



Rotherham Charter

The East Riding of Yorkshire

Appendix: VOICES Narratives

10th July 2019



Contents

Pages

3	Young People
7	Parent Carers
17	Schools and settings
25	Local Authority Education
38	Care
51	Health

East Riding Narratives: Young people

7 young people with special educational needs and disabilities (SEND) attended ranging in age from 17 to 24.	
Going Well	Could be Better
<p><u>Key narratives</u></p> <p>Young people feel there are specific settings in which they are made to feel welcomed and cared for because adults are approachable and there are other young people with additional needs</p> <p>Being able to have a say and make decisions helps young people to feel valued and included</p> <p>Having time to meet with other young people is important</p> <p>Friends can help young people have a voice</p> <p>Team activities can help young people to develop relationships together and provide spaces to communicate with others</p> <p>Having an established school council allows young people to feel they are partners in their school or setting</p>	<p><u>Key narratives</u></p> <p>There are times when young people feel they are treated differently</p> <p>Support children and young people in having the confidence, not just the opportunity, to speak about what they want</p> <p>Young people want their voice to be heard</p> <p>Young people do not feel included when they experience separation from their peers</p> <p>People don't always know how to speak to young people</p> <p>Young people wanted people to work with them when planning transitions</p> <p>The young people are concerned about future career opportunities and better support and understanding of needs by employers</p>
WELCOME AND CARE	WELCOME AND CARE
<p>Young people feel there are specific settings in which they are made to feel welcomed and cared for because adults are approachable and there are other young people with additional needs:</p> <p>"Never welcomed before until coming X school. Coming to X was an eye opener 'cos I finally find a place where I feel I belong... [they were] just friendly, kind and they're approachable. I know that I can talk to any of the staff members... it's</p>	<p>There are times when young people feel they are treated differently:</p> <p>"The treat us differently... they treat us like we are not actual people. They treat us just different to them but we're not, we are still human at the end of the day and sure we have a few problems but it doesn't make us any different from you or I... we just need that extra little bit of help. It feels quite hurtful to be fair";</p> <p>"[Are there any other things people do that</p>

<p>just a nicer place than I have ever been"; "[I was] welcomed to X... I was having problems in mainstream schools and when I came to X I felt a lot better but at first I was worried that I wouldn't fit in 'cos I thought that other people might have different disability but I have found out it is a good place. <i>[What makes it good?]</i>... A lot of students there have got different disabilities and needs. <i>[Does it feel like there is a mix of different people?]</i> Yes. <i>[And does that feel like a good thing?]</i> Yeah it is"; "[Do you feel like you meet people who really care about you? And what are those people like?] The staff are always there to talk about anything you may need to say. <i>[So do they feel approachable?]</i> and I know that X is always there to talk about anything you want to talk about"; "Everything is going alright with me [currently] 'cos it has just been a whole new experience of joining X"; "Best move I have ever made... and I have been to a lot of schools."</p>	<p><i>make you feel different?]</i> Like when they stare at you and look at you... it makes me feel a bit uncomfortable"; "I was kind of isolated in school but it is difficult to see how the school could have changed it because I don't want them to say, 'Oh everyone has got to talk to X' 'cos then that is singling me out, do you know what I mean? I don't want them to go over the top to try and do something and really singles me out."</p>
<p style="text-align: center;">VALUE AND INCLUDE</p> <p>Being able to have a say and make decisions helps young people to feel valued and included: "...I moved to X a couple of years ago and when we were planning my care for X the social worker and the people involved made sure that I was heavily involved with it and organising what I felt like I needed... I was always in the meetings, we had quite a lot of meetings and I was always there and we er had meetings before hand to talk with the head of the faculty and all sorts of people from X... the disability support team... all sorts of different people were there..."; "... [the meetings] it has helped because it has meant that I could get what is most</p>	<p style="text-align: center;">VALUE AND INCLUDE</p> <p>Support children and young people in having the confidence, not just the opportunity, to speak about what they want: "I didn't have such a good experience at school... I always had an opportunity to speak but when I was younger I didn't perhaps have the confidence to speak out... in school I was quite isolated but now I have moved on from school it is a lot better and I am a lot more confident"; "...one think I noticed is that you make friends very early on and even the first few days and the first few weeks can be important to who you stay with and so I think that was... and when I first went to school and I was quite shy or something and</p>

appropriate for me [...and you got to say what you thought was right for you?] yes"; "...just recently me, x and y planned a trip to The Deep and we actually planned it ourselves. We had to decide the entire thing, where we were going, how we were going to do it... what we wanted to eat. We decided that ourselves. We had to organise the entire thing. [How did that feel?] Brilliant! It felt like you had control"; "...X, Y and Z helped us with phone calls and stuff. The majority of time we organised the stuff."

Having time to meet with other young people is important:

I am always included when I go to X youth club because there are a lot of different people who I can interact with. [Are there any other ways you feel like your opinion is valued?] They actually listen to us, 'cos my school was a bit like X's school... but most of the time I was bullied and put down on the ground... but when I went to X I got a chance to speak out and meet people I might have never met before."

I didn't talk to people and then everyone got into to their own groups... [How could that be made better?] Maybe if they did some sort of assembly about awareness or something like that."

Sometimes young people do not feel their voices are heard:

"...before I didn't [have a good experience]"; "[Has anyone else experienced people talking for them?] Yeah. It was a like a member of staff always talking over me and they were just there butting in all the time [...so people interrupting you?] Yeah"; [Were people just saying what they thought you should have and do?] Yeah. [And how did that feel?] I felt scared, I felt lonely."

Young people do not feel included when they experience separation from their peers:

"...most of the time I was kept away from the other student's because staff literally thought that I was dangerous to the other students so I was always kept away, always kept out of the classes, never got to decide something for myself... so most of the time I just used to leave school, just when I got the chance just go. [Did you feel separated and isolated?] Yes I was put in a room by myself with two other staff members who just sat me down at a desk with some work... [and that is different now?] Yes. I am in classes and I enjoy coming to school;" "...maybe for people who are not as confident at socialising like me, they could be given comfort and support rather than being left in a corner"; "[how was that process of moving schools?] It wasn't fun cos every time I made a friend I had to leave so at one point I just gave up and just didn't say anything to anyone ... At one point I just stayed in the house for two years and that really affected me. [So that moving around a lot] it wasn't good"

COMMUNICATE

Young people want their voice to be heard and appreciate when it happens:

"...but now I am with a different CAMHS [Child and Adolescence Mental Health] worker it is a lot better. [What has happened? What was that change that...what has changed?] Well, my medication wasn't always sorted out properly but now it is 'cos I could speak my mind and tell them what was wrong. [Because you were able to say what you thought?] Yeah, they managed to sort my levels out completely and now I am just level... [Were you given an opportunity to be heard?] Yes. [Having an opportunity to say what you think, is that important to you?] Yes, because you can't have someone speak for you to truly get what you need... you have to speak for yourself";
"Just to treat you like a normal person, treat you as the same basically, be treated as an equal because we are all equal. It doesn't matter where we have come from, what disability we have, we are all equal at the end of the day and we all deserve to be heard."

Friends can help young people have a voice:

"...one of my friends around me she always stood by me and she gave me the voice to speak out... through High School having my one friend helped me through a lot."

Team activities can help young people to develop relationships together and provide spaces to communicate with others:

"...we had done out door changes where we had to work together. Team building activities [How was that?] ...it was fun. Also communication. Yeah communication,

COMMUNICATE

People don't always know how to speak to young people with disabilities:

"I feel that a lot of people they don't know how to talk to people with disabilities. Like they don't... not like they would talk to anyone else. They feel that they have got to be in some different way or... I don't know how to explain it...";
"...like mainstream school, they need to get a better understanding, they need to understand better to help us and also the general public, they should understand more as well... so they should know how to act with us not treat us differently... so more people having more awareness"
"[What are good ways for people to talk to you? What would you like when people are trying to speak to you, to find out your opinion?] Just be kind and respectful [...and what does that look like?] Talking to you in a manner that they would like to be treated";
"[What would it (talking to young people) look like when it is not done well? What would you not want?] Aggressive."

team building, everything. *[So was it good to have those activities to do together?]*
 Yes. It helps you get to know people...
[spaces and opportunities] to mix with other people."

WORK IN PARTNERSHIP

Having an established school council allows young people to feel they are partners in their school or setting:
"[Are there any places where you feel included and that your opinion matters?]
 The student council";
"[You mentioned school council earlier and is that something that makes you feel like you are working together?] Yeah, 'cos we have all got our own opinions and we all got listened to and then we all discussed it.
[And do the things that you offer, the things you want changing, do they change?] Yeah, 'cos like we've gone to non-uniform in September and I put the idea ahead and we all talked about it and it went ahead so we have gone non-uniform in the school in the sixth form."

WORK IN PARTNERSHIP

Young people want people to work with them when planning transitions:
"...when I leave school next year I want to go to college, so it would be helpful to have people to help me with that transition [What kinds of things would they help you with?]
 Well... managing finance and things like that";
"...things are going well, I just have to think about what the next stage is... I have got to think about what I have got to do next. That's the hard part. It's always changing and... [...and so that moving on is an important stage... and what would you like people to do to help?] Just be there for support , just help us out with any problems, be there for morale and mental support."

The young people are concerned about future career opportunities and better support and understanding of needs by employers:
"It can be difficult, especially when you are trying to find a job or something, not many people will take you on, which I have had from many experiences of trying to find a job, they have just said, 'No' completely";
"[Special Educational Needs] it needs to be understood in a workplace";
"[...is anyone else concerned about jobs or anything like that?]... I am a little bit because of my need";
"[It's important] having someone in the work place who actually understands it... like having a CAMHS worker in the work place so you can go to them if you need any help."

East Riding Narratives: Parent Carers

Attended by 8 parent carers all of whom are members of EYPCF (East Yorkshire Parent Carer Forum) including 2 steering group members.

Going Well	Could be Better
<p><u>Key narratives</u></p> <p>A nurturing ethos in some schools and settings helps children and young people feel welcomed and cared for</p> <p>Being part of a supportive group like the Parent Carer Forum helps parent carers to feel cared for</p> <p>Getting support from an early age enables parent carers to feel people do genuinely care about their child or young person</p> <p>It helps when practitioners support parent carers in looking at different provisions for their child or young person</p> <p>Optimism grows when it is felt a child or young person's provision or curriculum is right for them</p> <p>Demonstrating a detailed knowledge of a child or young person helps parent carers feel their child is understood and their needs are being addressed</p> <p>Certain key individual practitioners are valued for their care and support by parent carers, and they place their trust in them</p> <p>Listening to parent carers, and putting the child or young person at the centre, restores confidence</p> <p>Sharing ideas and strategies demonstrates there is trust between parent carers and practitioners and</p>	<p><u>Key narratives</u></p> <p>Individuals who work hard to care for children and young people should be better supported by the wider system</p> <p>In some schools the ethos seems unwelcoming to children and young people who are struggling and parent carers can feel they are being blamed</p> <p>Parent carers feel that some practitioners do not understand their child or young person's needs and that resources are the primary focus instead, which leaves them feeling practitioners do not empathise with their needs; more training is needed</p> <p>Parent carers need to be trusted more as experts in their child or young person to help others to understand their needs better and avoid a negative impact on their wellbeing</p> <p>It is important that the right provision and services are made available to meet children and young people's needs in the East Riding</p> <p>Parent carers can feel that their child or young person is separated and excluded because they are not wanted</p> <p>It is really important to listen</p> <p>Confidence and trust can be destroyed by insensitive questioning</p> <p>Processes and systems need to be communicated in accessible ways</p>

<p>respect for each other's' expertise, which has a positive impact on children and young people</p> <p>There are working groups that have been set up to look at areas of need or concern within the Local Authority</p>	<p>It would be better if parent carers were supported more holistically, taking into account family needs</p> <p>Parent carers feel it would be better if SENDCOs (Special Educational Needs and Disabilities Coordinators) in schools were given sufficient time to be able to do their role well</p> <p>Relevant services being involved in meetings would help to support the development of partnerships:</p>
<p style="text-align: center;">WELCOME AND CARE</p> <p>A nurturing ethos in some schools and settings helps children and young people feel welcomed and cared for: "The ethos in the school, is very accommodating"; "...my son is in mainstream but they have a nurture provision, and they have nurture provision on the site and...that is the whole school. My son knows every single teacher in that school, and they all understand his needs, and they all make an effort."</p> <p>Being part of a supportive group like the Parent Carer Forum helps parent carers to feel cared for: "The Parent and Carer Forum, if I hadn't have found you lot I don't know where I would be."</p> <p>Getting support from an early age enables parent carers to feel people do genuinely care about their child or young person: "I've got very positive experience from Portage, they've been amazing from the start. When my son started nursery I was very clear from the start about his behaviours and how he was, he had support from nursery, he had an Education and</p>	<p style="text-align: center;">WELCOME AND CARE</p> <p>Individuals who work hard to care for children and young people should be better supported by the wider system: "And that one person who is always in that corner... gets a lot of pressure from the other people because that person always feels that they are having to be sticking their neck out, putting their neck on the line and it shouldn't have to be like that"; "That lady came from a primary and started working with him but the barrier was the rest of the teachers who were not taking on board what she was saying"; "We've found that the SENDCO tried to help but the Deputy Head of Year and Head of Year over rule what she has said, '...and we have our behaviour policy, a few days in isolation and most children realise they don't want to be there...' but he's not most children. No, he's got additional needs and an EHCP..." "...because it is that one person it does not work, the entire system does not work. So for example when my son was in mainstream school, there was one pastoral person who was really supportive of him and when that one person could not be there for him everything will just go awry and nobody else was supportive, nobody else was willing to</p>

Health Care plan from the end of nursery, he has full-time support at school."

It helps when practitioners support parent carers in looking at different provisions for their child or young person:

"His mainstream school really supported me and went with me to look at all the schools";

"I assisted in what the local authority wanted me to do, to go look at other schools, I did that... I had the support of his co-head teacher who came with me."

listen to me, nobody would... nobody had the patience for him."

In some schools the ethos seems unwelcoming to children and young people who are struggling and parent carers can feel they are being blamed:

"I think some schools... they don't welcome and don't care for you and they make you feel like you're a troublemaker... and I think as far as young people are, it must be terrible for some of these young people going and being treated like that because they are not going to think that anybody cares...";

"...and Y was socially excluded throughout his secondary school, so much so that by the time he finished he wasn't ready to go to university because he wasn't ready, he had no social skills whatsoever, so he had to have two more years of a life skills programme to give him that confidence to go to university, but at every Annual Review I said this will impact on him in later life but they wouldn't listen...we felt very unwelcome in school not just by staff but by students as well";

"We had comments on social media which was mentioning A and the school as well and so the school weren't happy with that, you know, he was not good for the school's... image";

"It's a culture of blaming parents, they do not listen... and I keep thinking about it and when my son was growing up he was such a bright and vibrant child and because of this blame, blame, blame, and when he was in school I felt the same as you...it was always my child... thinking, 'Oh my God it's my child, the one that's going to kick off' ... I was trusting them and taking on what they said to me and I was always blaming my son by telling him, 'Oh gosh, don't do this, don't do that' and looking back now over the years he is low in self-esteem, low in confidence, he's developed anxiety and is on medication for

anxiety and now I'm blaming myself";
"I feel like we...'cos I blame myself as well, like we've just stolen his light, to the point where he just hated school, he wouldn't go to school and they started threatening to take me to court and to do actions and do this";

"And then you go to school and they were frustrating to the point where he gets angry and he breaks stuff, and then they turn around and punish me for it and ask me to pay for it and they exclude him";

"And I think you go into some environments and they say upgrade your parenting."

Parent carers feel that some practitioners do not understand their child or young person's needs and that resources are the primary focus instead, which leaves them feeling practitioners do not empathise with their needs; more training is needed:

"There is some issues around them generally genuinely not knowing, but there is some issue of them thinking about resources. So they are not emotionally connected in the way that the parents are so they can stand back and say we haven't got the resources";

"The Head at my child's first school had never come across a child like my son before, 'He's going for assessment tomorrow...the name doesn't really mean that much I just want to make sure I am meeting his needs";

"She said, 'I have met people with autism and ADHD [Attention Deficit hyperactivity Disorder] but I've never met anybody like [my child] before' and was completely out of her depth, and the way she dealt with him and some of the things she said was because she had never come across someone like him before";

"[What could the local authority do to make it better?] Educate SENDCOs... Training, for the whole staff not just the SENDCOs. If you could start with the SENDCO...";

	<p>"I've worked in two different authorities and there isn't a lot of opportunity for training but I think primary school teachers are under a lot of pressure for things that aren't important, they are spending a lot of time on things that are irrelevant, like times tables, instead of mental wellbeing of your children. Times tables are important, spelling is important, but your child's well-being and mental health and understanding of humanity and kindness tops it";</p> <p>"I agree that training for staff is paramount. When my son was in mainstream they had a SENDCO come to school from a primary school and she was brilliant, all the SENDCOs before they did not meet his needs, they did not understand";</p> <p>"...there have been massive gaps in the service in the area [Speech and Language Therapy]...it is the same for Physio' as well, trying to get hold of some staff...I'm trying to get an Educational Psychologist into school, there is a massive shortage..."</p>
<p>VALUE AND INCLUDE</p> <p>Optimism grows when it is felt a child or young person's provision and curriculum is right for them:</p> <p>"I just have that relief that now he's in a school, he's there and he is now in Year Six, but I feel good that he is going to be there until he is 16, he's not going to be excluded which is damaging to their self-esteem and mental health";</p> <p>"That's what I liked about X school because they had a big sensory room where they can go and regulate themselves, and another area with the ELSA [Emotional Literacy Support Assistant] where they have board games and sand pits and it's all fantastic";</p> <p>"When he's in the right place, he is very enthusiastic, when he is doing practical things like DT [Design Technology], music,</p>	<p>VALUE AND INCLUDE</p> <p>Parent carers need to be trusted more as experts in their child or young person to help others to understand their needs better and avoid a negative impact on their wellbeing:</p> <p>"My son was diagnosed in 2017 with Oppositional Defiance Disorder. I don't feel comfortable with that diagnosis. I sometimes think he's got PDA [Pathological demand Avoidance] which is often a misdiagnosed as Oppositional Defiance Disorder. I have raised it with CAMHS [Child and Adolescence Mental health Services] but it isn't recognised in this area anyway";</p> <p>"I visited the school and I knew as a parent that this was the school for my son but getting there took a long time after a fight";</p> <p>"A parent knows which school is going to</p>

food tech. he's absolutely brilliant and his teachers say they can't believe it's the same boy they hear about in the staff room because he's helpful and wanting to do everything. So it's not all bad."

Demonstrating a detailed knowledge of a child or young person helps parent carers feel their child is understood and their needs are being addressed:

"When we went to the Annual Review we went to the Head teacher's office and she brought everything up on the screen, exactly the list of the needs that were being met and where he was at each stage. And it was like a spreadsheet, right in front of our eyes. It was amazing."

Certain key individual practitioners are valued for their care and support by parent carers, and they place their trust in them:

"In my experience, it's there's always been one person within the system that's been supportive";

"In his new school the TAs [teaching assistants] are supported, the Head is massively involved, if something is going on with the child, she is there, she is a hundred percent backing the staff, the school ethos and the way they approach it";

"In the school that he is in...his teacher is absolutely fabulous, she will read for him";

"I talked with a lot of teachers over the years and some are brilliant with special needs";

"...that SENDCO at X, she was so enthusiastic, and wanted to learn, but she was the only one."

meet their child's needs";

"...as soon as he was at preschool I said I think he's got a bit of dyslexia. I've got this dyslexia, dyscalculia and dyspraxia myself so I could see it";

"He's been excluded lots of times not for major things but for getting frustrated and throwing his books down or refusing... they just call it continual defiance but it's because he's missed so much school before, he can't cope. You can see that he is behind. He's run away a few times because he's not wanted to go into isolation, he's had about 30 days of isolation";

"...and it was like when you said, it's like when you are trying to explain what might have escalated that situation nobody would... it was like I was making excuses for him";

"And I've said, 'Listen this isn't working, we have to change this.' He's going to school which we wanted him to do, he's no longer interested in football, which is when anybody asked him, 'What are you going to be?' He used to say, 'I'm going to be a footballer'... nothing else mattered in the world except football... now he won't go. I said, 'You've got to look at this again, you've got to review it,' they said, 'No he's got to engage first before we review it'";

"I've had someone from the Council; I think she was from Education and Inclusion... and I've said to her, 'I don't think this is the right provision, for my son,' and it was only a temporary thing and he has been there permanently now, and I said, 'We need to look at something else' and she said, 'Oh no, the Council won't even consider that because that's more money.' It's about need though and I said, 'Exactly, the school isn't meeting his needs.'"

It is important that the right provision and services are made available to meet children and young people's needs in the East Riding:

"They've allocated him this place at a school in the East Riding, I don't think it'll be the best place for him but for the moment we are having to accept that and are on a waiting list seeing if we can find a different school";

"So I am very disappointed that our local special school are now being told, 'Only severe, no moderate.' So where are our children meant to go?";

"There needs to be somewhere in between, there is mainstream or specialist, there is nothing in between for the level of need";

"My special school is out of county but it's only 18 miles away... it is closer than the one in the local authority but that was the fight I had but... why can't they have that special school here?";

"I wanted him to go to X [provision], they refused... first they said X was... because it's not East Riding, he wouldn't get first preference, and then they said they have to look at all the schools in the East Riding first and then they want to send them to some other far place, B or somewhere over Lincoln, just some far places and I was just saying, 'No.' And then I realised it just came down to money...";

"And I think that the local authority should look at...that there is no provision for children in the middle. So my son struggles with being in a mainstream school but he also struggles with being in a special school... He's actually gone worse from being there... and they have agreed that he actually doesn't fit in this environment but there is nothing in between";

"My school son has got ADHD and he is in a special school Part of the issue is that he doesn't want to be in a special school. Even though it is a specialist school I feel that the staff don't have the skills to support him";

"I think what a lot of schools are lacking is a time out zone, so for my children if they

	<p>feel they are getting overwhelmed, because I do it I have five minutes, I have five minutes to myself, and my kids have their own space where you go to that area."</p> <p>Parent carers can feel that their child or young person is separated and excluded because they are not wanted:</p> <p>"Now he goes to this special school, in order not to deal with him, they take him to this special place, this special school three times a week... just so they don't have to deal with him in school, and he absolutely hates it and then he will not go";</p> <p>"They get used to it [exclusion], not going to school, and now he said 'Well, just exclude me then' and then his brother is kicking off because he's like, 'Why is he allowed to stay at home when he's being naughty?' They don't see it as a sanction, he doesn't learn from it because it's not what he needs";</p> <p>"And I feel like they are also excluding him, they are also isolating him";</p> <p>"It's like a place where they offload these children..."</p>
<p style="text-align: center;">COMMUNICATE</p> <p>Listening to parent carers, and putting the child or young person at the centre, restores confidence:</p> <p>"Moving into Adult Services, I've now got a social worker who is absolutely amazing, she does listen to X, she does listen to me, and we will work really well together and we sort things out together...She listens, she puts X at the centre of everything, every decision."</p>	<p style="text-align: center;">COMMUNICATE</p> <p>It is really important to listen:</p> <p>"But when he goes to assembly he is made to read. He says he can't read it."</p> <p>Confidence and trust can be destroyed by insensitive questioning:</p> <p>"I've had an absolutely horrific time with the first two schools. They questioned me, 'Was he sexually abused? Is that why he's behaving like this?'"</p> <p>"Sometimes I feel that I'm not that confident 'cos they were making me feel like it was me, you know, they were knocking my confidence, the teachers were knocking my confidence and social services saying, 'Has he been sexually abused?' Because he was displaying sexual behaviours... You've been</p>

	<p>there, you sometimes start to doubt, 'Is it you? Is it your care?'"</p> <p>Processes and systems need to be communicated in accessible ways: "I pretty much felt in his first EHCP I had very little understanding of the process, because I was very thrown into the deep end with it. I do have a little bit of understanding of the Code and provisions, but I knew he wasn't ready for school."</p>
<p>WORK IN PARTNERSHIP</p> <p>Sharing ideas and strategies demonstrates there is trust between parent carers and practitioners and respect for each other's' expertise, which has a positive impact on children and young people: "For me now the school works with me and we work together, and in previous schools that didn't happen, and as a parent you are told that you are the expert on our child which we are. I am always aware that the school environment is massively different to a home environment. If he's had a bad day we don't go out. In his current school we talk and I can take tips from them and they share resources with me, we can use the same strategies between home and school to help. But before, I was constantly making excuses because that's how they perceived him. I wanted to come to a positive resolution but it was like I was excusing behaviour or saying it's because of this and I was just trying to explain. Now that makes such a big difference, because it's a long-term improvement in his behaviour"; "When I went to the positive school, that we're at now, I said to them that techniques that work with him are the ones that you would use with Pathological Demand Avoidance. She said, 'Oh yes,' and</p>	<p>WORK IN PARTNERSHIP</p> <p>It would be better if parent carers were supported more holistically, taking into account family needs: "I had to give up work because there is no wraparound care"; "At one point when he was getting excluded all the time and I went in hospital, I came out and I wasn't well at all and I stayed at home all day but I wasn't well enough to look after the boys, and my husband works and couldn't get much time off at that point and it was just getting on top of us so we asked if there was anywhere we could get a little bit of support where someone could just look after him for a few days.. if he gets excluded again or just to help us, because we just can't really,... I don't know what to do"; "I rang up for respite but they said they don't offer it my child wasn't disabled enough"; "And they wanted a report from social care and I couldn't get the report and when it's come back from social care they are basically saying I have escalated services, to escalate things to get the things I need..."; "I get very little support, I have to do everything myself and I'm fortunate that I can do that. I can read information quite quickly and present myself quite well so... I've had quite difficult interactions with practitioners. I really feel for parents who</p>

when we were talking about his behaviour she said, 'Oh we've had children like this before and we do this and we do that' and when I talked about things we did she was positive, they were using them at school. She was showing me, I had a wobble cushion, they have another boy with a wobble cushion, he takes it around and the other children accept it and they know and if he forgets it, they take it to him..."; "I help them write the plans...they were nice but they just didn't get it."

There are working groups that have been set up to look at areas of need or concern within the local authority:

"And I know the local authority have started working groups to look at the number of people out of provision 'cos it is high."

don't have that ability to do that, I would sit there and think I have confidence, I can do this... even if I don't I can pretend that I know what I am talking about... but what about parents that can't do that? It's not fair"

Parent carers feel it would be better if SENDCOs (Special Educational Needs and Disabilities Coordinators) in schools were given sufficient time to be able to do their role well:

"The SENDCOs, it's not just SENDCOs, they are teachers as well, or Headteachers... It's a really in-depth job and they've got everything coming at you and they should just be able to concentrate on that... they should have people who are just the SENDCO and that is just their role. At my school in North Yorkshire that was the model we had to work to. We had a teacher who became the SENDCO and that was her only job because we needed that, there are so many children."

Relevant services being involved in meetings would help to support the development of partnerships:

"When they have their Annual Review they only seem to have school staff, they don't have a Social Care and the Health... they are not properly included in the plan. They invite people but they don't turn up, they send their apologies."

East Riding Narratives: Schools and settings

<p>11 attendees: 4 Head teachers; an Assistant Head teacher (Sixth Form); 3 SENDCos; Head of Foundation, Learning Support Co-ordinator and Course Manager (Further Education), and from a range of settings including a pre-school, 2 specialist settings, 2 primary schools, a secondary school, 2 Further Education colleges and a representative ERYC (East Riding of Yorkshire Council) Education, Improvement and Learning Service.</p>	
Going Well	Could be Better
<p><u>Key narratives</u></p> <p>There are examples of schools and settings want to establish caring relationships with parent carers</p> <p>Carefully planning transitions is recognised by school and setting leaders to be vital in welcoming new children, young people and families well:</p> <p>There are examples of the local authority showing care towards families</p> <p>It is recognised that the local authority is investing in support for children and young people across the age range</p> <p>More provision is being established within mainstream schools</p> <p>Some schools describe how having a good relationships with parent carers helps; they work hard so they feel parent carers can talk to staff</p> <p>People are being honest and acknowledging the difficulties</p> <p>There is a perception that things are progressing and getting more rigorous</p> <p>There are some examples of service practitioners working in partnership with schools and settings</p>	<p><u>Key narratives</u></p> <p>It would be better if the schools admissions process was completed collaboratively and schools and settings had plenty of time to prepare for transitions to welcome young people and their families</p> <p>Early intervention and EHC processes often seem delayed</p> <p>Paper work can be out of date, making it difficult to know how best to support children and young people</p> <p>It is felt things would improve if there was reinvestment in mainstream schools for provision for children and young people identified with moderate learning difficulties</p> <p>It would be better to have a consistent EHC Co-ordinator with whom staff in school and parents could make contact</p> <p>It is difficult to work together collaboratively because of officer workload</p> <p>Individuals need to have the SEND [Special Educational Needs and Disabilities] knowledge to be able to make decisions</p> <p>It is hard to work together when it feels like there are inconsistencies within processes</p>

WELCOME AND CARE

There are examples of schools and settings want to establish caring relationships with parent carers:

"We have an amazing Parent Partnership and I have learnt a lot about being able to feedback to parents, being able to reassure parents";

"...thankfully we have got good relationships with them";

"...so it's what can we do, not just as a small school but through everyone coming together, to make sure we are able to provide from these vulnerable kids."

Carefully planning transitions is recognised by school and setting leaders to be vital in welcoming new children, young people and families well:

"So, we have gone through a very long reintegration process, they actually wanted them to start in October, we didn't start until January because we had to put so many things in place including having part of our building modified";

"...that lovely bit of being in the class they are going to be in, parents meeting each other and remember our parents don't meet and greet at the gate because they are coming from all over";

"Some of these children need a long run in... and if the Preparing for Adulthood pathway was more robust and having a checklist of things that need to be done in preparation for that..."

There are examples of the local authority showing care towards families:

"We had a multi-agency discussion where parents said, 'My in-laws said that they would pay £3000 or whatever it is to have a private assessment completed' and they were told quite categorically by East

WELCOME AND CARE

It would be better if the schools admissions process was completed collaboratively and schools and settings had plenty of time to prepare for transitions to welcome children, young people and their families:

"I would prefer to sit around a table and look at all of the admissions for September and we could sort of prioritise because my worry is that you might take in October/November, like fill up your places for September, the children who are on the cusp, who are perhaps on the autistic spectrum and might be able to manage in mainstream, and then what happens in May if you get a child with profound needs and would never manage in a mainstream, and I just think it would be so much better if we could sit down with Educational Psychologists and the Head Teachers, Speech and Language Therapists, everybody and look at who knows this child... it shouldn't be first come, first served";

"We are getting the [admissions] consultations through right up until last week, which makes it impossible to plan ahead and also the documentation that you are often provided with, upon which you are going to make a decision, is out of date";

"There is no transition";

"My three kids, that are coming this week, have already missed transition... so they have already missed that...";

"We have had young people coming through where we get the information the week they arrive and that sets us off on the wrong foot with parents because it doesn't make us look professional...";

"I think the allocation of places is not very helpful... there was no information that came through, we were just told that we were going to get this child but nothing else came

Riding Authority don't do that, we as an authority, the school, it's our responsibility."

and you need to have them on role by such and such a date and they need to be in school. It was only because the parent rang me to say that they had had previous issues erm and I actually spoke to the previous school erm at quite great depth that actually if we brought this child in at the time that they wanted them to come in we would have completely failed the child";

"Going back to admissions it is really important to have that transition, whether you are the most mainstream child in the world or whether you have additional needs";
"Young people come to us with no notice at all."

Early intervention and EHC processes often seem delayed:

"Early intervention, well that's really... when I am waiting eighteen months for appointments and waiting for reports to be sent back and children are transitioning without the right up to date information";

"I can't use the word early with interventions because it's not early enough";

"It [assessment/EHC process] isn't a quick process and I am having to say that [to parents] from the very first time I post that application form because if they have expectations that they will have an appointment in a couple of months that isn't ever going to happen and then they lose faith in the system moving forward";

"We sent our annual review information in in November because we were told to get it in at deadline. We didn't get it back until we rang and said, 'Where is it, where is it?'... and we didn't get it through straight away, we had to wait two weeks until we got the call back and the things that came through were out of date, they didn't have the things we had put into the annual review and so we had to chase that back up again and we got an apology and we got told that there had been a change of staff";

	<p>"We had another child who needed support... we waited a long time to get through the process, we went through the process got to the panel and it was rejected, the reason it was rejected was it was the wrong reason. It didn't make sense";</p> <p>"But now they are thinking actually, we are two terms down the line and you are telling me it is going to take another term before we can even set the ball rolling and I just think that we are really beginning to lose that trust."</p>
<p style="text-align: center;">VALUE AND INCLUDE</p> <p>It is recognised that the local authority is investing in support for children and young people across the age range: "...[information] is possibly more towards the pre-16 rather than post-16, but I would agree with your point that there is quite clearly a lot of resources going into the local authority now to try and bridge that gap."</p> <p>More provision is being established within mainstream schools: "I am working with a local school, I've got a room on their site 2 days/2 and half days a week... but it's worked because parents can see their children in a mainstream setting."</p>	<p style="text-align: center;">VALUE AND INCLUDE</p> <p>Paper work can be out of date, making it difficult to know how best to support children and young people: "I personally find that East Riding EHC and annual review documentation is not as in-depth as any of the other local authorities, so for example North Yorks, when we get North Yorks consultations we know everything... but with East Riding I got an EHCP for a student who had actually been with us all academic year... and in the picture on the front he is about eight and he is now sixteen";</p> <p>"There is a real inconsistency in the quality of the EHCP 'cos there was a time when they had locums writing them and it was just sort of cut and paste from a statement... that's why you were getting the out of date pictures and out of date information."</p> <p>It is felt things would improve if there was reinvestment in provision for children and young people identified with moderate learning difficulties: "We are pushing the local authority to use rooms on mainstream sites to offer that [Moderate Learning Difficulties] provision...";</p> <p>"We are getting increasing numbers of children with complex needs that we don't..."</p>

	<p>we just don't have the space for, we don't have the building to accommodate... we don't have a nurture group or whatever you care to call it and there are so many children from that middle ground";</p> <p>"I think that has been detrimental to many, many families... we had a fabulous provision in East Riding, Moderate Learning Difficulties [MLD] school, it did fabulous things for that cohort, the staff were trained and the kids got brilliant outcomes and they were looking for college placements, they were looking for employment ... and now they have had to change their designation to Specific Learning Difficulties but because they have still got an MLD cohort parents are going round thinking, 'Severe and complex needs? I don't think so.'"</p>
<p style="text-align: center;">COMMUNICATE</p> <p>Some schools describe how having a good relationships with parent carers helps; they work hard so they feel parent carers can talk to staff:</p> <p>"For me I think the relationship we have with parents is fantastic and erm we are trying to make them feel they are perfectly able to say how they feel and always listen and sometimes the challenge is that we don't always have the answer."</p> <p>People are being honest and acknowledging the difficulties:</p> <p>"I think the LA have recently acknowledged there is... they know the problems schools and colleges are facing with communication with the SEND department and there is a whole chunk of staff going that they are addressing."</p>	<p style="text-align: center;">COMMUNICATE</p> <p>It would be better to have a consistent EHC Co-ordinator with whom staff in school and parent carers could make contact:</p> <p>"We are not communicating well enough, we feel like our hands are tied...";</p> <p>"...we don't always know who the EHC Co-ordinator is and we don't always get the feedback from annual reviews and that sort of thing and it can be a barrier, which causes additional frustrations, which we are managing with parents... I think that's the biggest thing for us";</p> <p>"...we used to have an EHC co-ordinator for the school, which was brilliant, now it's by post code so if there are eight co-ordinators we can be dealing with eight...";</p> <p>"If schools were EHC Co-ordinator specific or the other way round it worked, it worked brilliantly because they got to know you, you got to know them, one visit and they could see several issues and concerns";</p> <p>"...and parents are ringing me...to ask if they</p>

	<p>can come to the school yet and it is not me who is making the decision, thank god... and then I am ringing [EHC team] and they say it isn't my problem, well it is my problem because it is me they [parents] are ringing and I do feel for them because they need to know what is going to happen and if they are then told that they can't come for whatever reason they need to know what the alternative is";</p> <p>"Before I was with a specific EHC Co-ordinator before and I knew I could ring and ask any questions, but now if I ring and I actually get hold of an EHC Co-ordinator I then tend to say well while I am on the phone could you also tell me about x, y, x."</p>
<p>WORK IN PARTNERSHIP</p> <p>There is a perception that things are progressing and getting more rigorous: "...in terms of that sort of straddle from the old statementing process to the Education Health and Care plans that's taken quite a long time to settle down in my mind... it's taken quite, you know... I am sure we are all involved in that process and that's becoming much more rigorous. I still think there's a sliding line but we are playing catch up but we are not far off."</p> <p>There are some examples of service practitioners working in partnership with schools and settings: "You get those nuggets (of good practice) that you hang on to."</p>	<p>WORK IN PARTNERSHIP</p> <p>It is difficult to work together collaboratively because of increased officer workload: "And when we have spoken to the EHC Co-ordinators obviously they have got big caseloads which is expected"; "I think there is, there's been an increase of about 50% in EHCP applications and that's a lot"; "We are constantly told by [different services]...that they are under staffed, over worked and they can't meet deadlines 'cos they don't have a full complement of team to work with"; "We have had all of our Ed Psych. appointments cancelled since April"; "My understanding of having a geographical spread of EHC co-ordinators is exactly that, geographically spread, but it doesn't seem to be caseload related... but I thought the model that you said of having a person who is responsible for X amount of learners and then they progress them through the system: Early Years, into primary, into secondary, into post-16"; "Because of the area of East Riding they</p>

have a lot of time travelling and things and they have said that that can cause difficulties in terms of getting back to parents and that kind of thing because the area is so large”;

“They [EHC co-ordinators] all have a massive area to cover”;

“Even if they are sectioned it is still a big area.”

Individuals need to have the SEND [Special Educational Needs and Disabilities] knowledge to be able to make decisions:

“Erm Education, Health and Care plans are out of date, we all know that, but that really isn't good enough is it? And er we have tried to work in conjunction with the local authority to get them up dated and er I am talking about young people who are leaving in seven/eight days time and that is also for children who are looked after... but it is about not being able to access someone that knows the system and can make a decision”;

“...we get through to a front desk, we don't get through to decision makers, they're taking messages er... I mean last week I got through to the front desk and the person said, 'Please bear with me 'cos I am on supply so didn't understand the process.' Yes they are recruiting and have recruited but often it's people, in my own opinion, that haven't the SEND knowledge...”;

“My concern is that those good people are not being replaced with people who have the gravitas and expertise...”

It is hard to work together when it feels like there are inconsistencies within processes:

“We see an inconsistency between when schools apply for an EHC and when parents apply for an EHC and there is a completely different path that seems to be followed if a parent makes the request for assessment.”

East Riding Narratives: Local Authority (LA) Education

9 attendees: Children's Commissioning Manager; SEND (Special Educational Needs and Disabilities) Strategic Manager; Principal and Senior Educational Psychologists; Senior Early Years and Development Advisor and FISH (Families Information and Support Hub/Helpline) Manager; Senior Education, Health, Care Commissioning Officer; Lead Teacher for the Deaf and Manager of the Physical Disability Team; 2 Education, Health, Care Commissioning Officers ('EHCCO's).

Going Well	Could be Better
<p><u>Key narratives</u></p> <p>There is honesty from practitioners that there is more to do but also passionate commitment to continuing the journey in partnership, illustrated by the number of people attending the <i>VOICES</i> event</p> <p>LA Service Managers within SEND are highly responsive to addressing urgent issues raised by parent carers</p> <p>There are some good examples of reflective practice in partnership with parent carers improving the quality of experience, and the desire to work more in this way:</p> <p>Some managers speak of valuing the people in their teams</p> <p>Many officers care, showing understanding of, and empathy towards, the experiences of parent carers and they recognise that acting on challenging conversations is an important aspect of their role</p> <p>The Parent Carer Forum is a valued strategic and operational partner</p> <p>The efforts of the EHCCO team are valued by many families</p> <p>There are examples of services committed to working with families from</p>	<p><u>Key narratives</u></p> <p>Practitioners want desperately to repair the loss of trust that seems to exist between parent carers including the Parent Carer Forum, and the LA; some LA managers and officers have reached the point of distress</p> <p>There seems to be a focus on what is going wrong</p> <p>It feels as though parent carers who shout the loudest do get what they want, sometimes at a cost to other parent carers</p> <p>Some parent carers are already prepared for battle, which may be due to past experience or the information they received at the start, but this makes it hard to then have positive conversations and begin co-producing</p> <p>Because they are aware of the reason for parent carers feeling upset and angry, managers and practitioners do not feel able to be open and honest about the impact on their own wellbeing of what is being said to them on</p> <p>Although it is perceived to be more efficient, electronic means of communication and social media can make building relationships and sharing understanding more difficult</p>

<p>the start</p> <p>There is agreement it would be good to focus more on what is working well</p> <p>There are some very good systems in place providing regular communications and updates for parent carers as well as immediate sources of support</p> <p>The Participation and Access Group checks out all information to ensure that it is accessible</p> <p>Communication between strategic managers at the local authority (LA) and the Parent Carer Forum is good because of the commitment of the steering group to attending meetings and being involved in strategic discussions; this is highly valued</p> <p>Regular feedback meetings to address parent carer concerns have been designed with the Parent Carer Forum to involve the right people</p> <p>Making space to speak with people on the phone or face-to-face can be helpful</p> <p>There are examples of very positive relationships with parent carers</p> <p>There is commitment to person-centred approaches, particularly the co-production of EHC plans</p> <p>Partnership working with the Parent Carer Forum when frameworks are reviewed can involve feedback from parent carers changing processes</p>	<p>Parent carers are not always made aware of why some strategic and operational decisions are taken, or the influence they may have had on these decisions</p> <p>Parent carers not involved directly in partnership working with the LA indicate they are not always aware of what is happening</p> <p>Practitioners can feel the systemic challenges that need to be made are daunting enough, so despite wanting to have open discussions about them with parent carers it does not feel like the right thing to do to as parent carers have enough to deal with</p> <p>The demands on the Parent Carer Forum steering group seem too great</p> <p>There is a perception that the Parent Carer Forum is resistant to involving a wider range of parent carers and it feels difficult to talk openly with them about this</p>
--	--

WELCOME AND CARE

There is honesty from practitioners that there is more to do, but also passionate commitment to continuing the journey in partnership, illustrated by the number of people attending the **VOICES** event:

"In terms of our commitment to co-production we've got an awful lot to learn...but I think the amount of practitioners and parents and carers here, I think that really demonstrates that we really do want to make this work";

"There is a joint commitment to our continuing journey";

"There are some incredibly passionate people, and you can just see in the emotion, here, that people are desperate to do their best for the children and families, and I think everybody shares that...everybody does."

LA Service Managers within SEND are highly responsive to addressing urgent issues raised by parent carers:

"The responsiveness of ourselves as managers. We quite frequently get a phone call or an email in a morning saying, 'I need to speak with you urgently' and everybody's busy, parent carers are really busy...we're also busy...but we generally meet with...that day or the next day, to arrange to meet with them to discuss those issues and agree with them to take them forward. In terms of responsiveness and visible, I think we really do go above and beyond in terms of that."

There are some good examples of reflective practice in partnership with parent carers improving the quality of experience, and the desire to work more in this way:

WELCOME AND CARE

Practitioners want desperately to repair the loss of trust that seems to exist between parent carers including the Parent Carer Forum, and the LA; some LA managers and officers have reached the point of distress:

"For me, the biggest thing is trust...the Parent Carer Forum don't particularly trust us because they tell us. I'm not sure, and I guess if we were open and honest, I feel that we don't have that trust in the Parent Carer Forum...because of things that happen, things that get forwarded to us, things that we hear and see, it's not there. And so I think...we have to...being honest it's not there, from them or from us, and I don't really know how to get trust back, really";

"We do have, unfortunately, situations when the officers within our team, who are incredibly dedicated and hardworking, go above and beyond in every case that they're involved in, that doesn't necessarily filter through...some really difficult things we've been made aware of as a team in terms of how people have been spoken about. That's a real challenge for us. We would like to be able to overcome that and get to that position of trust";

"I think it's really important that people do recognise that by throwing in certain words, like that [like tribunal at the start of a process], it gets everybody's backs up, it makes everyone anxious, and in not starting from that point of respect and trust, where you're working in genuine partnership...";

"I think if we're being open and honest here...I've been to many meetings over the years where that has been an opening gambit";

"Some of that is probably from those people's previous experience of things that actually, you get what you want when you go

<p>"The last meeting we had for the QA [Quality Assurance] Steering Group, we'd shifted from it being about individual children to how do we help the teams...we do quality monitor...cross-referencing that to how the team does its own...they're self-monitoring quite well, but at the last meeting , really open and frank, they said, 'You need to go away and do this' to us all, to the point that we said, 'Well let's not do a new plan if we've not finished these ones' because they're reoccurring themes, let's dig through these and the parent who was there on the way out said, 'This feels really positive because you're all looking at yourselves' but that's what we do..."; "In this situation it was really positive because she gave some really valid...it was actually more positive about us than we were, we were really critical...she was, 'Oh I think that's really good, don't worry"; "Where it happens it is really, really good...it does work, when it works."</p>	<p>down this route, but that's really difficult...to change that and say, 'Look, that might have been successful before...but you know, threatening somebody with tribunal, which is hundreds of hours of work, around something that...could have probably been resolved by a cup of tea and a conversation...but the whole energy is this, then, because I'm afraid to say something, afraid to explore...because it it's mentioned in a room you can have it, all those sorts of things...it's not helpful I think as an authority."</p>
<p style="text-align: center;">VALUE AND INCLUDE</p> <p>Managers speak of valuing the people in their teams: "We're really fortunate, we've got an incredible team, an absolutely incredible team who are really supportive of each other." Officers care, showing understanding of, and empathy towards, the experiences of parent carers and they recognise that acting on challenging conversations is an important aspect of their role: "We do get paid for our jobs, you know...and I think it's because people care.. but we recognise that caring isn't enough, you've to do the actions...so I think parents have it a lot worse, you know, if they've fought to get [to an EHC* plan],</p>	<p style="text-align: center;">VALUE AND INCLUDE</p> <p>There seems to be a focus on what is going wrong: "It's very rare that parents get in touch with you to say how fabulously you've done with a child or, 'Thank you very much.' We do get it, now and again, we do get parents saying, 'Thank you very much' but more often than not it's, 'Why haven't you done this?...You're just taking too long.' I get that, this is the process we have to go...so maybe as an authority we need to speed up processes, but we haven't got the staff..."; "You do have people who have not had good experiences might shout little bit louder because they're not happy with how it's gone at all."</p>

how many years have they fought before that? So...we understand they come prepared for a battle."

The Parent Carer Forum is a valued strategic and operational partner:

"I think the QA Group...there is always a representative of the Parent Carer Forum that sits on that, so when it comes to looking at the QA of EHC plans for example...that's very much an equal process and everybody's voice is heard";

"The Parent Carer Forum's very active...very involved in activities for SENDCos [Special Educational Needs and Disabilities Co-ordinators] and the SENDCo...Conference and Young People... TYLER [The Young Leaders of East Riding] ...I think very active and inclusive in terms of our offer to the networks."

The efforts of the EHCCO team are valued by many families:

"...for the majority of parents they are understanding of some of the challenges particularly that the EHCCO team have, so they are aware of those and are understanding of it, even if they are not necessarily having the most positive experience there is a recognition... for the majority the team is trying to get it right."

There are examples of services committed to working with families from the start:

"...we always start any involvement with a child or young person with a joint consultation with parents, we won't do anything with an individual child or young person without that initial kind of shared understanding of what are the presenting needs, where are the strengths? A joint, collaborative approach from the very beginning, and we keep that the entire way

through so that we don't then...part of the planning of interventions, what we are suggesting they do, so everyone has their shared role in that from the beginning."

There is agreement it would be good to focus more on what is working well:

"I would really value support in terms of that, in terms of how we work with the Parent Carer Forum on that...";

"It would be great to find a way of getting some of those positives down so they can be shared and come out into the world...there are positives out there";

"We've got great, amazing things, fantastic examples of...what's worked well."

*Education, Health and Care plan

COMMUNICATE

There are some very good systems in place providing regular communications and updates for parent carers, as well as immediate sources of support:

"We have the Families Information Helpline; we do the bulletin that goes out every fortnight to parent carers, things like the LOOK AHEAD, 'Shop & Save', all those mechanisms as well. But there's also a number where people can ring, 'cos obviously the Helpline's manned Monday to Friday so, that's the number that tends to be on all the literature and information 'cos then someone 99% of the time is going to get somebody responding to a telephone call or an email, whereas if they're trying to contact somebody who's working out in the field, that's not always possible, so having to leave an answering machine message or whatever, they can ring the Helpline and talk to somebody who can take on that query...the Helpline

COMMUNICATE

It feels as though parent carers who shout the loudest do get what they want, sometimes at a cost to other parent carers:

"I know from experience that we have parents who shout loud; threaten tribunals, going to the paper, doing this doing that, and you have to react to that, but I also know I have families who are desperately wanting something but are following the process and you're there going, '...we're doing this, we are trying, we're moving forward' and I just think...they are the families that get lost. And they shouldn't, they're all equal...There are times I want to sit down and tell a parent exactly what I think. You can't, because you are the officer, and they don't know the pressures they're putting people under."

Some parent carers are already prepared for battle, which may be due to past

take the SENDIASS [Special Educational Needs and Disabilities Information, Support and Advice Service] calls as well."

The Participation and Access Group checks out all information to ensure that it is accessible:

"We have a Participation and Access Group where...if we're designing some guidance or something...that's reviewed and regularly it comes back saying, 'It's too jargony'. Anything that goes out is filtered through that group...quite a lot of our groups have representation but always a Parent Carer Forum representative...in our High Needs Strategic sub-groups there's always a parent carer, two parent carers, sometimes three, so there's not that burden if somebody can't make it...anything that goes on the Local Offer has to go through that group...and bounces back if it needs to, to redo."

Communication between strategic managers at the LA and the Parent Carer Forum is good because of the commitment of members of the steering group to attending meetings and being involved in strategic discussions; this is highly valued:

"In terms of working with the Parent Carer Forum, certainly the [steering group are] extremely committed and they sit on all our strategic sub-groups...in terms of that communication at a strategic level and involving them in our plans, in our strategy, I feel its valued that they do spend an awful lot of time with us...I think we would say that as strategic managers at least one of us sees them at least once or twice a week...it's a huge amount of time for those two particular individuals...that's really appreciated. Certainly it works well that we have that relationship with them." "They're in every day aren't they?"

experience or the information they receive at the start, but this makes it hard to then have positive conversations and begin co-producing:

"...but it makes it very difficult when you're not wanting that battle, to make that a positive conversation, because...they've battled all their life for it so, 'This is the next battle I've got to do.' We need to work really hard to say, which is where the co-production meetings are really important, to say, 'We don't want this to be a battle. We want you to get the best for your children...however, the end point might not necessarily be a 100% what you think it's going to be at the beginning. Because together we'll work through things.' But it is really tough, and it's tough when you're management level trying to filter those conversations so they're...because to be honest I would be that parent! I would be that parent who everyday is saying, 'If this is what I have to do...'; 'This is not how I want to spend my life,' but I think there is then sometimes the lack of recognition of the hours we spend dealing with that are actually hours we are not the doing the processes we need to do that would have got those children what they need";

"I think sometimes, going into fresh situations, I get quite frustrated at times, that sometimes the services that are there to support parents often start it off from a kind of adversarial point, so you're starting from a point where you think, 'Whoa, why are you even mentioning tribunals at this stage?' It's not helpful to anybody in that situation, because to pull back from that...we're at the start of the process, the start of the situation, let's look at what's important to that child, here and now, and get a plan together...";

"The need to give the information to the parents about what their rights are...I know that if I was a parent and I heard, 'You need

Regular feedback meetings to address wide-ranging parent carer concerns have been designed with the Parent Carer Forum to involve the right people:

"When we were aware of the issues that parents were having, and discussing the ways forward, we set up these regular feedback meetings. Originally it was just a small group of representatives from the Local Authority and the co-chairs of the Partnership [Parent Carer Forum] but what we found is that some of these issues were wide ranging, covering wider areas, so with them we said...'How can we do things differently?' so we widened out the meetings, where we've got representatives of the Parent Carer Forum and a range of workers there, practitioners there, who can actually address some of the questions, so I think things are moving a bit more quickly rather than having to wait for things to happen, so we're trying to as hard as we can, moving forwards with that...and agreed with the parent carers how to take this forward, it was a joint agreement to try a different way of working."

Making space to speak with people on the phone or face-to-face can be helpful:

"I think there have been some very productive conversations and sometimes you don't expect...some valuable conversations to move things forward...forums, speaking to parents or them calling us...I think sometimes a phone call, or sitting down in a space together can help resolve issues."

to know about your rights' what you're saying is, 'You're not going to get what you want, so let's just skip the process'...and I don't think that's necessarily the intention...in the Code of Practice you've got to tell everyone their rights...and all the letters have got it on the bottom, and it's right that that happens, but I think that sometimes I think in the meetings, verbalised, the perception potentially of parents...";

"You do speak to some parents, and in an initial consultation, for example...there've been a few where it's started talking tribunals and you're thinking, 'Are you having a laugh? We're here, in this initial meeting, let's look at what's important, let's look at what we can all do to make a real difference here and now for your child. Where that's coming from I don't full know. It's coming from somewhere."

Because they are aware of the reason for parent carers feeling upset and angry, managers and practitioners do not feel able to be open and honest about the impact on their own wellbeing of what is being said to them:

"They don't want to hear that";

"We can't have an open and honest discussion about...I think parents feel able to express...how we make them feel, I don't think as local authority officers we feel able to have that open and frank discussion...we have to be professional...if we sometimes spoke to people how we're [sometimes] spoken to we would be disciplined...I'm aware of the emotional impact on officers resulting in quite a lot of sickness and absences. And I'm not putting blame on parents and carers, for me it's about...you need to have that trust...we're not always going to agree, absolutely not, but you need to be able to have an open and frank discussion about, 'I understand what you're saying, this is what we do, this is what we're going to do to work

through it”;

“And it’s that kind of understanding, isn’t it, when that level of respect goes, and communications, those criticisms, that we’ve all felt, are very, very personal, which is just unacceptable”;

“And the emotional toll that has on the team, and the energy...that requires, it is exhausting.”

Although it is perceived to be more efficient, electronic means of communication and social media can make building relationships and sharing understanding and more difficult:

“I do think emails and all this, and social media, can fuel...that can sometime cause us to put our energies into that...there’s only so much head space”;

“[When people begin initial conversations talking about tribunals] Maybe it’s coming from the social media type of things, where people talk on social media”;

“And spending a lot of time reading those emails [from parents complaining].”

Parent carers are not always made aware of why some strategic and operational decisions are taken, or the influence they may have had on these decisions:

“I’m not sure necessarily whether the parents realised the impact they had on that pausing and things [the development of the short breaks framework] I think potentially they had thought, ‘Oh we were going here and it’s stopped’...Well it hasn’t stopped, we’ve realised that it was going in a direction that wasn’t really going to meet the needs that you’ve fully identified”;

“I think what’s quite hurtful for some staff is that all of that work’s happening and you’re explaining it, but parent don’t seem to know it. And we’re like, ‘Well, let’s do, let’s go and have this event’ and then told ‘No, we don’t want to do it in that way’...and so we

respect that's the way that communication's going to go but if it's never getting out there and we're only ever getting the negative in."

Parent carers not involved directly in partnership working with the LA indicate they are not always aware of what is happening:

"I feel sometimes, however much you try and share and include and inform and co-produce, that's not filtered out to wider parents and carers so then that is reflected on...'We don't know what is happening'; 'We don't know what you are doing about this either' and I don't know how else we can share that. We need to look at different ways of sharing it because it's not getting out there, or it's not understood."

Practitioners can feel the systemic challenges that need to be made are daunting enough, so despite wanting to have open discussions about them with parent carers it does not feel like the right thing to do to as they have enough to deal with:

"Historic things that the team are now... working through, and parents shouldn't have to take into account that these are things we are working through, we understand...but that's the reality, that's the challenge, we know where we want to be, we've done anything we possibly can to get to where we want to be, but it's not going to be tomorrow and we need to work hard to make your journey as good as possible but knowing that we might not be a 100% where we want to be, but we do want to say, 'How can you work with us to do that?';

"But it's that bit that it feels quite big...you don't want to frighten anyone by going, 'This is what we're working through' but the reality is...I know the team are doing way more hours than they're supposed to be doing...there's only so much...while we put

	<p>those changes in that will make those positive impacts we're still carrying on, and then it's very difficult for that communication because it's not...if they're not answered then...it's quite difficult to fit all that in...that isn't an excuse or a reason, that's the challenge, as actually from a parent's point of view a day to us is really quick because there's so much going on...a day to a parent is the longest when you're waiting for your child to be happy...so that's it...you know, having those forums to start it...because I have been up to here, and I care [cries]."</p>
<p>WORK IN PARTNERSHIP</p> <p>There are examples of very positive relationships with parent carers: "We have a good relationship with most of the parents...we are a very specialist...service...we have a very different relationship with parents than schools do because we work very closely with families...and we get involved from a very young age, sometimes from birth, so we can develop those relationships ...we build it from the beginning"; "I think that it's important when we're going to engage with parents, if we're going to set up something, that it's parents who've had positive experiences as well as negative ones...so they could maybe temper the others and say, 'Yeah, yeah it does get better, you are going to come out.'"</p> <p>There is commitment to person-centred approaches, particularly the co-production of EHC plans: "I think that for us as officers, we work with parents all the way through...the EHC process, before we embark on the plan we go through the paperwork, the parents are there at that very first meeting, we talk</p>	<p>WORK IN PARTNERSHIP</p> <p>The demands on the steering group of the Parent Carer Forum seem too great: "I have a huge amount of respect for the Parent Carer Forum [steering group] because they put so much effort and time in, and I think that's sometimes to their detriment, I worry about their own...wellbeing."</p> <p>There is a perception that the Parent Carer Forum might be resistant to involving a wider range of parent carers and it feels difficult to talk openly about this: "...whenever we try and reach other parents or work with other parents, that comes with a backlash as well in terms of, 'Why are you meeting with other parents? We're the Parent Carer Forum'...we have quite a battle in terms of that"; "It's how we have those discussions because we try and have those discussions, it's immediately shut down, and so we go back into our own little bubble"; "I want to be able to have open discussions with them, and I'm sure they'll feel they can't with us"; "It makes me feel we're not able to do that in a forum with a parent carer because is</p>

about what the process is like, how they will be involved in any way, we make sure they're aware of how it all works. Then, when they embark on the process we sit with them to do the meeting with the draft plan, and if the draft plan does get agreed then we set with them again and look at the draft plan, make the amendments they want to make etc etc. So we work with them the whole way though that process”;

“I think there’s an element of the role that we undertake in our team that’s historically worked really well and that’s around the the co-construction of the draft Education, Health and Care plan, so we have a meeting...co-produce elements of that Education, Health and Care plan, that’s facilitated by one of the Education, Health, Care Officers 'erm and that’s very much done in co-production with that parent voice, that young person’s voice being central to that, any other professional whose supporting that child or young person, and that’s historically something that’s worked really well and we’ve always had positive feedback on. That’s something that for our team has and does work well...”;

“...we use lots of person-centred planning tools and strategies, so that’s something that we have used right from the off when the reforms were embedded, and we’ve continued that so you won’t find any of the Commissioning Officers going anywhere without their roll of flip chart and bag of coloured pens, and it’s very kind of shared, 'Everybody’s welcome’...it’s very much that everybody’s voice contributes to that process.”

Partnership working with the Parent Carer Forum when frameworks are reviewed can involve feedback from parent carers changing processes:

that going to go back and, 'They've identified they're not doing that.'”

"...there have been attempts to do some of the co-production, particularly around new tendering processes, where we have invited the Parent Carer Forum...to have a look at the short breaks framework and...developing consultation questions, how did we do that consultation, which then led to having a bit of a pause after that to really look at...a wider...taking the needs of the children and parents on board to say, 'Halt, lets pause the direction we are going in...let's find this out and make this a bigger short breaks framework'...and that's restarting again...and all the parents...the Parent Carer Forum are involved in doing that. That's a big piece of work really. We'd like to get to the point where that happens all the time... I think that's a really positive piece of work."

East Riding Narratives: Care

<p>7 attendees: Interim Team Manager for the East Riding Care and Support Service; Information, Advice and Guidance Officer (0-25 Service); Development and Implementation Lead (Adult Services); Social Work Services Manager; Supervisor 0-25 SEND Team (North); Early Years Inclusion Team Manager; Portage Worker (0-25).</p>	
<p>Going Well</p>	<p>Could be Better</p>
<p><u>Key narratives</u></p> <p>Despite the pain involved in the experience of restructuring, practitioners remain passionate and they care</p> <p>The Early Years approach ensures that services work together and with parent carers from the earliest stages</p> <p>The skills and knowledge families bring are affirmed from the start by the Portage service</p> <p>Early Years and school teams work closely together to support children transferring from settings to school</p> <p>Transitions to Adult Services for young carers are managed sensitively and in partnership with them</p> <p>The Stamp of Approval scheme facilitated by Portage tries to ensure that settings and nurseries are inclusive and child-centred</p> <p>There is substantial training for nurseries and settings to help staff identify additional needs early that is flexible and responsive to changing needs</p> <p>Feedback from some parent carers about their experience of the EHCP [Education, Health and Care plan] process is extremely positive</p>	<p><u>Key narratives</u></p> <p>Greater transparency and a focus on the respectful, enabling role Social Care can have might help increase trust</p> <p>The Stamp of Approval scheme is a valued tool for strengthening inclusive practice in settings and nurseries but there is insufficient capacity to develop it further</p> <p>The process of restructuring has impacted negatively on the wellbeing and sense of worth of some individual practitioners, and on parent carers</p> <p>The size of the local area can make meeting everybody's needs a challenge</p> <p>Better communication for practitioners and parent carers about some planned restructures might alleviate some of the stress and anxiety inevitably involved</p> <p>Greater mutual understanding of different roles and responsibilities within the LA, especially following various restructures, and better communication between services about information received, would improve experience</p> <p>Keeping in touch with parent carers even if statutory timescales are not met due to capacity issues would reduce frustrations and help restore relationships; text messaging could be explored</p> <p>Processes for communication, understanding and information sharing</p>

<p>Parent carers, children and young people undergoing the EHC process have been informed of their key points of contact</p> <p>Collaborative events that involve Children and Adult Services coming together, particularly related to Preparing for Adulthood, have been helpful in improving mutual understanding and there is a will to build on this</p> <p>There has been some clear communication combined with events about the planned restructuring for practitioners in Adult Services</p> <p>The Portage approach makes parent carers the key partner and involves them and other services in regular family-centred meetings</p> <p>Portage workshops offer free training for parent carers, setting staff and other practitioners together as partners</p> <p>There are some good examples of person-centred joint working across services</p>	<p>between Children and Adult Services in particular could be strengthened further Sometimes only the negative stories are heard</p> <p>Restructuring makes it even more important to evolve a joined up approach and more co-production with parent carers, children and young people</p> <p>More emphasis on a community approach could be empowering for families</p>
<p>WELCOME AND CARE</p> <p>Despite the pain involved in the experience of restructuring, practitioners remain passionate and they care:</p> <p>"I think a real positive is when you're speaking to staff you've got lots of really passionate staff, it doesn't matter what area you're looking at, whether you're looking at areas, whether you're looking at the adulthood, the staff, despite what's going on structurally within the authority, the staff are still passionate about it";</p> <p>"...and it was kind of that passion, and passion within the team, 'Whatever, we're</p>	<p>WELCOME AND CARE</p> <p>Greater transparency and a focus on the respectful, enabling role Social Care can have might help increase trust:</p> <p>"I think it's hard for parents carers to trust ...a statutory...service is... about the parameters ...to show all the time that we can do things differently when we've got that flexibility...enabling, empowering, respectful...engagement with people...transparency...";</p> <p>"Yes, I think it's about empowering families to do those changes themselves rather than forcing them upon them and saying, 'This is what you need to do' and making suggestions</p>

gonna make it work";
"I am a great believer that despite all this the restructure provides massive opportunities, really positive opportunities, you know, and I think we need to take those as we can, but it's a huge, huge organisation and you know we think of our bit and you think of your little bit and I think we have to keep that in perspective, you know when we're looking at it or when we're moaning or, you know, not having a good day. You know, what is the purpose, what are we here for, what are we trying to do? You know, who are we trying to do it for? That's where the passion comes in."

The Early Years approach ensures that services work together and with parent carers from the earliest stages

The skills and knowledge families bring are affirmed from the start by the Portage service:

"I think as far as Portage is concerned...we work in partnership with parents, so from the get-go, usually, sometimes we facilitate the next-step discussions and, you know, make it clear that from the on they are, we are, in partnership with them and they are the senior partner really because they know their children best."

Early Years and school teams work closely together to support children transferring from settings to school

Transitions to Adult Services for young carers are managed sensitively and in partnership with them:

"We at the Care and Support Service, we do work closely with the Children and Participation Rights Team and [they] support young carers, so when those young carers are coming up to the age of

of how you can..."

<p>eighteen we do meet and have a conversation, you know, rather than just saying, 'Right, it's over to that team.' There is kind of a transition meeting and it's a gradual phase over so many months and then we will undertake an adult assessment for that young carer. So we do work well with that."</p>	
<p style="text-align: center;">VALUE AND INCLUDE</p> <p>The Stamp of Approval scheme facilitated by Portage tries to ensure that settings and nurseries are inclusive and child-centred</p> <p>There is substantial training for nurseries and settings to help staff identify additional needs early that is flexible and responsive to changing needs</p>	<p style="text-align: center;">VALUE AND INCLUDE</p> <p>The Stamp of Approval scheme is a valued tool for strengthening inclusive practice in settings and nurseries but there is insufficient capacity to develop it further</p> <p>The process of restructuring has impacted negatively on the wellbeing and sense of worth of some individual practitioners, and on parent carers:</p> <p>"Personally, I've found it very hard because I've had to...work more hours for less money. I've had to take another role because my job finished and it's it hard to keep positive. Well. you feel undervalued I suppose. But that's just personally. But there are other staff in the same position";</p> <p>"That's really important though, isn't it, that sense of feeling undervalued, given what we are talking about, that if we feel like that, how do parents feel and carers... I suppose it's what do we do better then as organisations to be better at valuing our own staff and telling them, because there will be lots of people who will hear that and think, 'Oh we did this and we do value them,' but actually if you don't feel it we need to make sure that you do. I think we can all feel undervalued at times but there's a difference isn't there, when it's something you haven't really been involved in and you can feel like you've been done to, and I guess it's trying to learn from that as well";</p> <p>"The restructure for professionals is also for parents as well. Parents know the</p>

restructure's going on and they don't know whether they've got the same worker, is that service that they've got for the last ten years going to be there, how are we going to access different services. So it's a stressful time for them as well. All of us really";

"We're just having it [restructure] in Adult's...";

"...every year now a new Head of Service has kind of... we've just undergone a restructure but at a much higher level, at strategic level and worked its way down really. We're looking at kind of, developing kind of the front door, basically, it's about how we're gonna manage, it's about how we're managing with all the volume of referrals we're getting both in Adult Social Care, in Adult Social Services and for carers as well. We're all under review. We're all looking at new processes, you know, it's just to enable us to be able to manage 'cos it's not gonna stop it's just gonna get more and more volume, it's gonna be crazy."

The size of the local area can make meeting everybody's needs a challenge:

"People are driving literally an hour everywhere almost, to get...";

"Yeah, because you're not just thinking about our team, we've got three teams, North, East and West team, and each area, so I cover the North team for example, if you're going from the top of the county to the bottom of the county, you're going from near Scarborough to near York, so you can travel an hour and a half, so you could see, you go to a meeting in Scarborough and then a meeting in Bridlington and a meeting in Pocklington for example, and you could spend three quarters of your day driving...I know it's about managing your diary but sometimes it's about meeting the needs of the parents and the children so you need to do that. It helps sometimes";

	<p>"I drove over a hundred miles yesterday, so that has an impact when we're visiting families, when we're visiting settings. It is difficult for us to manage, and particularly out the East where the road network's not great, you can't just go across to get to the East";</p> <p>"Yeah, we've got quite big rural areas, there's not a lot of things around there really."</p>
<p style="text-align: center;">COMMUNICATE</p> <p>Feedback from some parent carers about their experience of the EHCP process is extremely positive:</p> <p>"You get some really positive feedback from parents that say, 'Yeah, everything was within the timescales, it was brilliant, they kept me in the loop, I knew what was happening, yeah.'"</p> <p>Parent carers, children and young people undergoing the EHC process have been informed of their key points of contact:</p> <p>"There was a letter that went out...was it in the wintertime, a couple of months ago wasn't it? Where every child with an EHCP was notified who their co-ordinator was and who their family support worker was. I think that was an attempt to communicate with parents about who was their point of contact."</p> <p>Collaborative events that involve Children and Adult Services coming together particularly related to Preparing for Adulthood have been helpful in improving mutual understanding and there is a will to build on this:</p> <p>"We had a real good event...and that was about Preparing for Adulthood but it gave us a really good overview of what services are out there, so that when we are working with families we can say, 'Look,</p>	<p style="text-align: center;">COMMUNICATE</p> <p>Better communication for practitioners and parent carers about planned restructures might alleviate some of the stress and anxiety inevitably involved:</p> <p>"That communication really, making them aware of what the restructure is and what the hopes and aspirations of what that restructure is, how it's going to benefit a and family, how it can benefit them and services within the East Riding...I don't know how that message was sent out to families";</p> <p>"I've been through restructures for kind of years but it's never a good experience I don't think, and it's kind of understanding, I think sometimes, why don't we have those messages as to why things have happened";</p> <p>"If you're not informed then how can you?"</p> <p>Greater mutual understanding of different roles and responsibilities within the LA especially following various restructures, and better communication between services about information received, would improve experience:</p> <p>"There is communication within the local authority...being aware of what each other does, you know, we've had lots and lots of restructures and, you know, the word isn't out there yet so we don't know each other's' roles very well, and if we don't know it and understand it, how are parents and children and families going to understand it, so I</p>

these are the services out there.' So we know a lot more about those services, rather than just going in blind so we don't know...it was a good event";

"We've started working more closely...by doing the Preparing for Adulthood events and what have you, meetings...about working more jointly if you like, between Children's and Adult Services";

"Because it's a massive step for anyone but for children with additional needs it's huge isn't it, we need to make sure they're going from the services they get in Children's and that's mirrored in Adult's, rather than just going to Adult's and becoming a small fish in a massive pond, really, and just getting missed."

There has been some clear communication combined with events about the planned restructuring for practitioners in Adult Services:

"We've had the Building The New Tomorrow so we've had quite a lot of events which have involved Social Care staff to inform them of the changes and what's happening, the new vision, we've been given booklets. We have been kept informed on a regular basis...but that's just for Adult Services";

"Because if you're aware then you can look at it, and I mean from those events, I mean all my team have come out of it, been very positive, and excited because looking at the new vision, because they're informed."

think we've identified that that is an area we need to do some work on";

"...a work in progress...it was a huge, huge restructure, it was you know, a big, big change. I think we are reflecting on it and kind of people changing as a result of that because we've realised some things are not maybe working as well as we want it to";

"How we're dealing with information that we're getting so that people get the right service at the right kind of time; because you always hear the...about people having to tell their story three times over and it's trying to trying, really, to avoid that and I think that better communication in all our bits of service, whether it's kind of locality social work teams which are slightly different to kind of SEN teams, but it's the same kind of job, you know, the same job, we're trying to do the same thing, working with people";

"When you don't know what the new services do, how can you confidently say to parents this is...this is such and such...when you're not so sure yourselves. It's about what services have we got and how we all interlink those services, and are we linking in with the right services, or should we be linking in to another service?"

Keeping in touch with parent carers even if statutory timescales are not met due to capacity issues would reduce frustrations and help restore relationships; text messaging could be explored:

"I think a problem that we have that frustrates a lot of parents is timescales, so things like EHCPs there's sometimes timescales are missing and that's frustrating for parents...obviously that's because we've got such a huge number of children and we've got a reduced number of staff, but if that communication was open with parents and, kind of, saying, 'We're not working to time frame at the moment' but just kind of

keeping in touch with them about that, I think sometimes parents maybe feel they've been forgotten about when maybe they haven't. Just that, kind of, touching base a bit more frequently might kind of build those relationships with parents and the EHCP team probably";

"Something that we get back from parents sometimes is, 'No one's told me, people haven't been in touch with me, I don't know where my child is going to school in September' for example, and even if deadlines aren't met, it's just a case of getting in touch with that parent and saying, 'Look, you've not been forgotten about, we're just waiting for this to happen, things are going on in the background' and that's all parents want to know. I don't think...obviously they're upset sometimes if they don't get the school or they don't get... but actually they want to be kept in the loop about what's happening, to know that something is going on";

"I mean you could probably do things at a corporate level where you...set up a text system...I'm not saying you do that for everything but something as simple as that would actually save a lot of staff time. We're not very savvy I don't think about using that I suppose, it just occurred as you were talking, because people have that twenty day there's a set kind of process isn't there, you could send regular texts to people about that bit and if there's something more specific then get on the phone and talk directly, but that might...because you expect that when you're ordering something from Amazon...";

"If you got a text to say that's been received, that's the stage that it's at might be something that's useful";

"We've just started to oversee the blue badges as well, there's been a massive change around that and there's a bit of a text like for parents, they get told which

stage it's at, whether it's the Customer Services stage, whether it's with the 0-25 Team to be looked at, they need to send more information, so just something like that so parents know the stage that they're in. That's all they want to know really, and that's a lot of feedback that we get as practitioners though, 'It got sent off weeks ago. No one's been in touch. The school haven't been in touch.' No one knows what's happening. A lack of communication really."

Processes for communication, understanding and information sharing between Children and Adult Services in particular could be strengthened further:

I think we probably need to work better. Our FISH [Families Information and Support Hub] Team, we used to receive a sheet of names and addresses of parents and the person that they care for...when they were approaching the age of eighteen but that's stopped, but whether that's to do with the GDPR, I think probably, so maybe we need to...relook at that and a different referral process";

"We work 0-25, we cross over a lot with Adult's and actually going over from a Children's Service to an Adult's Service is a massive jump, so sometimes we're sat in meetings with adults that we don't even know as professionals but we're introducing a person to a service but we don't really know very much about that service, so us understanding more about what Adult's do."

Sometimes only the negative stories are heard:

"We only tend to hear the negative stories sometimes, when timescales aren't met";

"And remember them";

"I don't think we've got any results have we just to say that, 'Look, before the restructure this was happening' looking at positive stories really, so it's been about

	<p>eighteen months since the restructure so it's quite had to gauge really"; "What we had [before the restructure] wasn't working very well and we had to do it better."</p>
<p>WORK IN PARTNERSHIP</p> <p>The Portage approach makes parent carers the key partner and involves them and other services in regular family-centred meetings: "Then we'd [Portage] go onto facilitate family meetings where we'd invite any professional that's working with the child, parents, ourselves, and we would hold a meeting looking at really, what's been happening, what's happening now, what's happening next, and have those meetings regularly, and always taking into consideration the parent's views."</p> <p>Portage workshops offer free training for parent carers, setting staff and other practitioners together as partners</p> <p>There are some good examples of person-centred joint working across services: "Each day we [0-25 SEND Team] have a duty worker on the phone and they take information from parents, other professionals, colleges, schools, a bit of a request for support really, and every Monday we have a support meeting and discuss about, discuss the cases and whether we feel it's a Family Co-ordinator role, an Information and Guidance role, a Portage role, and one of the first things we always say to that is...'Go to the family and introduce yourself' and have that home visit, where they feel comfortable. Rather than getting them round a table like you said, in front of all professionals, they might not feel comfortable, you</p>	<p>WORK IN PARTNERSHIP</p> <p>Restructuring makes it even more important to evolve a joined up approach and more co-production with parent carers, children and young people: "I think we've got a lot of joining up to do, a lot of people doing very similar things or overlapping things in different places, and that all needs pulling together, and that is very difficult. Difficult for professionals to understand, because who is the right person in which team? But for parents, for a parent to understand that as well? And I think obviously the co-production is gonna be really, you know, kind of crucial in that, and feeling in, and kind of getting that, those voices heard, and those experiences, 'This is what it's like for us.'"</p> <p>More emphasis on a community approach could be empowering for families: "And that community approach as well, because we can't parent every child, that's what communities, that's what parents do...you're right in saying, empower them, whether that's some advice or whether it's actually about the house that they live in or the fact that they can't get a job, you know it's a whole variety of things isn't it, so..."</p>

<p>might not really get out of that parent what they want from your service, as I said we do that home visit, get all the information back and put a bit of a plan together tailored for that individual, and then if we need to we have a TAF [Team Around the Family] meeting, but just making sure that parents are comfortable in everything that's done really, making sure its person centred and tailored towards the individual."</p>	
---	--

East Riding Narratives: Health

4 attendees: Strategic Health Lead; Designated Clinical Officer; Clinical Commissioning Group Manager; Public Health Lead.

Going Well	Could be Better
<p><u>Key narratives</u></p> <p>There are examples of working in co-production and person-centred practice</p> <p>Important key relationships already exist</p> <p>Parent carers and Health practitioners seem increasingly comfortable working together as equal partners, which is valued by all those involved and informs next steps</p> <p>There is enthusiasm from different agencies about being included in partnership working</p> <p>People feel comfortable with working together to incorporate the views of others, which is valued by those involved and informs next steps</p> <p>Outreach projects such as the Maternity Voices Partnership (MPV) are seen as valuable and there is hope they will impact on those at the margins</p> <p>Mistakes within Health are recognised and admitted, viewed as learning opportunities; practitioners are reflective about learning from them</p>	<p><u>Key narratives</u></p> <p>Areas for improvement have been identified around governance</p> <p>Practitioners recognise that parent carers can identify needs but may not always have access to the necessary resources</p> <p>Co-production needs to take time to include all groups</p> <p>Investment needs to be made for a more person-centred approach and to develop a culture of trust</p> <p>There is a sense that co-production is happening but that it needs to be happening in a more holistic and genuine way</p> <p>There is frustration when efforts do not seem valued and there is a feeling of wasted opportunities when there is low engagement in attempts to work together to respond to needs identified by service users</p> <p>Changes happen and it can be difficult to ensure these are communicated in a timely manner to those for whom there is an impact</p> <p>Decisions are sometimes made without consulting those they will</p>

There are open lines of communication within Health and transparency is seen as vital

Joined up thinking and a consistent approach to knowledge is viewed as important

There is a developing understanding of how different agencies work

Practitioners want to find other ways of communicating that reach out better to some local communities

Families within the system recognise how things work and offer peer support to other parent carers

There is hope amongst practitioners that this is an important and valuable time to continue what is working well and to make things even better for those in local communities

There are initiatives already happening that appear to be having a positive impact and are informing future practice

There is optimism for future growth and development

affect, resulting in a lack of trust in being able to communicate with people in the local authority

A culture of openness needs to be developed throughout all services so that learning and improvements can come about

There are additional layers or levels of communication which can lead to frustration when Health practitioners are unable to directly access those with whom they need to communicate

There is emphasis on the importance of continued information sharing and use of the Local Offer

It is hoped that changes will improve experiences, however, changes can also lead to difficulties because of the impact on consistency and established relationships

Resources, in particular time and people, are not always readily available to do all that practitioners would like to do including make stronger relationships and this can lead to frustration

There is recognition that there needs to be systemic change as well as the need to appreciate and understand the differences that exist between services

<p style="text-align: center;">WELCOME AND CARE</p> <p>There are examples of working in co-production and person-centred practice: "I think all of that is on an individual basis. The co-production is really there and it's really person-centred and it's the main thing that you're planning around."</p> <p>Important key relationships already exist: "I do think we've got some really excellent relationships with parents and carers, and children and young people."</p> <p>Parent carers are valued for their expertise on conditions but it is recognised that parent carers should not be expected to undertake this role: "Parents do become experts on conditions but they shouldn't be expected to be."</p>	<p style="text-align: center;">WELCOME AND CARE</p> <p>Areas of improvement have been identified around governance and accountability: "It was identified in the peer review that there were improvements that could be made within Health around a more strategic...strengthening the governance, so that if something has been agreed and actioned, that actually it's answerable somewhere and we need to tighten that up."</p> <p>Practitioners recognise that parent carers can identify needs but may not always have access to the necessary resources: "What we're hearing is that people are going to Crisis. And Crisis are getting overloaded and people don't need to go to Crisis. People aren't getting seen as quickly as they need to be. If people knew where to go and when to go then we'd be reducing the pressure on those kinds of services because when people do need it, they need to be able to access it in a really timely fashion"; "So parents are going in to say to a Head 'It's actually you're statutory duty to provide this, this and this.' It's embarrassing in't it? Saying 'You should have a policy on this...what is that?'"</p>
<p style="text-align: center;">VALUE AND INCLUDE</p> <p>Parent carers and Health practitioners seem increasingly comfortable working together as equal partners, which is valued by all</p>	<p style="text-align: center;">VALUE AND INCLUDE</p> <p>Co-production needs to take time to include all groups: "It took us quite a while, I think, to work out the things that weren't being done, because sometimes it takes a</p>

those involved and informs next steps:

"Certainly from parents and carers, I think there would be lots of good feedback on being partners, just seeing each other as equals, not having any differentiated discussions, you've been as open and transparent, the same as you would be with colleagues from Health";

"My whole SEF [Self-Evaluation Framework] really has been co-produced with the Parent Carer Forum to establish what they want me to be working on because the gaps come from discussions from them";

"There's pockets or people and it's sort of gathering the troops";

"So, what we do well is we do engage with the Parent Carer Forum and we include parents of children with SEND";

"I've got that level of trust in Health that I can go to a manager and say, 'This isn't happening, can you go and speak to the Director of Commissioning?'"

There is enthusiasm from different agencies about being included in partnership working and outreach projects such as the Maternity Voices Partnership (MPV) are seen as valuable; there is hope they will impact on those at the margins:

"The people who are presenting are just as enthused as me. The people from EHaSH [Early Help and Safeguarding Hub], the Wellbeing Centre";

"Maternity Voices Partnership was set

while, doesn't it, to see the impact; it's a lesson learned";

"It's difficult because working in Public Health, the things that we do is for a general population. So while we do stuff for target groups, it is generally for anyone and everyone."

Investment needs to be made for a more person-centred approach and to develop a culture of trust:

"We need more people";

"Academisation hasn't worked for SEND";

"But I don't feel that I've got the trust to go to the local authority and say, 'You know, that decision will impact in these ways and that's a direct, detriment really to the children and young people that we're trying to provide service for.' That's not transparent, I don't think, in the local authority."

There is a sense that co-production is happening but that it needs to be happening in a more holistic and genuine way:

"I think what we don't do is engage with other parents [parents of children and young people who do not have SEND]... so probably that bigger group that we work with, we don't do as much co-production as we should";

"I think there's a lot more work that could be done in co-production";

"We've been co-produced to death, to within an inch of our life. I've sat through the Rotherham discussions twice. It's like democracy, it's just a word, in't it? It's heard and often used

up to look at some of the outreach and how to engage families”;

“There’s a Health expo Maternity Voices Partnership (MPV) stand, aimed at mental health and homeless. MPV has a strong emphasis on post-natal mental health.”

but it’s like ‘Let’s get on with it and do it’”;

“There’s a level of it [co-production]. There’s a level of compliance but it should be everything, ‘We’re thinking of doing this; would it impact on you?’ Because they wouldn’t necessarily understand how it’ll impact.”

There is frustration when efforts do not seem valued and there is a feeling of wasted opportunities when there is low engagement in attempts to work together to respond to needs identified by service users:

“Another thing that came out of our peer review was that the inspectors were asking the parents and teachers and carers about referral services for emotional wellbeing support for children and young people. It was feedback that they didn’t know where to refer apart from CAMHS. So we pulled together a training event. I was asked to do it as soon as possible so I found out when the last exams in the schools were which was 24th June. A lot of work went into it. It’s been really well advertised in the Head teacher’s bulletin, SENDCO forums, everywhere. And I’ve had three secondary schools say they can come. Three. Out of eighteen. The primary schools, we have 118 primary schools, and there’s about 35 that said they could come”;

“I’ve been asking local authority colleagues, please can you push it, what can we do? And all I’ve got back from them is, ‘It’s the wrong time of year, they’re tired, the teachers are so

	<p>tired.' We're all tired. We've spent hours on it and have spent £2,000 on this place next Monday. And because I've had to now reduce it so we're only doing it in the morning and not in the afternoon but I still have to pay for the food. And Health, we don't have that money to waste. And I had to fight like mad, didn't I, to get the money from our senior directors. Twice I had to go in and explain why we needed it. I had to explain because the feedback from our review is that we need to educate the teachers, the schools and the SENDCOs. And I'm very disappointed";</p> <p>"That's Health money that could go on an operation or a care package";</p> <p>"I don't understand. I'm very disappointed. All I'm getting back from people from the authority is that they're tired."</p>
<p style="text-align: center;">COMMUNICATE</p> <p>Mistakes within Health are recognised and admitted, viewed as learning opportunities; practitioners are reflective about learning from them:</p> <p>"I think that's what we're really good at in Health, 'Right we've messed up there, we can improve it'";</p> <p>"The Parent Carer Forum applaud the way that Health, even when we're doing it really wrong, that we hold our hands up and say, 'We've got it really wrong, what could we have done? We really want to learn from that'";</p> <p>"We're quite a reflective CCG [Clinical Commissioning Group]. And we do sit</p>	<p style="text-align: center;">COMMUNICATE</p> <p>Changes happen and it can be difficult to ensure these are communicated in a timely manner to those for whom there is an impact:</p> <p>"I think there's communication that we could improve on, informing parents that providers are changing, things like that because it's all part of that. It's all in hindsight, isn't it? It's about feeding that back and learning from it and making improvements";</p> <p>"There's parents out there that don't know how to refer and we need to do things different";</p> <p>"They said it'd be better in the autumn. But the summer holidays are a</p>

down and we're quite humble, aren't we, and we say 'We're rubbish at this. Now how can we improve?'"

There are open lines of communication within Health and transparency is seen as vital:

"I can go to my Director and say, 'What's going on?' Because I speak to him like I speak to a parent and carer because we speak to everyone the same, don't we? It's what it's about."

Joined up thinking and a consistent approach to knowledge is viewed as important:

"We have a weekly email, Hot Topics, that goes out to all our GPs";

"Twice a year we have an event. It's called 'Protected Time for Learning.' It's for all our GPs in East Riding. CCG pay for out-of-hours to come in so all practices are shut down for an afternoon so every GP and Practice manager attends. We had 300 GPs. We thought, 'This is our moment!'"

Practitioners want to find other ways of communicating that reach out better to some local communities:

"From a Health side we try every angle, we really trying";

"The introduction to Chat Health should help as well for Health Visitors. Children and young people can text any mental health concerns."

Families within the system recognise how things work and offer peer support to other parent carers:

"What I've found, I work mostly with

prime time for an increase in referrals, aren't they? People are bored, they're at home, kids are isolated, they live in rural... Come September they could hit the ground running."

Decisions are sometimes made without consulting those they will affect, resulting in a lack of trust in being able to communicate with people in the local authority:

"But I find that within our, within Health, I'm very operational in the role that I am really, but when you're the face of that, that's when people are coming to you and telling you, and feeding that up through the relevant structures is quite difficult. But strategic decisions, massively, impact, massively impact on what is going on the shop floor";

"Like yesterday. A decision was made that'll throw Health into nightmares and no discussions have been made. The decision has been made from the local authority that will impact directly on children's health";

"But I don't think I could go up the ranks in the local authority and say 'You've made a decision and it's absolutely... I don't know if you can go back on it but it's damage limitation, how can we crisis manage that?";

"I don't feel, and I certainly don't feel my equal partners within the local authority, that they've got the level of trust to be able to go up and do that [talk to those in the most senior roles] otherwise mistakes wouldn't happen would they?"

A culture of openness needs to be

families trying to manage medical conditions around school and trying to avoid any unnecessary EHC [Education, Health and Care plan] requests ... I think we're at a point where parents are more empowered and knowledgeable about what's going on. If they've been in the system a while and they're sort of advising partners on what to do."

There is hope amongst practitioners that this is an important and valuable time to continue what is working well and to make things even better for those in local communities:

"There's a spark of optimism that this will make a difference because of the transparency, and you can't fix things if you don't know what's broken."

developed throughout all services so that learning and improvements can come about:

"There's a lack of willingness to be transparent, or air you're dirty washing out in public, because we've been celebrated for doing that in Health"; "But there's a lack of that from other agencies."

There are additional layers or levels of communication which can lead to frustration when Health practitioners are unable to directly access those with whom they need to communicate:

"For Clinical Commissioning, we don't have direct access to the schools. We have to go through the local authority, they're our way in, so that's the frustration";

"I sent an email out to quite senior people in the local authority saying, 'This is the situation, any ideas on how to promote it?' Not one of them got back to me."

There is emphasis on the importance of continued information sharing and use of the Local Offer:

"Parents with new concerns, no, I don't think they know where to go. And the Local Offer, you have to know it exists, don't you?";

"We're looking at having a clearer strap line" [with regards to the Local Offer];

"It's difficult because if you don't need that thing at that time, it goes in one ear and out the other. And when you do need it, you don't remember";

"We need to get the message out to people, these are the services which are available, this is when it's appropriate to refer";
 "Don't ring Crisis unless you're in crisis. It's about re-enforcing the message about mental health conditions; it's irrelevant to them. They'll chuck it in the bin or they'll put it on a shelf and forget about it. Then when something does happen, they ring CAMHS [Child and Adolescent Mental Health Services]";
 "Keep drip-feeding so that when something is an issue, they know where to go and they think actually that rings a bell. Because we're never going to remember everything because there's so much."

WORK IN PARTNERSHIP

There is a developing understanding of how different agencies work:

"In the last few months, the joint working that the CCG has been doing with the LA towards the SEND agenda, I think we've built up quite a lot of good relationships. We've both got an understanding of each other's role and how it all fits together."

There are partnership initiatives already happening that appear to be having a positive impact and are informing future practice:

"We've done some excellent work with Health Visitors and Early Years Support, it's a really good example of the local authority really working with Health and parents and carers to

WORK IN PARTNERSHIP

It is hoped that changes will improve experiences, however, changes can also lead to difficulties because of the impact on consistency and established relationships:

"I think there are improvements but because of the constant changes it's difficult because it's all around relationships, isn't it? And when people leave or providers change then that's very upsetting really for parents."

Resources, in particular time and people, are not always readily available to do all that practitioners would like to do including make stronger relationships and this can lead to frustration:

"And it's just, like, that's not co-

change their systems and that came from the Act really. We've channelled all of the early identification stuff to come through Early Years Support. The Health Visitors have been really brilliant at rolling that out. And there's evidence of that because if a child comes into the system after they're three and a half, that gets deep dived into, to say that somebody from Health knew about this or why didn't you know about this? And what we've done now is reduced it now. So very rarely do they come in unless they've moved into the authority or got a brain injury. That is a really good example, but we can't live off the fame of that forever, we need to grow that in other areas";

"Also the Future in Mind refresh, you know, we share information and I just think that's working very well";

"The Withernsea Mental Health Group's been set up to work with the school and that's multi-disciplinary, multi-agency looking at working in quite a deprived area in Withernsea, so there is a lot of outreach to look at what the needs are of those pupils, young people in that school, particularly on the SEND agenda, non-engagement, opting out of education and looking at what can be put in place to support. And what can be put into place to support whilst young people are waiting for support from Health agencies as well, in terms of emotional support";

"There's a community steering group that was involved, that was brought together with the police agency, as

production";

"It's very, very difficult, isn't it, because it's all about relationships. And when cultures are different in organisations and one doesn't know what the other is doing";

"They gave us ten minutes. What can you say in ten minutes? And we tried to get the SEND agenda in but we had so many things we wanted to say but it was well received";

"We'd agreed to do some listening groups. The director said he would come and do a listening event, parents and carers could come and say what's going well and what's not going well and have an action plan at the end of it.

It's never happened. It's never happened which is a real shame. I don't think it's lack of willing, I think it's lack of capacity within the local authority at the moment because of the changes that are going on";

"We do need more leaders. There isn't enough of us."

There is a recognition that there needs to be systemic change as well as the need to appreciate and understand the cultural differences that exist between services:

"I don't know how from a Health point of view we can improve operationally on the shop floor, if you like, it's the strategic stuff that worries me";

"There are some big improvements that need to be made. Sometimes I think that when you're working across organisations that have got completely different cultures, and different individuals that come from different

well really, in terms of petty crime and serial offenders and families that were getting into difficulties. So that's probably a good example of co-production";

"From going to listening events myself, it's where I get my, a lot of my workload from because I know where to target because they're really vocal, the Parent Carer Forum are. They don't just come to you with problems, they've often got the answers, and in a way we can be those people to give them a voice. It makes it so much easier, why would you not?"

There is optimism for future growth and development:

"I think it's good we're trying a different way";

"And that's where we can support with that, to try and say 'Well that is something that we would expect from Public Health or that we would expect that from wherever.' And we can get people around the table."

backgrounds, that understand that we cannot actually do what we're supposed to be doing without the link of knowing what the issues are... how can we source what things are, what the needs are of that community and if perceptions are a bit skewed about what people think is Health and what they think is Education";

"Going to have to think about how to educate schools more so I need help from local authority colleagues who know the schools";

"Different cultures, policies and procedures. They have their ways of working and we have ours but we all need to work together to get the best outcomes for the kiddies."