

Revisiting Choice - Part 1

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Choice is the most powerful word and the most abused word in the current lexicon of the disabilities services system. For some people choice means that how they want to live has been discovered and carefully supported. For others choice is an excuse or the basis of a bizarre rationalization. Perhaps because choice is the word de jour, it has been used to argue that congregate facilities are needed in order to ensure residential "choice". An even more egregious example is justifying the use of pain to control behavior to allow "choice among a full range of treatment options". (The same argument could be made to retain "bleeding" as a treatment option for the flu.) Other abuses are more subtle. When you look behind the rhetoric of agencies which say "we offer and teach choice", you find places that ask people what they want to wear but not who they want to live with. What appears to be absent is depth of understanding and a sense of balance. A single word is being used for complex concepts. Too often, there is no recognition of the need for an individual balance between honoring choice and ensuring safety.

Preferences, opportunities, and control Choice, as it is being used in current disability discussions, appears to have 3 related concepts embedded in it - preferences, opportunities, and control.

Preferences include not only what someone likes but also their desires and dreams. Preferences includes: who people want to spend time with; what to do during that time; and where to spend their time.

Opportunities are the available array of: people to spend time with; things to do during that time; and places to spend that time. Opportunities should also include being able to spend time by yourself. Preferences reflect what people want while opportunities reflect what is available.

Control is the authority to make use of an opportunity to satisfy a preference.

Looking at preferences, desires, and dreams Any effort to support choice should start with discovering what is important to the people who are being supported. What do people want in their relationships with others? How do people want to spend their time? What do people want to do (and not do)? What kinds of environments in general and what specific places do people want to spend time in or avoid? Do people have dreams about how they would like to live and do they have nightmares about what they are afraid will happen to them? While answers to these questions are sought (with varying degrees of emphasis) in all of the formal processes for person centered planning, careful efforts are required.

Many people lack the life experiences necessary to know what they like and dislike Will something that sounds desirable to a person feel that way when it is experienced? Some people want to try things or live in ways that put their safety or health (or both) at risk Many people need to have a life of their own before they can have a dream of their own. As people try things (and as they age) their preferences change. In a system that offers real choice, people continuously have opportunities and are continuously supported in expressing their preferences. Supporting choice requires that there be recognition that everyone has preferences and desires regardless of the severity of disability. Supporting choice also requires that we recognize that what we need to know is taught by the people that we support. Some of what my colleagues and I have learned about preferences from the people that we have listened to follows.

We have taught learned helplessness, now we need to teach trust Many people have experienced systematic ignoring of their preferences. This is an unintended consequence of current "individual" planning and professional practice within the disability system. We cope with the poverty of opportunities for the people we support by suppressing their preferences for what is absent. "Learned helplessness" has been taught and many of those we support have learned this lesson well. For these people, what needs to be taught is that we can be trusted.

Trust is "taught" by having those with control listen to all expressions of preference and, where possible (and sensible), to help people get what they want. "Teaching choice" is a poor label. Those who teach must remember that they are not "offering choices" but soliciting preferences and then demonstrating that staff can be trusted to honor the preference expressed. Staff must learn to acknowledge the preferences that people are expressing with their behavior while not asking what people want until there is a commitment to honor their requests.

Shouting (with behavior) has been the only way to be heard Most of us have had the experience of raising our voices in the belief that it will increase understanding. We shout so that we will be heard. A number of people with disabilities have learned to "shout" with their behavior because it is the only way that they are heard. If you do not like your current job, complaining about it does not produce change. Acting in unacceptable ways does produce change. Complaining about who you live with is unlikely to get you a new roommate, but aggression often works. "Shouting" gets our attention, but rarely gets people what they really want. We need to listen for the preference that is underneath the shouting. Once real preferences are understood (and acted on), the need for "shouting" with behavior is eliminated (although the person may always be someone who has a loud "voice").

Most of what people want is modest What people want is usually modest. When critics say that we cannot afford choice they have typically confounded what is important to people with what might be nice to have. There is also a difference between learning what is important to people and taking someone on a guided fantasy. Careful planning discovers preferences such as: having a say in who helps me; having privacy in the

bathroom; being asked not ordered; going for a walk when I want; and (for one person who uses a wheelchair) to be able control the direction in which I face.

A few people's desires are not modest. While the vast majority of people have modest desires, there are a few people who sincerely want frequent trips to the tropics, a car continuously at their disposal, and support staff who take on the role of servants. They may see these as essential to a reasonable quality of life. They are "virtual yuppies", without the income needed to support their desired lifestyle. They are also unusual, as careful planning identifies very few people with these expensive tastes. Where rational decisions are being made about allocation of resources, these people are disappointed with the outcome.

Some people have reasonable requests that are difficult to afford. The fact that someone wants something, even if they see it as very important, does not mean that it has to be delivered. However, we do have an obligation to respond to sincere requests as we can. For example, there are many people who would like to try living by themselves. The cost of support (in staff and housing) presents a real challenge to those attempting to create a system of support. The demand for living alone is somewhat reduced when there is more careful listening. For example, some people really do not want to live alone but simply do not want to live with other people with disability labels. Other people have always had to share lives (e.g. it is Tuesday so we all go bowling) and have not learned that you can also live with someone where you only share space.

After these situations have been clarified there are still many people who simply want to have the experience of living by themselves. Where people have been able to live by themselves for a year or two many would like to have a roommate for company (but not to share lives with). Some people, however, find that living alone is the only way they wish to live. The support costs for most of these people decline dramatically as behaviors change, skills are learned, and connections to the community are built. However, the cost of support for some people remains high. From the perspective of a system, a small percentage of people can always be supported in relatively expensive lives. The challenge is to not have that percent exceed the resources available.

What people don't want is as important as what they do want. In learning people's preferences, it is important to discover what they dislike. Simple lists are not adequate, we must go beyond a statement that George likes barbecues and dislikes broccoli. We have a significant degree of control over who we spend time with and what we do. We use that control to avoid people and activities that we strongly dislike. People with disabilities have not had that control. In the absence of being able to "vote with your feet" we need to insure that those things that people hate or strongly dislike are absent.

Choice making is not a solitary activity Figuring out what we want is usually not a solitary activity. To tell people that yesterday we made the choices and that today they are in charge is to ignore that few of us make significant choices without discussion. Before we make major decisions, such as changing jobs or changing partners, we have typically discussed the "pros and cons" at some length. We seek advice, support, and

people who just listen. We strive to determine what is right for us. We frequently get conflicting advice and pick the advice that agrees with what we want. We reserve the right to make "bad" choices after we have heard the "good" advice. People with disabilities need the same opportunities.

What people ask for may not be what they want People will ask for those things that they know about. One woman who was being assisted in leaving an institution said that she wanted to move to a "group home". One man said that he wanted to live alone. The woman who said that she wanted to live in a group home spoke very little English. She knew that she wanted to leave the institution and the only place away from the institution that she knew of was a "group home". The man who said he wanted to live by himself thought that the only choices that existed were to live by himself or with other people with disabilities. The woman is living happily in supported living and the man is living in a house that he wanted where he rents rooms to 5 people who have no formal disability labels.

When people express a desire for a job (or anything else) where their disability or circumstances preclude obtaining what is asked for, we need to listen to what lies beneath the surface. One man said he wanted to be a pilot. After a lot of discussion we discovered that while he did want to be a pilot he also just loved airplanes. We could not help him become a pilot but we could help him get a job at an airport.

Some years ago I worked with another man said that he wanted to have a job just like his father's. His father is a well known research scientist with the federal government who determined what projects got funded. Many conversations later we found that the characteristics that mattered to him were that he be treated with the same respect that his father received and that he wear a tie to work. We helped him find a job where he wore a tie and ran a large copying machine at a facility that did scientific research. If you were a scientist who wanted your latest journal article copied you went to his copy center. If you just filled out the form your article would get copied in turn, if you treated him with "respect" he would do your copying while you waited.

Sometimes what people want is not possible A woman I met in the Midwest, Susie, wants to live with her mother. It is so important to her that she sees it as the only acceptable place for her to live. Unfortunately this is not possible. Susie had lived with her mother for several decades and mother had been the person who provided care and support. After a sudden loss of capacity Susie left her home and entered a hospital and then a nursing home. The supports necessary to support Susie in her mother's house are available and affordable. However, Susie's mother would not agree to her return regardless of the supports that could be provided. This is not to disparage Susie's mother. She continues to be deeply caring and intimately involved in Susie's support, but she is "burnt out" as a caregiver.

In these circumstances our obligation is to acknowledge and honor the positions of both Susie and her mother. Honoring her mother's position requires that we not use guilt or otherwise coerce her to support Susie's return to her home. It requires that we support

her in developing her new relationship with her daughter. Honoring Susie's position requires that we acknowledge what is important to her and help her get on with her life. We have to avoid the temptation to deny the presence of a preference that cannot be realized. We also have to help Susie deal with a very real loss and to help her begin to develop new relationships. She needs support in her changing relationship with her mother and in developing new relationships.

Helping people be safe and happy requires thought and effort One of the traps of the current system of planning is that we determine how people can be safe before we look at what they require to be happy. We forget that there is no such thing as a risk free life, that risk is relative and has a context. What we need is to begin with an understanding of what is required for the "pursuit of happiness" and then seek to reduce or avoid risk within that context. What is not acceptable is to simply say it was his choice, that is why I stood by while he hurt himself. Helping people be happy and safe requires thought and creativity. The following stories give some examples of the efforts needed.

A story that I enjoy telling (and writing about) is that of a man who wants to go for walks whenever he wants and who also thinks that, when he crosses a street, traffic should stop for him. The initial thinking was that he needed one to one staffing across all waking hours. The cost of the staffing necessary for a couple of walks each day was an expense that was disproportionate to the result. On the other hand not being able to go for walks on his schedule significantly reduced the quality of his life. Further discussion lead us to realize that this man would be happy to live in a rural setting. He moved to a house on a five acre Christmas tree farm where he goes for walks whenever he wants without having to cross a street.

One man that we did planning with liked to use "found objects" in his art projects. The challenge was that he would "find" objects in stores and leave without paying for them. He understood the concept of money but was remarkably uninterested in it. The people who supported him could have said that it was his "choice" and let him be arrested. Instead they would go to stores with him, with his money in their pocket. (He would give his money away if it was in his pocket.) As they left each store the support staff would ask if he had "found" something in that store and, if yes, the staff would pay for it.

We got a phone call several years ago from a service provider asking for help with someone who was severely injuring himself. This man is now described as a tall, charming, ladies man who does not use words to talk. At the time,. his brother said that he looked like a hockey goalie with the helmet and all of the padding that he wore to keep from injuring himself. There were people who said that he needed a "more restrictive" setting and there were people who said that pain should be used to control his behavior. The service provider could have argued that an institution would be the "safe place" for him to be. Instead we were asked to help the provider "listen" to what this man was asking for.

After listening to what he was saying with his behavior and after listening to what those who loved him knew, we found that there was no single answer. However, there were a

host of simple things that we could do. There were many ways in which we were not listening to how he wanted to live. Some examples include that he: needs to close all doors (except for his bedroom door at night) and to line up all shoes; must be able to make and eat his own snacks when he wants them (including raw onions with salt); must not be ignored (even if it is planned); and he must always have a non-glossy magazine to hold onto. His life is not perfect and he still gets upset occasionally. On these infrequent occasions he still needs people who keep him from hurting himself. However, because we have been listening carefully to what he is asking for he is living in his community. He lives (and goes to concerts with his brother) without pads, splints, or a helmet.

Choice requires opportunities and sharing control A preference is something that people want. Unless they have already experienced it they will not know whether or not they like it or not. Many people with disabilities have never had the life experiences necessary to determine how they really want to live. Honoring choice for these people requires opportunities and taking advantage of the opportunities may require encouragement. As people begin to find that their choices are honored they want control over those choices. Honoring choice requires that control is shared. This is the subject of part 2 of revisiting choice.

Revisiting choice - part 2

Choice, as we are using it, is a simple word that contains 3 concepts - preferences opportunities, and control. Learning people's preferences is a complex and on-going activity. What people want (and the values that underlie their desires) provide a picture of how people want to live. This was the subject of part 1 of "revisiting choice". However, learning how people want to live is only the beginning. It is the necessary foundation but just the foundation. In order to get the life that you want and to maintain it you need opportunities and control.

For people with disabilities the absence of control and opportunities is a devastating combination. Flooding people with opportunities or simply handing over control can be equally devastating. Everyone needs opportunities and everyone needs control but they need them on their own terms. People who have never had opportunities need to sample life in their own way. Some people need to dive in. They do not want and cannot tolerate transitions. Others are most comfortable with first putting a toe in. They want lengthy and careful transitions. Both need the control necessary to change their minds. Some people have been demanding control over significant aspects of their lives and we have seen them as having challenging behaviors. Some have given up hope and we see them as withdrawn or even as compliant. However, regardless of the severity of disability, people want control over parts of their lives.

Providing opportunities, sharing control. Having control is how we maintain a balance in our own lives. Each of us needs control sufficient to keep (or secure) what we value in our lives and to reject (or leave) situations that we cannot stand. One definition of emotional health is that we recognize what a balance is and that we recognize opportunities that enable us to maintain or enhance that balance. That is, we are able to use opportunities to get more of what we value or less of what we dislike. Control is what allows us to try new things and discard them when they do not fit. Control is what we require when we find our lives out of balance and we look for the opportunities that will bring a positive balance. The situations we find the most frustrating are those where we lack control and/or where the opportunities that we need are absent.

Control is a complex concept. Having control means that we have to make decisions and all of us create a set of positive rituals or routines that allow us to get through much of our day without treating each situation as if it were new. Most of us do not want absolute control. We may joke that if we were in charge of the world we could fix things, but most of us want (and welcome) limits to the areas where we have to make decisions. We conform to large sets of societal rules without much thought and only remark on those few areas where we disagree. Those of us who live with others find that we have to share control. Each of us has our own rules that we insist that our partner honor and our partners expect the same of us. Where expectations regarding behavior are not met, or are mutually exclusive, conflict arises. The outcome of a resolved conflict is a mutual agreement on the behaviors expected. Our vision of the best outcome is that our

partners will see the error of their ways and the wisdom of our words. A more rational outcome is that each of us will better understand the other and make the compromise that works for the relationship. In reciprocal relationships control is shared.

If we apply what works for everyone to people with disabilities, then we should be helping people with disabilities to have sufficient control to maintain a balance in their lives and to create their own rituals and routines. We should help them develop relationships (both paid and unpaid) where control is shared. A brief description of what the disability system should be doing is: to discover how people want to live; provide them with the opportunities necessary to get the lives they want; and help them have the control needed to maintain it. Many of the challenges in doing this arise from the disabling environments in which people have lived. We have created these environments with a binary view of control. Either I have control or you have control. The idea that control can and should be shared seems to be an alien concept.

Control, opportunities, and preferences as developmental triplets. Parents support the development of their children by asking the child to choose from alternatives and then honoring the choice the child makes. As children grow in capacity and experience the span of control gets broader. Children may move from what they will wear, to when they will go to bed, to how they spend most of their waking hours. They move from nearly constant supervision to doing what they want within defined (and often disputed) boundaries. Parents transfer control slowly. All parents worry about whether their children are "ready". When a child breaks a rule about the boundaries of behavior the child loses control for a time (smaller children may go to their rooms, older children may be "grounded"). Parents share control with their children while they are transferring it. Typical children go through phases where they rely on their parents control for most things, go through a period where they both want and do not want parental control (teenagers can simultaneously tell their parents that they are ruining their lives while wanting limits to push against), and end up, as adults, with control regardless of their parents desires.

For people with disabilities the analogy with the developmental process that children pass through is both helpful and dangerous. It is helpful in that it provides some guidance as to where someone is and how we might help them move forward in a safe and rational way. The analogy breaks down as the inevitability of autonomy for typical children is not present for people with disabilities. It is dangerous in that we are talking of supporting adults who may have already been trapped by developmental concepts such as mental age.

Control and capacity. How much control we have and what we have control over should be a function of desire and capacity. However, our stereotypes of people with severe cognitive impairments cause us to overlook the capacities that are present. I have met a number of people who do not use words to talk but who are good at training staff in listening to their behaviors with regard to what they want. They demonstrate a much greater capacity for (and interest in) controlling their lives than they are given credit for. At the same time we need to recognize that positive control is learned and

control should be coupled with a knowledge of consequences.

We need to ask what are people asking for and how can we help them get it without putting them at unnecessary risk. It can be as simple as supporting Rhonda, who uses a wheel chair, in being where she wants to be. Any sunny warm day she will want to go outside and enjoy the sun. Unfortunately she is also very allergic to pollen and needs to be told, on days with a high pollen count, that she would not enjoy the consequences of going outside.

Timing and opportunities. Timing is important in how people respond to opportunities. We tell our friends that we are not ready or that we will do it when we are ready. Opportunities have a developmental sequence, people need to be offered what they are ready to try. What people are ready for and when they will be ready requires judgment. Given the uneven, but generally impoverished, life experiences that people have had they need to be encouraged to try new things. They may need to have an opportunity presented again and again. Judgment is required to determine where encouragement stops and coercion starts. At the same time a lack of experience coupled with uneven deficits in skills and capacities makes people more vulnerable. Opportunities can lead to injury and judgment is again required. There is little growth that comes without risk. People need to be able to fail and to feel hurt. Supporting people in having opportunities so that we will know what they will want tomorrow is as important as it is to learn what people want now.

What opportunities we provide, hold back, encourage people to find, or protect people from, depends as much on our values as they do on the preferences and capacities of the people we support. We need to listen to ourselves when we say that someone is not ready or that they should be able to do something simply because it is their choice. Our values influence and often control what we support. We need to talk about what our values are so that we understand the basis on which we are making decisions. We need to remember that the opportunities that are made available depend on the values of those with control.

Looking for control. Most of us seek, and to a large degree achieve, the amount and kind of control that we want over major aspects of our lives. Control is part of what gives us the predictability that we value. One of the more devastating feelings that people report is being out of control or experiencing a loss of control. When we have less control than we desire, increased emphasis is placed on the control that remains. For people with disabilities who live in very controlled settings control is sought where ever it can be found. Some of the behaviors that we want to change around food, aggression, self-injury, and sexuality are a reflection of a lack of desired control over other aspects of life. When people gain positive control over their lives the behaviors that have caused us concern may diminish and with some people vanish.

The difference between sharing control and giving control. Control is not a fixed quantity. It ebbs and flows in our relationships and it can ebb and flow with the people we support. An agency in North Carolina that is supporting people with severe and

persistent mental illnesses as well as cognitive impairments sees control as moving toward the person supported whenever possible but also returning to staff when the person supported has an acute episode. Someone with a severe seizure disorder maybe able to do some things when the seizures are under control and should not have the same opportunities when the seizures are not under control.

Rethinking choice. Our recent history is filled with stories of people whose lives were totally controlled who now live in happy interdependence. People who were seen as not competent to select what to wear are now living in their own homes. We are also hearing of the people who have been injured when some one used choice as an excuse to not think. We need to recognize that the people we support are the experts on what they want while we are their partners in helping them get it. We need to have relationships where we share control and continuously support people in gaining as much control as is possible. Many people, especially those with severe disabilities are only asking for modest control. They want to be able to: control the pace of life (to not be rushed); to be listened to (to only go to bed when they are sleepy); and to have a say in who their staff are (to only be supported by people that they trust).

In our relationships we should help people grow and remember that there is a dignity to risk. At the same time there is no dignity in serious injury. We need to see the key to growth as starting with understanding what people want today and then helping people find opportunities so that they will know what they want tomorrow. We need to recognize that everyone wants and needs control over some aspects of their lives. Our jobs include supporting people in gaining that control.

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