

Families perspective

*Hollie Rawson – Research Assistant, Complex Learning Difficulties and Disabilities Project
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As part of the initial stages of the Complex Learning Difficulties and Disabilities research project, families of the 60 cohort children and young people were interviewed to gain a deeper insight of the children's motivators and learning – at school and in the home, to help us shape a profile of engagement and a pathway to personalised learning. Other areas covered in the interviews included communication between home and school, fondest memories of the child, and hopes for the future. This article gives a brief summary of some of the broader themes from the interviews.

The theme most prominent from all of the interviews was that of the happiness the child brings to the family and the pride and elation that follows witnessing their child achieve, however slight this may be. Parents discussed memorable and joyous events, such as the first time their child: spoke, defying all medical beliefs; walked in a frame, despite being told they might never stand; overcame anxieties and took part in a school production. However it is also the smaller things that these children do that provide the family with joy daily:

'when he reaches out for your hand to stroke or hold'

'It's the little things... I just love taking him out because he buzzes, even just driving in the car. I like just seeing him happy.'

Another area which was discussed frequently across the interviews was the battles families have endured through their children's lifetimes to get the support and services their children require. Fights for statements, resources, equipment, school placements, respite, one-to-one classroom support and therapeutic intervention leave families exhausted, but shows the persistence and determination required to receive the best opportunities for these children. This persistence is also demonstrated through the approach families have to their child's acquisition of new skills and concepts:

'...you try and try again, and if that does not work, try something else'

The majority of families are very happy with their child's school and education, with many families having seen significant development in their child since they have been attending a school appropriate to their needs. Some acknowledged how hard it can be to see little, or no progression in their child's learning despite determined intervention, and for some to accept that they may even regress:

'I didn't realise his learning would be so difficult – sometimes it seems that he is progressing and then he takes two steps back'

Families who are not as satisfied feel that much of the curriculum is not suitable for their children. They feel that there is too much emphasis on specific subjects such as French and Geography, for example, and not enough on basic life skills, communication, social interaction, play and therapies. Other parents feel their children are not challenged enough – they feel that some educators underestimate the intellectual capabilities or potential they have. Sometimes these are often masked through having limited communication, profound physical impairments, or through behaviour and bravado. Parents interviewed stressed the importance of personalisation, in both the curriculum being tailored to individual need, but also to the child's motivations. Asking families about how their child learned in the home when growing up, many said that this was achieved through using what motivates them as both a tool to teach and/or as a reward. Siblings were often part of this learning, helping to read, write, and assist with daily living skills.

Linking with the importance of personalisation came many references to the need for consistency both at home and at school, and the value of relationships. Some children need the predictability of the routine to engage without anxiety, others require the same approach used with them consistently everyday to enable them to understand their environment and make a contribution. Other families stress the importance of the staffing being consistent; without the same team of people working with the child daily, staff cannot learn the complexities of their health, learning and behavioural needs, which ultimately limits the child's progression. Good relationships between children and staff, children and family, and staff and family provide trust and the basis of consistency, and stem from knowing the child well. One parent said:

'you need to know him to help him'

Communication is the families' dominant priority for their child's development. Families say that it is wonderful to have different communication systems in place, both low and hi-tech, but they would like the proper use of these explained to them to ensure consistency between school and home. Some families would like there to be more of a focus on appropriate communication strategies for their child.

'When she started using the DynaVox, for years I'd dreamt that she could speak to me and now she can answer you and she has a voice. It brings tears to my eyes. Communication is a massive part of our lives, but you don't know if you don't have it.'

All families want good communication with school and care. In the main, communication is good, with regular correspondence via home/school diaries and telephone calls with teachers, teaching assistants and key workers. Families say that this ensures both sides are informed of important goings-on and keeps them at ease. For others this communication can be inconsistent. Some would like diaries to focus more on positives and content of the school day, rather than just behaviours. Many parents, particularly those with children in residential settings, would like more information and photographs showing what their child is learning, as they do not have communication systems such as the home/school diary in place.

Families did discuss anxieties for the future: will their child's behaviour be tolerated in the community; will they be able to communicate what does the future hold for them – will they ever be able to work? The main desire for the future was for their child to be happy and to be reaching their potential, with a focus on developing communication and independence skills:

'...for him to keep progressing and become more independent'

'...for her to have as normal a life as possible. To be able to go out and work and get a career. To be happy and get somewhere in life.'