

1) RACH	Feedback given by Lorraine Tinker, specialist nurse	
Talk Health Recommendations	Update from professionals	On-going / follow up questions
? Parking priority should be given to those with a disabled badge allowing them to queue jump	This has been a massive problem for the hospital. Longer term plan to build more car parks. In short term, parent carers can be told to ring the hospital and ask to be put through to the parking security. Parents who have blue badges will be allowed to jump the queue.	
? Parent carer involvement in regular groups	Various hospitals around the country have successful children/ young people user groups and they are planning on learning from these models.	Marion asked how they were ensuring CYP with SLD/very challenging behaviour can be included in service development? Lorraine will be looking at this and asking Amaze/PaCC advice on this. Jenny mentioned there is the AHA group who could be used to feed into RACH decisions
? Parent journey training for all	SSV staff are doing regular bespoke sessions within the Alex e.g. communications. Open to all members of staff	Consultants/medical staff attending training/
? 'All About Me' Documents	The specialist nursing team has been looking at this in more detail – working with Clear Communication Company. Developed own Health Passport in conjunction with PaCC. Based on model used in Bristol. Can be used in various places e.g. health appointments, respite, trips etc. The health passport is available to be downloaded from Amaze website, Council website. The parent/carers can fill it in and take it into hospital. In adult wards it is put on the end of hospital beds – will try to do same in RACH. One of the team will be introducing it in RACH next week. Encourage people to use it. Working on communications handbook – tips/resources for communicating with CYP with limited communication	What plans are in place to help CYP move from the RACH to adult hospital care? We have plans for transitioning all young people to adult services in each speciality, this is on an individualised basis for some specialities and work extremely well in some services eg: respiratory, diabetes, oncology, where there are joint clinics for patients being transitioned and there are CNS able to assist in both children's and adult services. When a young person with complex needs moves to adult hospital care can the hospital communicate more directly with the parents

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	(makaton/PECS/symbols etc) which will be available soon.	<p>so that they can explain procedures to him and support him?</p> <p>This is to be addressed by the adult teams and requested, during transition of the young person this should also be highlighted to the paediatrician when transition commences. The adult services also have a Hospital Liaison Nurse for Learning Disabilities - Mary Woods at Royal Sussex County Hospital Sussex Partnership NHS Foundation Trust <i>Tel: Brighton 01273 664975, email: mary.woods@sussexpartnership.nhs.uk</i> who may be a useful link for families</p> <p>Is the health care in neurology adequate given the needs of the LD population of young people especially when they are about to transfer to adult care?</p> <p>This maybe more of a question for primary care to assist with as it . Children and young people with epilepsy and LD are looked after by Dr Tounce at the Alex and are transitioned in the usual way. There is often community paediatricians involved in children's care if they have LD and epilepsy</p>
? Disabled children given priority	Future appointments will be sent out with parking instructions. Consultants have been reminded about appointments starting on time. Will try to cluster appointments on same day where possible.	Why are SEND children not given priority e.g. ASC – no flags waved at RACH out patient. Waiting is a major problem for ASC kids.

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	<p>Parents/carers to ask for this too.</p> <p>Surgical lists are harder to influence. Small babies/CYP with diabetes need to go first. CYP with additional needs can be flagged up and moved up the list.</p> <p>If attending level 7 for operations parents can ask for a quiet area to take child. Can ask to see play therapist to help explain what will happen.</p>	<p>Trying to see how these kids can be prioritised. Lorraine will take back again. Will look at if they can be flagged on IT system.</p> <p>Can children with additional needs be offered more support when they are in hospital e.g. visited by a member of the PRESENS staff? This happens in the some of the London hospitals.</p> <p>We would be happy to learn more about PRESENS and the integration with hospitals. Education is provided by the local authority but we would be more than happy for PRESENS staff to come into the Alex and work with children and are open to this idea.</p>
? Specialist disability liaison nurses	<p>Kings College Hospital example given. Task would involve more than just RACH. Sussex Nursing group has been set up – but is still in the early stages. Needs to be worked on across Sussex.</p> <p>Focus will be on epilepsy and Children’s Community Nursing</p>	

2) Seaside View	Feedback given by Jenny Brickell team manager, Tracey Young, specialist nurse consultant, Jo Lord, Physiotherapy team manager and Bridget Morden, OT team manager	
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? Trial innovative approaches to reduce waiting times e.g. Therapy Assistants	<p>Physiotherapy does have a technical instructor – supporting physios in schools. Additional admin support means that qualified physios can be used in more hands on delivery.</p> <p>There are no more resources so it is a juggling act re. professional/qualified staff and admin/support staff.</p> <p>O.T. and SLT services have both spent time in training up class room assistants which is having a better impact in schools.</p>	
? Transparency about waiting times and eligibility and provision of exercises/advice whilst waiting	<p>Working on improving local authority’s website – Amaze has done some analysis against the SE7 websites and suggested lots of recommendations. They are committed to having web info as good as that on Amaze website. Parents will soon start to see improvements.</p> <p>Trying to improve the process of how referral process works – can be quite complicated. There is a tight process now on referrals which are tracked closely to minimise waiting times. They have a commitment when writing to parents that they will give an indication of how long they may have to wait for an appointment.</p> <p>Commissioners expect a performance analysis so they can work out how long people are having to wait for different appointments/clinics. Data managers receive can help identify patterns and potentially clear hold ups in the system.</p>	<p>Will there be protected budgets for therapy services, given how critical therapies are for these children? As budgets stand for 2013/4 NHS budgets not massively different that for this current year. However, have to balance budget for all therapies e.g. community nursing, therapists,</p> <p>No cuts from family’s point of view during 2013/4. Amaze/PaCC needs to work to ensure this remains the same for 2014/5 as this budget year will be even harder.</p> <p>Is the SLT service confident that it is meeting the needs of CYP with SLCN? Is there a full and up to date audit of need for each disability group and is the current provision in line with the needs of each specific profile? Is</p>

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		<p>this available to parents? We are confident that we meet the aims of our service “ to provide equitable and needs based support and intervention for all children with speech, language, communication and swallowing difficulties from 0 – 19yrs across universal, targeted and specialist tiers of provision”. We do not provide a service based on the child’s disability, but on their level of speech, language, communication or swallowing need. There is no specific profile for each disability group, but a profile of speech, language, communication or swallowing need for each individual child which is provided to the child’s family.</p> <p>For services with long waiting lists are there strategies for families with acute difficulties, that are not life threatening, to be doing with their children whilst waiting? We do have information sheets for some specific conditions but I will raise this at our next senior managers meeting in a month or so that I can be clearer what the current position is and also see if this is an area we should develop Waiting time for SLT is currently 5 – 6 weeks.</p> <p>Services need to think about the specific</p>

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		<p>needs of low level service users who often receive less support and don't have relationships to help with on going difficulties. These families still have a great level of need which needs to be taken into consideration.</p> <p>Following an assessment or review, each family will receive written advice about the child's difficulties, and activities to support those needs. We encourage parents to contact us if they need further advice.</p> <p>Those with low level needs can still access on going advice and support if they are open to the service. It would be helpful to better understand what would be helpful or where the gap is. For preschool children families can speak to their health visitor and for older children there is obviously the GP</p>
? Information at Seaside View is good but could be better	All services put a lot of effort into new leaflets – identifying eligibility, what the service offers and are now written in a parent friendly language. All services now assessed by the Partnership Charter.	
Review of groups at SSV	Pre school nursery nurse groups had been running in same shape/form for years. Parents were voting with feet as not well attended. Nursery nurses did a review of what parents wanted. So far new groups are much better attended. Trying to link to mainstream services. Trying to change make up of groups from diagnosis to needs-led.	

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	List of groups is available	
CYP with complex health needs e.g. cerebral palsy	Looking to develop a health action plan for children/ young people in mainstream school – similar to the IEP. The health action plan will identify what is needed/happening re. therapy etc These children are all high users of health services. Appointments to have these done are being made	
		<p>How do you see the new EHC plans working in practice and how can they improve health provision for our children? Jenny updated that all professionals are working together to trial new format for EHC plans in SEN Pathfinder.</p> <p>However if a child has lots of different plans there needs to be better co-ordination around the review process. Social care reviews can happen every four months. e.g. Health planning for complex needs CYP in mainstream schools.</p> <p>Don't know yet how it will work if very complex needs – how will work in practice, may not get to just one planning/review process.</p> <p>Feel parents will experience the SEN process in more positive way, more joined up between EHC, less adversarial.</p>

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		<p>Aspiration of C&F Bill is to develop a plan as a joint/team approach, greater emphasis that the plan is jointly agreed together.</p> <p>Alison made point that Draft Children & Families Bill is currently only being applied for CYP with SEN not disabilities without SEN. Rachel responded that Amaze/PaCC (and other major organisations) are trying to lobby to ensure legislation changed to include this group.</p> <p>Ed Timpson – saying Code of Practice is up for consultation – the devil will be in detail.</p>

3) CAMHS	Feedback given by Fran Boulter, service manager, Matt Stone and Paul Goodwin	
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? Better information	<p>All referrals from GPs, schools or the parent/carer are at a single point of entry – Aldrington Centre. Here they then decide what service is the most appropriate.</p> <p>Guidelines for referrals –first draft on Council website which is due for review over the summer. This includes a referral process diagram</p> <p>Developing leaflets for Tier 2&3 – this is a work in progress and needs more development. They are starting to give out these leaflets at events</p> <p>Two routes on line – Council website is now up to date showing contact telephone numbers etc. There is more work to be done on Sussex Partnership NHS website. Someone has been identified to support CAMHS in Sussex to look at quality of website information. Work in progress</p> <p>Trying to put other info of who else can help e.g. national organisations. This will hopefully help families go to the right service initially.</p> <p>Developed new leaflet for Tier 3 for parents – what to expect, how long have to wait, what will happen at first appointment, menu of options might happen after, types of professionals might see.</p> <p>Developing more leaflets about type of interventions e.g. mindfulness to increase understanding.</p> <p>Right Here are developing a leaflet for parents in the same format as the leaflet that was designed for young people.</p>	<p>Why are referrals not proactive but often made when families are at crisis point?</p> <p>Who is leading on local offer? Can put on Amaze website?</p> <p>When? Needs to be in place for Local Offer</p> <p>When? Needs to be in place for Local Offer</p> <p>Can put on Amaze website</p> <p>When? Needs to be in place for Local Offer</p>

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? Extend the CYPOSC user satisfaction survey	On-going process. Parents/ carers/ and young people are asked for feedback at end of each intervention	Please can parents have feedback from the survey carried out by CYPOSC?
? Transparency about pathways of care and waiting times.	Tier 3 - If a young person is new to service they will be seen within 4 weeks however if felt at risk/need they will be prioritised and seen quicker. If they are coming back to the service and need more help then they will be contacted in 7 days to explore the issues. Tier 2 – They will endeavour to see all within 8 weeks but are currently not reaching this in all cases due to extremely high demand. Trying to address with commissioners. Hopefully will get it down within few months.	What are current average waiting times for tier 2 & 3? Would it be possible for mainstream CAMHS and the Learning Disability CAMHS to work better together for families having to access both services? Fran acknowledged there was sometimes some cross over and that they would take this on board when trying to improve and develop the care pathways. However each part of CAMHS works differently and there would be the need to look at the interventions from each pathway acknowledging that some CYP need them from different pathways. For services with long waiting lists are there strategies for families with acute difficulties, that are not life threatening, to be doing with their children whilst waiting? Services need to think about the specific needs of low level service users who often receive less support and don't have relationships to help with on going difficulties. These families still have a great level of need which needs to be taken into

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		consideration.
? Training for psychiatrists in the parent journey	<p>Fran fed back this issue at consultant meeting in November – helpful reflection to think about how the parent/CYP experience CAMHS for all CAMHS staff.</p> <p>Considering joint training with Amaze. Rachel to follow up</p> <p>PaCC Rep been able to sit on interview panel – great input making more inclusive/collaborative process.</p> <p>Induction process – considering how staff can meet people from Amaze to hear about family’s perspective. Will try to include existing psychiatrists in this too.</p> <p>Tier 2 also using parents for recruitment – will try to use a parent or young person on an on-going basis.</p>	
? Autism specialist needed	<p>Brenda Davis, clinical psychologist, is developing autism services locally. Stage 1&2 care pathway has been developed.</p> <p>No specifically employed autism specialist – but feel existing skills mix is covered/can be provided</p>	<p>Will CAMHS be seeking accreditation for their work in ASC from one of the independent bodies e.g. The Autism Education Trust?</p> <p>Pls confirm this is the case – some concern from parents about this.</p>
? Behaviour network for children with severe behavioural difficulties	CAMHS working with the Council’s parenting team (Triple P courses) and schools to help deliver on this one. Needs further development but they are utilising existing resources, targeting behaviour management strategies in partnership.	
		Why are there not more early interventions services for anxiety disorders/phobias? Paul reported there are a range of services via schools in Tier 2. Parents should contact the

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		<p>school and ask for a pre-referral to XXX service.</p> <p>Alison mentioned there are other CVS organisations out there in the city www.wheretogofor interactive map for YP mental health and emotional well-being</p>
Alternative Help		<p>Diana asked if a YP hasn't been taken on as a referral are parents advised who else is out there – why are there not the right people to help and where else can they go. Tier 2 said they sometimes signpost to other agencies and explain why that service might be better – but acknowledges they could get better at this.</p> <p>Tier 2 suggested often schools make the referral (maybe to start a family CAF) rather than the GP as the school is more likely to know the CYP better.</p>

4) GPs	Feedback given by Kathy Felton, commissioner for Women's and Children's Health	
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	Recent changes from PCT to CCGs are complex. There are 7 layers of commissioning for children's services and a national commissioning board too. One constant thing is that parents/CYP – need to be held at centre of all decisions. The answer is not always straightforward.	
? Consistency of how families are treated – Partnership Charter for GPs	<p>Kathy urged parents to build relationships with their local GP practice encouraging their GP to understand their child's issues better. GPs are independent contractors and to get all of the different GP practices across the city on board to work consistently together will be a challenge.</p> <p>Want to keep getting feedback/solutions from parents – via PaCC – to keep informing planning/development.</p>	
? A route map of services available. Want more information. Hard to find info on line	<p>GPs agreed they needed a route map as not all felt understood all services available out there and routes to</p> <p>Contact a Family has produced some resources for GPs about how to make GP surgery more accessible.</p> <p>Amaze Through the Maze – too big</p> <p>Need to develop short summary for GPs</p> <p>Developing website for all CCG/GPs – will ensure strong section on CYP and will work with PaCC to ensure CYP with SEND material is appropriate.</p>	
? Home visits given routinely to children with disabilities	GPs are nervous about committing to home visits as the equipment they need is often in the surgery. They accept that	

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	sometimes it is appropriate and would help offer this where they felt it was possible/needed.	
? Training for GPs on power of attorney/mental capacity act and responsibilities when young person turns 18.		<p>At 18 GPs take on responsibility for co-ordinating a young person's care from SSV (paediatric consultant to GP) – what is happening to ensure they are ready? This is a priority area in adult services e.g. health assessment tools. Cameron Brown to circulate what's being done about this. We are considering using the Health Passport Form developed by Seaside view with GPs. This could be particularly valuable at this point of transition.</p> <p>Need to train up GPs in Mental Capacity Act – they have a responsibility to do annual health reviews etc.</p> <p>Ruby asked about the availability of physiotherapy when they move into adult services. Jo said there might be a drop off as the YP moves into adult services. No overall co-ordination role. Where a young person has been receiving physio services at the Alex I would expect them to have a transition plan into the Adult Team.</p>

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		Jenny mentioned the roll out of the new EHC plan which will go up to 25 so should help secure input as move into adult services.
? Training for GPs and families/needs of CYP with SEND	<p>GPs need to be skilled up/more expert in some child's care. All GPs attend Protected Learning Schemes training sessions 4 times per year.</p> <p>Agreed to run an adapted Parent Carer Journey training at one of these sessions – bring to life with case studies.</p>	
? A holistic approach needed by all GPs		
? Eligibility for referrals needs to be clearly explained and all communication routinely copied to parents		
? Amaze and the PaCC can represent parent carer views on a city-wide basis (unlikely to participate in PPGs)		
Prioritise appointments for families with CYP with additional/complex needs	GP Localities meeting agreed to help prioritise CYP with complex needs by offering first appointment and separate room to wait if not.	Kathy agreed waiting for GPs for CYP and SEND especially CYP with ASC is not at all acceptable – will keep trying to find solutions. I have a slot to talk about this at the Practice Managers forum on 30 th May.