

Promoting the Balance Between Risk & Personal Choice

by Mr. Johnathon Crumley and Ms. Lisa Meyer



Providing community supports to those with Intellectual and Developmental Disabilities has never been more exciting and challenging as it is today. With individuals increasingly transitioning into integrated community settings, the question now more than ever is: How do we identify risk factors and provide supports to minimize these risk factors in a person-centered way? How do we protect the individual and ourselves as we support them to experience a well-lived life- a life characterized by their preferences and choices?

Recently, IntellectAbility developers of the Health Risk Screening Tool (HRST) and Support Development Associates (SDA), teamed up to conduct a pilot training in coordination with a community integrated provider in Magee, MS called Brandi's Hope.

Brandi's Hope is a provider agency that delivers community services to more than 190 people and their families in seven locations in Mississippi. CEO Danny Cowart and his wife Brenda opened Brandi's Hope in June 2010 after the loss of their daughter Brandi Erin Cowart, who was born with a rare and fatal chromosomal disorder.

Mr. Cowart decided to begin using the HRST in 2014 as a way to help individuals with DD and their care supporters to be proactive in detecting and addressing health risks. He also wanted to incorporate personcentered principles in the process of gathering and following up on information gleaned from the HRST, particularly the "HRST Service and Training Considerations", a document which reveals other needed supports and training based on the areas of identified risk. Understanding the importance of bringing these two practical applications together, Mr. Cowart approached IntellectAbility and SDA about the need for PCT Plan Facilitation and HRST training for Brandi's Hope staff.

When facilitators Johnathon Crumley (HRST) and Lisa Meyer (SDA) got together to combine their efforts and resources, their goal was to create a facilitated learning environment that clarifies how information gathered utilizing the HRST and the PCT tools can be used collaboratively to support people with developmental disabilities in having a better quality of life. This resulted in a two-day event focused on training support staff on how to use the HRST in conjunction with the Person Centered Planning Tools for plan and outcome development. It was a huge success!

Mr. Crumley and Ms. Meyer were pleasantly surprised by the success of the merger and the overwhelmingly positive response received from the folks at Brandi's Hope who participated in the training. During the training, a young man who receives supports and services from Brandi's Hope named JB*, and his team learned how to use information from the HRST to respond to identified health risks. While the team was reviewing and discussing the HRST Considerations, JB was very actively involved in the conversation. The discussion stimulated by the HRST and the PCT tools caused JB to share information about a medical evaluation that had been done by his physician.

The evaluation information that JB shared with the group revealed a strong connection to information gained from JB's HRST.

The success of using these concepts as a way of helping people find their voice was obvious by JB's reaction and the reaction of his team. We learned by using the PCT Discovery Learning tools that JB loves to play basketball and it is "Important to" JB to be physically active. The HRST revealed a connection between his antiepileptic medication use and its effect on bone fragility, an obvious threat to JB's ability to be active. The team now knows how to support JB's bone health so that he can enjoy many more years of the activities he loves. When JB's mother was asked, "How will JB's ability to continue doing activities he loves be supported by the information you learned from the HRST and the PC tools?" she responded, "Because JB was so open, he gave us all some good information so that we can support him in activities that he truly enjoys doing. The HRST points out any risks [like the bone fragility issue] that we need to look for while he is doing activities he likes."

The truth cannot be ignored that our quality of life is directly related to our quality of health. This is true with the population at large and is also true for those with I/DD. To experience a fulfilling life, we cannot ignore our health risks. In time, unmanaged health risks will demand our attention. Sadly, for many, by that time it is too late. Another truth common to all, regardless of disability, is that a large portion of our sense of self-worth and self-value is gained by our contribution in life, both in our own life and in the lives of others. Again, however, our ability to be a contributor in our life is largely dictated by the quality of health we are experiencing. If you need further convincing, think back to a time when you were dealing with a health issue of any kind -perhaps it was the flu, a broken arm, a surgery or a migraine headache. There is little doubt that during this time your quality of life was affected, as was your level of contribution and involvement.

These dynamics make detecting health risks early and incorporating this information into a well-designed, person-focused plan all the more vital and important. It is the best way to ensure that we are setting the person up for a maximum opportunity to be a contributor in the life

they want (as revealed by the Person-Centered Planning process) while at the same time providing a way for support staff to be aware and engaged in managing health risk that are both obvious or less than obvious.

Three things result from this work of risk identification and person-focused planning: First, the person's desires of what they want their life to look like are revealed and acknowledged through the personcentered discovery process. Second, in supporting the person's endeavors, the team can work from a greater sense of security knowing that health risks are not being ignored but actively managed. Finally, the person is positioned to experience an exceptional quality of life full of personal preferences and real choice!

As an agency CEO I believe the HRST will allow a team to bring information about the person's health risk to the planning process in a methodical manner that is thorough and objective. The people who know the person best may not know the details of what certain risks present in the person's life. HRST combined with the instruments/forms used by Support Development Associates brings a good balance of the "Important for and Important to" in the planning process. At the end of the day the person can have a living ever evolving plan for outcomes with strategies for supports to overcome barriers to maintain those desire outcomes.

-Danny Cowart, CEO of Brandi's Hope



*Not a real name