WSoA Listening Event 7th July 2022
Preparation for Adulthood
Questions and Answers

1. Is there strategic planning in place to look at enough suitable independent living facilities for those with Cerebral Palsy (wheelchair users) and those with complex medical needs?

   Garry Parvin responded
   We are commissioning new developments all of the time and have a big commitment to this. There is an event called South Yorkshire Market Position Statement at New York Stadium and that is the commitment that we need to develop more supportive housing and supportive living. Part of that is making sure that housing is developed to a particular standard, being accessible and sustainable. Rotherham is presenting a cabinet report in September about how we embed this.

   Helen Sweaton added
   We are working very closely between childens and adults to maximise the learning opportunities, particularly for the younger adults with very complex health needs to try and reduce the number of transitions that they have to experience. We're looking at some of the learning that adults have, around providing provision for adults with very complex needs. We are looking to see if we can start that when a young person needs to transition, rather than then having to transition into something that is specifically childrens and then transition into adults. We have been piloting this scheme and it has been successful. We are working closely with provider to see if we can extend OFSTED registration so it can be used in a safe way and a much bigger footprint than the pilot scheme. It is a work in progress and we aren't where we want to be yet, it is happening nationally, and we are being innovative as there isn't a blueprint to follow. We very much welcome ideas and feedback to help us develop in that area. I'm not aware of anything specifically for young people with Cerebral Palsy but it would certainly apply to wheelchair users and people with complex health needs.

2. I have been informed that if young people are fully NHS funded, they cannot have access to social services (even though this is where the independent living speciality is). Is this correct and if so, can you explain the reasoning behind this?

   Helen Fisher responded: If someone's fully funded, then it would be health that's leading the support but that doesn't mean that they can't access any social support. If it is relation to supported living, we have linked in with CCG and supported CCG to source appropriate independent living.

Helen Sweaton Added: If a parent carer has had a specific difficulty, then I am more than happy for them to contact me then I can liaise with colleagues

3. I would l like to see joined up childrens and adults' services across education and health care, are there plans to implement this? Other than joint commissioning, where is it in practice?

   Helen Sweaton responded: What we're working to create are services that have a seamless transition. My interpretation of a joint service is a service that both adult and children access. Because the adult population is bigger the childrens element then struggles for capacity. For example, we're currently working with end-of-life palliative care, there was a proposal that we made the joint services with children and adults accessing the same service. I'm against that as it will reduce the amount of service that's available for children and young people.
   I'd like more context about the question; is it a specific service?
   We are working to link the services between adults and childrens so there is a seamless transition and you don't have to be reassessed.

   Jayne Fitzgerald commented: When we're talking about joint services, we're meaning health social care etc, but we can get clarification.

   Helen Sweaton commented: I am working with Jayne Newton who is responsible for the continuing health care for children with very complex health needs to make sure that we have a good interface between the health service and local authority.

4. How do you plan to communicate to young people and families what is available in health education and social care so we know what is available? other than the Local Offer where unless you know what you are searching for you can't find information on?

   Garry Parvin responded: There is the local offer which was flagged in the written statement if action. We're also working in the adult side and making sure its updated and correct. We are aware that there is still more work needed on The Local Offer, the new things that have been added are quite impressive. Once we get it into being a living Local Offer the interaction will be more accessible and the interaction on there will make it the best in class. I appreciate that people want to see more than the Local Offer but it is contributing to the wider source of information available.

   Harry Clarkson commented: The "My Front Door" webpage pulls together a lot if information around adults and adults with learning disabilities or autism. I looking to try and do it in a phased approach, and to get it done quickly, I want to get providers information on there as quickly as we can. So, people can go on there and get information on the options available for them. I'm also keen to add some success stories in there, we have some amazing stuff going on in Rotherham but it's not being showcased. I think it would be a help to everybody to be aware about the good stuff that's going on.

Once it's launched properly, I'd look to get feedback from community groups, professionals etc to find out where the gaps are. I hope that we'll be able to link it with the Local Offer then online you'll be able to map out a pathway for people.

Helen Fisher commented: I note that the question says other than The Local offer and makes reference to that unless you know what you're looking for it's difficult to navigate. Whilst we've been looking for a central place for the information, maybe what we should be looking as is how accessible that is. If people are finding it difficult to navigate that's where we need to start or and see what other alternatives and sources of information would be of benefit to people. See what barriers there are to the local offer and or see what people would like to see.

5. As not all schools communicate well with parents, where can parents find more information on what should be happening regarding PFA in schools and colleges and when?

Julie Day responded: We should be working closely with schools to make sure that SENDCO's feel empowered. Some of the SENDCO's are telling us that they don't know enough about what is out there. Schools can commission all sorts of career advice for all children, not just those with SEND. We need to use some of the forums that we have already to provide some generic strategic messages, we have the SENDCO network forum which we're trying to gather momentum with and make sure that there are meetings that SENDCO's cannot or do not want to miss. We had one recently and Kevin Rowland from D of E attended to pass on some messages. We need to bring the right people along to talk about effective reviewing, effective Y9 transition planning review. Getting all the right people around the table; making sure it's person-centred planning, getting appropriate decisions around who's going to support that young person. With the family to understand what the pathway is going to be into the rest of the school life and into adulthood. We do need to work more closely with our SENDCO's and the SENDCO forum is a positive first step.

Helen Sweaton added: Do we look at how else parents would like to be communicated with because we do rely on schools to send out a lot of information. If parents are saying that some schools don't do this quickly or accurately enough is there another mechanism that we can use? if there's another distribution list? If there is, then it would be helpful to be able to use it.

Julie Day added: Linked to that we do have the schools SENDCO's email addresses, so our specialist inclusion team who facilitated the SENDCO network event can now email them. As a result of the event, they now have access to the SENDCO Padlet, which is a central information hub but can also be used for messages, so there is an opportunity to use this. I'll take that back and discuss how we can understand what pieces of information we can share with SENDCO's that can go on the padlet as the first next step.

Jayne Fitzgerald commented: The Y9 review in the code of practise about PFA outcomes, maybe use the SENDCO network to have a push on that. How are we measuring that? What difference is it making in terms of a young person in Y9? Some schools are doing it earlier and there's already some good practise out there. We need to see what barriers there will be against a PFA focused review and get the feedback from SENDCO's so that it does happen.

6. What is PFA? and what should I see happening at what stage? is there a process or flow chart? workshops would be helpful.

   Helen Sweaton responded: Garry referenced that we are developing a quality assurance network and in order to develop that we did some limited engagement around to identify what are the priorities around Rotherham. We looked at what people expected to happen and what we did get from the feedback was that people would like flow charts to be available online, a website that when they hover over things it would take them through the PFA process. It will be a while before we have the capacity for the council system to host that let alone getting the time and capacity to develop it. What won't be a challenge is to use the information and feedback that we've got to develop a flow chart that says what we expect. We can get that communicated but going back to the last question need to see how, if via the Local Offer we need to make the information more accessible.

7. Where and how can we find better SEND information about colleges and schools for year 12 and 13? They have to stay in education but it's so hard to find any information out as a parent or young person living with additional needs about what's available.

   Julie Day responded: The perfect scenario is, is that the setting has a detailed piece of information on their website around how they support vulnerable learners. Schools have to have a SEND school information report. If there is a 6th form in the school the reference has to be in the SEND school information report, the titles and information that should be in the report are detailed in the code of practise. All of those reports and the information from post 16 providers should link to the Local Offer. It would be further exploring on the Local Offer to find the information from the post 16 providers so that parents and young people can see what's happening.

8. How can you ensure that parents and young people can see a clear pathway based on need within PFA?

   Helen Sweaton responded: The EHCP should do this, I'm not sure that creating another thing would be helpful, but I am interested if anyone has any other ideas. Particularly if parent carers have any ideas what we can do whilst the improvements to the EHCP process are taking place.

9. How important are hopes and aspirations and how are these gathered and included in planning for the young person?

   Garry Parvin responded: The EHCP would be a fundamental document there.

   Kristie Denston added: One of the central parts of the care act is wellbeing, hopes, aspirations and goals, that is our starting point and is as individual as the person is. We've had a young lady who aspired to be an actress and a young gentleman who wanted to be a professional plane spotter. They now both through action, planning and support have the professional routes for their aspirations and dreams. It's the central theme and is very much in the forefront of social cares action, planning and support with young people, their families and networks.

10. How does RMBC/CCG support young people who want to go to university and whilst at university?

    Kristie Denston responded: The young lady who wanted to be an actress did attend university. We reached out to local networks and equivalents in our services in the area that she wanted to go away from the family home. Universities have increased pastoral and specialist support; we will openly and freely work with those support services in good time, to implement services that would mirror those which would be available in the local area. It will be strength based and down to individual needs, goals and aspirations at the time.

    Jayne Fitzgerald commented: The last few questions are all around communication. People know what services they are there once get to university. It's how we as a local area are giving that information early enough to young people with SEND. Communication is a theme so maybe we should look at some kind of strategy around how we are sharing that information.

11. How are GP's informed when care goes back to them at adult services? The impact on parent is that they then become the keyworker again and young person and parent loses independence.
    Are there any plans to implement robust transition in health services from childrens to adults that mitigates the impact on the young person?

    Garry Parvin responded: There are programs of works around transforming care, which is principally around people with learning disabilities although, the remit has been expanded to include autistic people. There are some key aspects of a national programme of works, one being the enhanced health check with autistica, they're linked with the University of Newcastle and are doing research about that. There are these programs to make sure GPs are able to play the role of co-ordinating around health. We are doing some work as part of the WSoA looking at complex medical and mental health needs, around those pathways GPs will be playing a significant role. We are working with primary and secondary care to ensure the transitions are as smooth as possible.

Catherine Hancox commented: It's worth bearing in mind that not everyone with complex medical needs has autism as well and what happens to those cohorts that don't have a diagnosis of autism?

12. How do families find out about social care criteria in adults which is very different to childrens services?

    Helen Fisher responded: It's a challenge for us but for now there is the Local Offer. There is the adult's that people can navigate but you have to be on the adult's website, there is no natural link in. It makes you aware if you may or may not be eligible and what we probably need to be doing is being a bit more prescriptive around it. In terms of eligible needs in the care act it's not as black and white as we would like it but there is key information within the care act that's easy to understand. Parents of a young person don't know what they don't know around the care act, what we need think about is simple information on the Local offer and adult website to at least to be able to give people an understanding around that. For the young people that we are working with it probably needs to be part of what we do, early on in the conversation and to start the conversation around the eligibility being distinctly different within adults. I think it comes as a shock for people, and it's about putting some information on the Local Offer and on the adults website. Then we need to think about if we are having those conversations early enough both in CYPS and adults around the different eligibility criteria.

13. Is there a strategy for RMBC to ensure that all aspects of transition in every area of a young persons life is covered to avoid a gap in service provision and avoid our young people falling off cliff edges and ending up in their bedrooms out of education employment or training?

    Garry Parvin responded: A strategy needs to be considered and developed; we need to think of it in the wider context with the PFA board.

    Helen Sweaton Commented: It's definitely something we need to think about. As a council employee a strategy means something very different when you work for a council. A strategy and policy are something that's owned by cabinet, it's not a decision that any of us would be able to make, we would have to escalate it. It's not an officers decision if we have a strategy or policy, these things have to be collectively agreed by our cabinet members and the leader of the council. It's something to think about in the board whether parent carers do want and if it's something to propose for our elected members to consider.
    Separately to that and the bigger issue that lot of people are telling us if that:

    A: they're not aware what should be happening in terms of preparation for adulthood.
    B: What we're doing to make sure that what should be happening is going to happen even if we know that it's not happening now.

There is a lot of work around that and the WSoA does give us some very clear priorities but that's by no means all of the work that's happening. I think it's worth thinking about when the PFA board meets; the action plan that it's working on; the documentation that highlights the reports; that comes through that demonstrate the work that's happening and what we're aiming towards; what our outcomes are in terms of the board, how we communicate those in an appropriate way. I think that they're aligned but two separate conversations, that is an officer thing and that is something that we can get on with and do. I don't want to promise people that we can have a strategy when there's no one that can agree to that at the moment.

Jayne Fitzgerald commented. I have had that conversation with a parent, it's very much a strategic vision that we're all partners, as families and young people. What it's related to everything we've spoken about before, flow charts, information. Having that common vision PFA for children and young people with additional needs in Rotherham. Bringing all of the information together and making sure that it's reflected in lived experience, current experience and what people know about what the Local Authority is doing for PFA.

Garry Parvin added: Where are parents getting the information from? What sites? It's important for us to know where to target some of this work, is there something we can do quickly to bring things up to speed.

Claire Callear commented: As a parent of a 13-year-old ASD son who has an EHCP who goes into Y9 in September I have heard nothing regarding PFA. I would have expected the communication to come from school but it hasn't. The only reason I know about PFA is because of my involvement with the forum. There will be many parents like me who would otherwise know nothing about PFA and aren't getting information passed on to them. The link between the SENDCO's being given the information and passing it in to parents is broken.

Action Point
Jayne Fitzgerald and Garry Parvin agreed that RPCF will carry out a consultation to find out where people are getting information from regarding PFA and how accessible the information is.

Websites mentioned:
https://www.autistica.org.uk/
https://www.rotherhamsendlocaloffer.org.uk/
https://www.rotherham.gov.uk/homepage/33/my-front-door
https://www.employmentisforeveryone.org.uk/