

Minutes of Northumberland Parent Carer Professional Forum (PCPF)

Venue: Stannington Village Hall

Date: Tuesday 2 October 2014 10.30-13.00

PRESENT:	Alison Bravey (Minutes), Mark Bagott, Debbie Bakkali, Karen Carnaffin, Louise Dawson, Mary Johnson, Kath Lennon, Janet Millington, Joanne Nelson, Amanda Richardson, Elizabeth Richardson (Chair), Doris Ross, Joy Rutter, Robbie Seaman, Jacquie Simpson
APOLOGIES:	Ann Brown, Jean Hedley, Helen King, Ann Jolley, Carol Leckie, Michele O'Brien, Ben Sanderson, Angie Scott, Fiona Tarn, Gill Turner, Judith Turner

ITEM	DESCRIPTION OF DISCUSSION	ACTION BY
1.	Welcome and introductions	
2.	<p>Minutes of Last 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: information regarding appropriate childcare. Parents/carers have noted how difficult it can be to find suitable childcare particularly for older children/teenagers. Should be referred to the Local Offer or Families Information Service. Referrals to the Family Support Team are through a social worker. This continues to be an issue – item to be carried forward to future Forum meetings. • PIPs (Personal Independence Payments) – the issue of vulnerable young people with disabilities now being responsible for decisions affecting their lives (including applying for PIPs). It was felt that this may see them missing out on services or benefits they might be entitled to if they do not have someone (e.g. their parents) to advocate for them. Other sources of support/advocacy include Contact a Family and Cerebra; need to be included in the Northumberland Local Offer. • CYPS (Children and Young People's Service – mental health) - In It Together representatives have met with Judith Turner, the new Head of CYPS to discuss issues raised by parents at Forum locality meetings. Parents feel that things do seem to be changing with the service and that there is less of a waiting time for appointments. Parents are sometimes not aware that it is a time limited service. Should be support in the community to back up CYPS services when a child/young person is discharged; e.g. through schools nurses/GPs. <p>Discussion: It was noted that professionals in the community are spread pretty thinly and realistically they would not be able to pick up all children discharged by CYPS. The LISTs (Locality Inclusion Support Teams) also have finite resources. New systems in CYPS mean that a child who has been discharged can be referred back at any time. The senior duty manager prioritises urgent cases on an individual basis. Primary mental health workers (it was noted that there is only one in Northumberland at the moment) can also pick up some cases.</p>	
3.	<p>Feedback from In It Together locality meetings:</p> <p>South East/Central Northumberland – Amanda Richardson and Joy Rutter: Main issues:</p> <ul style="list-style-type: none"> • The lack of training provision for parents/carers of under 6's with ASD; equivalent of Cygnet training. • Feedback re the Local Offer – parents not able to find it. • Concerns that some services won't offer support to children unless they have a diagnosis. 	

Discussion:

Whether a child does or doesn't have a 'label' (diagnosis) shouldn't, in theory, make a difference to the support they receive. However, feedback from parents suggests that this is not the case. Medical professionals are trying to 'de-medicalise' things, by not jumping to a diagnosis, but this can be unhelpful from the parental perspective. It was noted that sometime professionals mention a diagnosis in a clinic, but then do not write this down in a report. It can be useful for parents in their discussions with schools about the support that their child requires to have a diagnosis recorded; it can be a 'lever' for other services. Parents feel that it can also be helpful for clinicians to make recommendations about what interventions may be helpful for the child in the educational setting. It was noted that medical professionals are not educationalists, so may be wary of 'treading on the toes' of their colleagues in education, feeling that they shouldn't be making recommendations to schools. The process of how professionals and parents work together towards appropriate outcomes for individual children should be more transparent through the EHCP (Education, Health and Care Plan) assessment and planning. Should also identify where there are 'gaps' in services; e.g. lack of occupational therapy.

It was noted that some schools work better than others regarding SEN Support in school and that this can be tremendously variable across schools. Need to have the key people around the table when discussing a child's needs for the 'system' to work effectively.

The issue re training for parents of under 6's with ASD to be fed back to the Locality Inclusion Support Teams. Local Offer issue covered in minutes under Information Sharing.

Kath Lennon

West Northumberland – Alison Bravey:

Alison provided feedback on behalf of the West Locality meeting, which she currently facilitates, and mentioned that she is hoping that a parent will feel confident to take over the running of this meeting at some point in the future.

- **CYPS:** The parents were pleased that Chad House in Hexham is being refurbished to make it more 'child/young person' friendly. It will reopen on 20 October. It was queried why CYPS professionals couldn't see a child in their own home where they were more comfortable.

Discussion: The initial appointment is clinic based, but there is no reason why subsequent meetings couldn't be at home. CYPS professionals tend to go with what the young person or their family want. It was noted that some young people don't want their parents to be present at their appointment.

- **Support for parents** - the parents talked about how isolated they had felt during the process of diagnosis and getting their child's needs met. Three had received support from a volunteer from the Parent Partnership Service (now known as the Northumberland SEND (Special Educational Need and Disability) Information, Advice and Support Service) and mentioned what a difference this had made to them. Parents benefit from having someone to talk to about the issues they are facing. Opportunities to talk to other parents who have children with similar needs can be very helpful.

Discussion: It was mentioned that In It Together and the Northumberland SEND Information, Advice and Support Service are currently in the process of training volunteer SEND Parent Mentors who will provide parents with information and support around the Local Offer and SEND Code of Practice. The charity Scope has Parent Befrienders – parents of children with disabilities who are trained to offer support to other parents.

- **Feedback re special schools**

All of the parents at the West locality meeting have children in special school and felt that this was the best thing that could have happened for their children. The environment is less busy, the curriculum at a more suitable level, there is access

to specialist provision and staff, etc.

Discussion: The important role of special schools was acknowledged and the pressure on special school places was raised as an issue for the Local Authority.

North Northumberland – Elizabeth Richardson, Jacquie Simpson:

- **CYPS** also discussed.
 - **SEND Reforms** concerns for parents with child at SEN Support level (previously School Action and School Action Plus. Need for some schools to engage with parents to ensure that a child's needs are met.
 - **Post-16 provision** - it was felt that in North Northumberland this is poor and that the provision offered through Dilston College outreach (first set up last year) is very ad hoc. Parents/young people need to be given clearer information about what will be provided through a placement. There is an issue that if their mentor is off sick the young person is not able to attend the outreach and has to be cared for at home. The educational curriculum is over 3 days rather than 5 days. Young people can be asked to leave the course if they have poor attendance, which would then leave them with nothing. Other options for Post-16 are very limited. Northumberland College is not suitable for some young people and Border Links/Newcastle Colleges are a long way for young people to travel or might not be appropriate.
 - **Headliners** - film company commissioned by Department for Education to produce a film about the experience of children/young people with SEND and their families re services in Northumberland. The final version of the film will be played to council officers and lead members at a future board meeting. Clara from Headliners attended the locality meeting and interviewed 4 parents on camera. Parents and carers are asked a set of questions which were designed by young people at Collingwood special school. Parents don't have to be filmed, they can also respond by e-mail - a written report will be produced. Feed back to the Local Authority about how service users feel about the changes to services through the SEND Reforms and what their hopes are for the future – powerful messages. A film is be made for every Local Authority in England. Clara is happy to arrange meetings or to attend parents groups. Ben Sanderson and the REC (Respect Equals Change) group have been involved with the project.
- Suggestions re who else Headliners might contact:** Dorothy Lewis, Blyth Children's Centre; Kim Graham's Parents ASD support group in West Northumberland. Need a mix of mainstream and special school feedback to get the broader picture.

4. MAG (Multi-Agency Group) Autism – feedback

Dasl^{ne}: Mary Johnson outlined the work of Dasl^{ne}; the database of children with ASD (Autistic Spectrum Disorder) in the north east. There are 355 Northumberland children on the database. 600 families on local listings have a child with a diagnosis of ASD, but not all have consented to be on the database. The group has a Facebook page – Dasl^{ne}.

- An event called 'A Little Bit Autistic' with speaker Professor Uta Frith will be held at the Herschel building at Newcastle University on 9 December at 5.30pm. It is not necessary to book.
- Research study into anxiety and phobias for children with ASD; target age group 8 to 14 years. Involves simulating the environment where the child feels very anxious using a computer monitor. An Occupational Therapist/Researcher will work with the child to try and reduce their anxieties in these situations. This work will be rolled out to the NHS. Includes specific phobias such as dogs, birds, bridges/heights, supermarkets, canteens, etc.) Can be a lengthy process of desensitisation. It was noted that there is no specific scale for measuring anxiety in children with ASD.
- Dasl^{ne} have fact sheets about ASD in community languages, including Bengali, Chinese and Polish. Could be included in the Northumberland Local Offer.

	<p>Other points raised by MAG Autism group:</p> <ul style="list-style-type: none"> • Re-audit of NICE (National Institute for Health and Care Excellence) guidelines for ASD in Northumberland. • Sensory needs – the LISTs (Locality Inclusion Support Teams) in Northumberland no longer have access to Occupational Therapy provision. Children with ASD don't have access to an Occupational Therapist unless they have fine motor problems. There seems to be no recognition of the sensory dysfunctions and needs of children with ASD in terms of provision of appropriate assessment /interventions. Some parents use a private therapist using the child's DLA money. <p>Discussion: The lack of involvement of Health and Clinical Commissioning Groups was raised at the National conference for the National Network of Parent Carer Forums as an issue for lots of Forum areas. It was suggested that Eileen Higgins, the Designated Medical Officer for Northumberland be invited to the next Autism MAG pre-meeting (Gill Turner to be copied into the e-mail)</p> <p>The need for commissioner/senior management representation on the Parent Carer Professional Forum was flagged up. It was suggested that Local Authority Commissioners are copied into the Forum minutes and invited to attend at least two Forum meetings per year to discuss issues directly. Suggestions for other professionals to be invited to future meetings: Jane Harrison, Strategic Lead for the SEND Reforms; Lynn Bryden, Senior Manager Commissioning; Sharon Willey, Northumberland Care Trust; Ann Jolley, SEN Lead Officer; Siobhan Brown, Northumberland Clinical Commissioning Group. It was also suggested that Daljit Lally, Executive Director, Wellbeing and Community Health, and Andrew Johnson, the newly appointed Director of Education and Skills, are copied into the Forum minutes.</p>	<p>Elizabeth Richardson</p>
<p>5.</p>	<p>Changes to the Disabled Children Team</p> <p>With the future re-structure of Education and Skills, the Disabled Children Team will be moved away from the umbrella of Education, to be located within the Adult Services Directorate and will be managed by Sharon Willey for a 12 month period to enable her to complete a review of how Disabled Children Services may look and be provided in the future.</p>	
<p>6.</p>	<p>Information Sharing</p> <p>CYPS (Children Young People's Service) – Robbie Seaman</p> <p>The service has been split into two teams:</p> <ul style="list-style-type: none"> • Through-put services: managed by Katie Paul • Integrated services: managed by Robbie Seaman <p>Through-put service will deal with waiting lists and caseloads prior to 20 August 2014 as well as the provision of necessary interventions. Integrated services will deal with new referrals from 20 August. Aim is to reduce waiting lists and get children/young people seen as soon as possible. Not all workers are in post yet – may be awaiting references and checks or serving notice periods, but this will be resolved by the end of the year. Children/young people with Learning Disabilities will be matched with specialist Learning Disability nurses.</p> <p>Choice and Partnership appointments: the Integrated Choice Appointment will in future identify whether the child/young person will remain within CYPS (to be matched with the appropriate professional) or be signposted elsewhere. Partnership appointments - interventions with appropriate worker. A time limited service; this will be explained at the beginning of the process. Goal based process – appropriate interventions will be planned. The aim is the matching of practitioner skills to patients.</p> <p>Discussion: a "Hub" model of support for children/young people has been piloted in Blyth and will be rolled out to the Cramlington area. Has been very successful. Professional representation from different services (including Locality Inclusion Support Team, CYPS, Children's Centres, Social Care, Health) look at what would be</p>	

the most appropriate support for referred children/young people and their families. Assessment to identify needs before identifying a worker. Aims include cutting down on inappropriate referrals to CYPS, addressing any child protection issues and avoiding duplication of services. Focus on early intervention and prevention using Early Help Assessments (EHA).

Local Offer website – Karen Carnaffin, Families Information Service

Website was 'live and compliant' on the 1 September, but there have been teething problems due to issues with Open Objects, the website designer commissioned by the Local Authority. Opted for same version as the Families Information Service website through Open Objects so the two websites would be compatible. The Local Offer website is live, but there is considerable 'work in progress' to get the website to where the Local Authority would like it to be. The Local Offer is a very important information/service tool. It needs to be user friendly and the information must be maintained and kept up to date. The information was contributed by a range of services and childcare providers who were e-mailed a template to complete. Every service will be responsible for their information and in future given access to their pages on the website and sent e-mail prompts to check whether the information is still accurate. Need to look at what information is missing and what is out of date. Karen noted that the Families Information Service is a very small team which has limited capacity to take forward this area of work; really need a dedicated worker specifically responsible for the Local Offer. Karen is responsible for the technical aspects of the Local Offer website and Jane Harrison is responsible for the content. Paul Crulley from the SEN Monitoring and Assessment Team has worked with schools to make sure their 'Local Offers' or SEND Information Reports (outlining the SEND provision the school offers) were 'live' on 1 September.

Family Support Team/Short Break Care - Debbie Bakkali

Moved offices to Ashington in September. Framework for Short Break provision to be published next April 2015. Some services have been reduced because of funding constraints. There is to be a review of service providers and available funding. Information can be found on the Family Support Team/Short Break Care pages on the County Council website. The pages also contain links to the websites of other services/organisations. There is not open access to Short Break Care for all children with disabilities; they must be referred by a social worker. It was noted that there has been poor response to some events the team has run, need to unpick why this was the case. There are Short Break schemes across the county (most are full) and the team seeks feedback from services users re the schemes. Events/Short Break opportunities are mainly publicised through the website because the cost of publishing leaflets/magazines, etc. is prohibitive.

Discussion: It was noted that not all parents have the internet to be able to find out about events and services. Suggestions for other ways of reaching families with information included; booklets; use of Facebook pages; InfoLink database (parents contacted via e-mail). CYPS use a service from Action for Children to get feedback from parents/carers.

Scope Face2Face Befrienders launch – Joy Rutter

The launch was well attended by parents and professionals. Emotional stories from parents provided very powerful messages for the professionals. The Befrienders have all been trained by Helen King from the charity Scope. They are parents of disabled children themselves and will provide support to other parents of disabled children. Parents can either self-refer to the service or be referred by any care or support professional. Referral is through Helen King – Joy to forward most up to date leaflet to Alison Bravey to be circulated with the Forum minutes.

Discussion: Parents who need support may feel that they receive a better understanding of their situation from a parent/carer who has been through the same

**Joy Rutter
/Alison Bravey**

	<p>process. Can lead to benefits for services the parents are involved with, e.g. CYPS, because the Befriender can talk the parent through what to expect and how the service might help. Some parents may have a mental barrier re asking for help.</p> <p>Speech and Language Therapy; pre-school children with ASD – Janet Millington Janet covers pre-school children with ASD in West Northumberland and Norma Jackson covers the rest of the county for pre-school. Also cover sensory feeding difficulties and therapy programmes for children on the spectrum.</p>	
7.	<p>Any Other Business</p> <p>Covered under Information Sharing</p>	
8.	<p>Dates of future meetings:</p> <p>Thursday 4 December 2014 and Thursday, 5 February 2015</p> <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>	

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
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 DasI [®] e
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
Helen King	Community Organiser Face2Face North East, Scope
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
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
Louise Woodman	Supporting Young People Manager, Employability and Skills Service