

Notes from meeting with Richmond Parent Carers Action Group (RPCAG) on 15th July 2011 for the SEN Task Group Review.

Those meeting RPCAG from the SEN Task Group were:

- Cllr Blakemore (Chair); and
- Cllr Chappell

Cllr Blakemore passed on apologies from Cllr Day who was not able to make the meeting.

Action: The representatives from RPCAG asked that these notes be fed back to Cllr Percival and Cllr Hodgins. The members of the SEN Task Group said that they would feed them back.

NB: Representatives from RPCAG felt that there should be an input from health services into the review.

Historically the London Borough of Richmond upon Thames had a large number of SEN related tribunal cases. In May 2007, the UK Government published a report *Aiming High for Disabled Children: better support for families (AHDC)* which was the culmination of the Disabled Children Review.

One of the corner-stones of the policy was to encourage and help fund parent forums to give parents of disabled children a voice in local empowerment mechanisms, foster better relationships between service providers and parents and allow parents to contribute their expertise to help shape services.

RPCAG was established in 2007 and facilitated by Contact a Family. It was established by parents of children with additional needs due to concerns about the lack of support they received and in order to help influence the development of services provided by the Local Authority for their children. RPCAG is affiliated to Me Too & Co which supports RPCAG with their administration facilities and expertise.

RPCAG is *the* official forum for additional needs and has a good relationship with the London Borough of Richmond upon Thames (due to the work of council officers). It has a website and facebook page where it shares information and provides support to parents of children with additional needs.

Representatives' personal experience and views:

Please note: This has been anonymised as much as possible to protect both parent and child as this will be attached to a publically accessible document in the final report.

Representative 1 (J):

J's child attends Linden Lodge, has global developmental delay and Cerebral Palsy. The reason for his involvement in RPCAG is concerns about the provisions for children with disabilities and SEN.

J said that in his opinion there had been no effort to improve the facilities at

Strathmore as the focus was on inclusion. J's child goes to a school out of borough the journey takes 1 ½ hours each way (total travel time of 3 hours per day).

J has concerns about the end of school (transition), residential respite payments and that in his opinion the educational psychologist is pro-inclusionist but does not fully consider the wide spectrum of needs to the detriment of those who do not fit into a mainstream environment.

The main source of holiday support comes from the Croft Centre. J said that he is able to cope but there will come a time when he and other parents will not be able to. Respite is a serious need for carers as is portage.

Representative 2 (M):

M's child is 6 years old has autism, severe learning difficulties, global delay, and epilepsy and attends the Russell School.

In M's experience, no one explained the statementing process and M had to find out about it herself. She and her child did not get a judgement from an educational psychologist for 4 years and only managed to get one because she pushed for it.

The statement was not changed by officers to accurately reflect her child's needs and no annual review took place nor was there a progress report. M was not informed and therefore did not realise she had to request another review in order for things to move forward for her son.

M has not seen the Head teacher at the school to discuss her child's SEN needs, she has not had input into her child's education: Her son is on the PECS programme but this is not an effective method for him. M said that he responds very well to intensive interaction and that this would benefit him at school but the school has not discussed his needs with her.

M said that in her experience there has not been continuity of staff supporting her child and this was due to a high turnover of staff at the school: One SALT went on maternity leave and was replaced by another who then also went on maternity leave.

M said that her child was not able to pull his trousers up on his own but since teachers from Strathmore school have been teaching in the school her son has been able to do so. Their input into her child has made a massive difference to him.

Representative 3 (B):

B's daughter is severely mentally disabled, has Severe Learning Disabilities (SLD) and problems with dexterity and co-ordination. Her condition results from Myelination being delayed. B said that his daughter cannot speak but is able to communicate through sound and has a minor grasp of PECS. B said that he had a similar experience to M in that he does not see the headteacher, no face to face contact, little communication and no feedback. B recognised that the lack of communication between parents and the school is because children are being transported to school (by the council) and that therefore, there needs to be a

different method of communication.

B said that there is not an equal extended schools provision for children with SEN and the extended schools provisions that exist in the borough are not accessible to children with SEN. In his view the council is not doing enough to encourage or promote it. Many of the borough's extended schools provisions are sport based which is not suitable for many children with SEN. B said that there is a disabled basket ball club but this takes place at 5:30pm - if a child is schooled out of the borough they cannot access it as they will not have returned from school in time for it. This is exclusionist rather than inclusionist.

B said that the school his daughter goes to is a specialist school but apart from a one week provision for younger children the school does not offer anything.

B said that it has been up to parents to sort out for themselves and their children these kinds of activities

Representative 4 (Se):

Se' daughter is 8 ½ years old, has Pallister-Killian syndrome, is visually and hearing impaired, wheelchair bound with severe learning difficulties and epilepsy. Se's daughter attends Linden Lodge. Se said that the school (which is out of the borough) is run like clockwork and is a fantastic provision because of the headmaster, things are filled into the book every day and they receive pictures of their daughter at school so they are aware of what she is doing and how she is progressing. Se said that she school is very progressive and they currently have a new curriculum specialising in the aurally and visually impaired. She added that all the children love going to school and the escort that accompanies them has been with them for 2 years.

Se said that when her daughter was diagnosed it would have helped if there had been more information available and easy to access. Se said that she has also experienced a frequent turn-over of therapists in relation to her daughter's care.

She said that whilst specialist schools have the knowledge it is much harder for this to be accessed in the mainstream setting. She said that if there was a health specialist on site, they would be able provide that knowledge.

Se described the experience she has had with the OT: her daughter's wheelchair is too small and it took a year and a half to get the correct chair for her. Se said that this was normal because the resources and co-ordination are not there.

Se added that for children with SEN it is sometimes necessary to **adapt the house but that because officers have not had the requisite training** they do not understand, planning applications can be blocked and it takes a great deal of effort to get it pushed through.

Se said that in terms of summer provisions there is the Tree Tops residential unit which is attached to Linden Lodge. She said that last summer Children Services cancelled their provision but this year are running it even though they said the previous year that they did not have the money to pay for it. This type of thing creates more stress for parents as they have to source for themselves summer

provision for their children.

Representative 5 (SI):

SI's son is 16 years old has moderate learning difficulties and autism and attended the Gateway. He moved from Freemantles School to the Gateway which proved to be beneficial. SI said that the Gateway has a big SALT provision but not for young people aged 16-18. SI's son still needs SALT and is now going to W. Thames College. SI said that he was going to W. Thames College because the courses offered are more vocational and they offer BTECH foundation and level 1. In terms of travelling, he has had travel training and has had the experience of travelling on the bus by himself

SI said that in she thought everyone should have this type of training and that al the pupils at the Gateway had this. She added that her son has had 2 years work experience. She said that **parents of children with SEN have to be more resourceful and push much harder for their children;** nevertheless, *every child* should participate in work experience.

Representative 6 (Je):

Je's son is 5 years old, has autism and is currently at the Buckingham Unit (in borough).

Je said that whilst her son has been at the unit there have been 3 SALTs. The first SALT was excellent and had intensive interaction with her son which helped him but she left after half a term and his progress subsequently declined. The third SALT has also left and her son has been without one for 3 months. Je asked the teacher why there had been no therapist available for 3 months and was told there was no therapist available and when Je asked why this was she was told that the teacher did not know as the head of therapies was not responding to her calls. Je then contacted the head of therapies and head of SEN herself and made an official complaint. Finally she was told she could have a SALT but they were newly qualified and had no experience of autism. Being aware that there was a qualified therapist at Clarendon Je asked if that therapist could also work at the Buckingham unit. This was agreed. Most importantly, what Je wanted to point out was that the only reason this action had been taken was because of her position at RPCAG and the contacts she has. This should not have been the case as it is a legal requirement to provide SALT for these young children.

Main points to come out of the information shared by representatives from RPCAG:

Re inclusion:

- ◆ Needs to be **more training for Learning Support Assistants.**
- ◆ **Learning Support Assistants need to be more focused on the child's needs.**

- ◆ Criteria for Learning Support Assistants need to be looked at and the overall standard needs to be raised.
- ◆ **GPs should have more involvement and input in decisions relating to children with additional needs**, particularly those with severe and multiple needs.
- ◆ There is room and need for **inclusion into mainstream provisions** inclusion **would be better and more effective if specialist units were attached to mainstream schools**.
- ◆ **Behavioural support is not properly addressed in the borough and more needs to be put in place** – proper measures and support. There also needs to be recognition of the fact that this is the case. Children with Asperger's tend to be excluded from mainstream provision as mainstream schools do not take this into account.

General concerns and wishes

- ◆ Representatives of RPCAG feel that there is little investment in the specialist provisions within the borough (particularly Strathmore) and that the strategy has been for the council to invest in inclusion in mainstream provision, not to support specialist provisions, which are needed.
- ◆ **Information about services and provisions should be in one accessible location rather than spread out.**
- ◆ **Lack of continuity and retention of key workers for the child.** The turn-over or constant changing of staff in particular OTs, SALTs and social workers, is disruptive to the progression of children with additional needs. The representatives from RPCAG felt that perhaps it would be better to have older and more experienced staff that are well paid working with children with these kinds of needs because continuity and consistency are very important for children with such needs.
- ◆ **Lack of effective communication:** More information and better communication of what the process is and how to access help and resources is needed. This information should be available from a central source Many felt that Richmond upon Thames' website is not a helpful or easy tool to access information with (the lay out and ease of finding information). Effective communication and support particularly at the beginning stages is essential as it makes a massive difference to parents and their ability to cope.
- ◆ **Lack of (face to face) contact between staff at the school and parents and lack of parental input.** Many said that they would be happy with regular 10 minute telephone conversations, ideally 3 times a week, with the school to discuss their child and to receive feedback. There may be things in the home environment that parents do not realise affect their child's performance / behaviour at school and being informed could help alleviate some of these issues. One way to do this would be to video the child, assess the behaviour

and send the recording to the parents at home so that they can see it and if required make changes in the home environment. There may be things that are done in the home setting that would be helpful in the classroom but without input these things are missed. **Parents feel that they are distanced by professionals from their child's care and have to fight to see professionals.**

- ◆ **Lack of educational psychologist involvement in the child's care** – It is in RPCAG's view detrimental to the child if they are not seen regularly by the educational psychologist. The educational psychologist sees them once at the beginning but experience has been that educational psychologists are not seen after that. They are supposed to attend annual reviews but they do not appear to do so.
- ◆ What will happen to Children with additional needs when Richmond merges? Will parents be able to access the provisions? Will there be funding issues? If for example the child goes to a school in Hounslow is the child still classed as out of borough?
- ◆ **If services are outsourced and outsourced to businesses, there are concerns about the quality of service, accountability and the ability of the local authority to monitor provision. Will the voices of concerned parents be listened to and heard if this is outsourced?**
- ◆ Personalisation I, particularly personalised budgets – **many parents** do not want to manage the budget nor have the time or expertise to. They **want more of a say in how services are provided not to manage the budget.**
- ◆ Personalisation II – **Schools need to look at what works for the child not make the child fit around what works for the school.** Tailor make the learning process to the needs of the individual child.
- ◆ There is a **far greater representation / better representation for children with physical disabilities compared to other additional needs** as it is easier for them to integrate into the mainstream.
- ◆ **Lack of effective diagnosis and appropriate planning for children with autism or learning difficulties such as dyslexia and dyspraxia.** Many children with autism are unable to remain in the borough unless they are high functioning.
- ◆ **Lack of adequate provision of SEN schools in borough.** Strathmore School - the physical building is not safe. Some representatives said that they would like a provision like Linden Lodge in the borough.
 - ◆ In borough provisions:
 - The Croft Centre is a special needs centre for the borough and the portage service is situated there. **Portage is a very important service especially for the under 5s and needs to be built up.** The portage service is losing its premises and parents are concerned they will lose the provision all together

Concerns about it potentially no longer being at the Cross Centre.

- Small Steps is an out-of borough provision but is considered by RPCAG to be an essential provision; it is attached to Green Meade and helps parents to help children who have cerebral palsy or other forms of motor and sensory impairment.
 - National Autistic Society holds regular meetings and provides workshops and talks. They provide OT, dance and movement and SALT. It is currently located at Heathfield Children's Centre. Concerns about its future there due to funding.
- ◆ Concerns about the **future of the current in borough provisions given cuts to funding and the councils move to become a commissioning council.**
 - ◆ **Lack of support:** Parents feel that they have to fight for all the resources their children need which adds to them feeling isolated and not supported.
 - ◆ **Lack of Secondary School provision:** the lack of secondary provision needs to be addressed. Parents would rather keep their children within the borough but cannot / do not do so as they do not feel the provisions are there.
 - ◆ **Transition:** concerns about their children and their children's future post school in terms of finding work, care and support.

RPCAG would like:

- ◆ 2 SEN secondary schools one for multiple and profound needs and one for children with moderate learning difficulties.
- ◆ Educational Psychologists to be brought in at the very early stages and for them to be attached to specialist units.
- ◆ Provisions should be up until the age of 19.
- ◆ Accessibility and more input for and from parents.
- ◆ More disability awareness training amongst mainstream schools, colleges and within the specialist provision.
- ◆ Better catering for children on the autism spectrum.
- ◆ Holiday provision and extended school provision that takes into account that a large number of children travel out of borough to attend school so normal times are not workable.
- ◆ Training for council officers in relation to SEN and how it can impact on day to day requirements such as house adaptation.