

Service, Support and Success

The Direct Support Workers Newsletter

Families and Staff: How to move from competing to complementary perspectives



By: Yona Lunsky, PhD

Janet got another call from Sonya's parents, complaining about everything. These days, it feels like there is something upsetting them almost weekly. Why does it have to be her job to be the one having to deal with this?

Mark was petrified to call Josh's brother Jason again, who is also his guardian. He had heard stories from other staff about how hard it can be to talk to Jason and his wife. Reaching them in the first place is almost impossible and how was Mark going to explain that Josh lost it earlier today when they were going shopping and he smashed his special headphones and Ipod, and also hit another staff?

Many staff can relate to either Mark or Janet and the difficult families with whom they have to work. Doing their job is challenging enough, with all the people they are supporting, and all the organizational details they are responsible for on top of that. No one told them that they had to work with families. They came to the field because they wanted to help people with developmental disabilities. This other business was not part of what they signed on for.

Lesson Number 1:

There is no such thing as difficult families. There are just families with difficulties.

Sometimes when we have an interaction that is difficult, we put it on the person, especially when we feel like we are being criticized by them. But chances are, if the family is giving us a hard time, they are having a hard time. Finding compassion can change what we think in that moment. It can allow us to listen a little differently, and soften our approach. And that little bit of softening can make a huge difference in any interaction. Mark may find it difficult to have to tell the parents about Josh's behaviour but Mark has to remember that hearing about it is even more difficult. It's important to remember that the information you are sharing often has a powerful emotional impact.

Knowing that families may have difficulties can also impact how we talk about families to other staff. It is very stigmatizing to label a family as difficult. It might feel supportive in the short term to let it all out and complain to another staff about a family. But complaining about a family is very different than sharing frustration or stress about a situation, and seeking advice or support to help that situation. And in the end, complaints about the difficult family don't help that family, or their family member with a disability, and they don't help prepare staff to support that family or individual any better.

There is a story of a man on a long train ride with the most unruly children. These kids were making noise, getting food on their seats and the floor, fighting with one another, and even running up and down the train car. A nearby passenger, busy trying to complete her work for a very important business meeting, was having the worst time concentrating and so regretted not paying the extra money for the first class fare. A shy woman, she was not able to complain right away but, as time passed, she became more and more frustrated. Finally, when the chocolate milk of the younger child almost spilled on her laptop, she got up the nerve to approach the father and give him a piece of her mind. She was about to open her mouth, when the father started gathering his children and their belongings to get off the train. He turned to her and said, "I .. I am not sure what to say. Their mother just died and we aren't really ourselves. We are on our way back home after a terrible week or so. I don't even know what to expect when we get off this train but I knew that I couldn't drive. We are meeting some friends when we get off the train... I am sorry."

What if Sonya's parents are having marital difficulties themselves, or if one of them has a newly diagnosed illness or has not slept properly in months? What if her parents had an experience with a previous group home or with a teacher in high school where their daughter was neglected and they didn't speak up about their worries then until it was too late? What if they've lost trust in the service system and no one has ever bothered to try to earn it back?

What if Jason was never prepared for his new role as guardian of his brother and he has to squeeze it in, in addition to a very demanding high pressure job and a young family? What if his brother's frustration is impacting how comfortable Jason's wife feels when Josh visits their toddler son? Any stories about Josh having difficulties make her worry about how Josh will be in their house.

Lesson Number 2:

Family perspectives may be different but that doesn't make them wrong

When filming a movie, the film maker makes use of different camera lenses at different points in the scene. The wide lens takes in the broader scene but doesn't feel as intimate. The narrow lens is excellent for close ups, but a whole film that way can feel too intense and difficult for the viewer.

The narrow lens: The family knows their family member extremely well. They have been there since the beginning and have done their best, sometimes with fairly limited tools and supports, to do so. They know about the situation today, but they also know about all the situations that have happened before. They know current staff, and they know past staff. If staff change every year, someone receiving developmental supports for 20 years may have met 20 different primary workers, in addition to all the other staff who also provide some care. So, when it comes to history, family holds that close-up lens. They know much more than any staff, no matter how caring or good, can possibly know about their family member. A problem in the group home? This may not be the first time. And family might know about what was tried before, what worked and what didn't. Difficult behaviour that is just how that person is? Family might know what life was like before that behaviour was there, and even how it slowly emerged. It may be how that person is now, but it is not who the person always has been. This kind of detail can be like gold, if we are prepared to listen.

Wide lens: Everyone has a blind spot. Knowing someone so well, doesn't mean knowing how that person's situation is similar or different than other people. In this way, staff have a distinct advantage over families. Through their experience across the sector, they hold the wide lens. They not only know that one individual, but they know many individuals and they know what works and what doesn't in many situations. And this gives them a very important perspective families simply can't share. Not only have they spent time with lots of people with disabilities, but they are surrounded by other staff who they can bounce ideas off of, and get advice from when needed. They are resource rich in a way families are not.

It isn't about who is right, or who is smarter; it is about what is in the best interest of that family member everyone is trying to support. And this is where the two perspectives together are greater than the sum of their parts.

Lesson Number 3:

There are no easy answers. If there were, we would not have these challenges.

The situations of Sonya's worker, Janet and Josh's worker, Mark, are not unusual, and they are not easy to solve. Complex problems require creative, collaborative solutions.

But big problems don't start out that way and small efforts can make a huge difference to prevent problems from growing, and to slowly resolve them. Reflecting on my own family's successes and struggles over the past 25 years of receiving adult developmental supports for my sister, we have learned a number of valuable lessons.

1. Keep families in the loop when things are going well, and not just when there are big problems. It is important for us to hear the positives, to share the joy and the successes, even if they are small. That also builds positive relationships between staff and family. It can be easier to make that difficult phone call when the relationship is strong. Furthermore, when there is a trusting relationship, families might be more likely to reach out and let staff know about their difficulties and ask for help.
2. If there is something to say, and it isn't good, be available to talk about it. Leaving a quick phone or email message without being available to debrief is its own kind of torture because family need the space to process it with you. You may think the family understands the situation and implications from a quick note or call but, in fact, their interpretation may be very different from yours and the only way it will become clear is through dialogue. That dialogue needs to happen close in time to when the issue is raised, and it may take a little longer than you have planned. If the task seems daunting, reach out and get support from a supervisor on how to best approach this.
3. If the situation concerns you as well, you can share that feeling with family. You do not need to give the false impression to family that you know exactly what to do, or that the situation does not worry you. Doing so may lead the family to feel that you don't care or would not be able to relate to how the family is experiencing something. Even though telling a family you are also upset does not help to resolve the situation, it can be validating. In difficult times, it is important that staff and family feel like partners and not adversaries.

4. Avoid judging. It can be very painful to watch a family not be as involved as you think they could be with their family member or being involved in a way that you think is harmful. But without being part of that family, and sharing that family history, it is difficult to know why a family behaves in a certain way. Judging that family for their choices won't help to make them choose differently. Understanding their perspective, on the other hand, might allow you as staff to come up with ways to enhance family involvement in the future.
5. Get to know family. Staff and family are like a tag team in a relay race, passing the baton to one another when it comes to caring for and supporting someone with a disability. Knowing the family better can also allow you to better support family connections in a way that is beneficial to the person you are supporting in your agency.

I wanted to write about this topic because I have seen this happen time and time again when I wear my clinical hat, but I have also sat on the other side of the table, holding that narrow lens with my own family. There is nothing harder than watching your family member struggle, and feeling like you and staff are not part of the same team.

We have had some difficult family circumstances over the years that were impacting my sister when we really needed the help of her staff. My frustration did not help at those times. Recognizing we needed support, and having an established trusting relationship with staff, we were able to ask for the support we needed. But families may not always know how to do that. Remember that families can manage these issues by themselves for a very long time, and that some of their past experiences with care providers may have been negative, which makes trusting or working well with current providers a difficult process.

My family and I are so grateful for support we have received over the years from so many staff who came in with their wide lens to spend some time with my sister. They have taught us that we are not the only ones who can love her and appreciate the gifts she has to offer. They have helped to expand our own view, and they have shared our joy and our pain. It is only through mutual trust, continued respect, ongoing dialogue and hard work, that we can bring our complementary perspectives together.

Yona Lunsky is a clinical psychologist and scientist at the Centre for Addiction and Mental Health. She is also the sister of someone with a developmental disability and has had many opportunities to sit on both sides of the table.

Editors: Dave Hingsburger, Vita Community Living Services and Angie Nethercott, North Community Network of Specialized Care, Hands
TheFamilyHelpNetwork.ca

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