

A Crisis is Not an Excuse

by Michael W. Smull

Most crises requiring behavioral support and system response for an individual with a developmental disability can be anticipated. They should not come as a surprise. Those who present complex behavioral “problems” are people who are usually already known – often well-known – to the system. Those who receive services and complain with their behavior about those services, are typically familiar to those who oversee and manage the services. It is often the case that when the individuals first came to the attention of the system they were not listened to, and instead efforts were made to have them comply with the rules of the agencies, programs or residential settings. The efforts did not work. As the individuals escalated their “complaints” about the services and circumstances, there was typically an escalation in the interventions, leading to people being “discharged” and becoming a “crisis.” They were moved to new settings or service providers, and the cycle began again.

For most of the people with developmental disabilities in this situation, there is time for careful planning, for reflection. Part of the reason that the planning does not occur is that we’ve created a culture of chronic crisis. The officials who make decisions about where people live are typically told of someone who needs a new place to live with little lead-time because an agency has decided to “discharge” them, a psychiatric hospital has someone who should not be admitted, or an aging parent has been hospitalized. In these circumstances, the person needs a place to sleep that night. Looking at how someone “wants to live” necessarily takes a “Maslowian” back seat to having shelter. But the temporary shelter often becomes a permanent place to live, at least until that person informs us with their behavior that they can no longer tolerate the situation into which they were “placed.” Those who need immediate shelter (with insufficient time for planning) are telling us what is lacking in our system; however, they are only seen as individual “problems” that need a quick solution. There has to be a quick solution because the officials need to move on to the next crisis. In a crisis culture there is no time for thought about real solutions, and the cycle of having today’s temporary solutions adding to tomorrow’s crises is maintained.

Learning from Crises

The officials who are asked to make the crisis “placements” have the opportunity to break the cycle of crisis. They may have to help the person move “now”, but they don’t have to wait until the quick solution turns into the next crisis. They can require that evaluations be done to learn how the person wants to live and look for alternative frames of understanding the person’s needs, preferences, and behaviors. The goal should be a better balance. Balance implies that the person gets more of what is important to him or her as a unique individual, and that issues of health or safety are effectively addressed within the context of how the person wants to live. One way to look at this balance is to ask those involved the following questions:

- Is there a good balance between how the person wants to live and staying healthy and safe?

- Is the person (and those who know and care about the person) satisfied with the balance?
- Where there is dissatisfaction, where things are not working, are there other ways of interpreting or understanding the issues affecting the individual and the meanings of the person's behaviors?
- Do any of these alternate ways of understanding the individual's issues and behavior suggest positive actions that could result in a better balance?
- If these alternative ways of understanding are acted upon, how will people know if the changes work?

Just as learning to analyze behavior using a behavioral frame is a skill, so is learning to listen to how a person wants to live. For those who practice "positive behavioral supports" it is a clearly overlapping skill, but it is sufficiently different to warrant separate training. It is a way of listening that uses a somewhat different framework, and applying that framework requires practice. It is about listening carefully and intently. This intense kind of listening has been called active listening (Farston, 1996), and it has been described as a "mindful" activity (Langer, 1989). Too often there is an assumption that professionals already know how to do this. There is an expectation that a professional can go to a day-long workshop providing an overview of three kinds of person-centered planning training, look at a couple of sample "person-centered" plans, and then go forth and effectively learn how other people want to live. My experience and that of my colleagues is that it is a rare person who can pick up this new skill without extensive structured practice. It is even more challenging to apply this skill when there is a crisis. In a crisis, there is no time for reflection, for puzzling something through. In a crisis there is pressure for a quick solution. Applying a skill that is still being developed in a crisis setting is a recipe for distortion and disaster. Only those already skilled can effectively respond.

When officials engage in an analysis of multiple crises they often identify deficits in system capacity. For example, they often see a need for training in the frames of understanding that we have labeled "person-centered planning." Or they may find a need for mental health professionals who are able to effectively evaluate and treat people with cognitive impairments. Quite often a need is identified for support services that permit people to have a place they call home and opportunities to contribute to communities. The best officials see the challenges of those in crisis as symptoms of system deficits. These "best" officials also see development of new capacity as one of their core responsibilities.

For those whose crisis arises because they can no longer live with their families, an important opportunity has been lost. In such situations, the system typically waits until people are in crisis before offering support, and then it is too late. As a result people move out of the family home and the system begins all over again to try to build community for people who have lost community due to its delayed response. The time to learn what is important to the person is while they are living with their family. Many parents are happy to develop plans with their sons and daughters and to begin to act on what is being learned while they are active and able. Parents who do not have the energy to take the lead in planning still have extremely valuable information about the person. When we wait until the parents are disabled, deceased or defeated, we have lost the information and the opportunity for building community that could have occurred.

Using Person-Centered Planning

There are ways pre-crisis planning can occur other than the funding of a large number of new service coordinators. Among the alternatives is to recruit parents who are interested in acquiring the skills needed to help other parents plan, and then to pay them to help other parents develop and implement plans. Self-advocates are another neglected resource. Increasing numbers of self-advocates are being helped to develop plans on themselves. Many of them are interested, capable,

and willing to assist others in developing their own plans. Parents and self-advocates may not always have the specialized clinical knowledge needed for some people to be healthy or safe, but they make excellent partners as they almost always know how to see things through the lens of having a better life. They will almost always push for a better balance.

If new conceptual frameworks are to be broadly applied, there needs to be extensive training and support in learning how people want to live and in addressing issues of health and safety in the context of what is important to the person. But there also needs to be recognition that different conceptual frameworks rest on different sets of assumptions. In the old conceptual framework, an often-unstated assumption was that professionals knew what was best and should make decisions for people. When this assumption is explicitly discussed it is rationalized with concepts of generalized incompetence, such as mental age (e.g. “He has a mental age of four, so of course we are going to decide what is best”). In saying that we know better, we ignore the fact that everyone has preferences regardless of cognitive capacity, and we ignore the complexity of intelligence (Gardner, 1993). In a rush to an over-simplified view of self-determination, we hear the equally perverse statement: “I was in charge yesterday but because we now believe in self-determination today you are in charge.” The preferences that we have today are largely based on our prior life experiences. Much of what we want depends on what we have tried; an absence of opportunities narrows preferences. For all of us choice has boundaries and control is shared; within this “new” conceptual framework what is true for the typical person is also true for those who use disability services.

In sharing control, the goal is to help the person have as much positive control as is possible. The role of the professionals and members of the person’s support team is to look for the best balance between what the person wants, what others want for the person, issues of health and safety, and the use of limited public resources. This is an ever-shifting balance and one that frequently has tensions between competing interests and perceptions. It does require new skills. Some of these have been discussed but there are others (e.g., the skill of negotiation) that are needed. The experiences of those who are moving down this path also indicates that acting on these concepts and using these skills requires extensive changes in policies, practices, and organizational culture. However difficult all of these efforts may seem, they are easier to accomplish and far more rewarding than seeking compliance from people who do not like where, how, and/or with whom they are living.

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