Participants shared stories that, for them, answer the question, “Why is doing supported living worth the work it takes?” They wrote headlines that summarize the main ideas in their stories. These two diagrams summarize the reported headlines.
Think about a time when your relationship with the family of the person you support was good for you and for the person you support. Describe the characteristics of that good relationship. What worked about the way you and the family communicated?

- Open communication and mutual respect; saying “hello”, greeting each other. When staff are more open to the family, the family’s suspicion of the staff goes down.
- Direct communication between the companion and the coordinator and the family.
- If we are providing good care for the person, the parents are more relaxed.
- Even when we disagree, we still listen to each other and may even “agree to disagree”
- We do the little requests.
- We give and take to reduce or eliminate the power struggle.
- We talk a lot.
- It works better when the families are open to the ideas that companions have.
- It really helps when the families appreciate and acknowledge the contributions that staff make.
- We try to take the “long view” and work to do what’s going to be best in the long term.
- We accept the family members as members of the whole team.
- We accept that the parents are always going to be there and that “parents are going to be parents.”
- Vaulda Kendall Browne says “We don’t tell parents to ‘Let go. We tell them to ‘Let grow!”
- We have to accept that no matter how much we care about or love the person we support, we are not the person’s parent.
- Things work better when trust is there, but we can’t just assume trust. Trust takes time and experience to grow.
- Talk openly and honestly about what is going on.
- Respect the teachings and experience of the family.
- Try to keep a good attitude.
- It’s really important that we find time to be together with the families socially when things are going well. Good relationships don’t develop when the only time we meet is when there’s a problem.
- Sharing responsibility between the staff and the families works best.
- Parents often can’t believe that people who are not family can enjoy/like/love their child.
- Embrace what the family contributes.
- When parent demands seem overbearing or silly (the crease in the pants, the ironed sheets, etc.) can we ask ourselves is this the real
problem or is the complaint just a symptom of something deeper that’s not being said?

• Find a way to let the families say how they are feeling. Create safe places where people feel safe to say what they really think and feel even if what’s said is sometimes hard to hear.

• Do things together.

• Avoid power struggles.

• Have group discussions between families who are open to new things and have successfully expanded their view of their child and tried new things and families who are struggling.

• Be the professional. Work toward the vision.

• People we support need both their families and their staff. Neither replaces the other. Each brings a unique contribution to the person’s life.

Some real challenges and struggles that we face as we try to do a good job.

• Taking the long view is a good idea, but we can lose a lot of great staff along that road. Some people just can’t deal with what the families demand and the way that some families treat us. That’s not only bad for staff it also causes a lot of changes and losses for the person we support.

• Sometimes it feels like it’s just not worth putting up with it. When people degrade or insult me. When I get treated like an “idiot.”

• RACISM. Some of us confront that every day. If we’re an organization devoted to social justice, we can’t tolerate racism. We have to deal with this quicker. We’re trying to be more up front with families about this and let them know our values so they can decide to choose us or another agency to support their son or daughter.

• We are not “the help” to be ordered around and there just to do the dirty work.
Finding the Way Back

Holding on to one another through good and bad times is vital to experiencing the benefits of supported living. Sometimes it is the person with a disability who is in a difficult place in their life; sometimes it is the staff person. Participants in this discussion drew a lifeline that identified high and low times in their experience of supported living. Then they described the ways that have worked for them to lift themselves out of the low times and find their way back to a sense of satisfaction in the work. This list summarizes their strategies. People and situations differ a lot, so these possibilities often include the word “sometimes.”

• It’s important to have someone you can trust to talk to. Sometimes this is someone who will be a sounding board or a source of advice; sometimes it is just someone who will allow you to vent without judging you or trying to fix things.

• Sometimes you need to just walk away from a situation for a little while (after making sure someone is filling in for you).

• It is very important not to underestimate the person you support. Most people that you have a relationship with can deal with honest communication as long as it is not dumping blame on them. Most people can figure out things that they can do to improve a situation if they have the support to do it –sometimes someone else needs to provide the person that support.

• Sometimes we get down because we are stuck in trying to fix something for a person we support that can’t really be fixed by anyone else. In these situations we need to support the person to live through the situation, doing what we can to help.

• Sometimes it is like we are digging ourselves into a hole we don’t want to be in. We just keep on digging and making the situation worse, even though we may know we should stop and figure out a way to get out of the hole. In these situations it’s important to take responsibility for needing help to stop and to reach out for that help.

• Grief at the death of someone we care about, and the effects of grief on the people we support, families and co-workers, can bring us closer if we grieve together or lead to a long low period if we isolate ourselves and deny the loss. We need to mourn together over the losses that come into our lives together.

• Loss of a person can make us aware of all of the people who are connected to our well being –and to the reality that some of the people we support feel loses even more deeply because they have few people in their lives. Realizing this can lead us to take some action to bring new people into the person’s life, not so they will forget about the person they lost but to bring some new connections and new experiences.

• It can be important to be honest enough with yourself to give up and say “At this time in my life, this particular relationship is a bad match for me.” Sometimes facing the possibility of giving up and talking it through with a supervisor or someone else that you trust opens up a way to go back to the situation with new energy. Sometimes it leads to a match with a different person.
• Taking time to remember the ways a relationship with a person has added value to your life and the person’s life can put a difficult time in perspective.

• It can help to remember that the person needs me and that my work with the person fulfills an important need in my life.

• It can help to sit back and look at the situation analytically. Think about the situation as a system that includes you and produces something you don’t want. The cause of the difficulty might not be direct and obvious: trouble might start with small things and take time to develop. To get a better understanding, change your point of view: instead of thinking about yourself ask what all this looks like to the person you support; to a co-worker or a family member you may be having trouble with? Re-focus on what works to get more of what the person you support wants from life; sometimes thinking about working to get more of something good can shift the whole system around.

• Sometimes, what’s needed first is insight into myself before action to fix things. The more I understand myself, the more I can understand others. Especially when I feel helpless, or victimized, or when all I can seem to do is blame others, I may need to deepen my self-understanding: troubles or tragedies in my own life may be influencing the way I am in this relationship. This can be important if a blind spot in me leads me to focus my efforts to change a situation on something that is not really the key to changing it. It builds personal maturity to be willing to seek insight.