Choice and Control[*]

Part 1: Reflections

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We seek to have a system where people who use long term services and supports have lives of their own choosing within their own communities. We want a system where support is offered to develop and maintain the web of relationships that defines "community." For adults, we want employment to be the norm and not the exception[1]. At the core, we want everyone who is receiving home and community-based services (HCBS) to have informed choice about:

- Where they live

- Who they live with

- What they do with their time (including who to spend it with and employment)

- What they do with their resources

- Who/what entity provides the services to support the choices that are made

It seems simple. Everyone has preferences, likes and dislikes, things they want to be present or absent in their lives. So, if we learn what each person wants to have present or absent, record the learning, and describe how it can be achieved, we have a person-centered plan. Support the person in deciding who or what entity can best implement the plan, have structures to capture ongoing learning, and you have supported people in exercising choice. [2]

But choice is much more complex than this implies. Choice is not just about preferences, having choice with control is how we:

- Give purpose and meaning to our lives, creating our own unique definition of being fulfilled;[3]
- Develop and maintain the reciprocal relationships that sustain us
- Create supportive environments for ourselves and maintain the practices within them that reflect our culture [4]

[*] The opinions in this paper are the sole responsibility of the author but the learning that informed the opinions are from participants in our community of practice, the Learning Community of Person Centered Practices (www.tlcpcp.com), notable among them is Mary Lou Bourne. Much of the information on the boundaries of choice and managing risk reflects her learning. Thanks also go to Caitlin Bailey of the National Leadership Consortium for the references and the commentary that goes with them.

- Manage our day to day lives so that we have more of the moments that make up good days, fewer of the moments that make up bad days, and can cope when we experience loss or have a bad day[5]

And supporting choice requires that we recognize that:

- Everyone has preferences, likes and dislikes, and this is true regardless of the presence, nature, or severity of disability, age, or condition(s)

- Everyone communicates these preferences, but some communicate them differently. Some people can only communicate with their behavior[6]. Some people have given up telling us as no one has listened. Some people have escalated from words to behaviors because we did not act on what we were being told. Regardless of how people communicate we need to have the skills and structures needed to listen and act on what we hear.

- Questions about how someone wants to live require exploration and reflection. Most people need to be engaged in a process of discovery and exploration before being able answer questions about how they want to live. This is particularly important for those who haven't had control over the key elements that determine quality of life, have had limited life experiences, and/or don't know what is possible[7]. For these individuals, a structured process of discovery followed by support around possibilities, priorities, and tradeoffs is needed for informed choice.

- Some people know just what they want from the long-term support and service (LTSS)system. They have done the reflection without system support and do not want or need to engage in an elaborate or even a simple process to arrive at an answer they already know. But, some are asking for what is available without knowing what is possible. One of the challenges for those who work in the system is to be able to distinguish between the two groups and to offer assistance to those who would benefit.

- Those who have not had control or experienced a loss of capacity often need to try new things to discover what they want. All of us learn through trial and error. Most of us can think of something we were reluctant to try that turned out to be an important part of our lives. Conversely there are things we thought we would love that we do not want to repeat. For people without the relevant life experiences, trying and learning is essential.

- Past trauma may impact current choices. Where we are listening to trauma survivors we need to take the impact of trauma into account.[8] For some people that means understanding what a safe environment means to them and helping them to get it. For many there is a need to have good clinical input into how we understand and how we support the person so that they are in an environment that is healing.[9]

- What someone wants may present a risk we should not support. The best response is often more complex than simple prevention. Those who are paid to support people are expected to provide the support in a way that assures reasonable safety without unduly constraining choice. At the extremes, this seems clear. A person receiving 24-hour support who wants to live in city and walk by herself, but does not cross streets safely will have people with her. (And may have a goal of learning to cross streets safely.) But what about people receiving 24 hour support

whose weight gain has resulted in high blood pressure or diabetes? Where is the boundary between encouraging and coercing? Do we have a deep enough understanding of the person and her/his circumstances? What about those whose aggression needs to be constrained but who are in a setting that is toxic and is the source of the aggression? A part of the essential skill set for those who plan for services is being able to assess not just severity and nature of risk but the complex issues that go with understanding and addressing risk.

The more dependent the person is on publicly-funded services the greater the potential for not being listened to, for losing control, for the setting to be determined by what is funded and available, and for life within the setting to be determined by what works for those delivering the services.[10] But this is not the goal or the intention of those who manage systems or those who provide services. To be successful we need to understand the complex issues embedded in supporting choice and have processes and structures that addresses them. This essay provides a brief overview of the issues and a process.

What do we mean by informed choice?

Supporting people in having informed choice requires that:

- The person knows what she or he wants,

- The person knows what is possible, and

    – What is possible includes what is desirable

- The person knows and understands the risks and "trade-offs" and has been assisted in finding the best balance among them.

Choice and boundaries

Choice has boundaries for everyone, so the question isn't "are there boundaries on choice" but should the boundaries on choice be different for this person who is using services? And if the answer is "yes", how and why are the boundaries different? As we look for answers we should keep in mind that:

- Restricting choice is restricting liberty and any restriction beyond those imposed on ordinary citizens should represent the least restriction.[11]
- Even where there is guardianship or other legal arrangements, there is an expectation of the use of substituted judgment and supported decision-making[12]. There is an expectation that the legal representative learns what the person would choose and supports that choice unless there is an issue of risk. Even then the guardian is expected to help the person have as much of what they were looking for as possible, with best practice being supported decision making.
- The more dependent someone is on paid services the greater the responsibility of the organizations providing the services in discovering and supporting choice. Those who plan and implement plans need to keep in mind that greater dependence does not automatically translate into greater restrictions.
- Where there is a tension between supporting choice and assuring health and safety, the thoughtful resolution of that tension (one that describes a working balance between them), is part of the core of person-centered practices.[13]

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The boundaries on choice for all of us include:

- Those imposed by society

    - Laws

        - One of the boundaries on our behavior is the set of laws that describe what the boundary is and the penalty for crossing that boundary. Where someone's disability, age, or condition is mitigating, the legal penalty may not be assessed but there are often other consequences (e.g. social isolation, behavior interventions or programs that restrict liberty).

    - Expectations/values

        - Each setting within a community has a set of expectations that those who wish to be valued follow. There are typically expectations of dress, appearance, and behavior. These expectations and values vary from family to family and culture to culture.

- Our personal values

    - Our expectations of what is and is not acceptable behavior affects who we will spend time with, what we do with our time, and how we use our resources[14].

- Tradeoffs. One choice creates boundaries on other choices.

    - One of the significant challenges for all of us is the recognition that we cannot have it all. There are always tradeoffs. Most choices, once made, impact and often limit other choices. It can be the immediate choice (eating dessert) that impacts on a longer-term choice (losing weight). It can be a dislike of cold winters and the importance of living near your family in Minnesota. Spending money on one thing reduces the amount available for other things. It also involves learning, as when an initial compromise between competing priorities is found to be less than satisfactory. And it changes over time. Making significant decisions and the compromises that go with them is often done with the support of someone you trust. For those who use services having a trusted supporter who helps you find the balance that works for you is at the core of supported decision making. It is support, not control, and the person at the center makes the final decision. Some examples -

        - If it is important to you to live near your extended family, or with people who share your culture, then that creates boundaries on where you live.

        - People may move to take a job or be near their place of employment. Others may choose to undertake long commutes so that they can continue to live in a desired (or affordable) place

        - People take on responsibilities (e.g. grandparents raising their grandchildren, parents who are the primary support for adult children with disabilities, children

supporting aging parents) that they see as more important than the time they would have had for leisure or to fulfill personal goals.

- Resources

    - All of us make choices about what we do with our resources and experience the tradeoffs that go with those choices. When looking at our income we know that spending on one thing means we do not have money for another. To have the income we see as necessary we may work more than one job and reduce the time for other pursuits (another tradeoff). But the resources available to us includes more than money, it includes those available from family, friends, and from our communities[15]. Where we live and who we live near impacts on the resources available for our support[16]. What family and friends are willing and able to offer and how that balances with our needs is another resource boundary.

- Our individual assessment of reasonable risk.

    - One person's assessment of excessive risk is another person's definition of "real" fun. Whether it is an assessment of physical risk such as sky diving, bungee jumping, or swimming with sharks, or an emotional risk such as public speaking we each make assessments or what constitutes reasonable risk. We each evaluate risk and its immediate or potential gain against our assessment of consequence. Does the immediate pleasure of dessert outweigh the short-term consequence of going off our diet? We balance gain and consequence, using our own calculus, to determine whether we will follow advice that reduces health risks, such as sufficient exercise or sleep, or a balanced diet.

People with long term services and support needs have these same boundaries on choice as do typical citizens. But those in the US who are receiving services funded by the Center for Medicare and Medicaid (CMS) as home and community-based services (HCBS) typically have additional boundaries[17]. CMS says the setting must:

- Be integrated in and support access to the greater community

- Provide opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources

- Ensure the individual receives services in the community to the same degree of access as individuals not receiving Medicaid home and community-based services

For people who use services one of the core questions is should there be additional boundaries? Those who provide the services are expected to both support choice and mitigate risk. We are asked to decide what constitutes reasonable risk. Where do we simply support choice, where do we encourage alternatives, and where do we exert control? How we consider risk and how we mitigate risk is addressed briefly in what follows and in detail in a separate paper.

Consequences

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Choices have consequences. Some are immediate, some are long term. Some enhance the quality of our lives and some have a negative impact. For typical citizens that right to make legal choices with bad, even ruinous, consequences is unconstrained by society. The boundaries on choice imposed by society through statutes are largely present in the form of the consequences that occur after the choice is made. Those of us who drive over the speed limit are risking the consequence of a fine, increased probability of accidents, and increased insurance costs. Consistent spending in excess of resources can result in bankruptcy.   But for people dependent on the service system there is an expectation that the organizations will support choice making while preventing the exercise of choice where there are potential harmful consequences.[18]

While we want to prevent harmful consequences, we must also recognize that much of the learning about choice comes from having made "bad" choices[19].   But, we want it to be learning, not trauma. Where there is repetition without the expected learning, we need to understand the reason for the lack of change in behavior that reflects the learning we anticipated, and determine if there is a way to help. And all of this needs to be balanced with everyone's right to make bad choices.   Within disability-based services we often hear people talk of "natural consequences", which always refers to the negative consequences experienced after making a "bad" choice. What is often missed is that the behavior may reflect being trapped in a setting that is toxic to the person or that there may be less painful ways of learning that the person missed because of their circumstances.[20]

Trajectory

As Michelle (Sheli) Reynolds, (of the UMKC Institute for Human Development) has noted, the consequences of making choices not only determines the present but it often creates a direction for the future, a trajectory[21]. For people with Intellectual or developmental disabilities decisions that lead to segregated settings earlier in life make efforts toward inclusive settings later in life less likely and more difficult. If we want people with significant disabilities to have relationships within the broader community as adults being in inclusive classrooms as young children creates a foundation to build on[22]. If you leave school for work in competitive employment, then helping you leave a segregated work or training setting later is not an issue[23]. But it is not only the "big" choices it is also all the recommendations that set expectations that are made by professionals throughout a person's life

Quantity and Quality of Choice

There is literature that shows that too many choices overwhelm the person making the choice. In the Paradox of Choice, Barry Schwartz[24] notes that

> "…as the number of choices keeps growing, negative aspects of having a multitude of options beings to appear. As the number of choices grows further, the negatives escalate until we become overloaded. At this point, choice no longer liberates but debilitates." (pg2)

For most of us, in most circumstances, a few desirable choices are sufficient. But they must be desirable, taking a vegetarian to a butcher shop is not an acceptable way of offering choice. It is not uncommon in some systems to be told that the only choice available is either this house with a vacancy or to be homeless. Where the housemates are not people the person would choose to live with this is not an acceptable choice[25].   There is the other extreme. In some systems, people with disabilities and

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their families, have reported being given a list of 50 service providers and told that they needed to "choose" one. Without guidance and support in making an informed choice, those being asked to choose report frustration and fear as they don't have the information about the quality of services offered or a process to determine the best "fit".[26]

Choice and culture

We are supporting choice, in large part, to help people be a part of their own communities and each community has its own culture. As noted by Chavis and Lee[27]:

> "Every community is organized to meet its members' needs, but they operate differently based on the cultures, religions, and other experiences of their members...Global migration has led to an assortment of communities based on people's needs and desire for that sense of trust, belonging, safety, and caring for each other."

Culture has a dramatic effect on choice but its impact can be missed if disability is the foreground and culture is the background[28]. Supporting individual choices around spiritual life and celebrations is a beginning but the impact of culture goes beyond both. American culture emphasizes individual choice and the importance of autonomy. Other cultures are more deferential to collective choice[29]. How authority for choice making is vested also varies from culture to culture. Authority can be primarily with the person, or with particular family members, or with professionals. (See Sheena Iyengar's Ted Talk: The art of choosing[30]) Where there is a tension between the person's desires and those of key family members or professionals, what consideration should be given to each? How should the issue be addressed? If we only listen to the person about a choice, what will the consequences be? If part of what matters to the person is being a valued member of his or her family, his or her community, then we must understand and account for the culture of the person. We still support the person in her or his choice but it needs to be an informed choice.

Choice architecture

How choice is presented influences the choice that is made. This is often referred to as choice architecture[31]. The example often used is that of participating in a retirement savings. When new hires must opt in to be part of plan, participation is much less than if they have to opt out. Sales of gum and candy are higher if they are placed where you wait in the checkout line.[32] How we present choices for those who use services has a significant impact[33]. For those who have spent years in segregated settings being in an integrated setting can be seen as a positive opportunity or as a frightening prospect depending on how it is presented[34].

What needs to be absent

Part of what drives the desire for change is the need to eliminate or avoid things that the person dislikes, finds irritating, or cannot tolerate. It is not about having a perfect life. The presence of some things that we dislike is inevitable and part of the tradeoffs that we make in life. (E.G. Almost everyone with a partner can describe aspects of the partner's behavior they find irritating.) But when we cannot tolerate something we seek to change our environment. Many people with significant disabilities or health challenges have found themselves trapped in settings that had aspects that they strongly disliked

or could not tolerate[35]. Where people cannot change the setting their response is "non-compliance" while the response of the service system may be a behavior program or medication (or both) with the goal of having the person conform[36]. The response of the person who feels trapped may be aggression or depression.

Part 2 - Supporting Choice – A process

First a framework

In the work that The Learning Community for Person Centered Practices (TLCPCP) has done we have found it helpful to use a framework that divides issues in to what is "important to" the person and what is "important for" the person.

What is important to a person includes those things in life which help people to be satisfied, content, comforted, fulfilled, and happy. It includes:

- People to be with /relationships

- Status and control

- Rituals or routines

- Things to do and places to go

- Rhythm or pace of life

- Things to have

What is important for includes:

- Issues of Health

  - Promotion of wellness (ex. diet, exercise)

  - Prevention of illness

  - Treatment of illness/ medical conditions

  - Issues of Safety

    - Environment

    - Well-being (physical, emotional)

    - Free from fear

  - What others see as necessary to help the person:

    - Be valued

    - Be a contributing member of their community

Learning – discovery, relative importance, and connections

We have found that this framework works well as a focus for learning and describing what matters to each person and separating that from the issues of health, safety, or being valued that may not matter to the person. We have also learned that while this can be a critical part of supporting choice, a discovery process is needed to learn what goes into the framework. Having a set of questions, ways to ask them, and a structure to organize the learning helps people to recognize a broad range of things that matter to them and their relative importance. While the process and framework work with everyone, it is critical for people who have significant disabilities or health conditions. If we are going to engage in supported decision-making, we need to begin with helping the person sort what matters to them from what matters to others. [37]

The connections between important to and important for

None of us attend to our own issues of health or safety unless there is an aspect that matters to us[38]. Unless there is something that is "important to" that impacts on what is "important for" us we don't address what is important for. The degree that attending to an issue of health and safety impacts on the well being of the person the more important finding the connection is. When we ask people why they stopped smoking we hear people describe issues related to their health but we also hear that they quit for a variety of other reason (e.g. concern for their children; cost; how it made them smell). People who exercise regularly often report their motivations as being how it makes them feel, who they do it with, or the pleasure of competition (even if it is with themselves). They are pleased with the health benefits but for many that is not why they engage in healthy behavior.   The only difference between people using long term services and supports and the general population is the degree to which others can (or seek to) exert control over the lives of the people they support. If you want someone to better manage their diabetes, lose weight, exercise, or otherwise voluntarily engage in healthy behaviors there must be a connection to what matters to them that is stronger than the gain they get from the unhealthy behavior. The connection, the motivation, may be directly related to the issue- e.g. those who tell you that they take the medication that reduces the likely-hood of a stroke because a stroke is something that they wish to avoid. Alternately, the connection may be remote. An agency that I worked with discovered that Greg, who didn't like to take important medications, would not take them if you watched, but would take them if you put them out, ignored the medication, and talked sports with him.

Relationships

Most of us, when asked what is most important to us, will reply with the names of family members and then our closest friends. The "family" may be traditional or constructed, but they are the people who are typically most important to us. Next are close friends. These reciprocal, caring relationships have much to do with our quality of life and create safety in a way that paid relationships cannot. It is relationships that define community.[39] These are largely stable relationships which have evolved over time. Their development required time spent together in valued roles. For people who have lived segregated lives, opportunities to develop relationships beyond family have often been restricted to other people who use services and to those who are paid to support them.[40] For all of us building meaningful, reciprocal relationships with people takes more than presence. We need to get to know

and appreciate each other over time. One of the reasons to emphasize employment is the opportunity it presents to develop stable, lasting relationships.[41]

For people who rely on paid relationships we also emphasize the importance of matching (and teach how to do it well). People who care about you as a person will do a better job of helping you have what is important to you and keep you safe. When a paid person takes you into the community they will do a better job of introducing you when they already have things that they like and admire about you as a person.

Control

Choice without control is a road to depression (or aggression). Without control, choice is just a list of preferences. Choice and control are bound together and control has the same boundaries and issues. But control is also something that you can delegate to others.[42] In our relationships, we often tell the other person to choose for both us. How much control we delegate and over what varies from person to person and relationship to relationship. But delegating control is very different from someone taking control. When we accept employment, we accept that our employer has significant control over our work behavior. But within expected boundaries. When what the employer expects is not acceptable we look for other work. Delegating control does not need to be formal but it does need to be specific (control over what), voluntary, and revocable. When people need significant support, those receiving the support want control over how the assistance is given. When others are given responsibility to make decisions for us, we want them to learn our preferences and make the choices that we would make if we had control.

Status

Seeking status is typical human behavior. It can be your place in a "pecking order," being ahead of others.[43] It is often something that makes you proud, that gives you a positive feeling. People routinely compete in activities that have no economic reward where the reward is status. The sense of accomplishment and regard from others. One of the reasons that employment is important is that paid, competitive work confers status[44]. While there are aspects of status that are general (like employment) there are also aspects that are individually defined. What creates status for one person may not be perceived as status for others. It can be the shoes you wear, the car you drive, where you live, or your bowling score.

Rituals and routines

We all have routines and those routines that matter we refer to as rituals. We notice their importance when something happens to disturb them. Their importance varies.[45] Some people find that they are only mildly irritated when a routine is disrupted, others find it very distressing. Moving from one activity to the next often involves a small transition ritual. Changing clothes when we come home from work is an example. When someone is described as "having difficulty with transitions" one of the questions to be asked is whether there is a transition ritual that will help. Where rituals are important they need to be known and honored. Where they cannot be honored we need to know how to help the person cope

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and if it happens with any frequency we need to ask why the person is in a setting where a part of what is very important to them is absent.

Rhythm and pace

Most of us have a pace at which we move through life. There are those who hate to be rushed and need a leisurely pace. There are others who want things to happen without what they see as wasted time. There are times when we want things to move slowly and times when we want them to be over as soon as possible. Some people are "night people," others are more motivated and energetic earlier in the day.

Things to do and things to have

How we spend our time is a one of the critical things that we want to have some control over. What we enjoy doing and what we dislike doing needs to be known and, where others have control, honored.[46] We all have possessions that matter to us. They may be photos of loved ones or photos that document important events in our histories. They may be sea shells that represent a memory of a trip to the beach They may be collections or single objects. They may also represent the status that comes from having a smart phone or fitbit. But whatever they are, we need to know about them especially where people are at risk of losing control over where and how they live.

How do we help people learn – discovery skills

The categories listed above help people think about what matters, but the learning benefits from structured ways to have conversations. Our approach has been to teach people to use a set of discovery skills to provide that structure. Not every skill is used every time. Knowledge of how to use them, when to use them, and what you can learn through their use is the subject of a 2-day training. The discovery skills we ask people to learn are:

- Relationship map
- Rituals and routines
- Top tips or 2-minute drill
- Good day/bad day

We also expect people to learn skills that help keep learning alive. These are:

- Working/Makes Sense Doesn't work/Doesn't Make Sense
- The 4 + 1 questions
- The Learning Log

Describing these in any detail is beyond the scope of this essay and the reader is invited to learn more about them by going to www.tlcpcp.com or www.sdaus.com. Descriptions are also on youtube (do a search using the authors name).

Who to learn from – who to talk to, who to listen to

The person is the primary contributor to the learning that underlies informed choice and the final decision maker. But when we are developing a plan, the person is rarely the sole contributor[47]. We always learn from the person and have the person control as much of what is in the plan as is possible. However, other people are expected to contribute and the more significant the disability or condition, the greater dependence on others.   The question then arises as to who else to learn from. A standard answer for many people using services is "the team". These are the people who are assigned the responsibility for providing the services and it is reasonable for them to have input. While they are expected to provide good support, they may or may not have the information needed to support informed choice. Our experience has taught us that only those with a personal connection are good informants regarding what is important to the person and how to support them in a way that accounts for both what is important to and what is important for. There is rarely a list of who these people with personal connections are. But it is easy to find them. We ask the person who she or he feels close to and do this using the relationship map. Where the person cannot complete it, we ask some of those who spend the most time with the person to complete it (preferably we have 2 people complete it separately and then compare and reconcile). Those who are closest to the person are then asked a simple set of questions:

- What do you like, admire, and/or appreciate about the person?
- How long have you known the person?
- How much time do you spend with the person?

The answers to these questions clearly indicate if there is a personal as well as a paid relationship and help give the plan developer an idea of what aspects of the life of the person would have knowledge about. The answers to what they like and admire give the information to be used in the person's introduction.

What people read first matters – the trap of confirmation bias

It is not just what we have learned but it is also how we share the learning. We must present the information in a way that does not reinforce assumptions about people with disability labels, does not reinforce what is referred to as confirmation bias[48]. (The tendency to search for, interpret, favor, and recall information in a way that confirms one's preexisting beliefs.) People with disabilities and older adults are often introduced by a document – a plan, a history, a summary. Nearly all begin with the disability and level of function, what the person can and cannot do[49]. Presenting this information - albeit important - first reinforces the perception of someone who cannot make choices, who needs others to decide.[50]

If we think about how we introduce one friend to another, we share our positive impressions – with a focus on those that the other person might appreciate. If we consider how we are taught to develop resumes, we emphasize strengths and relevant positive experiences. Those of us who are asked to develop biographies learn that we are being asked to describe why someone might want to listen to us or read what we have written – there is no expectation for us to list our challenges.

This is not to suggest or imply that disability issues are not listed or that challenges in support are glossed over. The issue is when the disability issues should appear (and how they are described). We strongly suggest that the order be:

- What others like, admire, or appreciate (a positive introduction)
- What is important to the person
- How to best support the person to have a balance between what is important to and what is important for
- Demographics and diagnostic labels as needed
- Outcomes and actions needed to achieve them

The trap of the "happy plan" or choice is not an excuse

Presenting what we like and admire about the person first and then describing what is important to the person does not mean that challenges or issues are ignored or glossed over. Ignoring or distorting the issues and challenges that the person has does a disservice to the person. One plan said the person "puts things away for a rainy day" when the issue was that she would take and hide things that belonged to her housemates. This positive distortion was far from helpful for her when she was moving to a new house. Her housemates began their relationship being angry with her and those that worked in the house felt blind-sided by the behavior. The opportunity to discover why she did this, how to best prevent or cope, and the implications for housemates was lost. Instead the person experienced another failure.

Choice is not an excuse for inaction. Saying that we can only present positive information in our descriptions goes hand in hand with the myth that being person-centered means that the person can do whatever they want, without regard to consequences.   Where the barrier to a desired life is a behavior, where there is a behavior that devalues or causes harm, there is an obligation to understand, help the person manage the behavior, and help the person change. Where the person does have challenging behaviors, respectful and accurate descriptions need to accompany any diagnostic label.

Tradeoffs (revisited)

Informed choice requires that people are making conscious tradeoffs. It is exceedingly rare to make the core choices of where to live, who to live with, what to do with your time, and how to use your resources without having to balance the importance of one thing against another[51]. A logical progression would be one where we first reflected on those things that are important to us and their relative importance. Then look at what a reasonable balance between what is important to and what is important for us. Finally, explore the choices we have and seek the combination that comes closest to the what we imagine would be ideal. This rarely happens as described. The actual process is more likely messy and to have different drivers. For example, many people who are looking for work, find the job first and have the location of the job create a set of boundaries on where they will live. People who are looking to emigrate to the US will often seek out those they know, who have already immigrated, and choose to live nearby. They then look for work in that area. Older adults may seek to live in communities with other older adults. People with and without disabilities may find that proximity to

family is the most important. Some people may say that access to public transportation is most important. And some will say both. But family may live where there is no public transportation and the tradeoffs must then be weighed.

The process of supporting people in making the tradeoffs that go with informed choice has to take into account the complexity of choice. Then recognition of the responsibility that comes when we have a strong influence on the process and the outcome (as in supported decision making). Or where we have substantial control over the process and the outcome (as where there is guardianship). Where these are present we need to:

- Begin with what we know about what is important to the person
- Engage in a discovery process with the person to learn more
- Work with the person and those they designate to develop a complete "picture" of a desirable life
- Advocate for what is described
- Continue to advocate when substantial compromise happens because what is available is deficient
- Continue to learn as people have experiences

Also, keep in mind the principles learned by those who study choice. Since people don't choose between things, they "choose between descriptions of things" [52], how those who are supporting choice making describe the options will strongly influence the choice made. There is no change without loss and loss aversion teaches us that people tend to strongly prefer avoiding losses to acquiring gains[53]. Studies have shown that the gain needs to be seen as significantly greater than the loss if people are to choose the gain. And what is perceived as powerfully desirable by one person may be seen as mildly desirable by another. But again, how desirable it will be seen depends, in part, on how it is described and who is advocating for the change. What causes people to agree may be the power of the relationship of to the person advocating or the desire to avoid conflict[54].

All of this makes it tempting to use a "best interest" standard even when attempting to support the person's choice. Being a neutral party, who is supporting the person to make their own decision, is more difficult than it appears on the surface. But the greater the awareness of the challenges by the person doing the supporting the more likely it will be the person's decision.

Addressing issues of health and safety – issues of risk

We use the word risk in a way that is similar to our use of the word choice – a single word that reflects a complex array of issues. As choice and control are intertwined - so are risk and choice. We all have the "right" to make bad choices. Personal development and growth occurs from the learning that comes from making choices – both good and bad. If we "protect" people from making any bad choices, we are unnecessarily restricting liberty and inhibiting growth. If we see supporting choice as an absolute (or as an excuse for inaction) people will be hurt. We must recognize that some risk is part of everyday life for all of us, and efforts to eliminate all risks are both doomed to failure and counterproductive. Some of the efforts to eliminate risk also reflect a fear of liability, a fear that a failure to have a restrictive response will result in being sued. Those who manage risk well, put the fear of litigation aside. They

recognize that mitigating risk begins with asking questions and seeking the answers. When the person's "choice" creates a risk of harm to themselves or others there is an obligation to respond. Because choice and risk can be in conflict, issues of risk can limit choice[55]. But, there is also an obligation to seek to mitigate the risk with the least restriction of the person's liberty, preferably with no restriction.

Each time we are asked to assess risk we need to ask:

- What is the nature of the risk?
- Why does the person wish to take the risk?
- Is there any gain or learning that might arise from the risk?
- Are there ways to support the person that provides the gain or learning while mitigating the risk?

Then -

- What should our response be?

Exploring these questions in the detail they require is beyond the scope of this paper and is being developed in another paper. But many of the risks that raise concerns reflect that the "important to/important for" framework is not being used. Where the ideas and reflections that have been raised in this paper have not been addressed: where people do not have positive control, where things that need to be absent are present, where the connection between important for and important to is ignored – risk is likely to be present[56] and can be mitigated by changing the environment[57].

Conclusion

Choice and control are the foundation of the system we are seeking for those who use long term supports and services[58]. But they are simple labels for complex issues. Effectively supporting informed choice requires an understanding of its challenges and nuances. We need to support people in having positive control while recognizing that while control can be delegated, the delegation can be revoked. In this paper, I have attempted to give an overview of the complexity and challenges of supporting choice. But it is just that, an overview. I have also outlined the framework for thinking, learning, and decision making developed by the Learning Community for Person Centered Practices. The readers is invited to explore the literature cited in the references and the resources on the Learning Community's and SDA's websites (www.tlcpcp.com and www.sdaus.com) It is my hope that those who manage and work in the LTSSS systems will find this useful in making the changes needed so that people exercise informed choice and have positive control over their lives.

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