

# Minutes of Northumberland Parent Carer Professional Forum (PCPF)

Venue: Stannington Village Hall

Date: Thursday 4 December 2014 10.30-13.00

<b>PRESENT:</b>	Judith Arundel (guest speaker, Healthwatch), Alison Bravey (Minutes), Mark Bagott, Debbie Bakkali, Karen Carnaffin, Louise Dawson, Helen Elliott (guest speaker, Healthwatch), Michael Kelcey, Helen King, Kath Lennon, Dorothy Lewis, Julia Lyford, Janet Millington, Joanne Nelson, Amanda Richardson, Elizabeth Richardson (Chair), Eileen Robinson, Joy Rutter, Sharon Willey
<b>APOLOGIES:</b>	Mary Johnson, Carol Leckie, Doris Ross, Angie Scott, Jacquie Simpson, Gill Turner

ITEM	DESCRIPTION OF DISCUSSION	ACTION BY
1.	<b>Welcome and introductions</b> – it was suggested that Carol Macdonald from the Portage Team be invited to a future meeting.	<b>Alison Bravey</b>
2.	<p><b>Minutes of Last Meeting:</b> The minutes of the previous meeting were amended and agreed.</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>Support for parent of children with ASD</b> – it was queried whether Kim Graham from the West LIST (Locality Inclusion Support Team) still runs a support group in West Northumberland. The Hexham Branch of the NAS (National Autistic Society) were on the circulation list, but are no longer receiving e-mails. Kath Lennon to check.</li> <li>• <b>MAG Autism group</b> – invitation to interested parent representatives from In It Together to join the pre-meeting.</li> </ul> <p><b>Diagnosis of medical conditions/support for parents of children with ASD – Discussion:</b> Medical professionals may be cautious about rushing into a diagnosis, particularly for very young children, or using certain terminology. This is about wanting to do the right thing rather than to delay the process. It was noted that parents welcome honesty and openness, but can feel frustrated by lengthy processes when the possibility of their child having an underlying medical condition has been raised with them. It is not about parents wanting a label for their child; it is about unlocking the support that can come with a diagnosis. It was noted that there used to be courses and a lot of help for parents which are no longer available because of funding cuts (e.g. the Hanen 'More than Words' course).</p> <p>Parents often feel blamed or judged as 'bad parents' because of the way their child is presenting. Children may be excluded from school because they find it difficult cope in the school environment and this impacts on their behaviour. Problem of children 'slipping through the net' and parents feeling desperate because they can't access services. Should be more about assessment and observation of a child's difficulties and appropriate interventions, not just diagnosis; e.g. positive behaviour support from childhood to adulthood. The behaviour of children with ASD needs to be looked at differently and handled in a different way.</p> <p><b>LIST perspective</b> – some schools don't have the appropriate training to work with children with particular needs. It is about schools recognising the need to ask for help and support. Need to have the tools and develop the strategies to meet a child's needs. Need a willingness from schools to take this on board – information sharing and up-skilling. It was questioned whether schools which do not do the right thing by their pupils with SEN and disabilities should be 'named and shamed'.</p>	<p><b>Kath Lennon</b></p> <p><b>In It Together</b></p>

It was noted that a child having an EHCP (Education, Health and Care Plan) doesn't wave a magic wand - it is about how funding/provision is used. Need to signpost parents as much as possible to support available to them, including courses. It was noted that some parents are 'ready' for their child receiving a diagnosis and some are not.

The LISTS are currently piloting the use of Autism Education Awareness Standards. A document which sets out the evidence required regarding what the school has put in place will be sent to every school applying for Top-up funding or an EHCP. It is currently in draft form with the Head of Education and Skills. Kath to bring the document to a future Forum meeting once it has been finalised. It was queried whether LIST professionals can also work in the child's home - the Team does mainly work in schools, but can go into the home as well.

Kath Lennon

- **Local Offer – Karen Carnaffin**

The website is up and running. There is a facility for organisations to enter events and other information. Need to register their details to be able to do so. Once submitted the update goes into an In-box to be authorised to be put on the website. All feedback re the Local Offer is welcome. There hasn't been a great deal of feedback about the Local Offer so far, but it has not been widely promoted. Capacity issue re work on the Local Offer - staff working on the website on top of their other work commitments. Karen has enquired about dedicated administrative support and is waiting to hear about this.

It was queried what is happening with regard to out of date information on the website. Users are matched with their registered e-mail addresses so can check what information to take off. Will be able to search for information on key words. It was acknowledged that the website is not yet where it should be and everyone needs to work together to ensure it is fit for purpose. It was noted that the website is very difficult to find. It was queried how the feedback on the Local Offer through consultations with parents (the "Local Offer shopping list" exercise) had been used. The website needs to be much simpler; for example, providing comprehensive information through searching on keywords. Need to continue to consult with parents about what works for them. It was noted that the Northumberland County Council website will be updated in April 2015 and its accessibility will be looked at. It was queried whether Local Offer is a stand-alone website independent of the Local Authority. The website is part of Family Services Directory and the database managed by the FIS (Families Information Service) which also contains the directory of OFSTED registered childcare providers. Linked through Northumberland Council Council, but not owned by them. It was suggested that the work on the website could be done in partnership with the voluntary sector to share the job of updating it, to avoid duplication. As a one-off could bring people together to speed the process up.

- **Request for training for parents of under 6's with ASD** - has been fed back to the LISTS. LIST staff working to the Barnardos age category for the training which is for over-6's. Early Bird and Early Bird Plus for young age groups would require funding (not available at present) and a training licence to take it forward. There has been one-off ASD training through the Blyth West Children's Centres.
- **Headliners film project – the** deadline has been extended until the end of December. Any interested children, young people or parents can contact Clara from Headliners at [clara@littlebigbutterfly.org](mailto:clara@littlebigbutterfly.org)
- **Designated Medical Officer - invitation to Forum meeting** – Eileen Higgins the DMO has been contacted, but has not responded as yet.
- **Short Break Care** – the Short Break Statement worked on in April 2014. It went to senior managers, but has not yet been published. Debbie to feedback when she has more information.

Debbie Bakkali

3. **Feedback from In It Together locality meetings:**

**South East/Central Northumberland – Amanda Richardson and Joy Rutter:**

- **Social care:** Issues re disability awareness with social care professionals where parents are referred to their local Social Work team rather than the DCT (Disabled Children Team). It was suggested that training is given to social work teams to help with understanding disability issues. Some parents felt that when they met with district office staff the focus was on safeguarding/parenting issues rather than disability of the child. Parents of children with disabilities can be very vulnerable at the time they seek help and need the professionals working with them to have an understanding of the difficulties they face. Parents may be referred to the DCT, but their child doesn't meet the criteria for DCT involvement and the family don't end up getting the support they need. Sharon Willey to feed these issues back to colleagues within the Local Authority. It was noted that the family may end up needing a lot more resource if they don't get support they need because this may lead to a safeguarding situation.
- **Childcare for training events:** Issue of some parents not being able to attend training events because of the cost of childcare – where children under school age and parents don't have family support. At some events childcare is provided. It was noted that there is a list of OFSTED registered child minders on the FIS website. Most services/organisations would not have the level of funding available to pick up childcare costs. It was mentioned that Children's Centres have crèches where children could be looked after by early year's staff. Would have to tailor training around the fact that the maximum time that children can be away from their parent is two hours. Workshop style training fits in with this - have all families together at first, then the children go to the crèche, and all meet up again for a shared lunch. Childrens Centres training rooms would accommodate a maximum of 30 parents. Use this model for Mellow Parenting courses and training for parents with mental health issues. The availability of free meeting rooms was queried: suggestions, children's centres, Colgate Cottage (bespoke provision at Blyth Valley Children's Centre for families of disabled children).

**North Northumberland – Elizabeth Richardson:**

- **CYPS** some positive feedback, but feedback tends to more on the negative side. Parents can wait a long time for an appointment and the service then offered is inappropriate to for their child's needs.  
**Discussion:** Services need to work closely together to avoid duplication. Some parents have been told that the waiting time would be shorter if their child is re-referred to the service. It remains an issue for some parents that they attend the Choice Appointment with their child, but then wait a lengthy time for the next appointment. Judith Turner to attend Forum meeting in February. It was mentioned that families were not waiting so long for ADOS appointments (assessments for ASD). Parents report that coming together with other parents whose children have similar needs has a positive effect on their mental health and wellbeing.

**West Northumberland – Eileen Robinson:**

- **Healthwatch:** did a presentation which was really interesting. Independent health and social care consumer champion - feedback the experiences and views of services users, including parents. Gave contact details for parents to link in with them.
- **Transition:** Child to adult services, school to Further Education. How long is further education funded? LDA (Learning Difficulties Assessment) is not a legal document whereas an EHCP is. How long can a young person remain college? At 18 a young person is looked on as being an adult and their confidentiality must be

Sharon Willey

	<p>respected. Issue of when the young person does not have the ability to put their views forward properly. Example given of Connors rating for ADHD. When the person being assessed is a child, the inventory is done by the child, school and parent. When they are a young adult it is purely their view and the problem is that they may not have insights into their own difficulties – the consequences of this could be massive. It has implications for parents/carers as well as the young person.</p> <ul style="list-style-type: none"> <li>• <b>Transitional Plan:</b> transfer of Statement or LDA (Learning Difficulties Assessment) to an EHCP if deemed necessary over the next three years. Inaccurate information on the Local Authority website. This needs to be amended so parents are clear which the priority groups are. The Transitional Plan on the Local Authority website states that children/young people with Statements in out of county provision will have a transfer reviews done this academic year, as well as children with the most complex needs and Looked After Children. Parents attend what they think will be a transfer review only to be told that it isn't. Parents of children in out of county provision now have to request that the statement is transferred into a plan. Eileen has raised this as a concern with the SEN Team.</li> </ul> <p><b>Discussion:</b> Query re rights of kinship parent – it was noted that only parents/carers with parental responsibility or young people have responsibility for an EHC Plan. Kinship carer would not have rights in this process unless they had legal parental responsibility for the child.</p>	
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<p>4.</p>	<p><b>MAG (Multi-Agency Group) – Autism: feedback</b></p> <p>Dorothy mentioned the A-Z produced by Sure Start. Could be put in Autism packs given to parents following a diagnosis. Parents need to be aware of what support may be available to them. Other suggestions for information to be included; Face 2 Face leaflets, In It Together leaflets, NAS (National Autistic Society) information, Early Support book, PECS (Picture Exchange Communication System), Social Stories, Visual Strategies.</p> <p>Dorothy running group at Blyth Children's Centre – action plan to link in with MAG – Autism plan. Norma Jackson (Speech and Language Therapist with a specialism in autism) to also link in. Other provision for children with autism: Toby Henderson Trust (the Trust were hoping to move to Cramlington from White House Farm, but this is on hold at the moment) and Autism Northumberland (contact person Leslie Cole).</p> <p><b>Discussion:</b> re how different groups can work together and complement each other through good dialogue, sharing of information.</p> <ul style="list-style-type: none"> <li>• Scope Face 2 Face service offers support to parents of children for a wide range of disabilities. Families in early phase of diagnosis (pre and post diagnosis phase). Offered six sessions with a volunteer; aim to build trust and resilience through close support to empower parents to seek and access appropriate services. Helen has written Service Development Plan for North Tyneside to cover Tyne and Wear.</li> <li>• In It Together training on disability led to a parent completing NCDN accrediting learning on Autism awareness. Looking to offer more accredited training opportunities in the future.</li> <li>• Kirsty Trimming (who is 25 years old going on 26) has set up a user-led autism support group run by young people for young people. Based in Blyth - young people can self-refer to the group.</li> <li>• Other organisations offering high quality support and information to parents; Cerebra, Contact a Family, Dasl<sup>o</sup>e.</li> <li>• In It Together SEND Parent Mentors will be available in the future to provide parents with information and support.</li> <li>• NICE (National Institute for Health and Care Excellence) guidelines for Speech and Language Therapy recommends that parents are provided with information about support groups and other sources of support and information.</li> </ul>	
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<p><b>5.</b></p>	<p><b>SEND Reforms update</b> Deferred until the next meeting.</p>	
<p><b>6.</b></p>	<p><b>Healthwatch – Helen Elliott</b> Healthwatch - independent health and social care consumer champion and voice. There are 152 local Healthwatches in England, one in each Local Authority area. Feed into Healthwatch England - mechanism to raise concern at National level. Local and independent service providing feedback about what is working and what isn’t. Adapt North East secured the Healthwatch contract for Northumberland. Feed back to the public about Health and Social Care. Provide an independent complaints service, including NHS complaints. ICAN advocacy service set up a year ago. Has seen an increase in number of people accessing advocacy support for areas such as taking forward NHS complaints. Outcome: issues resolved earlier rather than service users going ahead to make a full complaint. Aim is to enable and empower service users by giving them the information and support they need. Work with PALS (Patient Advice and Liaison Service), local Voluntary and Community Sector organisations, Commissioners and providers at county and regional level. Report to the Health and Wellbeing board. Has led to an improvement in services. Provide a free and up to date service. Service users can complete a supporter form to be put on the data base to receive information. Looking to set up Children and Young People reference group to give them a voice in how Health and Social Care services are run. Priority is Health and Wellbeing Board links with children and young people to get their voice heard. Also want to establish community links with other groups and peers. Contact details on leaflet. Helen has contacted the Splinter group and REC (Respect Equals Change). Early stages, currently developing Terms of Reference for the group. Step by Step guide and Self-help information pack available on website. Helen to forward information to be shared with the Forum members.</p>	<p><b>Helen Elliott</b></p>
<p><b>7.</b></p>	<p><b>Information Sharing/AOB</b></p> <p><b>Kath Lennon:</b> LISTs are rolling out Cygnet training. Have completed central, west and north. Blyth and Seaton Valley have a waiting list. Training for teachers and support staff, and newly qualified teachers.</p> <p><b>Helen King:</b> Scope Face2Face. Helen leaving the service to work for Adoption UK taking a lead on disability for prospective adopters of disabled children. Often adoptive parents do not receive the on-going support they require. Penny Dickinson will provide on-going support to the Scope Befrienders and take referrals until Helen’s replacement has been appointed. Contact details: <b>Penny Dickinson 07834140809</b> or <a href="mailto:penny.dickinson@scope.org.uk">penny.dickinson@scope.org.uk</a>. Can still use the number on the leaflet, but not the e-mail. Current funding will end in April 2015. Helen has submitted a service plan to the funder of the service; a private donor who is an advocate for disabled children and their parents. Now waiting for this to be agreed. Hopefully this will expand on the service currently offered. Helen was thanked for her contribution to families in Northumberland and wished well in her new job.</p>	

	<p><b>Debbie Bakkali</b> mentioned new project in Allendale for respite carers which includes hydrotherapy provision with disabled access. The Local Authority has booked to use. Contact person: Helen Hylton who provides training for free. Cost for use of provision. Christmas parties for disabled children – Saturday 13 December, Hepscott Conference Centre 1 – 3pm and Alnwick Garden Sunday 14 December 1 – 3pm</p> <p><b>Julia Lyford:</b> Splinter Group workshop ‘Will I ever be able to drive?’ Simulator for young people. Parents and carers welcome. Will also cover the assessment process with the DVLA and driving theory test issues. Will offer support with getting provisional licence and with driving theory test. Also running a workshop called “Everything you ever wanted to know about learning difficulties” where young people talk about their own experiences. Mentioned Employability enterprise - workshop for parents and carers. Looking at young people’s sense of their own identity regarding employment.</p> <p><b>Helen Elliot:</b> distributed Healthwatch leaflets. To request more leaflets, e-mail Helen at <a href="mailto:helene@healthwatch.co.uk">helene@healthwatch.co.uk</a>. Helen asked whether group issues raised at the Forum could be taken forward by Healthwatch.</p> <p><b>Dorothy Lewis:</b> mentioned that an electronic version of the “A-Z of support for Children 0 – 5 with additional needs and disabilities in Northumberland” is available the Blyth Valley Children’s Centres website at <a href="http://www.blythvalleychildrenscentres.org.uk">www.blythvalleychildrenscentres.org.uk</a> To also be put on the In It Together website.</p> <p><b>Janet Millington:</b> mentioned a student working with children with autism who have autism, developing useful strategies.</p> <p><b>Mike Kelcey:</b> Youth Service - a county-wide team covering 4 areas so able to respond locally. Senior area worker in Ashington and Newbiggin covering the south east. It has been flagged up with the Youth Service that there is nothing for young people with additional needs in South East/Ashington. The REC group have a participation team. Northumberland C of E Academy has an after school group. Looking for opportunities to work together to build capacity and more play/leisure opportunities for young people in the county.</p> <p><b>Alison Bravey:</b> Northumberland SEND Information, Advice and Support Service (previously known as the Parent Partnership Service). Mentioned the much broader remit of the service to cover 0 – 25 years and children and young people as well as their parents/carers. Now covers Health and Social Care as well as Education. Mentioned Independent Support workers who will guide parents and young people through the Education, Health and Care Plan process. These will be provided through Aspire Personalised Care Solutions, who are the Independent Support agency for Northumberland, and the Northumberland SEND Information, Advice and Support Service.</p>	<p><b>Elizabeth Richardson</b></p>
<p>7.</p>	<p><b>Any Other Business</b></p> <p>Covered under Information Sharing</p>	
<p>8.</p>	<p><b>Dates of future meetings:</b>  Thursday, 5 February 2015,  Friday 8th May 2015,  Friday 10th July 2015  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
Mary Connor	Senior Manager, Early Intervention and Prevention
Mark Cusack	Passenger Transport Operations Manager
Jane Harrison	Strategic Lead, SEND Reforms
Eileen Higgins	Designated Medical Officer, Northumberland
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
Daljit Lally	Executive Director, Wellbeing and Community Health
Carol Leckie	School Adviser, Partnership with 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
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
Angie Scott	Parent Representative, West Northumberland
Jacqui Simpson	Parent Representative, North Northumberland
Katharine Taylor	Clinical Managers, Children and Families, Northumbria Healthcare Trust
Carys Thomas	Parent Representative, MAG Autism group
Andrea Thomas	Parent Representative, North Northumberland
Gill Turner	Consultant Paediatrician, West Northumberland
Judith Turner	Community Clinical Manager for Northumberland, CYPS (Children and Young People's Service)
Jane Walker	Virtual School Headteacher and Vulnerable Groups Manager
Sue Welsh	Head of Therapies, Northumbria Healthcare, NHS
Sharon Willey	Northumberland Healthcare, NHS