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Abstract.

Describes the concrete supports used to facilitate difficult conversations with people with Prader Willi syndrome within a Rogerian practice framework. (The use of objects and visual strategies to assist people with Prader willi to externalise triggering topics).

Content

My name is Christine Ford and I have worked in the disability sector for approximately 30 years - predominantly in a behaviour support role while operating within a positive behaviour support model.

I currently work for Community Connections, a community based disability service that primarily offers staff support to people living in their own home. We also provide support for people with complex needs and requiring full time support. Community Connections adopts a person-centred approach so people can live the life they choose within their own community.

I work regularly with people with Prader- Willi syndrome in a behaviour support capacity. This mainly involves working with the person and their support network to reduce the impact of the person's challenging behaviour.

One of the challenges that support staff regularly raise, is having conversations with a person about their behaviour without triggering adverse reactions. The topics of these conversations can include but are not limited to: managing conflict with their service provider; managing interpersonal relationships and interacting with others; managing weight and diet; understanding rules and boundaries; taking responsibility for causing harm and managing their own emotions.

All these topics have the potential for the person to become emotionally elevated as would be the case for any of us who need to talk about difficult personal issues. Staff report the typical responses when triggering issues are raised can be rigidity, inflexibility, argumentativeness, general opposition to topics discussed and, at times, tantrum type behaviour that can result in aggression or violence.

When working in a behaviour support role it is important to be able to have “ awkward or challenging conversations” with the person supported, and the challenge for the practitioner becomes how to have these conversations in such a way that the person is supported to regulate their emotions, discuss triggering topics, express their view and understanding of the situation and be able to listen to differing perspectives from their own.

This presentation is a reflection on the practice tools and techniques that I use to have conversations in behaviour support and education sessions with a person with Prader Willi and when there is a requirement to discuss difficult subject matter.

All of these tools can be found in disability/psychology/counselling literature, and this presentation describes how they are framed, sequenced and used with the population of people we support.

Framework : Setting the scene for conversations

Most of you will be familiar with Carl Rodger’s work. He was a psychologist who built on the work of Abraham Maslow who is best known for his “ hierarchy of needs” . Carl Rodgers maintained that to create a growth promoting climate when working with a person for change, that three principles needed to be in play : (1) congruence (genuineness or realness), (2) unconditional positive regard (acceptance and caring), and (3) accurate empathic understanding. .

While he was considering these elements in a therapeutic context , my belief is that they have direct application to working with individuals with Prader Willi in a positive behaviour support context and when teaching a person emotional regulation skills.

Adopting these principles can reduce direct confrontation with the person, creates a low arousal environment and, when reflecting back to the person using empathetic understanding, creates an environment of repetition that often allows for greater learning.

An unexpected consequence of using this approach in my experience, can be the reduction of anxiety for the person you are speaking with, as their concrete experience of their interactions with you is one of feeling supported and listened to, within the context of clear boundaries which, as we know, can create the opportunity for learning and retention of new knowledge.

Setting the scene for difficult conversations requires preparation and laying down clear boundaries around the time together for the person and at times for the support staff. In my work I have found the following process to be helpful :

1. A written agreement about the when, where frequency of sessions. (this also can be in a social story format) This needs to be developed in the first session to set and also to manage the person and their system systems expectations.

Working Together



 Christine and  have agreed to work together to figure out how to manage some hard things in life.

Like everything in life there are some rules around working together. The rules are:

1. That we will both be on time 
2. That if we are sick and can't make it we will let the person know soon.
3. That people try to tell the truth and are respectful 
4. That if a person does not turn up for two sessions without good reason the work ends.
5. That if the person says something that causes others to worry that they might hurt themselves or others then they can tell others

Date.....

2. A confidentiality agreement that allows a mechanism to report self harm (or ideation of), or harm to others, or threats of harm to others, or self harm. .
3. Development of a “systems approach“ where either a service manager or key staff person is included in all sessions. (The support staff are briefed prior to engaging in the process about their role, and how language is used in the sessions .).
4. Routine for each session with the same opening and closing .
5. A homework sheet of a visual activity based on the education session for the person to do during the week .
6. A workbook in which visual information and notes are put , that remains the property of the person supported.
7. Use of the 3rd person concept - Instead of using terms such as” you “or the persons name when discussing behaviour, framing the sentence structure using the third person e.g “People often try to breathe out slowing when they start to feel anger, they say this can help”

Initial Engagement sessions.

Spend (1 hour) sessions on relationship building, amplifying the person's positive behaviours , and setting up confidentiality and session agreements.

This will help provide a firm foundation for future sessions.

Parallel to this process it is important to manage others expectations around the speed of changes in behaviour , and about what is discussed in sessions.

My experience is that supporters will want to discuss issues that have cropped up that week , and while this can be helpful for some weeks , it can also potentially derail some of the key areas of skill building and emotional management techniques that you are wanting to teach .

To manage this process I have developed a support sheet for staff attending sessions with the person supported so they are well briefed on their role.



Information for support workers attending education sessions with the person you support .

Firstly thank you for agreeing to sit in and be a support . The purpose of the sessions are to provide education to the person you support and assist the person you support to develop some positive behaviours around specific issues .

Some people ask that you attend the whole sessions , other people just want to share what they have been doing at the end of the session . These sessions are confidential for the person , and it is up to them if they have support people attend , this is preferable.

When people are wanting to change their behaviour, they like all of us do better when they have the consistent support of the “ system “ around them . By being part of the session with the person you support, you can reinforce the learning during the week , or prompt the person to try out some of the strategies

If there is a specific issue you feel needs to be discussed , then please email or phone me prior to the session rather than bring it up in the session , as this can have an impact on the work that we are doing .

The tone of the sessions are positive and strengths based as people learn best in this type of environment.

Please feel free in the session to positively reinforce changes the person has made, and please bring up any times when you have noticed them do well so we can discuss how they did this positive behaviour .

Please email me with any questions
christineford@ccslt.org.nz

Tools and Strategies used within this framework.

We know that people with Prader-Willi generally are concrete thinkers and to help people process information and concepts, language needs to be based in concrete terminology.

Along side this most of us who are imperfect humans know that talking directly about things we may have got wrong or are embarrassed about can be uncomfortable and feel confrontational regardless of the sensitivity or the skill of the person asking the questions.

To navigate these two issues around triggering conversations I have used Narrative therapy techniques.

Narrative theory considers these issues of shame and embarrassment within the context of “externalising conversations” and suggests that the person is encouraged to understand “that they and the problem are not the same thing “

<https://dulwichcentre.com.au/articles-about-narrative-therapy/externalising/> .

Narrative therapy is a tradition of [counseling](#) that “views people as separate from their problems.” This allows people to get some distance from the issue to see how it might actually be helping them, or protecting them, more than it is hurting them. With this new perspective, individuals feel more empowered to make changes in their thought patterns and behavior and “rewrite” their life story for a future that reflects who they are, what they are capable of, and what their purpose is, separate from their problems.

<https://www.psychologytoday.com/nz/therapy-types/narrative-therapy>

In the context of my work I have done this externalizing process verbally but with the added component of using objects, small figures, social stories and comic strip conversations to make the issue a concrete concept. .

When using the figures I begin to talk the person about the issue and start setting up what they are describing with the figures. My experience is that very quickly the person takes over and starts to select and place or move objects themselves . It is then possible to ask questions about the scene and explore and clarify using multiple perspectives (eg what do you think that person may be thinking or feeling).

You can also check around understanding of any theory of mind issues by asking some questions such as ' what do you think that Nana was thinking, or how might she have been feeling.

Another part of this externalising conversations process is to take photos of the scene for the person to refer to later and as a way of reinforcing learning and as a way to revisit issues that come up often.



Another concrete tool that can be utilised are Jenga blocks (Small wooden rods). In early sessions the person identifies some of their thinking and fears that occur at the time of their conflict with others. These are written on individual blocks and arranged in a wall between the figure that represents the person and others in their life or things that they want to attain in their life.

In subsequent sessions when there is an issue that needed to be deconstructed, the person can select blocks they notice that were part of their thinking. In the same session alternative blocks can be created of replacement thinking that can help with the management of emotions and unhelpful thoughts. This idea comes from Cognitive behaviour therapy where the goal is to teach people that while they cannot control every aspect of the world around them, they can take control of how they interpret and deal with things in their environment.

<https://www.verywellmind.com/what-is-cognitive-behavior-therapy-2795747>

Other concrete objects that can be used are: Green and red tiles to create good way and bad way roads.



The good road and bad road concept draws on the work of Bill West and Lesley Ayland and the model they developed to address the need for a common, coherent narrative with which clients and therapists can effectively discuss behaviour and experiences.

The idea is presented that there are a range of actions that all people can take that result in a person going down a “Bad road” that can lead to negative consequences for themselves and others, and also the idea that there is a good road that can be taken that can lead to neutral or positive consequences.

In my experience it is essential to use the figures and and green blocks to illustrate the good road choices and skills the person currently uses from the very first session , so when you do start to work on the “ bad road “ scenarios the person has a context and some ease with the process .

Alongside this, good road choices and decisions need to be amplified and celebrated. Often people with challenging behaviour have internalised a view of themselves as a person who engages in bad behaviour and gets things wrong, and the person can struggle to notice behaviours and choices they often make that are good or correct. Also when a person has a long history of challenging behaviour there can often be a sensitivity to feeling “ told off “ .



Plastic brain, heart and lungs: I use these to help the person think about how their body may have been feeling, when they are anxious or upset. Together we look for clues their brain or heart or breathing may be giving them about their emotions and their thinking. It is also useful to identify what anxiety feels like in their body if they are not fully aware of this . Once this information is gathered it can be used in a social story or a chart to prompt the person into self calming strategies

The next tool is 3 balls small , medium and large. These balls are used by the person to



represent the size of the issue, their response , or their feelings .

It helps the person look at the difference between the size of the issue and the intensity of the feeling. One wise person I was working with around this identified that the issue she had was the size of a marble but the feeling for her around it was the size of the whole world. When the person has laid out the balls, good questions to ask are , what can we think about that might help the ball be a smaller size , what was the size of your response, would you like to change the size of your response , how might a smaller response feel etc.



Using a warning system and a timer for talking about hard things. When you are having a session with a person I might say , today I am hoping to talk with you about a hard thing for 3 minutes , that means most of today we will talk about easy things, but for 3 minutes we will talk about something hard, is that something you can do? .

Giving the person as much control around the issue as you can , can also assist , eg asking them if they would like to talk about it now , or later , and asking them to be the time keeper of the three minute conversation.

I would also introduce talking about hard things by reminding the person that they have this skill eg “ I know you are I have talked about hard things before, I have always been so impressed that you have kept it together and be brave to hear about the hard thing.

Often before you have finished talking about the hard the 3 minutes will be up , at that point I will check with the person and say something like “ we are done now and can finish , unless you want to keep chatting about it , its up to you. “ Usually the answer will be yes and I ask the person to turn over the timer again , and remind them we can stop if its too hard.

After the hard conversation I point out the skills the person has used in the interaction - even if they have been argumentative or oppositional, I will comment on their ability to persist in communicating , or not swearing , or being respectful or being brave about hard things.

Sandwiching , a well known tool , where a potentially sensitive or triggering topic is placed between two positive things. An example of this might be “ When I see you I am reminded about how brave you are turning up here each week to talk about hard things. Today we need to talk about you swearing at you sister and I know that this might be hard, but I also know you want to have good relationships with your family.

Additional strategies and tools for education Sessions

- The use of comic strip conversations and analysis chains
- Use of simple drawing of figures with speech and thought bubbles.
- Ability to reflect and amplify back to the person positive behaviours observed “ I know that some of this stuff is hard to talk about , so I just admire how brave you are coming here to talk to me about the hard stuff”
- Ability to use gestural prompts and clear language to minimise confusion and allow the person to process information.

Taking the time in the initial sessions to build rapport and getting to know the person will guide you as to which tools to begin with and the pace of introducing the tools.

Thank you for listening. Are there any questions.

