

Service, Support and Success

The Direct Support Workers Newsletter

(Warning! Warning! Charts and Graphs Ahead)

What's the Point of Data?

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Have you ever had this happen to you? You are sitting in a meeting discussing a person who is supported, in walks the behaviour therapist, they start to ask questions, talk about the behaviour support plan and then it comes....“We need to start collecting data”. The dreaded words that every direct support professional hates to hear. Then the forms start to come out, and usually it is not just one, there are many of them. Not only does this add more paper work to the direct support staff who are already extremely busy supporting multiple people, it almost seems to be counterproductive as it only takes more time away from those who are the most important in this picture, the person supported.

So, if direct support professionals perceive data as a hindrance rather than a help, why do behaviour therapists value and emphasize its importance so strongly? The goal of this article is not only to explain the importance of collecting data and encourage other professionals to consider the value in its collection; it is to debunk some of the common myths surrounding this process. Not only can collecting make the jobs easier, it more importantly can drastically increase the quality of life of those supported. Yes, the reality is that in the beginning, collecting data does take up a lot of time and is a pain, but the long term gains can be tremendous. As they say;“no pain, no gain”.

Here are some of the ways that this, at times, painful task can and will be more than worth it in the end:

Insight:

As direct support staff you spend the most valuable time with the individual you are supporting. You have the most accurate and insightful information. You can answer the questions asked and often know how to support the individuals the best. If the behaviour therapist is not asking for the input and insight from the direct support staff, they are not doing their jobs.

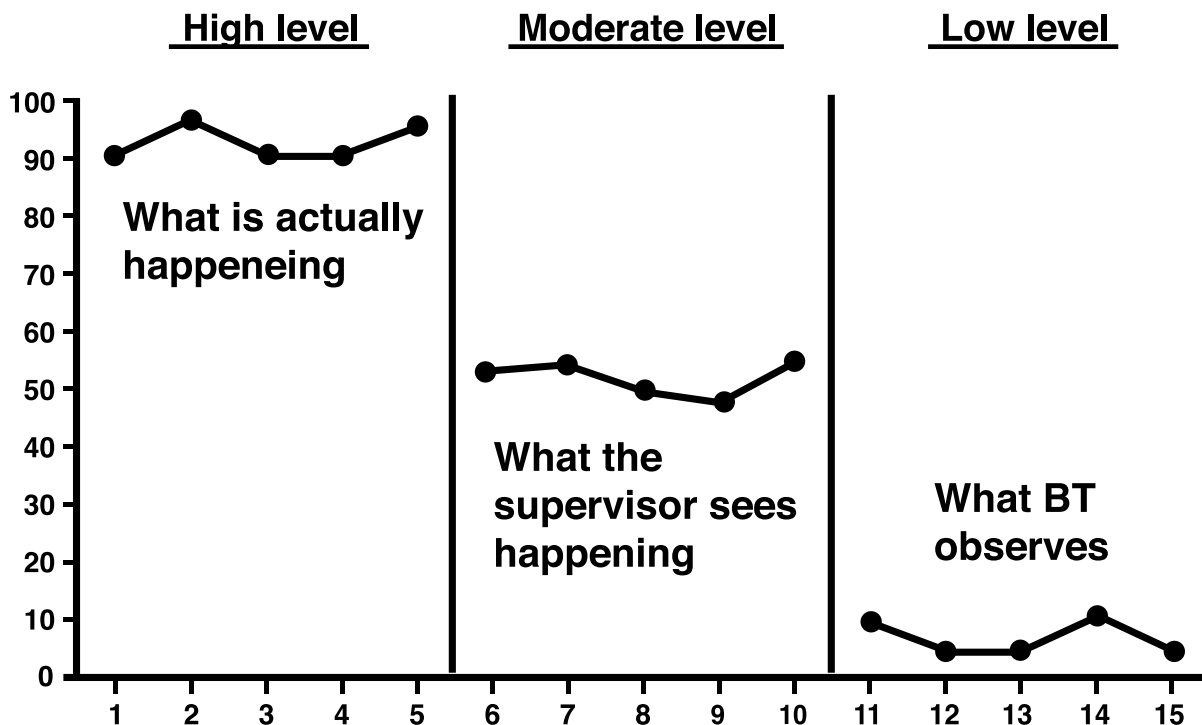


Hands

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Data collection allows those who do not get to spend as much time with the individual, like the supervisor of the home or the behaviour therapist, a glimpse into what is really going on in the person's daily life. Without that information, behaviours of concern can be misunderstood, or even overlooked all together. Here is an example of how behaviour can be misunderstood without accurate data from those who support daily:



Input:

Data collection allow more than one person to make decisions. When data is collected by different people in different environments it leads to better decision making. It takes the responsibility of decision making off any one person and puts it on a collective group of people. Consistent and non-judgemental descriptions of behaviour take the bias and interpretation out of getting to understand the individual. This way more people can have reliable input to best support the individual.

For example: one staff may see the undesirable behaviour in the evenings but they never work mornings and never take the person to appointments during the day. If we developed plans for this person we are missing a lot of valuable information.

Liability:

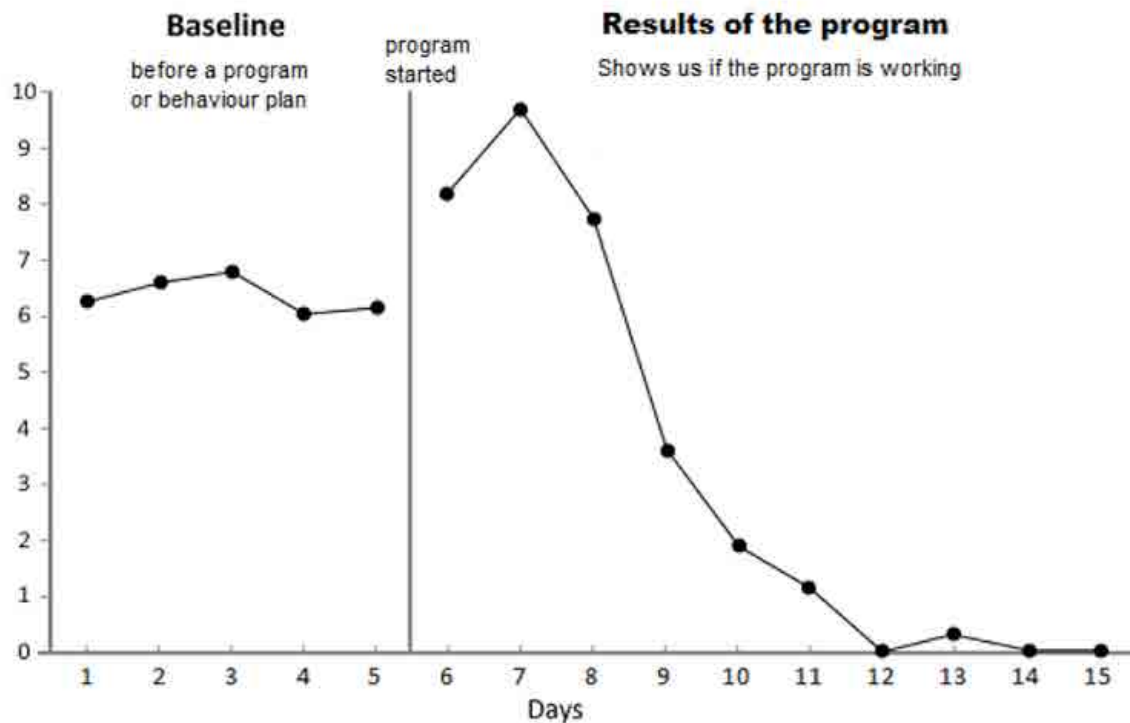
Sometimes the decisions we make are called into question. This may be by other support staff, management, even the police or the courts. When we can clearly articulate the reasons for our decisions which are grounded in data, we are better able to protect ourselves and the agencies we work for.

For example: for those people supported who engage in sexually concerning or abusive behaviours, there are often restrictions in place to keep them and others safe. If we want to look at reducing these restrictions we need data to support our decisions. If something were to happen that put another peer, staff or other community member in harm's way, we need documentation to back up why we made that decision.

Evaluating Programming:

Data, when collected correctly, provides a picture of what the behaviour looked like before, during and after an intervention. It can help to determine if a program is working or not. If the program is working then data can help guide progress by indicating when and how to move on. If it isn't working it shows when the program may need to move back a step, slow down or be scrapped altogether and a new program needs to be created.

Here is an example: what it might look like when the data is showing when the program is effective:



What are we Missing:

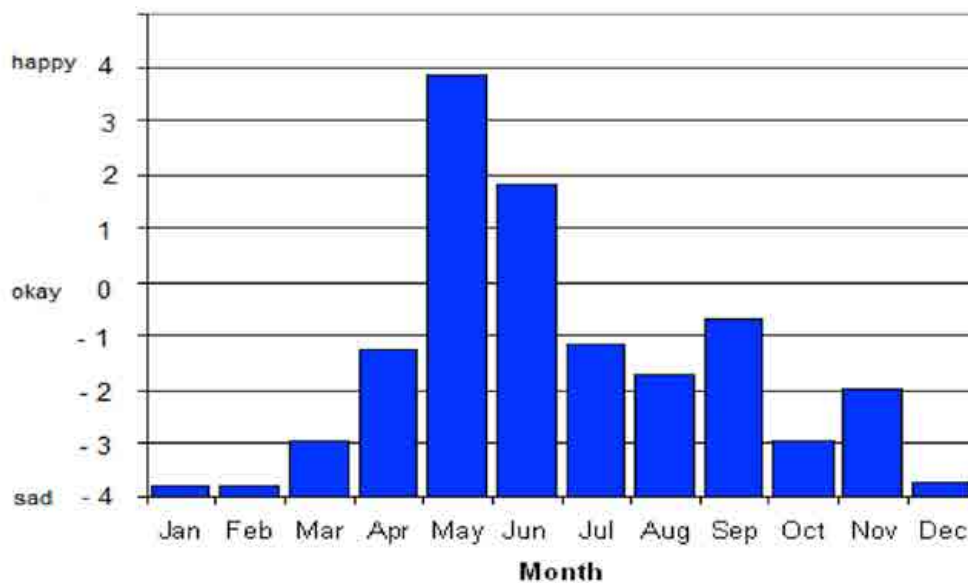
It is hard to believe, but even behaviour therapists can get it wrong and miss important aspects of a person's behaviours. Sometimes things we didn't think of can explain why behaviour is happening. Over time, data can show different trends in a person's life. Taking data on factors such as sleep, mood, menstrual cycles even weather can sometimes unveil reasons for behaviour that may not have been considered without it.

For Example:

If we are tracking mood over a number of months and our graph to look something like this than we might want to take the person we support to see someone about possible seasonal depression.

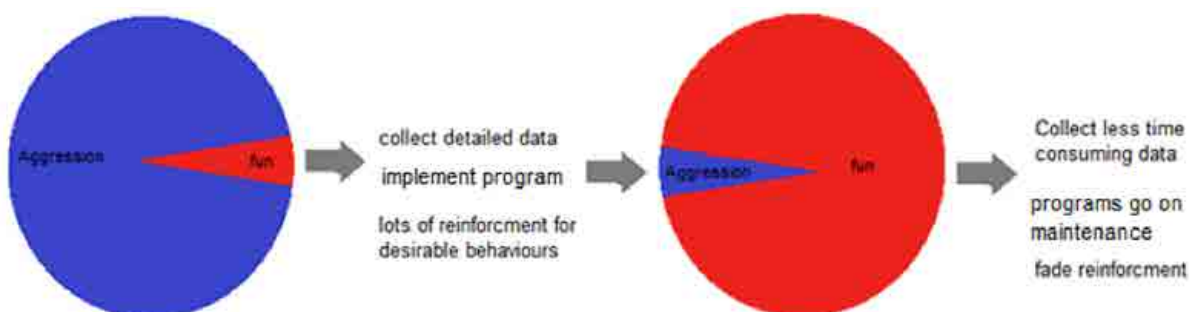
Makes our jobs easier:

Tracking data can be a lot of work but the purpose is to help figure out how to decrease negative behaviour. If we can understand the behaviour we can often react sooner or make changes that allow us to avoid the negative behaviour all together. As we get to know more about why the individual is engaging in an undesirable behaviour we can learn how to effectively intervene. Programming can become less intense by fading reinforcement. The problem behaviour can become less frequent or at times even disappear.



Quality of Life:

Ultimately most of us are in this field because we want to help people. Believe it or not, data collection can help to achieve this goal. It is through data that we can effectively monitor the person is on the right medication, if an individual has meaningful activities in their daily life, who they like to spend time with and when to respect privacy. Data collection allows others get to know the person supported and help ensure we are supporting them in a way that promotes their quality of life. Not simply make judgements about what activities and people we think should be meaningful.



For example:

An individual supported gets anxious in the community and at times becomes visibly upset. The support staff wants the person to be happy so they simply stops taking them out. The anxious behaviour stops but now person never gets to leave their home.

OR

An individual supported gets anxious in the community at times becoming visibly upset. The support staff collects data during these times. The data shows that the person only becomes anxious when there is lots of noise. They get the individual noise canceling headphones and avoid overly noisy environments and the individual gets to enjoy his community.

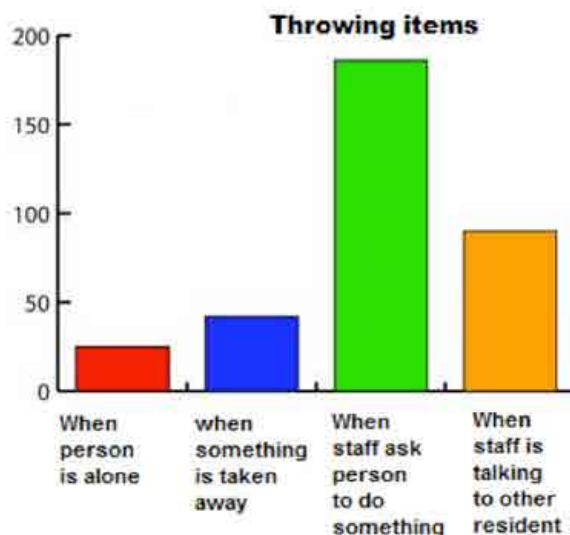
Which situation would increase your quality of life if that individual were you?

Identifies function:

Accurate data helps us figure out why an individual may be engaging in behaviour. Figuring out why behaviour is happening help us determine how we should react and also identifies what skills need to be taught to the individual so that they can communicate without engaging in undesirable behaviour.

For example:

This graph would suggest that behaviour is escape driven and that teaching communication skills for appropriately letting others know they don't want to do something would be beneficial.



Determine need:

Some behaviour can just be annoying and irritating. Let's face it, in this profession you are working closely with other people all the time and we don't always like the things others do (and they may not like what we do). Behaviour such as nail biting, rocking and swearing might be seen as problematic but do we actually need to intervene. Sometimes the answer is yes and sometimes, the answer may be no. By using data, we can determine that these behaviours don't actually need intervention. Data can help us figure out when and if behaviour is actually problematic.

For example:

A support staff reports that one of the people supported in the home yells at the television all the time. They start to collect some data to get a better idea of how often. The data shows that the individual is only yelling on Saturday nights. Once they start tracking what he is watching while yelling at the television they quickly discovered that it only occurs during Maple Leaf hockey games. They decide that no intervention is needed (don't all Maple Leaf fans do this?).

However, now that there have been several reasons given to support the collection of data, what happens when support professionals are asked to collect data that is too complicated, appears meaningless and is perceived to be cumbersome? Well, first thing first, if you are collecting data and do not understand what its purpose or what the desired outcome is, it is imperative that you arrange a time to meet with the behaviour therapist who implemented its collection. This will allow for clarification and understanding of the data's function in the support of the person. It is vital that all professionals in a supporting role not only understand but can articulate the reasons for and purpose of the data collection.

If you find the data is too much and feels not doable, bring your concerns forward and see if there are ways to make it user friendly. If a system of data collection has been introduced that is not user friendly, it must be reworked so that it can work within the boundaries of the staffs' duties. If it does not, and is not being collected accurately there is the potential to increase harm rather than decrease it for the person supported. This is when bad decisions are made on the basis of poor and inaccurate information.

There are so many reasons why collecting data is an invaluable process. Data can offer insight and understanding into a person's behaviour, it allows direct support professionals to share their knowledge and expertise with the clinical team and most of all, if collected correctly and consistently it can increase a person's quality of life.

About the Authors

Christa Outhwaite-Salmon has been working in the Program for the Assessment and Treatment of Healthy Sexuality (P.A.T.H.S.) at Mackenzie Health as the Central East Regional Educator/ Behaviour Consultant since 2003. Her role includes providing education, assessment and treatment to individuals with intellectual disabilities and their support teams. She is currently completing a Masters of Social Work through the University of Windsor.

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New Year's Newsletter

We were hoping to have a 'reader written' newsletter for the January issue and we had asked readers to write in a paragraph about good service and what they've learned from working as a direct support professional. Unfortunately we only received a couple responses, both were good but no where near enough to pull into a newsletter. We still like the idea of a reader written issue and will try again in the future. Thanks for those who submitted.

Editors: Dave Hingsburger, Vita Community Living Services and Angie Nethercott, North Community Network of Specialized Care, Hands
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Answers to FAQ's about the Newsletter

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