

"Families are a Help, not a Hindrance!"

A professional carer was overheard saying of one of the people she was working with: "Things would be a whole lot easier if only he was an orphan"

As sad and shocking as this remark is, I include it here to make the point that many service providers do not yet see that families of people with learning disabilities are a help, not a hindrance.

Steve Scown talks tactics on the often tricky issue of how best to involve families in ways that work for everyone.

The families' contributions to both their relative's life, and to the work we do, are vital. We're all on the same side and we need to be holding hands, not forming fists.

A recipe for conflict

The families of people with learning disabilities and autism often complain of feeling unimportant and left out when service providers get involved. Their impression sometimes is that once their loved one is "in the system", important decisions are made without their involvement, and that all their years of love and intimate knowledge go unnoticed and unheard.

This can be especially true when the family member leaves home for reasons that any family might struggle with, such as family breakdown or ageing parents. Throw in a dose of confusion about how decisions are made and what's on offer, and you have a recipe for conflict.

Of course, professionals have as their priority the well-being of the person at the centre of all this - not their family. Some can even see parents and families as meddlers - or worse. But most just see the conflict as a sad drain on resources and energy. As one former colleague put it: "I'm very tired of being at war with families".

Ultimately, most family members are just trying to do the best for their relative and what is clear is that the individuals themselves will almost always enjoy real benefits from having their family actively involved in their lives and forming an integral part of the support team that helps them live the life they want.

Research shows that people with learning disabilities who have regular family contact experience enhanced quality of life and enjoy better links with the community.

So how do you do it?

As I see it, there are two main challenges:

- the need to develop a family aware/family-friendly approach which involves a cultural shift in services and different ways of working with families.
- the need to adapt to the changing social market that personalised support has introduced, and proactively engage with families.

For a culture shift to happen, bringing families into the frame needs to be at the heart of everything we do; a grass roots shift towards something altogether more inclusive than is usually the case.

So when we are working out how best to support and communicate with the people we support, their families need to be on that agenda too. If we're reworking a website or drafting leaflets, we need to ensure the families are represented. In marketing plans and budget sheets alike - families need to be included. And if you're agreeing a day for an appointment, make sure it's at a time when a family member can come along.

With personalisation, it is important to work creatively with each individual to deliver results that make a real difference to their lives. By listening to the people we support and their families, we can continually learn and improve. It is important not to pretend to have all the answers because people change, as do the different services on offer.

The whole point of personalisation is that service providers put an individual at the centre of the process to identify their needs and make choices about who, what, how and when they are supported to live the lives they want.

But the ethos behind personalisation must also now extend to those individuals' families. Each family comes with its own needs. Some want to be heavily involved in every decision, while others just want to be kept informed. A lot of people do not have the faintest idea what a personal budget is, while others could give professionals a run for their money when it comes to the salient points of the latest SCIE [[Social Care Institute of Excellence](#)] publication. The point is that one size does not fit all, and it is the service provider's job to do the tailoring.

A family reference group

Mindful of the need to raise our game, we have put time and effort into developing significant and meaningful involvement with families of the people we support. We have established a family reference group to assist us in developing and implementing a whole organisational approach. We are calling this Forward with Families and it is chaired by Caily Ward. There are five other family members in the group, three of whom have no relationship with Dimensions other than this group.

We have found that honesty and collaboration with families works and means a better deal for everyone involved, especially the people we support. They benefit from a joined up approach, continuity of care and, most important of all, a better quality of life.

Regaining a family's trust

Jane* had a very bad experience with the manager of her son's home, which resulted in the manager's suspension. Her trust and confidence in the staff team were wiped out. Efforts were made to regain Jane's confidence but when she raised further concerns some years later it was clear she had no trust in the subsequent manager either.

So, when a new manager was selected, Jane's requirements were taken into account and the staff were supported to work with her to meet them. A regular visitor to her son's home, Jane wanted lots of information and access to her son's files. The new manager chose to rota herself on the days Jane made visits and spent time building trust through regular joint activities like supporting her son swimming or going to look at mobility cars.

The manager has built a relationship with Jane and is open with her at all times, even when she does not know the answer to her questions. The pair meet every month and Jane feeds into her son's path plan and has been invited to get involved in recruiting new staff for the service. Through listening and patience, the manager has turned the relationship around and there is now a good level of trust there.

The manager says: "There are still challenges as we walk the road together but trust is about the distance travelled. Jane clearly cares for her son very much and will always be challenging us about how we support him - but that's how we want it - wouldn't we do the same?"

*Not her real name.

About the author

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LISA Comment: It is sad when difficulties occur between families and service providers, when the sole focus should be on the person with a disability receiving quality of life care - having a quality of life.

Many of the difficulties occur as a result of the failure of each side to understand the other in the complex field of personal service provision and human relations. It would seem a MoU (Memorandum of Understanding) and a road map to quality of life care should be mandatory starting points for the person, their family and the service provider.

Extra 1: [Choice of Service Provider](#)

Extra 2: [Expectations on Staff](#)

Extra 3: [Power to Destroy](#)

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