

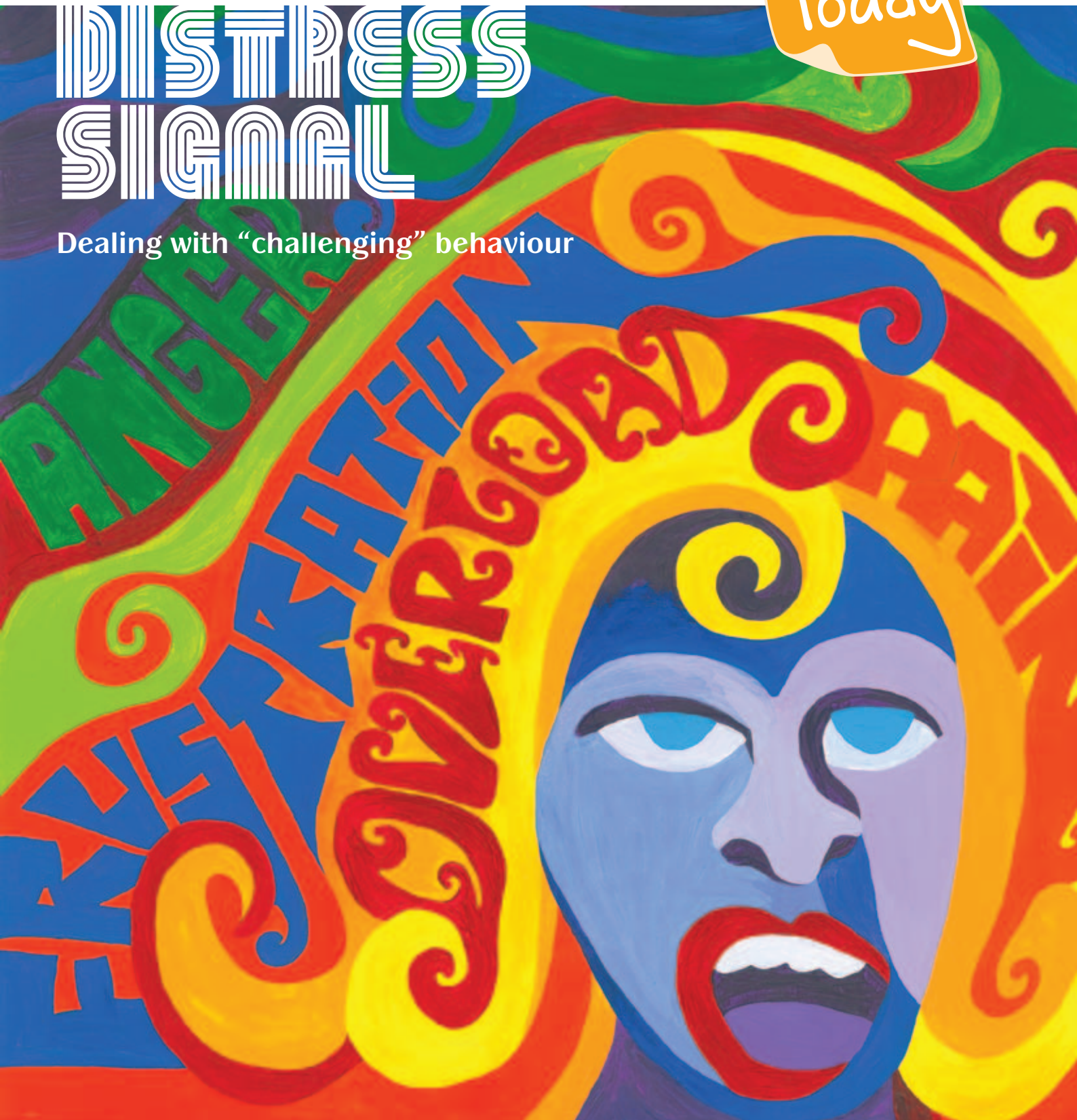
Learning Disability

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Today

DISTRESS SIGNAL

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**GROWING
FRIENDSHIPS**



Family fall-outs and how to avoid them

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

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.

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.

Families are a help not a hindrance

For a cultural 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 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 Cally 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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Building bridges: Cally and her son Michael (pictured above)

"As a mum – with my son supported by Dimensions – I often felt that the staff probably got the garlic out when I turned up to meetings because I was challenging and not scared to say what I thought.

"However, after a lot of work personally and at an organisational level, I now feel valued as part of my son's support team. We work together on everything and the primary focus is always getting a good life for him."

My top tips for getting it right are:

- Recognise and value the role families play in people's lives. People leave home but they don't leave the family. What limited research there is shows people who are in residential care or supported living and who have active involvement with their families have a much better quality of life.
- The anger families might express is often a result of their perception of poor services. They are just advocating to ensure a better deal for their family member.
- Communication is key. The aim must be to build honest and open relationships that are based on trust – because there often will be difficult issues that families and support teams must face together.
- Involve families in planning. Get them involved in monitoring the quality of the service, training staff and even developing the governance of the organisation.
- Family members are often the only people who play a continuous and lifelong role in the person's life and are a major resource in terms of continuity and the history of the person. With a high turnover of staff in some cases, maintaining contact and building good relationships with them is crucial.

Cally Ward, chair of Forward with Families