



PaCConnect on SEND Review – Wednesday 5th November 2014

PaCConnect on SEND Review took place on Wednesday 5th November 2014. The forum was structured into two parts, during the first hour parent carers split into 4 smaller groups explored some of the issues around services and looked at creative ideas to improve those services. On the second hour the forum was joined by three professionals who explained the SEND review and answered questions from parent carers.

1st Part: Parent Carers get together ...

Fiona England (PaCC Co-Chair); Paolo (Amaze Parent Participation Worker); Rachel (Amaze CEO); Sam (Extratime CEO); Michelle (8 yo in mainstream); Lisa (8 yo in mainstream); Jade (was special now mainstream); Diana (1 at Swan centre, 1 at mainstream); Colin (14 yo with statement); Debbie (17 yo with complex needs); Paul (son at mainstream primary SALT); Margo (son at Northeast Manor); Tracey (Northeast Manor); Tracy (Northeast Manor); Martin (Daughter at 6th form, son with diabetes); Caroline (type 1 diabetes, one with severe mental health needs); Pippa (5 yo with downs syndrome, downs view); Mimi (8 yo son with ASC in mainstream); Rose (18 yo at DVLC); Karen (Hillside); Claire (13 yo son ASC and complex at Downs Park); Cathy (mainstream secondary). Sorry if we missed anyone!

A) How could services have been delivered differently (more of/different options) to have improved your ability to cope/build your resilience as a parent/carer or sibling?

EARLY INTERVENTION:

- Back up early intervention with ongoing intervention and more proactive support rather than crisis management e.g. Time Out for Autism course at Seaside View great but when it ends there is no “checking in” service for parent carers; long waits for diagnosis appointments where parents struggle “in limbo”; long waits between diagnosis and courses etc. offered to parents, parents left to “fend for themselves”
- Better and more recognition of need for support earlier on
- Proactive caseworkers/keyworkers
- More proactive advice/advertising of services/voluntary organisations/parent support groups at early stage e.g. some parents are not signposted to individual parent support groups by service providers, they are signposted to Amaze only (although Amaze do then promote other parent support groups where they can)

STATEMENTING/EHCP:

- Don't let child's failure be the gateway to help; e.g. it is highly likely that a child diagnosed with a disability is going to need a Statement/EHCP so the SEN dept. need to work with, rather than against parents on this journey...
- Parents report reluctance to show positive achievements for fear of support being removed. Should be easier to access 'statementing' process BEFORE child starting school
- LA being resistant/oppositional to providing support – change of mind set/culture change needed
- Caseworkers need to be more involved, get out of office, meet/observe each child on their caseload over a period

- Assessment issues Statement/EHCP process – e.g. OT not deeming/needing OT in statement but child actually needs it
- Going through this process is tough on parents already coping above and beyond typical parents so improvements in all these areas would help relieve this added pressure

RESPITE/SHORT BREAKS:

- Accessing social life/skills should be easier e.g. leisure buddies for younger children
- Better support and respite as child gets older/more challenging, physically also
- Respite services are disappearing – stop this – children at more challenging end need better access to leisure – residential overnight services benefits WHOLE family with break/socialising opportunities
- More PA's needed, poor pay not attracting enough though
- More Extra Time – weekends and inset days – i.e. better Outreach support/services
- In home overnight cover where parents suffer chronic lack of sleep with 24 hour care children

OTHER:

- In-home behaviour management, not just office/surgery based – provide in school holidays too
- OT service great but waiting list too long, needs looking at
- Better school transport-home – logistics currently done in isolation of parents' working day, child left vulnerable – who is accountable for their safety? More training needed (for transport providers) Added Parental worry here -no appreciation of wider family needs if child dropped off too early
- Counselling support needed at actual time of crisis
- Person/organisation on call 24/7 for immediate support (not just A&E) if for e.g. child is suicidal
- Crisis support/safe space when in "SOS" situation
- Listen to parents – many feel fobbed off/asked too many times/feel they are not believed/listened to

b) How could services have been delivered differently (more of/different options) to deliver better outcomes for your child?

SEN/SCHOOLS/SENCOS:

- Teaching in classroom not outside of class – SEN code of practice says children with SEN should still have expert input from class teacher, INA's/ 1-2-1's there to facilitate and assist NOT to be the teacher - TA's / INA's too much responsibility
- Raise awareness/encourage and provide training/qualifications for all staff in SEN
- SEN changes/new code of practice needs to be filtered down to SENCOS and teachers
- SENCOS to have better knowledge of support available, not just in education
- SENCOS need to be SENCOS as main job, not second to teaching other classes/other subjects
- Access to I.T. equipment for young people
- Specialist Teachers/minimum standards
- Mainstream – too reliant on Heads to interpret and apply child's statement – advocate or LA SEN dept. should reinforce the statement AS SOON as things start to go wrong (early intervention)
- More understanding of the fragility of first years for child starting mainstream – services need to work with mind-set of EQUAL STATUS for children with SEN/D

RESPITE/SHORT BREAKS:

- Remove presumption that it will be hard to obtain respite - "Good Luck" with that attitude sets up for failure
- More Extra Time/holiday clubs – weekends and inset days as well as school hols

LEISURE:

- Provide more opportunities for SEN children to be part of their local community; confidence can be improved where opportunities for them to “hang out” with their friends are provided
- Youth clubs – need to be more inclusive and also specialist ones needed e.g. Autism Youth club
- Accessing social life/skills should be easier e.g. leisure buddies for younger children

LOCAL AUTHORITY:

- Local Authority to work with parent support groups rather than against – we are not the enemy, we want equality of opportunity for our children, nothing more. Listen and respect us more
- Closer working links with LA and parents

OTHER:

- More consistency needed from individual professionals; children are currently being treated differently, it shouldn't be down to luck that a service is provided or a person is doing their job properly with regard to a particular child
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- Consistent OT/SALT – not just initial assessments – parents need ONGOING support with this
- Support for families who need a lot of extra information and support facilities for this to happen
- Minimum standards throughout LA and areas inside LAs (?)
- Individual services need to work/communicate better together with the child/family at centre of their work – shadow each other? Visit together? Meet more often?
- Professionals to respect each other's areas of expertise and take on board recommendations etc.
- Better understanding that non diagnosis still requires more support than “average” child
- Services need to work WITH parents who can help shape the support they know their child needs
- Better understanding and acceptance of children's mental health issues

C) Have you got any creative ideas as to how the Local Authority (and Health and Voluntary sector) can improve services?**SEN/SCHOOLS/SENCOS:**

- Can expertise in special schools (training, etc.) be offered to mainstream schools?
- Specials schools open at weekends (BHIP at Five Ways was ideal – why did it close?)
- Ongoing / more training for teachers to support children suffering from trauma and depression in schools
- Bring in school transport to be part of the school's responsibility so they manage it
- Open schools on weekend as safe space
- Advocates within schools – can support at meetings etc. [Amaze Information, advice and support service can offer independent parental supporters for parents at school meetings]

RESPIRE/SHORT BREAKS:

- More respite
- A plan to recruit and train personal assistants and support
- Expand outreach services for all
- Expand Extratime, fund it so it can provide more sessions and be open at weekends

LOCAL AUTHORITY:

OTHER:

- It's a short slice of time this young adulthood/ late teens and is precious. I am really keen for there to be small groups formed to share activities and, if possible and where appropriate, bring these activities out in the community. They need not be expensive to fund. I have spoken with an arts therapist, music therapist, and a forest school teacher and they are all enthusiastic about working in this way with my daughter. I would like to find say another 4 young people who she clicked with and make this happen. It could be a simple pilot for other such groups to form.
- Counselling and support for parent carers; it would be good to make it automatic and people need to opt out if they don't need it (not fight for it)
- More funding, not less, as what's available now doesn't meet needs
- Problem: cash (& isolation). Solution: How to put forward salient evidence based information on the long term savings of early intervention
- Clearer system of accountability within LA at executive level with power to intervene when SENCO's refuse to action and implement psychiatrists / clinical psychologist, other professionals clear recommendations. SENCO's are gatekeepers and can have too much power
- Parent support mentor (s)
- 'Just Right' Programme of managing behaviour based on sensory integration and meeting children's sensory needs is being used in special schools and some mainstream schools across the city. Taught to the whole class it is a good means of identifying children who need a more specialised level of input for the OT service.
- Training for parents on managing behaviour at home where patterns of behaviour change is desperately needed. It will give a more consistent approach to managing behaviour and also by teaching parents how to intervene early it prevents that escalation that are then harder to control.
- A "Citizens Advice Bureau" or One Stop Shop for parents going through the 'Statementing'/EHCP process that is completely independent of the Local Authority [this should be what the new Amaze Independent Support service offers]
- Single point of contact for families to provide overview and guidance through the SEN/D "maze" [again Amaze offers information and advice – but not a key working service]
- Baby Speech and Language groups
- Group training sessions for parents alongside professionals with service providers
- Local Offer – "real stories", good and not so good alongside the directory as it currently stands. Rename it to something more obvious/user friendly?
- Individual services need to work/communicate better together with the child/family at centre of their work – shadow each other? Visit together? Meet more often?
- Local Authority could provide advocates for parents, and not just for those with a Statement/EHCP
- SEN Support "for life"?
- Early intervention – give families a lump sum of money to get their own respite [this was purpose of the social care personal budgets pilot –QUESTION: is this being rolled out..?]
- Tailor support to the individual specific needs of the child
- "Supply/demand website" – to use personal budget direct payments so families can find somewhere to go/help for INSET days etc.?

2nd Part: Parent Carers are joined by professionals ...

Professionals: Regan Delf (Temporary Assistant Director of SEND); Jacqueline Coe (SEND Review team); Bob Wall (SEND Review team)

a) Regan introduced the SEND review

Required to review SEND services from time to time as good practice, but also to recognise changing needs e.g. ASC the most prevalent category for statements.

Council has to check they are getting the best value out of all services they are buying – are the outcomes what they need? For example, mental health services inadequate for children yet spending a lot of money on them while at the same time there are raising rates of self-harm in the city. Need to spend money in the right way on the best things to best effect.

Jacqueline explained that Brighton & Hove spend a lot of money on children and young people (CYP) with SEND but not necessary spending in the right way, all historically spent. Need to restructure services to spend it better.

Also new Children and Families Act 2014 legislation – new Education Health Care Plan (EHCP), going up to 25, working more with key partners e.g. health.

Have had an on line consultation survey and also have attended lots of service team meetings to canvass the views/open ended consultations. Quite far along with this 'open ended'/what does everybody think stage.

b) Have identified 8 areas they want to do more work:

E.g. joint commissioning – probably we won't focus on this today, but 3 key areas/ideas we can discuss today are:

1. Provision for CYP is too fragmented across Education / Health / Social Care – parents often say they are their own child's keyworker – as have to repeat their child's stories time and time again. Want a 'tell it once' approach. Concept is whether we can pull provision E/H/SC provision together e.g. integrated service for very complex needs. Ideally in one place e.g. SSV and Extratime – one team around the child – so not separate agencies.

2. Not enough specialist support at home especially around challenging behaviour (helping families overcome the difficulties in an expert way) e.g. expert support to parents with ASC (as well as to school). Need more recognition that behaviour often worse at home than at school also on your own, no backup like at school.

Recognise that CAMHS isn't often the right solution.

One of the parentS (Martin) suggested that mental health of children is deteriorating (nationally) and need to intervene earlier e.g. proactive monitoring of how parents are coping to avoid reaching crisis support. Crisis support not replicated for young people – need to look at this.

Need to help partners in Health prioritise this – Regan met new CAHMS commissioner about improving tier 4 and crisis management.

Parents frustrated that they are often not believed about how bad situation is. One parent asking for help time and time again but respite only provided when police got involved due to child's bruising

Parents want to be empowered to support child, to cope with their behaviour – to reduce reliance on services later on.

3. Looking at transition to adulthood offer post 16 and post 19. Difficult as provision is meant to be extending to 25 but no additional money to provide locally. However, Council starting to look at what options they can introduce. Want to offer more vocational training, routes into employment/sustainable life opportunities e.g. Council apprenticeships, or with local businesses.

4. Joint commissioning – Council buying more services with health in a more integrated way e.g. mental health services

5. Respite – Links into integrated provision

6. Special schooling – There are currently 6 small special schools, with relatively high unit costs because of this. Could we integrate them more? Changes to funding arrangements give funding per place, so if places are empty, schools' finances can be precarious. 430 places currently – average school size 71 pupils. Accept that big is not necessarily better, although for professionals this might be the case.

7. Support Services, including early years provision - 3million budget overall which, if reconfigured, could achieve efficiencies and better outcomes.

c) SEND review timeline

We are moving from broad consultation into 8 more detailed areas. Might refine down into fewer groups – each area has a lead person working on them.

We are aiming to make key recommendations on each area in January'15; out to consultation firstly by Health and Wellbeing Board (councillors, other senior officers) then for wider consultation. Then those agreed would go forward in the next financial year to be implemented. However there are local election in May, which may change the timetable for taking the review forward.

d) Questions from parent carers

Q: New EHC Plans have come into effect – understanding is that should be very specific, needs based. Own experience is that this isn't happening. What recourse is there if parents not happy with new EHCP process?

A: Regan would be disappointed if not happy with the process. EHC Plans are meant to be more outcomes focussed. What's in the plan needs to be written from the advice that's provided by the professionals. We are doing quite a lot of training with professionals to provide better information as outcomes e.g. schools, educational psychologist, CYP, health service therapists & medical. Regan accepts not there yet. Liam introduced the new Independent Support service being provided by Amaze – who can offer help parents who need some support get their views across. Can we provide a high standard EHC plan we can share on the website or even send out good quality one to send out to parents as part of process so know what can aim for/what to expect? Could we develop good examples for each kind of additional needs?

In terms of redress, Council does have to offer mediation before going to tribunal. Three parents who have been through tribunal process had not been offered or been made aware of the mediation service on offer.

Need to improve information being fed out to parents – Jade suggested via the Local Offer.

One parent agreed that the mediation service is mentioned in the letter – could be more up front about talking/signposting about mediation offer

Could we give Amaze more funding to help people who need more support?

Q: Parents left to fend for themselves, if ASC given some leaflets, attend Time Out course, then left on own. Would be great to have someone ring you up once a month to 'check in' with parent before it gets to crisis point? Could be cheap way to avoid more expensive crisis point. Not eligible for respite (higher end of ASC spectrum) emotionally exhausting.

A: One recommendation from the ASC scrutiny report was for all families with ASC to have a key worker to support them. Regan agreed would love to be able to provide this – but resource implications. Should be able to offer advice especially at transition. Some good new initiatives to introduce ASC youth club with Autism Sussex. Also to extend ASC Support Service to offer a service to families as well as to schools.

Q: Where do families with SA/SA plus fit into this review?

A: Now about 7,500 CYP on SEN registers across the city. The Council delegates £14m to schools to meet these needs. Council's responsibility as a council is very much limited to providing advice, support and guidance about how to provide this, as well as training for schools, and specialist support services. Council can no longer really intervene – limited ability. Unlike the Pupil Premium money the schools don't need to monitor the expenditure. Can understand parents wanting more monitoring.

Could we encourage more parent voice about school action provision? Could parents with children with SEND be asking their schools about their delegated funding for SEN and what progress is being made with this, what it's being spent on.

Diana's point about wealth of information gathered for the review – to share with schools so they can also implement/use it to provide better services/support for the SA/SA+ children. Regan agreed a good point and can take on board.

Jade explained that the parents often have some innovative ideas e.g. 3 x parents and children being taught by speech therapist together instead of individual.

Q: What is the amount of money that needs to be saved from the review? How much do we have now, how much can we get, how much can we spend in future?

A: We do know where the money is spent. Part of the review is to look at whether we are getting the best outcome. £14m delegated to schools. No savings target. But government grant which supports councils is reducing.

£20-25m total saving for council per year over next 5 years.

£4-5m savings target for children's services – not prescribed how much needs to be saved from SEND review

What is the proportion of SEND of total children's services budget? Regan will confirm as not in her head. A lot of money come in and has to go straight out to schools. Then biggest spend is on social care/social work, safeguarding, then SEND services.

Very clear not going to get any more money – so if want to make improvements in some areas – need to save elsewhere.

Could some transparency be provided on the financing of SEN – Regan agreed that this should go on the Local Offer. What schools get on SEN and the underspends should all be in public domain. Will look to put on local offer.

Q: What's the difference between a statement and the new EHC Plan? Will all those with a statement definitely be given an EHCP?

A: Main difference is plan can go up to 25. Meant to be more child/family centred and more holistic/more balanced view of their needs. A bit more binding on health than previously) however, still difficult for the Council to require health to provide it). Need to jointly commission services between council and health.

Whenever there is an annual review it's checked whether the family needs the statement/plan. There is a published 'Conversion Plan' published on the local offer. Older children in transition are being prioritised first plus those who had a plan done in the pilot.

Concern from parents experiencing it's hard to get any hours written into the new EHC Plans. Regan replied that there's lots of research done about the number of TA hours meaning CYP gets less time with fully trained teacher. So whilst TAs do fabulous job esp in relation to access, however, if the TA is the person via education input is filtered it's not good for the outcomes of the CYP. So Council not keen for the 'currency' of input/support for child to be in 'hours'. Would rather focus is on the outcomes of child and the attention of the teachers. Don't want SEND CYP to be taught by TAs.

It's not about hours in the classrooms – our children need extra support from start to end of day e.g. before school, in school yard, after school etc.

Specialist help where required – Regan agreed this should be put into the plans.

Colin mentioned that often the support service is providing support to the TA/INA/teacher instead of pupils themselves. Fiona stressed it's essential to ensure outcomes are written.

Q: What external research & evidence is being used to inform review and what research is out there to see what benefits early support has on families in improving outcomes? Have you used this to inform the review?

A: Throughout the consultation we have been gathering a range of research and documentation to form part of our evidence base. We also been delighted to receive additional reports and documents and Amaze and the PACC have been brilliant at making sure that we have all the PACConnect reports, and those that Amaze have published in recent years so that the views of local parents are heard.

Q: Is the occupational therapy service part of the discussion on challenging behaviour? Many of the causes of this behaviour are due to sensory impairments.

A: Health provision at Seaside View is being considered, but this is essentially a council review and we have no direct control over budgets for health provision, as these are commissioned from the Clinical Commissioning Group from Sussex Community Trust.

Q: What provision is going to be made to ease communication for families? Are there plans to improve access to a single point of contact?

A: The need to improve communication for parents is a message that has come out loud and clear from our consultation and this will form an integral thread within any changes that we consider.

Q: What are plans for specialist units?

A: These form part of the review and we will be reporting any proposal for changes in our final report.

Q: Have you specifically consulted with parents whose children are currently educated within specialist units?

A: No, we didn't single out any specific groups of parents in the first stage of the consultation. However, in developing our options for change for the future, we will need to focus in more on particular provision (whatever that may be) and those who access it.

Q: It seems as though a lot of social care provision bundles those that are 18 + in with adults of all ages. Is this something that the government are looking to change?

A: It is largely true that adult social care legislation does not discriminate between the ages of adults over 18. However locally we would accept that the needs of young adults will differ from those who are older. The SEN review is focussed with looking at provision for children and young adults from the ages of 0 to 25. This will inevitably involve a review of what social provision is currently available for young adults aged 18 to 25, how this might be reconfigured and/or improved.

Q: Bob briefly mentioned the focus for the education being on vocational based training. What attention will be given on social and play based activities for those for whom vocational training is not valid in order that they should be happy and well and their needs met?

A: We are not entirely sure what this question is asking. Are you referring to training centres? These may be beyond the scope of this review.

Q: In relation to education up to 25, was consideration given to the age old problems of FE delivering a revolving door type of education simply because the funding structure doesn't fit? And why there is not recognition of the maintenance of skills?

A: This is not an area specifically under review, but we recognise the need for effective pathways post 16 in FE and other provision.

Q: Why did BHIP / Saturday club close? It was an already set up resource which just needed a bit of funding. To start a similar service up from scratch would be much more expensive?

A: Our contracted funding level to BHIP hasn't reduced and our review has highlighted the closure of some of the provision within our contractual agreement. We will be talking to them about this as part of our contract review system.

Q: Why there isn't more recruitment and training for personal assistants?

A: Although direct payments have given parents the option of recruiting their own PAs, we had not put in place arrangements to create a bank of staff for parents to access. We have identified good practice in adult services to develop options better and want to learn from this.