led to a culture change for communication. Some parents have limited availability during the day because of work and childcare commitments. Some support groups seem to have fallen by the wayside as a result.</p> <p>How do we change things in the direction that parents are asking for, especially in times of austerity? Need to grow networks. Parent Carer Forums need to get a foot in door with regard to working with the commissioners of services. Participation will be a key focus for OFSTED who will be inspecting Local Authorities from January 2015. DfE (Department for Education) SEND (Special Educational Needs and Disability) surveys are sent to the Local Authority and Parent Carer Forums for each area to gather their views on progress with the SEND Reforms. Particular issues are logged.</p>	

	<p><b>Discussion:</b> It was noted that Forums are constantly growing and developing. In It Together currently has 253 members, but numbers can fluctuate. Parent carer views are picked up at meetings and events as well as via e-mail and social media. When husband and wife both fill in the forms you get two views. Dads can have very different views about services compared with mums.</p> <p>It was felt that practice re participation varies from service to service and from situation to situation. There are some good examples of co-production, but also tokenism where parents are listened to, but the professionals then tell them how services will be run or where parents are consulted, but nothing changes as a result of their feedback. Sometimes resources can be targeted at particular areas of need for a period of time, but then withdrawn, leaving parents without a provision they really valued. Austerity measures within Local Authorities mean that this is becoming more and more the case.</p>	
6.	<p><b>Healthwatch – Helen Elliott</b>  Looking for feedback about health and social care services from children and young people up to 25 years and their parents. Health Watch is an independent organisation that feeds back to health commissioners. Also deal with complaints about health services – have a team of advocates. Accessibility project, providing large print and easy read materials for people with sensory impairments and physical and/or learning difficulties. Deadline for feedback from a questionnaire is the end of August. Helen to send the information again; also on the Healthwatch website at <a href="http://www.healthwatchnorthumberland.co.uk">www.healthwatchnorthumberland.co.uk</a></p>	Helen Elliott
7.	<p><b>Emma Shields – Health Improvement Practitioner specialising in supporting the involvement of young people in service evaluation and development</b></p> <p>Emma has been in post for nine weeks, but there was a nine month gap from the previous post holder. She is involved in service delivery for long term service users. Her role is about building relationships and providing a voice for the young people she works with. Service leaflets are in the process of being changed using feedback obtained from young people. The service operates the “You’re Welcome” process and is about young people identifying the health care that is appropriate for them. It has eight verifiers who are all young people who use health services. They access health settings to make sure that they are suitable. The verifiers look at particular areas; such as how they are invited in, how they are treated while they are there and whether they are asked questions that are appropriate for their needs. Emma is also looking to set up a participation group to gather young people’s views.</p> <p><b>Discussion:</b> It was queried whether the REC ‘Respect Equals Change’ Forum for young people with disabilities could be involved: contact person Ben Sanderson. The equivalent group for Looked After Children is called ‘Young Voices Making Choices’. Hospital passports were also mentioned. The service is about meeting the health needs of every individual, with everyone’s participation, from birth to end of life care. Work being done by the Splinter Group was mentioned and whether the hospital passport could fit in with an ‘employability’ passport. The Youth Participation Strategy multi-agency group, organised by Elaine O’Connor and Mike Kelcey, seems to have lapsed because Elaine has left the Local Authority. It was noted that much depends on the longevity of employment of professionals involved with particular pieces of work.</p>	
7.	<p><b>Information Sharing/AOB</b></p> <p><b>Gill Turner</b> had asked for the following items to be raised in her absence:</p> <p><b>The implications of cuts in adult services:</b> there was no one at the Forum meeting who was able to comment so this item will be carried over to the next meeting, which hopefully Alan Carrick will be able to attend.</p>	

**An update on the EHCP (Education, Health and Care Plan) implementation:**

**Discussion:** This area of work is being looked at strategically – the difficulty with meeting EHCP deadlines was that there were not sufficient resources and staffing for the work. The emphasis in recent months has been on streamlining systems, including paperwork, and employing more staff. The process of applying for top-up funding is to be linked into the paperwork for the EHC needs assessment application process.

**Kath Lennon:** mentioned the support that LISTs provide into schools. The Cygnet training for parents of children with ASD has been very successful. The training was developed by Barnardos, who are the overseeing body. They have allowed the age range for the training to be dropped from age 7 – 16 to age 5 – 16. LISTs provide support to families and schools who have requested input because of gaps in their understanding. One common issue is when a child's behaviour related to their ASD is not a problem in school, but is a big problem at home. Need to raise understanding with schools. Training programmes for SENCos, teachers and teaching assistants to be rolled out to schools.

The Educational Psychologists in the LISTs have been snowed under with the paperwork for providing advice for EHC needs assessments. The summer school break will provide an opportunity to catch up with the backlog.

**Janet Millington:** The Speech and Language Therapy specialist service is now fully staffed. Provides a service for pre-school children with special educational needs and for special schools. Case loads are increasing all the time; currently 100 cases for each member of staff where it was previously 80. The service covers four days per week and staff have to do their best with the resources they have.

The types of provision the service offers includes a 'Sign sharing' group, using a simple signing system for children with learning disabilities and Makaton training into some of the special schools (The Dales, Priory and Barndale) – rolling programme and refresher. It was mentioned that Shona Chambers from Cerebra also provides Makaton training that is free for parents (they just have to buy the training manual). There is a charge for professionals. In It Together are planning to organise a Makaton training event.

**Jean Hedley:** Children's Centres for pre-school aged children. Hub meetings in central and south east Northumberland where the needs of children and their families are discussed. The aim is provide wider family support for a child's education, care and childcare needs. Children's Centres in each locality have specialist services and groups to support families of children with particular needs, e.g. Downs Syndrome.

In the south east, Blyth Valley area, there is a weekly support group for parents of children with ASD. The first part of the meeting is for the parents and children together. They do activities so that the parents can see the progress the child is making; e.g. through the use of journals and memory activities. Friendships develop within the groups and this provides peer support for parents.

Colgate Cottage at Blyth West Childrens Centre is a facility that can be used by children and their families, and by professionals for appointments with children; e.g. is used for some physiotherapy appointments and by Portage, health professionals and other agencies. The aim is for an open door, inclusive service and to engage children. The Pre-school Advisory Panel was also mentioned. Looks at the numbers of children and emerging needs across whole of Northumberland to ensure that services reach the vast majority of children who need special provision.

**Amanda Richardson:** mentioned The Jonas Centre in Leyburn, North Yorkshire a facility which offers self-catering accommodation and caters for a wide variety of needs. More information at [www.jonascentre.org](http://www.jonascentre.org)

**Elizabeth  
Richardson**

	<p><b>Doris Ross:</b> Sharon Willey who line manages the Disabled Children Team is due to retire. Sharon is currently working on a report on services for disabled children and will come back part time to complete this. The report will go out for consultation once firmer decisions are made about what statutory social work services should look like.</p> <p><b>Discussion:</b> An issue is that some mainstream social workers are unaware of different services for children with disabilities. When they are not sure they should be seeking further advice, including from the Disabled Children Team. Doris will raise this issue with social care managers.</p> <p><b>Debbie Bakkali:</b> Holiday play schemes; a number of holiday Play &amp; Activity Schemes across the county are funded by the Local Authority e.g. Active Northumberland – open access archery and football, inclusive activities for all children. It was noted that you don't need to have a social work referral for Alnwick Garden Youth Group anymore; the Local Authority buys a number of places which are offered to children known to the service with the remaining places being accessible to families. The aim is to provide sustainable, universal, inclusive services that families can access readily.</p> <p>Blyth Valley Disabled Forum, Cramlington Voluntary Youth, Hexham Youth Initiative, Alnwick Garden and Wecan all offer a varied programme of activities. Information sent out to social care teams and is on the Local Offer website. Summer programme: Active Northumberland and Ability 2 Play are running activities in various locations across Northumberland, including Berwick, Alnwick, Blyth, Cramlington and Hexham.</p> <p><b>Discussion:</b> It was noted that most activities are in central and south east Northumberland and that more are needed in the north and west of the county. Another issue is that parents of children with special needs have to stay with their children during the activities whereas other parents don't have to.</p> <p><b>Julia Lyford:</b> outlined the work of the Splinter Group which covers young people from 18 to 30 years of age and is funded by a grant from 'Awards for All'. Will be running a conference for parents and carers '<b>From the Horse's Mouth</b>' on 17 November at Choppington Welfare for to provide information on different syndromes and learning difficulties. Will include interactive workshops run by young adults with learning differences, supported by key support agencies; bite-sized awareness-raising.</p> <p>The group also does work on awareness-raising with employers. One issue that has been identified is that when young people are assessed briefly by a care manager, they may end up with a package of support that is not appropriate for them. Need to break down the barriers through user-led input into services.</p> <p>Event on 14 October "<b>Driving – is it for me?</b>" at Storey Park Community Centre in Morpeth. Includes a full car simulator for the young people to use, a driver assessor present to answer questions, what to expect from the theory test, etc. By the end of the session, the young person will more aware of whether driving is or isn't appropriate for them and will be supported with next steps.</p> <p>Also have a residential event planned for Centre Parcs - 3 days in October.</p> <p><b>Alison Bravey:</b> distributed a pack of leaflets covering different aspects of the SEND reforms, independent support for parents and young people. The packs have been sent to all school SENCos and will be distributed to other relevant professionals.</p> <p><b>Elizabeth Richardson:</b> circulated flyers for the In It Together SEND Mentor project. The mentors are trained to provide information and support for parents and carers of children and young people with SEND.</p>	<p><b>Doris Ross</b></p>
<p>8.</p>	<p><b>Dates of future meetings:</b>  Thursday 1st October 2015      Thursday 3rd December 2015</p> <p><b>Venue:</b> Stannington Village Hall - all meetings 10.30 – 12.30</p> <p>❖ <b>(Pre-meeting for MAG Autism Group members from 10.00 – 10.30)</b></p>	

## 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 <sup>o</sup> 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
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
Sharon Willey	Northumberland Healthcare, NHS