

**Letter to parents/carers from David Blacklock, Chief Executive of People First Independent Advocacy and Chair of the Co-production and Engagement Working Group of the Cumbria SEND Improvement Programme**

**23/8/19**

Dear Parents and Carers,

First of all I would like to say a huge thank you to all of those who attended the session at Redhills, Penrith on Friday 16th August. Those of you who were there will know that there was a range of emotions in the room but overall I thought that the session went quite well. However it wasn't perfect and my team and I have noted comments and feedback on how we would do things differently and better next time.

The session had 17 parents and carers in attendance; I led the day and was supported by Sue Stevenson and Matthew Tognarelli from People First.

Special thanks must go to Rachael for helping us to take notes on the flipchart. Questions and ideas were also captured on post it notes during the day and these will also be included in the summary of the day.

There will be a full set of notes made available as quickly as we can; these will summarise the day, the discussion and lay out the flipchart notes as well as actions agreed.

It's fair to say there was a lot of emotions in the room, mainly frustration, anger and disappointment. We all worked hard to contain this and remain as positive as possible, however inevitably some of the negative thoughts and feelings surfaced. I think that it was important that this happened and it is entirely understandable. Where possible I tried to move us past any negative points of the session, as my view is that we have to acknowledge the negativity but try our hardest to remain as positive as possible, so that we can focus all of our energy on making things better. I could also see, however, that there were people present who wanted to accept "we are where we are" and others for whom it was very important to understand more about what had happened so far and why.

I could also see that some people had more information and knowledge, particularly about the complex health and care system, than others and that at the moment there are far more questions than answers.

So what's next...

- We will invite the 40 people who expressed an interest in the Working Groups to attend another session towards the end of September. We agreed that this group will continue to meet and act as a Reference Group, my hope is that the Local Authority and NHS will work with this wider group and attend regularly to check things out with us, share their thoughts and plans and that this will be a place where parents and carers can ask questions and receive answers. Other parents can attend if they like, by contacting Matthew at People First and asking to be included (this will help us to manage numbers, rooms etc.)
- We will seek a little more information from some of the 40 people, particularly about the nature of people's disability before using all the available information to help to identify people to sit on working groups. I know that the delay in getting people on the groups is a huge frustration to people, but we have to make sure that it's a fair process and that it's open and transparent.

Attendees of the 16th agreed that the decision will be made anonymously, i.e. names will be removed and the deciding factors will be:

- where people live, to give us the best spread across the county
- the age of peoples children/young adults
- the area of need
- the group that a person is interested in being involved with

We also agreed that we would have a small team of representatives for each group, maybe up to 4, only two at any one time will attend the working group, but having up to 4 will enable parent/carers to share the task and cover each other.

- We will then provide some training for reps around understanding the system, what the SEND code of practice says etc.
- Once we have the reps chosen we will decide together who attends the SEND Improvement Board to feed in key information
- It was agreed that a letter would be sent to the chair of the SEND Improvement Board – Linda Clegg, expressing how disappointed parent/carers are at the working groups starting without parents/carers being involved. This letter would also ask a range of questions that were identified during the session.
- At the last Improvement Board it was confirmed that when reps are in place, they would have the chance to meet with the Chair of their working group, and that they would be matched with a mentor/buddy who is a professional on the group, hopefully this will help people to settle in, get to know others and catch up. It's not perfect but we just have to keep taking steps forward.
- We are going to draft an engagement plan which will help even more parents to get involved, have their say and support the reshaping of services that aren't working. It was agreed that these engagement sessions would happen at different times of the day and in the evening, and when necessary there would be more than one session on a topic in different locations for example meeting with the NHS in the South of Cumbria and repeated with the NHS in the North/West of the county as they are different organisations.
- Healthwatch Cumbria has a training session which is aimed at helping people to understand the health and care system in Cumbria. This would be made available to those parents who want it. Working on this together should help people to be clear about which organisations are responsible for what things and who makes which decisions. We need parents and carers to have all of the right information so that they can influence in the right places/ways.
- We are going to ask for a glossary of terms (list of name/words often used by professionals) to be made available.
- The group agreed that they want a separate website made available (not the Local Offer) where all information will be made available, notes of all meetings that have already taken place, agendas, dates and times of future meetings etc. I don't think this will be a problem at all.
- Some parents/carers have already told us that the session was really difficult for them, mainly due to the high levels of emotions and the negativity that was present in the room. Unfortunately this may mean that some people won't want to stay engaged. Of course this is their choice and the first few meetings were never going to be easy, however I would like to ask that we all try to stay focused on the end goal, better services and outcomes for children/young adults.

If you are feeling upset, angry and quite negative please speak with me directly and maybe I will be able to help. It's important that when we come together we remember that we must be kind to each

other, look after each other and use all of our energy to make things better and more forward together. Parent/and carers are much stronger when we speak with one united voice.

Please note that I have now gone on annual leave for two weeks and will be back at work on 2<sup>nd</sup> September. In the interim please address any questions you have to Sue Stevenson and Matthew. Anything that can be addressed in my absence will be and anything outstanding will be brought to my attention as soon as I return.

David Blacklock

Chief Executive

People First Independent Advocacy