

How to help a parent who has a learning challenge *Let a parent tell you herself!*

Marianne Kroetsch is a parent who has been part of the Connections' family for a long time. She is also the 2012 winner of Alberta's **Norm McLeod Self-Advocacy Award**. Together with Connections' founder and Program Director, Lauren Raymore, they developed a how-to guide for supporting parents with developmental disabilities.

P . R . A . C . T . I . C . E .

Individuals with developmental disabilities require an opportunity to practice the skills they are taught to make the concept part of their repertoire. As an In-Home support provider, it is your responsibility to practice your profession with integrity, creativity and compassion. Marianne translated 'practice' into 8 tips.

P = Persistence

Sometimes the idea of having someone come into their home can be very threatening. Don't let this discourage you. Take the first few visits to establish a sense of safety and trust. Recognize it takes time to grasp the concepts you are teaching. You might have to present it several times at different meetings. Use repetition with respect. Be careful. Repetition can sound condescending. Recognize that sometimes the information you are discussing can be very personal and difficult for the client to talk about.

R = Respect

Speak with respect. Treat the parent as the primary caregiver and direct other professionals to do so as well. Respect the parent's life experiences and privacy. Set reasonable expectations -- take into account the individual's complex needs and current situation when helping to set goals. Be mindful that the information you present needs to coincide with the needs and values of the family.

A = Acceptance

Accept where the parent is at and work from there. Establish the immediate needs of the family. For example, if you are there to teach discipline but the family has no food, accept that your focus for that meeting must address the most urgent need. Ask questions: but only one question at a time to reduce confusion; Only ask questions that are relevant and purposeful. Be aware that many parents with disabilities have spent a great amount of time dealing with the 'system' and often answer questions the way they think you would like them to be answered. It is **your** job to establish an honest and trusting relationship which will allow parents to feel comfortable opening up to you.

C = Clear information

Stop and think before you speak: Ask the parent how they learn information best. Provide concrete information, one concept at a time, supplemented with a visual cue if that is helpful. Offer keyword notes so that the parent has a written reminder of what was discussed and anything that they may need to do before the next visit. Recognize that reviewing helps the individual to retain the information. Wait for the parent to process the information and to formulate their own questions.

T = Truthful

It is important to have an honest, professional relationship with your client. Make sure you acknowledge their hard work and accomplishments as well as concerns that you may have. When discussing concerns, do so in a respectful and non-confrontational way.

I = Increase skills

It is your job to work with families to increase their skills and abilities. Recognize that everyone moves at a different pace and it may take months to solidify an idea. Working with parents with developmental disabilities is a lifelong learning process and families do better when they can receive long term support. It is also your job to continue to develop your own skills to meet the ever changing demands of the people you support.

C = Creativity

Recognize that parents have often had numerous In-Home workers before. It is your responsibility to engage the parent with new and creative ideas. We do not make families 'fit into a box'. With the parent's approval, we build the box to fit their needs. Take the time to explore how you and your agency could best support the families and look to developing creative solutions.

E = Encourage

Being a parent is often the first role a person with a developmental disability has that gives them validation. Support them in this role. Often the parents we support say that they never felt listened to before they met Connections. Being respectful and encouraging of a person's abilities helps to build their confidence and goes a long way to establish a healthy, productive relationship between the parent and staff. Recognize that not all families look the same and encourage parents to make the best choices for their children and themselves.

*Thank you to Marianne for her spirit
and willingness to share.*