

Helping people find a balance: the role of the facilitator or Being right is not enough

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As we help people learn to do person centered planning with people with disabilities, repeatedly those who do the training are asked what to do when what the person appears to want conflicts with what a parent or guardian wants. As people learn to do plans they also ask what they should do when those responsible for implementation disagree with what is in the plan. In both instances the question is how to approach disagreements between the perceived desires of the person and those who with power in that person's life. For those people doing essential lifestyle planning this problem has been compounded by over simplifying the role of the planner. Those learning have heard the short-hand admonition that their job is to discover what is important to people and to then help them get it. What this epigram disguises are the complex efforts required to help each person find and achieve the balance that works for them. We need to help people find a balance:

- Between their own competing and mutually exclusive desires;
- Between the potential opportunities present and those that make sense for them to try;
- Between what we could do for each person and what they can (and might learn to) do for themselves; and,
- Between what they want and what others with power and authority will support.

The goal is not a perfect life, but a life that strikes a balance that works for the individual. Achieving the balance requires that those who develop plans not only be good advocates but good negotiators. Those developing the plans need to avoid the trap of thinking that this is the only chance to help the person get the life that they want but to see planning and implementation continuing and look for opportunities to create respectful dialogues between all of those involved.

A balance between the person's competing preferences and desires

All of us have mutually exclusive desires. This is true for everyone regardless of the presence or absence of disabilities. It can be about something as simple as Jon's dislike of shoe laces versus his desire for shoes that he sees as fashionable (that do not come with Velcro). The balance for Jon is fashion over convenience. For many people in our field, it is common to see that low pay is sole cause of high turnover. The simple view is that love of the work does not balance the low pay and people leave. Many conversations with the people who do the work (and research in other fields) suggests that low pay is a significant issue but not as significant as not feeling that you are listened to or treated with respect. Where agencies have practices that foster perception of being heard and respected turnover is reported as being much lower. The balance for

those doing the work shifts even though pay has not increased. (People still leave as the pay is too low.) The balance for everyone is complex and the factors that are considered (and how much weight they have) changes over time. It is no different for people with disabilities.

For people whose parent's views of what is important for them appear to disagree with that of the person, we need to begin with a respectful dialogue. In most instances the difference will disappear (or diminish) when mutual understanding grows. When friends and supporter views are different from their own views there is another balance that needs to be sought. It needs to begin not only with discovering what is important to people in everyday life but in discovering how important relationships are to people. When we advocate for people to get things that others object to, we also need to find out how important those relationships are:

- Between all the potential opportunities present and those that make sense for them to try;
- Between what we could do for each person and what they can (and might learn to) do for themselves; and
- Between what they want and what others with power and authority will support.

There is an initial balance as the first plan is developed and then the on-going balance as life evolves and our understanding deepens. Finding and maintaining the dialogue relies on respectful dialogues - between the person and those all of those involved. The balance is struck between multiple and complex factors:

- Often out of balance and moving to region that balance - no different for people with disabilities than it is for us - including tolerating a temporary absence of balance to achieve a better longer-term balance.
- Made more complex by the need to consider the factors that come from within the person with those that are outside the person.
- It is finding the best balance within the boundaries imposed by realities
- Not accepting the current reality as the only reality that is possible - pushing the envelope where possible seeking ways to redefine the boundaries