

This note provides a summary of the issues raised during discussion with a Mum of two children, one of whom has complex needs. She is solo parenting following the death of Dad.

- There is a high turnover of staff / professionals and agencies involved in the family's life.
- There is a lack of coordination between health and social care services.
- The child's voice is rarely heard in discussions, despite the parent's advocacy on their behalf, but the child is rarely involved in these discussions.
- Their child was recently unable to go on an overnight residential because the school would not support the child's tube-feeding. This is a clear example of them being excluded from activities. When this was challenged, the parent was advised to speak to the Inclusion Officer. Up until this point, the parent hadn't been told of the existence of Inclusion Officer existed or the possible support.
- There is no "road-map" of agencies and services, and when they can be called upon. While there can be support available, especially through the third sector, it's difficult to navigate the administration, as well as having to source it in the first place. This is the last thing you want to do, so you don't end up accessing support that might be very helpful.
- There is a lack of holistic services that wrap around all of the child's multiple needs. There is a lot of "box-ticking".
- Battles have to be picked because of the level of energy that it takes to fight. An example was given. The care package was increased following the sudden death of Dad. Within six months the local authority said they wanted to roll back to the package that was in place before the unexpected death. They also said that the support was not being used inappropriately (it was being used to provide after school care for the child, while Mum worked.) There is no other after-school care provision that could be accessed, and this provision was in the best interests of the child and the wider family. After an 18 month battle it was agreed the current care package could be retained but it would be "reviewed" in the future. Shortly, after this was agreed, the Mum was informed the package would be reviewed again.
- There is a lack of documentation of what is agreed in terms of support or agreed actions following meetings. This also leads to the Mum having to repeatedly go over their family's circumstances, which is retraumatising and has a significant impact on her mental wellbeing.
- They have had to reduce their working hours, yet this has had a significant impact on their wellbeing.

- All the discussions around the child is focused on the things they cannot do, rather than the positives of what they are able to do. This deficit approach has a high psychological impact on all involved.
- The child is well looked after in school, but there is no broader account taken of the family's needs. An example given was when the parent asked for support in starting potty training, the school refused to take the lead on this. The parent then started potty training over the holidays, but when they returned to school they said they couldn't support this as the parent had not done it in the way the school wanted to do it, even though the approach the parent had taken took account of their child's needs and preferences and was working well.
- Systems are very rigid, and do not show any compassion.
- There is "countless" administration and requests for information, and you need energy and support to be able to provide this.
- The siblings are often lost in discussions and support.