

Draft Minutes of Northumberland Parent Carer Professional Forum (PCPF)

Venue: Stannington Village Hall

Date: Thursday 4 February 10.30-12.30

PRESENT:	Mark Bagott, Vicky Box, Alison Bravey (Minutes), Karen Carnaffin, Helen Cowens, Alan Carrick, Lesley Cole, Janice Gerard, Gemma Gowland, Mary Johnson, Janet Millington, Joanne Nelson, Amanda Richardson, Elizabeth Richardson (Chair), Doris Ross, Nicola Strachan
APOLOGIES:	Debbie Bakkali, Helen Elliott, Kath Lennon, Dorothy Lewis, Julia Lyford, Eileen Robinson, Jacquie Simpson, Gill Turner

ITEM	DESCRIPTION OF DISCUSSION	ACTION BY
1.	Welcome and introductions	
2.	Minutes of Previous Meeting: Agreed	
3.	<p>Northumberland MAG (Multi-Agency Group) Autism</p> <p>The purpose of the group had been discussed at the pre-meeting. It has provided opportunities for networking, but not the strategic impact hoped for in terms of effecting change for children/young people with autism. Have strong parent representation and need to recruit and build links with key strategic partners.</p> <p>One aim is to ensure that parents of children in the early stages of the diagnostic assessment for autism have a clear understanding of pathways for different types of support. Meeting scheduled for 1pm – 2pm on April 20 at Autism Northumberland, to discuss the next steps for the group and review its Terms of Reference. Doris Ross to invite Lynn Bryden, Senior Manager for Commissioning.</p>	DR
4.	<p>Feedback from In It Together locality meetings:</p> <p>Not a particularly good turn-out for the meetings in South-East/Central or West Northumberland this time. In It Together to review arrangements for the meetings and how they are promoted to parents.</p> <p>North Northumberland</p> <p>CYPS: Parents raised concerns about having to talk about their child at appointments with the child present. Can be an issue if they want to raise concerns that may be uncomfortable for the child to hear.</p> <p>Discussion: Parents can request to talk to CYPS professionals without the child present. Every case is different and it will depend upon what the concerns are. It is helpful for the child or young person to be at the appointment. Parents would need to take another adult to supervise the child in the waiting room if they wanted to have a private conversation with the professional at the appointment. An alternative would be to ask to have the appointment at the child's school where the child could go back to class. The arrangements within the CYPS team will vary, but there should always be the opportunity for parents to talk to staff alone.</p> <p>It was noted that some young people may wish to have appointments without their parents' knowledge or presence and share information in confidence. This is dealt with on a case by case basis.</p> <p>Lack of support for a physically disabled child on a mainstream school trip:</p> <p>An issue was raised about a school trip organised without fully considering the needs of a child in a wheelchair.</p> <p>Discussion: Schools should complete risk assessments for school trips taking into account the needs of all the children attending. They should log the risk assessments on the Local Authority's Evolve system. Depending upon the nature of the trip it may need to be approved by the Health and Safety team based in County Hall.</p>	

	<p>Speech and Language therapy for a school- aged child: Discussion: The NHS Speech and Language Service not commissioned to provide a service for a school-aged child with speech, language and communication difficulties. This provision would be from the LIST (Locality Inclusion Support Team) via a Hub referral. The LIST has dual qualified teachers/speech and language therapists. The referral has to come through the schools and provide evidence of what has been done to meet the needs of the child. A child does not have to have a diagnosis for LIST involvement. It was noted that some children may wait a long time to get this provision and that some schools are better than others at making referrals.</p> <p>Support available where parents have issues with their child at home: e.g. meltdowns when the child comes home from school, but appears fine when they are at school. Discussion: Referral to the school nurse or primary mental health workers through the Hub. Would look at what is going well in school, what is working for the child there and how this might be applied to the home situation. May be less structured at home which some children find difficult. Communication between home and school to share information; e.g. through diary system. Parents can also self-refer to CYPS – duty system from 9am – 5pm with CYPS staff on hand to talk through issues. Intensive community support team available out of hours if problems escalate (e.g. risk of suicide, harm). The teams assess the risks and can give advice to parents, schools and clinicians. For chronic, low grade, non-emergency situations the best way forward would be a referral to the locality Hub who would identify the service best placed to help. Range of types of support – responsive to different types and levels of need. It was queried whether parents can self-refer to the Hub – they can't directly refer, but could go through their GP requesting help for themselves or for their child. The Hub is run on a 'triage' type system – the referrals come in centrally to a coordinator and are considered by a multi-agency group. If clear cut would go straight to the relevant service; e.g. school issues dealt with by LISTs.</p>	
5.	<p>Findings and Priorities for NICE (National Institute of Clinical Excellence) re the clinical commissioning of services for children/young people with autism: Joanne Nelson outlined the findings and recommendations of an audit of Northumberland, Tyne and Wear CYPS services for children and young people with autism. There is clinical guidance for management and interventions. The focus in on a 'life span' approach which takes into account the transition from child and adolescent to adult services. There are priority areas for work with other services and families; including:</p> <ul style="list-style-type: none"> • A local Autism Strategy MAG (multi-agency group) – need involvement of commissioners to be fully compliant. • Collaborative approach between professionals and services; multi-agency involvement • Transition to adult services – transition protocol with adult ASD teams. • Local Autism team - access to appropriate professionals depending on the age of the child; diagnostic pathway to ensure key professionals are involved, including those outside of the team. • Single point of access/referral for the Autism team. • Consideration of other co-morbid conditions as well as autism; referral for further assessment, if necessary. • A care co-ordinator identified for every child – named contact for the parent who will liaise with other professionals, coordinate provision. Could be any CYPS professional, including psychiatrists and clinical psychologists. • Assessments include a profile of the child's strengths and skills, and drawing up a needs based management plan. • Equity of access to specialist services and sharing data/demographics to improve services. 	

	<p>The audit identified that CYPS is partially compliant on the NICE recommendations, but there are some areas that need to be improved.</p> <p>Discussion:</p> <p>Care coordinators: It was mentioned that some parents find it difficult to get hold of their child’s care coordinator or may be reluctant to bother them about what might be seen as a minor issue – it was noted that the care coordinators have busy caseloads and can’t be available at all times. Parents can leave a message or if the issue can wait until the child’s next appointment can discuss it then. If urgent can phone the duty team. Parents can request a change of care coordinator if necessary.</p> <p>Sensory profiling: the issue of provision for children with sensory needs was raised. It is sometimes difficult to determine where their difficulties may be due to sensory factors/overload (e.g. sensory processing disorder) which may be a significant barrier to their learning/development. Services need to be commissioned to do this work. There is only so much that a school can do to address sensory issues and CYPS are not commissioned to do sensory work. Jigsaw Therapy services were commissioned to do this work for a time-limited period and it was very beneficial to the children who accessed it. However the funding is no longer available. The Toby Henderson Trust has received NHS funding for sensory assessments.</p> <p>Discussion: Funding cuts for Local Authorities putting more pressure on the delivery of services; (e.g. the Education Services Grant has been cut by £600 million). Government analyse how Local Authorities have used their share of the Education Services Grant in the past and if none of the grant has been used for therapeutic provision will conclude that it is not needed. Money is not ring-fenced. Budgets for all aspects of educational provision for next financial year are very tight and there is no ‘slack’ for other things. Local Authorities tend to focus on what they are required by law to provide.</p> <p>Parents can raise their concerns about the lack of provision for children with sensory issues on the Local Offer – this Local Authority must respond to this feedback and take it into consideration with the planning of future services. There is a feedback button on the Local Offer website. Northumberland Special School Head Teachers are also looking at the issue of the provision of different therapies for the pupils in their schools as part of their whole school development (including for higher level language skills/social skills). It was noted that better access to therapeutic provision for children in mainstream schools may decrease the demand for special school places.</p>	
6.	<p>Careers Guidance Team update – Janice Gerard, Employability and IAG (Information, Advice and Guidance) Manager</p> <p>Hand-outs were distributed giving details of the Local Authority’s Careers Guidance Team and a flow chart of careers information, guidance and advice provision for learners aged 13 – 25 years. Historically Connexions services funded by central government provided careers advice to young people. In Northumberland this was contracted out to an external organisation, but brought back in-house in 2012 in response to budget reductions the County Council had to make.</p> <p>The statutory duty to provide independent and impartial careers advice is now on schools, including special schools (with no additional funding). This will be monitored by OFSTED. It is up to individual schools how they provide this; some employ an adviser, some contract out and some use their own staff. They can also ‘buy in’ the Careers Guidance Team. Young people should receive appropriate, high quality guidance – but this can be variable according to who is providing it.</p> <p>The team is part of the Learning and Skills. It includes IAG advisers (previously called Personal Advisers) who work with vulnerable young people in Year 11, 12 and 13 who</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
Rebecca Campbell,	Service Manager, North of Tyne,
Karen Carnaffin	Team Leader, Families Information Service
Alan Carrick	SEND Commissioner
Lesley Cole	Autism Northumberland
Mary Connor	Senior Manager, Early Intervention and Prevention
Mark Cusack	Passenger Transport Operations Manager
Helen Elliott	Healthwatch representative
Rachel Farnham	Children's Services Manager
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 ¹⁹ 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
Ben Sanderson	Youth Participation Worker, Northumberland Youth Service
Jacque Simpson	Parent Representative, North Northumberland
Jill Stewart	Community Clinical Manager for Northumberland, CYPS (Children and Young People's Service)
Katharine Taylor	Clinical Manager, Children and Families, Northumbria Healthcare Trust
Gill Turner	Consultant Paediatrician, West Northumberland
Sue Welsh	Head of Therapies, Northumbria Healthcare, NHS