

## “When People Matter More Than Systems”

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### **Introduction**

We are at a point in our history where there is considerable interest in whether it is possible to do a better job of responding to people as individuals. This paper will attempt to do explore what this might mean based on the experience of people and systems that have been successful in doing so. Nevertheless, this question will take us into matters that may be quite difficult to grasp as it involves the revisiting of many of the core assumptions of our current thinking from a new and possibly unfamiliar angle. What we currently have taken to be “reality” may not in our future systems look at all like what is the current pattern of thinking and practice. So, to some extent, we need to be ruthlessly unrealistic if we are to permit ourselves to not become victims of today’s thinking as being the final word on what the future holds. This can be seen in something as simple as what we think a “person” is.

It is very easy to talk about individual people as being “persons” as this seems a self-evident reality. Nevertheless, just what exactly constitutes a person and where this identity is located is far more elusive than may seem so. Similarly, just what exactly helps a person become more of what they can be is equally perplexing. Yet these sorts of questions are at the heart of the task of developing optimal arrangements of support and living for individuals. Undoubtedly, our capacity to strengthen their ability to reach their potential will greatly depend upon us getting this right. It is not as simple a matter as just changing our systems as the respecting of the personhood of others goes well beyond the matter of systems and programs. It takes us deeply into the realms of the invisible but important values and ethics that emanate from our true natures as people. In

this way, each of our answers to the uniqueness of others is very much enmeshed in the very same type of uniqueness in ourselves.

The history of life for persons with disabilities has included far too much indifference to the dignity of their personhood and humanity for us to arrogantly presume that we have this question in proper focus. Our record of callousness and obliviousness to the ultimate worth of people with disabilities is not so trivial that we should think it can be reversed simply because we are momentarily paying it some attention. We have to be careful to not let the abundant talk of individualization confuse us into thinking that such sentiments are going to automatically set things right. As in all other generations, it will be our deeds that are going to matter. In particular, it will be very important to not lose sight of the intentions and motives that lie behind our words. What is truly in our hearts will eventually show itself for what it really is. The lives of the people we are concerned about already show the marks of the insufficiencies of our predecessors. Yet they undoubtedly shared the same idealism that we bring to such occasions as this and found the task harder than they had expected.

What our task is here today is to see if we cannot come to a better understanding of what it takes to deeply support the personhood and common humanity of our brothers and sisters, friends and neighbors, and fellow employees who live with a disability. In the sense that we all might live with a disability at various points in our lives, it is important to see that this is also a question of how each of us would insist on our own personhood being respected. To help us with this task it is my intention to outline the kinds of personal values and ethics that need to be present and continuously cultivated and lived if the prospects for persons with a disability are to meaningfully improve from today's circumstances. I will also attempt to describe the kinds of often radical rethinking of our formal programs and systems that would be most advantageous for supporting individuals. Lastly, I will issue some cautions about what I would call common oversimplified solutions to the question of individualization that need to be seen as more limited in impact than one might guess.

#### Person Centered Planning Versus "Personcenteredness"

It is useful to begin with the clarification of a key factor as to the order of our ultimate purposes. To the dominant technocratic mindset in our human service culture at this point in time, there is a profound temptation to try to translate all desirable human capacities into bureaucratic methodologies. Such a mentality locates such ostensible "solutions" as being solely a property of organizations and systems. In reality, one cannot get from organizations what is essentially lacking in the people who inhabit them. Well before an organization can make progress on matters of human sensitivity it must have nurtured these same sensitivities in the people associated with it. In this way, people and what they are authentically like are more predictable of what an organization can achieve than are the formal mission statements, policies and slogans that supposedly guide the individuals in the organization.

The “real” policies are written in the hearts of people and will express themselves in practice notwithstanding what is contained in official policy. In this way, person centered planning ought to be seen on at least two levels. The first is that of its increasing use as a formal tool of agencies and bureaucracies. The second is as a tool often used by widely varying but often sincere people seeking better solutions for people. In the first case, person centered planning methodologies are simply techniques and thus ought not to be equated with the kinds of qualities in people that would best underpin their use. Like all technologies the final product depends very much on the qualities of the people using it. Thus, person centered planning in the hands of people that lack sufficient regard for the person could actually be used harmfully.

It is much too easy for any of us as well as the formal human service systems to adopt person-centered approaches as a kind of technology and not see that an authentic adoption of their use would require profound personal and systemic transformations. Instead we may simply take up a supposedly new language and planning methodology while failing to see that we need to go much further. People with disabilities can guide us as to how we must change but we must first be willing to be led. The ethics underpinning our use of person-centered approaches will eventually reveal whether this approach ultimately leads to the liberation of these individuals or their continued oppression.

At the same time, it should be recognized that it is quite possible for a person to be treated quite well without the use of any person centered planning methodology whatsoever. Whole civilizations have come and gone without person centered planning so it is useful to recall that this, after all, is just a tool developed in the last several decades of the twentieth century and ought not to be endowed with all that much credibility. What should be taken seriously is rather the more enduring and universal question of the qualities of human beings that tend to result in other people being treated better. To use the language of today, the more profound question is one of “personcenteredness”. This quality could be thought of as the optimal or desirable ethical and values base of the kinds people who tend to bring about improved respect and treatment for individuals. In this sense, “personcenteredness” is a characteristic of people not systems. It would seem obvious that this is the more central factor to focus on rather than the utilization of a method that cannot, in itself, guarantee such human qualities will actually guide its actual use.

#### The Guiding Values and Ethics of “Personcenteredness”

It is useful to recognize that “personcenteredness” is something that begins within people and radiates outward to others. In all likelihood, it is a set of qualities in each of us that is very dependent on our deeper values and aspirations as to what constitutes being a good person. In this respect, it also reflects some sense of morality about how people ought to be treated. Even if we don’t always live up to such ideals it is important to see that they are nonetheless present in us or can be acquired by the sincere seeker. Equally they can be cultivated and refined over our lifetimes and are thus developmental in nature and can lead to yet further insights into the nature of our human nature and the ways that people can of assistance to each other.

What is also clear is that it would be silly to try to reduce such challenging matters to a simple formula. Our relationships to others and ourselves are far too important to be so readily codified. Nonetheless, it is useful to try to express the kinds of insights and ideals that would be helpful for the sincere seeker in regards to how they ought to be in regards to people, including people who live with a disability. What follows ought not to be seen as the final resting point for this discussion but rather as an offering of what might be the kinds of capacities we would see as desirable. In the end we must all find our own way as this is at the core of being a person.

#### A commitment To Know And (Deeply) Seek To Understand The Individual Being Served

It is not at all easy to understand others or ourselves. Even when one does understand something of whom another person is or even something of our own nature there is clearly much left to know. We can do others and ourselves a disservice when we presume to know what their or our personhood is. A better approach is to recognize that what we think of personal identity, while so seemingly fixed in many ways, is actually a “work in progress” and is always in a state of unfolding. “Knowing” is perhaps not as useful a term here as would be “appreciating” the person” since knowing is always a matter of degree whereas appreciating can still occur even when all is not known or revealed since it applies simply to what is currently evident. This insight tends to come more easily for people when their own “unfoldingness” as a person is better appreciated.

Since people are constantly changing towards unknown ends it seems sensible for the supporter of that person to recognize that they are to accompany that person’s daily search as to wherever today brings them. It would seem that one is never past the stage of “discovering” the person since the persons themselves are still unfolding. This suggests an ethic associated with the process of seeking to understand another person of an attitude wherein we see ourselves as mutually sharing in the process, to some degree, of searching for the personhood of the other. In this way our commitment and obligation is to remain an interest and curiosity in the person and to avoid assuming that all that is to be known about the other has already revealed itself. The difficulty in the past has been that we have assumed to understand people without actually taking the trouble of being open to what they may be. We also did not take the time to properly get to know people. We have too often limited and ignored their real identity and assigned them an identity of our making. All of these shortcomings could be overcome by a sincere desire to understand the person.

#### A Conscious Resolve To (Personally) Be Of Genuine Service

It would seem quite pointless to seek to understand people if one is not going to do something with what one begins to understand. Insight alone, without action to support the person in their struggles for a better life for themselves, would be voyeuristic and an indignity. More positively, insight coupled with a desire to act in helpful ways

nicely sets the stage for the kind of partnership of effort that would be of service. Still, there remains the question of what would be authentic service to another. This cannot be easily answered, as the proper response to the ever-unique constellation of wants and needs of each individual is something that is rarely self-evident. Nevertheless, the commitment to engage the question of what would be best for a person is essential to eventually settling on strategies of service. The key here is that the supporter resolves to be of service rather than just being present without a commitment to the person and their well-being. We tend to reflexively assume that our motives are the proper ones so a measure of searching honesty about ourselves can be valuable.

### Openness To Being Guided By The Person

A common criticism of services coming from service users, their families and friends is that of the person being served “on” or “at” or “to” rather than “with” the person. Service is done “to” people rather than in ways that enable the person to be an active force in their own life. This is often due to the professionalistic assumption that the service provider ought to or does have “answers” and that these have to be imposed on the person. Such an action can render the service user to be merely a spectator in their own life while the initiative and control shifts into the hands of the alleged “expert”. Equally, few services actually arise from and are guided by service users and therefore such an approach is often outside of the usual experiences of many professionals and staff. Consumers and families may themselves be schooled by their own experiences to believe that “professionals know best” and thus contribute unwittingly to their own disempowerment.

These errors can be limited by the supporter taking a quite different stance. It is both realistic and necessary that they seek, engage and submit to the instruction contained in the “guidance” offered by the person as to the directions and details of their lives. “Guidance” as used here is not the formal articulation of needs and wants so much as the ideals, hopes and fears the person holds for their life but yet may be unexpressed. This collaborative response requires a highly submissive posture on the part of the supporter to the often-opaque guidance that the person may offer. Nevertheless, it is valuable to assume that the person ultimately both needs and wants to be a decisive factor in their own lives even if they are unclear and not very articulate about what this might mean in practice. Though it may not seem so to many people, even those persons with apparently highly limited intellectual and verbal abilities might still have considerable capacity to sense what they most deeply need and want, and benefit as much as others from having this be respected. The key here is not what is mutually understood or not at a given point in the process. It is more the posture of the supporter in regards to genuinely seeking to be guided by the person. This desire for service done in the spirit of “withness” is very much bound up with honoring the person and seeking a “right relationship” with them.

### A Willingness To Struggle For Difficult Goals That Are Nonetheless Very Relevant For Specific Persons

If one is trying to be of service it is incumbent that we see that standing with someone carries with it obligations to seek out advantages for that person. Frequently, when these goals become too difficult there is the risk that they may be neglected in favor of easier ones. If this were to happen we could then expect that “personcenteredness” would simply come to mean only doing for a person what is easy, non-controversial, or lackluster. This would be a recipe for mediocrity though we can already see so many examples of it even with those persons who ostensibly have had the benefit of person centered planning. Clearly, there is a qualitative difference in efforts taken by people who are willing to attempt difficult goals that are meaningful for the person rather than just trivial ones that are easy to list as done.

#### A Willingness To Stand By Values Which Enhance The Humanity and Dignity Of The Person Being Served

In theory we could label all efforts oriented to an individual as being “personcentered” even if these resulted in practices that actually were less than beneficial for the individual. For instance, in many places it is quite common to interpret quite conventional practices as being individualized even though, in reality, they are actually quite standardized service arrangements. Normally, the justification offered is that these resulted from some form of individual planning exercise. This is clearly a simple renaming of practice to make it seem responsive to individuals rather than relevantly developing supports uniquely tailored to and “from” the person. This also represents a failure to take up the question of what is ultimately good for the person.

This example nevertheless raises to consciousness the need to be guided by values that uphold the person and their well-being. Perhaps a key value in this regard is the need to see the person’s life as being an important one. The tendency to devalue the lives of persons with disabilities is very much tied up with their experience of being treated as somehow “less” than others. When the supporter sees the life of the person as being as intrinsically valuable as his/her own, they are helping in a small but important way to radically bring society back to a proper regard for people with disabilities. This also helps enable the person to aspire to and pursue the many valued social roles they are denied by too low expectations as to what they deserve and are capable of. What is being asked for here is not some remote lifestyle attainable by only the privileged of society but rather the everyday richness of life that is widely available to all citizens. This, in turn, requires that we uphold the values that would make these life opportunities possible.

#### The Conscious Cultivation Of An Acute Sense Of Integrity, Loyalty and Fidelity To Those Being Served

It would seem purposeless to begin a relationship of service and support without being clear as to who should enjoy one’s utmost loyalty. Commonly, those in support roles find themselves in a conflict between their loyalty to organizations or perhaps other persons. If people are to “come first” then it is necessary that the priority that is to be given to them be made very clear. This is not easily done, even when the supporter is a friend or family member, because few people arrive in people’s lives without some

manner of conflicting interests. For this reason the ethic of deepening one's sense of what it means to be "true" to a person bears examination as it is the only way that we can begin to sort out what would constitute fidelity to or betrayal of a person. This question is ever the more poignant when it is realized how many times in the past the personhood of people with a disability has been overlooked and compromised. Hence, the struggle for integrity and loyalty ought to be considered a sign of conscientiousness and earnestness in seeking "right relationship".

#### The Recognition That Obtaining Quality Service For People Means A Continuous Struggle Against and With Vested Interests

The interests of a given person are always in danger of being compromised. Part of the desire for a more person centered approach can come from seeing just how fragile the security of one's personhood is in the give and take of our world. Those with allies in the struggles of life tend to do much better than those who do not have this advantage. Modern formal human services do not, as some believe, exist simply to meet the needs of the named clients. These services and those who struggle to make them work on behalf of the people have many other "masters" whose needs also demand to be met. These vested interests, including those of the supporter and his or her organizations, might have any number of unspoken and explicit "conditions" that underlie and shape the kind of supports the person served might ultimately obtain.

These supports are not as "fixed" as might appear and the character and quality of them will ultimately have a lot to do with the vision, commitment and effort of those who see themselves as the person's supporter. To do this, however, means to enter the fray on the side of the person knowing full well that this might bring one into collision with any number of other interests, agendas and goals that compete with those of the person themselves. If we are to make progress with "personcenteredness" we must struggle for what benefits the person. Such struggle is inevitable and its outcome can never be assumed to be what is best. Yet it is important to appreciate the example of those who have already made progress with this goal. They somehow seem to manage to move ahead in the very same systems and times as those of us who act like it can't be done. Perhaps we want the goal without seeing that the price of it will be struggle.

#### Flexibility, Creativity And Openness To Trying What Might Be Possible; Including Innovation, Experimentation and Unconventional Solutions

The technocratic character of our modern service systems has successfully turned most of "service" into abstracted "products" that we, in turn, "slot" people into. This fitting of the person to standardized service models means that the person must conform to the service rather than the reverse. Part of the promise of a person centered approach is the opportunity to start all over again and let the pattern of service emerge more from the needs of the person. This is not achievable unless the people in support roles begin and sustain the process by nurturing in themselves the qualities that permit unique answers to people's lives to flourish. Perhaps the most important of these are flexibility and

openness. No formal system can ever hope to be responsive if the people close to people lack these commitments, qualities and ethics.

Creativity is another of these key traits and it cannot be summoned up just because it is needed. These are qualities that should regularly challenge us, as they are very hard to assure. Nevertheless, the sincere seeking of them will bear fruit in the richness of countless people getting closer to their life's goals. The very notion of individualization is that we should do things differently from one person to another as may be merited. Standardized practices, models and systems undermine this purpose even if these are well intentioned. The error is corrected by seeing innovation, flexibility and variability as desirable rather than something that erodes the order of conventional, "across the board" practice. Equally, we should see the willingness of supporters to be creative as one of the central requirements of individualization and, hence, essential to the well-being of people.

#### Internalization Of A Sense Of Humility As To The Actual Value Of Service Being Rendered

If we believe that we are already "there" when it comes to being of service to another person we run the risk of not seeing where we might be able to improve. We must be able to be open to a greater truth than what we have done and seen to-date if we are to truly be receptive to what a person might someday be. If our efforts on their behalf are the focal point, there is very much a danger that we shall interpret the person more in the light of our own needs rather than theirs. Alternatively, if we are humble about our role then we can see more easily, and usually less defensively, that more is possible. It is common in people who are successful in their efforts to personalize supports that they regard their own achievements as lacking. This is not because they see their efforts as unhelpful. It is more a sense that even their best contributions will fall short of what they believe the person's potential to enjoy life could be. It is the person's prospects that are the measure not the satisfaction of the supporter.

It is not easy to be critical and questioning of oneself. Yet the willingness of the person, the supporter and those around them to question what now is may well be the beginning of whole new chapters in people's lives. Critical thinking, properly used, becomes a vision of what could be. Unrest about what has not yet been achieved is often the precipitating factor in breaking new ground. Complacency is dangerous because it tends to stymie the process of imagination and dreaming that precedes the actual achievement of the dream. There is nothing to be gained by not drawing satisfaction from the present, but care needs to be taken to not let "reality" be reduced to only what has been accomplished up to this point. The more humble we see our efforts to-date the easier it is to change them as better ideas emerge.

#### To Look For The Good In People And Help Bring It Out

It is unlikely that any effort at person-centered practice would be attempted if there did not first appear some possibility of something desirable and necessary

happening for a person. Such opportunities are more likely to arise when there are people present who take an active interest in the good things that could be present in a person's life. This searching for the good is critical both in detecting its potential and in affirming it through action. It is also true that the uncovering of the scope of the potential of people's lives is more likely to occur where people have a mindset that enables them to see more clearly what is often hidden by things such as social expectations, labels, stereotypes, reputations and the false steps taken earlier in life. This constructive and proactive view is essential to the process of building the kind of better lives that so many people would like to see for people with disabilities.

These lives of all people are dependent on the good that is in other people. This capacity for good and fruitful contributions from any number of people in our communities needs to be catalyzed in ways that benefit people with disabilities. In this sense if "inclusion" is to be beneficial rather than merely an empty legalism or goal, it is important that the contributions of countless ordinary people in our communities be enabled to occur for the benefit of people with disabilities. If people with disabilities are to have allies in their search for a better life it is necessary that efforts be taken to align themselves with people with disabilities. This process of "bringing out the good" in non-disabled persons is a natural complement to the comparable developmental process towards their potential occurring within the lives of people with disabilities. Likewise, people with disabilities must be supported so that they too can reciprocate in terms of their own contributions toward others and the community as a whole.

We need to recognize that we all need help in becoming the kind of people that are most helpful to others and the challenge of "personcenteredness" extends to our own struggle to become better people should we wish this for ourselves. Naturally, part of this has to be the willingness to see people with disabilities not as recipients of our virtue but rather as fellow travelers, contributors and allies for ourselves in the struggles of life. We need to be able to perceive and receive the gifts of people with disabilities if we are to be at all authentic in our claims of personcenteredness.

#### The System and Program Changes That Would Be Helpful In Fostering Person Centeredness"

It is very difficult to imagine a concerted effort at the personal level towards person-centered attitudes that would not at some point come up against the many inhibitions, if not outright prohibitions, that our systems of agencies, programs and practices create by their own "modus operandi". These agencies and the systems that have grown up around them are, in actuality, a radical experiment of the late twentieth century with formalized, professionalized, socially distant, hierarchically arranged, bureaucratically dominated, commercialized and technologized service. This is quite at variance with the way "service" or support has been provided in most societies in world history including our own. Yet to many people of the current generation, they have known nothing else. It should come as no surprise that they see such systems as a "given" and immutable to change.

Such a view of systems as being rigid and fixed for all time is deeply mistaken. We have been “reforming” such systems endlessly since they arose in force in the period after the Second World War. The sense of gravity with which such systems present and take themselves belies the actual fact that the present order might well be radically replaced at any point. These systems are vastly more changeable than it would seem. Nevertheless, this aura of “gravitas” tends to have a dampening effect on the imagination of the many people who feel that there is no alternative to being entirely defined and controlled by the present day system. They are captured and overwhelmed by these often very large and cumbersome systems. And thus are unable to play much of a role in visualizing something more advantageous.

Notwithstanding those with this paralysis of will and imagination, there are many other people who do not confine their thinking to what the current system customarily supports. Some people simply want to escape the control of these systems. They are frequently drawn to any number of alternative formulations of support that involve no contact with the system at all. For others the challenge is drawn by creating various ways to transform the existing systems towards patterns that are more helpful to individuals. Not uncommonly, this begins with small experiments at doing things differently and gradually expands in scope as progress is made. In many instances these small experiments coexist alongside mainstream efforts even though their character may be quite different from the majority models and practices.

People will be vulnerable to any system of care as their potential to miss the mark is not without foundation. This recognition can be seen every day in the testimony of service users, families, conscientious providers and public servants, advocates, dissident professionals and many others who experience what happens when things do not go well. For them, the question of uncritically trusting any system to work well simply cannot be safely assumed. Such people see this danger even in support arrangements that are labeled as innovative, alternative and progressive. Thus it needs to be recognized that even person-centered approaches will have the potential to harm people. It is therefore very important to be as critical of emerging patterns of care as we have been about those that have been established for some time. As long as people remain imperfect and imperfectable so will any system that is created.

There are many factors that make a contribution to the problem of people and their needs becoming less important than systems. These would include the presence of powerful vested interests, the effects of technocratic culture itself, the role of intrinsic human limitations and their impact on efforts to serve, the core role of ideology, values and beliefs in human service behavior, the difficult issues around human consciousness, unconsciousness and mindlessness, the intervening effect of priorities and commitments particularly of a rival kind to those centered on the person, the ever-present difficulties in ensuring the necessary presence of innovation and leadership, the omnipresent challenge of establishing valid and defensible personal ethics, the seemingly insuperable obstacle of

communications between people, the incessant politics of all human undertakings and the role of culture in setting the stage for how things are perceived and interpreted.

Given the preceding, it would seem daunting to try to create a better system for supporting people. Yet, we have no choice but to once again try some small experiments in treating people better. The challenge is to imagine the systems arrangements that would most enable ordinary, concerned and committed people to make headway through their own efforts. What follows here are some brief descriptions of a selection system design features that have demonstrated the capacity to do this. Like any set of propositions they contain within them their own dilemmas. These nevertheless provide some sense of a way forward given their success thus far in achieving progress on personcenteredness. Other useful factors could also have been included were there more time. These are, nonetheless, emblematic of the fact that there could exist formal systems that are far more responsive to individuals than the ones we are most familiar with. They therefore can serve as a starting point in our task of imagining better.

#### The Need For Service Systems To Not Give Professionals The Ultimate Authority To Define and Design Services

Though it was not always intentional, we find ourselves in a period in which the power to define what a service will be like is very much in the hands of the people who run our systems more so than most ordinary people including service users, families, friends and interested people in the community. As the depth of technocratic influence has grown with the rise of multiple human service human service bureaucracies, the control has slipped far away from the average citizen to those in the human service hierarchies. Commonly, these hierarchies act with undue deference to the people who are supposedly “expert” and hence sanctioned as unquestionable the views of the professionals involved. Whether this is correctly recognized as a bias towards professional ultimacy may not be as important as to whether there is another way to proceed.

The answer to this question is clearly that the people served, their families and many other “ordinary” people involved in their lives might just as well be involved in settling the question of what a good service ought to be as anyone else. There is good reason to believe that the overall vision of the people themselves and those close to them has as much validity as that of remote rented strangers when it comes to sorting out the key values and choices that come in making a life. Most services are actually planned, designed and negotiated far away from the participation of those who receive services. This pattern need not be set in stone as can be seen in the many fine examples of what can be accomplished when the person and those close to him or her are actually key players in the design of their own services. However, such a potential cannot be realized if consumers, families and others close to them are not treated as core designers and directors of their own supports. This does not in any way exclude professionals they trust from occupying key roles it just insists on a quite different vision of partnership.

#### Conferring On Service User’s and Their Allies More Meaningful Powers and Standing in The Service Design and Operation Process

It serves no point to encourage the participation of service users and those close to them in a process in which there is little that they can substantively influence. Many of our participation and consultation processes are very much on the terms of those who control such processes whether this is apparent to them or not. Even our bureaucratically required service individualization and planning processes, including many of those called “person-centered”, are in reality ones in which completing the process has become mandatory and meeting the needs is actually optional. Surely such unconvincing arrangements cannot pass the test of relevance and “personcenteredness”. What is needed is the creation of a quite different basis for the relationship between those being served and those who operate the service systems. This would apply whether the service is residential, employment, leisure or whatever.

This must begin with some conscious experiments with sharing the powers that heretofore have rested almost exclusively with the system. These are the power to plan or “dream” i.e. to envision the future direction of one’s life, the power to refuse to cooperate with plans or practices that are not acceptable to you, the power to propose and negotiate remedies and service proposals that are of one’s own making and, finally, sufficient control of the resources assigned to one’s support that would permit the person themselves to exercise initiative and flexibility. Such powers as these are not absolute, they simply would be delegated powers proportionately shared with the “small” people that are today massed at the bottom of service hierarchies. This may initially seem to many administrators to be a radical direction but the evidence that these powers can be adaptively used at the grass roots level is widespread. However, such examples need to be properly investigated, as many people in authority have actually not seen much beyond their own system’s practices. Nonetheless, such an investigation of tested alternatives and some experimenting with them would greatly help the process of rethinking today’s technocratic systems.

#### The Transfer of Power, Decision-Making, Resources and Creative Capacity “Downward” and “Outward”

These crucial core capacities are in many systems under the monopoly control of system insiders. Yet these are capacities that would be very helpful, if not essential, if they were located much, much closer to the people who most need them i.e. the service user and the people close to them. This would move our (controlling) bureaucracies from their role as “top down” regulators of people to something more akin to being enabling partners with consumers and families. At present, funders tend to relate principally to agencies rather than the people served and, hence, these agencies see themselves as the “agents” of those they serve. It would be better if the people could more directly speak and act for themselves. It is not likely that the individual’s best interests are served when an agency becomes their voice with the funder.

It is not sufficient to say that independent advocates make up for this lack of direct voice, as this tends to beg the question of why their direct voice was denied in the first instance. If the countless “small” people, who are the mass of

those served, are to regain some measure of meaningful influence in their lives, the powers currently expropriated from them by the design of the system itself needs to be reversed. It is not persuasive to deny otherwise competent people these rudimentary powers on arguments that some small minority might abuse them. There are any numbers of conceivable safeguards to minimize such possibilities. These do not require the utterly radical denial to the whole class of persons that are theoretically eligible for such roles and powers the benefits of them.

While the acquisition

and optimal use of such powers would be initially unfamiliar to many consumers and families, widespread experience with such transitions clearly suggests that competency increases with familiarity and the availability of suitable supports. In any case, the staffs of both funding bodies and service providing agencies are no less prone to errors of ineptness, inexperience and abuse of power. Consequently, it hardly seems justified to authorize a special preference for them to be exclusively empowered on the premise that they as a group are more dependable and demonstrate greater integrity. Far better that powers of this basic kind be shared rather than resting in the hands only of those who are paid to serve.

#### Conceiving of the System Becoming Increasingly More “Bottom Up” In Terms Of Where The Direction of Supports Occurs

The displacement of the principal control of supports from the person into the netherworld of the service system is greatly advanced by the large scale of our current systems and the layers of bureaucracies that control people’s lives. To a large extent, this pattern needs to be substantially changed beyond just the decentralization of key powers. This can be facilitated on a number of important levels of system and program design. The key would be the increased use of free standing, semi-autonomous and consumer/family governed mini-projects of support and service. By this it is meant supports that are largely designed, guided and even managed in some cases, as close to the person affected as possible. The presence of these sorts of enabling contexts would limit the extent to which consumers and families had to go “up” into the meta-system to get rather ordinary decisions made about their lives and supports. Decision-making on most matters of importance would occur as close to the person as practical. This would diminish by a great degree the amount of contact the individual would need to have with most of the formal service system in order to get the majority of what they need.

This increased use of micro-projects would normally not require the creation of new incorporated bodies as these projects could be largely hosted by existing agencies. This could be done under the auspice of negotiated “hosting” arrangements that would keep such agencies more in an enabling role rather than in the direct control and administration (i.e. vertical integration) role they currently occupy. Secondly, it would be part of the task of these hosting bodies to “absorb” as much of the bureaucracy as possible that would otherwise be inflicted on the service user and their family to deal with. The intent would be to create a “bureaucracy minimization shield” between the individual and the system. It would also serve to create a “platform” for service delivery that was “grass roots” in its informality, flexibility and responsiveness to the individual.

Under such small-scale conditions the individual could quite realistically be an influence in their own right thereby making “bottom up” supports development more feasible than in the “top down” orientation of even many of our smaller community agencies. It should be noted that smaller is not, by definition, better. Even small initiatives are prone to any number of imperfections, limitations and shortcomings. Their great advantage is that they are at a “human” scale. They are more readily entities within which “small” people can lead, problem-solve, invent, correct and otherwise become the influence they usually are not in large systems.

The capacity of particular individuals to do this ought to vary, as should the support available to help them succeed in making such a somewhat protected and safeguarded “platform” become more people friendly. Even if such options were introduced gradually alongside the existing system there would rather rapidly be developed any number of professionals, consumers, families and bureaucratic authorities that would be very comfortable with operating in such milieus. Needless to say these sorts of entities would be very helpful for responding to preferences of particular service users regarding geographic, neighborhood, cultural, linguistic and other factors crucial to their identity.

#### Establishing A Preference And Priority For Individualized Flexibility Over Standardization of Service Models, Practices and Systems

The endless creation of inflexible conventional service models contradicts at the level of practice the rhetoric of individualization. Standardized approaches owe much of their origins to the industrial era of the assembly line and the bureaucratic managers of that period. However, human service ought not to be reduced to being equivalent to producing standardized objects. People are not “things” though our systems now use the objectifying and commodifying vocabulary in which service becomes reduced to a “product”, “outcome”, “unit”, and so forth. This process has been greatly accelerated in recent decades by the take-over of service delivery by technocratic control and culture. This has intensified as our systems have become larger and more prone to dependence on technocratic classes in order to be managed—at least in conventional top down management terms.

A

better approach would be to conceive of the good or better system as being one that avoids, particularly at the level of the individual, becoming rigid and fixed. Though it may seem peculiar to phrase it this way, flexibility as experienced by the individual, ought to be standardized if anything is to be. Thus the decision-makers in our services and systems need to see that their first order priority is to individual responsiveness. Until they come to such a decision they risk placing the maintenance of the systems order as paramount. Consequently, they will likely never discover the methodologies that could quite readily cope with service delivery being variable in form.

Part of the

culture that needs to be overcome is that of seeing uniformity of practice as being equivalent to “equity” of service. In this approach individuals are forced into being

comparable administratively through the use of artificially created “norms” or averages for spending. Most such norms turn natural human variability into “in” and “outliers” wherein the “outlier” loses in favor of the logic of the lowest common denominator. Even the relatively recent practice in many jurisdictions of fixing the ceiling on (so called) individualized funding rates reveals the extent to which even “entitled” individuals remains hostage to unnecessary group norms. This is quite apart from the fact that most of this sort of funding simply gets re-spent in conventional service models thereby underlining that individualization is hardly what is driving things. By leaving funding in larger flexible “pools” overall net spending can still be controlled without sacrificing flexibility and responsiveness at the individual level or the portability of funds already established as needed by the person. However, it does mean a system in which funding would follow need and thus vary from person to person.

The problem is just not systemic it is also programmatic. Clinical and other service professional often lack a grasp of how to deliver supports in a flexible and enabling manner. This frequently comes from not having had the experience of working in models and partnerships where this occurs. It is also partly due to their not having been permitted, along with consumers and families to create service and supports “from” and “with” the people they support. It is interesting that when such preconditions do exist the majority of professionals can adapt providing they genuinely embrace the necessary ethics of power sharing and being guided by the people themselves. Negotiation, dialogue, flexibility, initiative and partnership are the desired “modus operandi” of empowered, decentralized individualization.

These aspects of “personcenteredness” are teachable, learnable, acceptable and persuasive to most fair-minded professionals.

It

would be improper to suggest that most staff and professionals are the impediment since so much of what is operative is more broadly at the ethical and systemic level and reflects the cultural assumptions of our time. Similarly, the problem is better cast as one of the habits and customs of the technocratic/professional paradigm that has grown up with the service bureaucracies. This pattern needn’t remain as being quite so dominant in the field and the experiments with some of the better person-centered approaches has undoubtedly been instrumental in creating a sense of what is otherwise possible. Nevertheless, without even more such experimentation we will tend to see more of what we already have. Surely it is time to move forward and try out some other ways of conceiving of how responsiveness to individuals might possibly be accomplished.

#### Investing In The Core “People Development” Needs Of A Grass Roots Focused System

There is little point in creating stronger roles and responsibilities for ordinary people and then leaving them struggling with profoundly difficult issues of a technical, values, innovation, service design and community change sort. While it is theoretically true that “small” people have a considerably underutilized potential this will not be made apparent unless it is supported in its development. It is also true that many consumers, families and their supporters will like most people behave in unnecessarily conservative

ways when they face conditions of uncertainty, insecurity and prospects beyond their familiarity. This fear related inhibition is not overcome without the provision of the kinds of supports that make embracing new and innovative challenges more comfortable. This means providing to people ample sources of education, values exploration, technical assistance, inspiration and encouragement. Much of this sort of thing is available to the staff of many systems but is not provided to the people who would form the base of a more grass roots oriented approach to supports provision.

#### Recognizing That The Formal System Is Only Part Of The Answer And Attention Must Go To Supporting Informal Initiatives and Community “Work”

The discussion of the meeting of the needs of people with disabilities has come to be dominated by what is happening in the formal service system. While there is no doubt these systems ought to be thought of as being helpful it is important to remember that it is the broader community that has the potential to enrich and satisfy the life goals of people with disabilities. Most of this “action” will take place very close to the person concerned and involve principally the informal problem solving and initiatives of countless “ordinary” people who do not see themselves as being part of any system. It is their largely unpaid “work” that a grass roots approach needs to nourish. This is best begun by recognizing its presence and permitting the existence of personal supports projects within which this “work” is expected to play a role. Our largely formalistic agencies place almost all their attention on money, staff and organizational matters and thus isolate themselves from the very community that is so crucial to meeting the needs of people with disabilities.

#### Some Cautions About Why Many So Called Consumer-Centered Approaches Might Not Be As Individualizing As Hoped

The desire to have better options for people is quite understandable as is the frustration of not being able to make progress on such goals. This can often result in imbuing anything that moves towards greater individualization with unwarranted hope. It also may lead to a wishful and utopian belief that “alternatives” to our present system will not face their own inherent shortcomings and perversities. All human systems eventually have their own “dark side” and it is wise to be on the lookout for these long before they materialize in an overt form. Just the simple presumption that all arrangements are flawed would spare many the inevitable disillusionments that come from putting any system on a pedestal.

Some of these are already evident in the way in which so many new options are rushed into panacea and “silver bullet” status. Despite the warnings of some of their creators, we can already see “person centered planning” being invested with a kind of potency that has commonly been associated with various quick fixes in the past. Person centered language and rhetoric has swept the field and it is very difficult now to even get a precise feel for what isn’t considered “person centered” given the ubiquity of this verbal unreality. Despite the call for people to “get a life” rather than just services and supports, the lives of too many of those served under this nostrum of person centered approaches

are every bit as entrapped in the service system as before. Most are still searching for a place in the community that is more than simply being a “client” in perpetuity. Person centered approaches are still having to come to grips with the very weak state of the theory and art of community inclusion and no amount of “dreaming” can, by itself, overcome this limitation in our capacities at present. Authentic person centered human beings and systems ought not to be thought of as quite so readily achieved simply by adopting the goal.

A similar pattern can be seen in the investing of portable, individualized, consumer directed funding as solving more problems than it can. These usually are, after all, just nominally individualized financing systems and they still must grapple with all the problems that originate from people and their nature not just how services ultimately get paid for. It may surprise many people to consider the prospect that ideologies and attitudes may prove to be more of a barrier to flexibility and individualization than money and how it is used. Yet, money always follows and is guided by values since it is an instrumentality that will ultimately be shaped by people and where they are coming from. This is easier to see and appreciate when one witnesses the weak pattern of supports innovation that occurs even when the financial resources are both flexible and abundant. In the end, people and what they are actually like are going to be the worst and best part of what occurs under the label of “person centered”.

To finish, it is important to return to the recognition that, come what may, we are the authors of our existence and it is essential that we see that this key aspect of our common humanity not be denied to people who live with a disability. There fortunately never was a fixed road map for the design of our service systems and hopefully there never will be. We are, in our freedom, compelled to take responsibility for our lives and the directions we take. Indeed, we can take the wrong road even when we think it is not. Nevertheless, we must take a path forward and there seems much of value in such a decision being one that we take with the people whose lives are most affected. If we are to be fully respectful of their lives we can no longer remain wedded simply to the services and systems we have today. Their lives show much more potential than we have been able to realize with our current arrangements of support. Thus the key message is that we must continue to search for what is better including experimenting much more imaginatively than we have done of late. We might err but we will move forward. Life awaits.