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## **The Challenges of Authentically Getting What People Actually Need On A Person-By-Person Basis**

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Much attention and energy has been given in recent years to developing new options for people with disabilities that would be more desirable alternatives to group based services. Naturally, a wide range of terms has arisen to describe these, such as “person centered”, “individualized”, “personalized”, “tailor-made”, “self determined” and whatnot. In many locations, the rapid adoption of such terms by so many people may create the impression that a virtual outbreak of person centeredness is underway. Yet, common sense indicates that this could not possibly be the case. After all, surely some situations are not at all “personalized”. Nonetheless, if we are unable to be more precise about what is, or is not “person centered”, then it risks being whatever anyone says it is, or wishes it to be.

In addition, without some way to sort out what is authentic from an impostor, it will mean lesser versions are going to be equated with outstanding ones. It also means that things that are the opposite of “person centered” or “properly individualized” will now be claimed to be the same. This may have quite sad results, as all of the advances possible in the lives of people that have been achieved with such difficulty in recent decades, will be nullified to the extent that regressive practices become allowed to camouflage themselves as beneficial, simply through relabeling themselves with contemporary slogans.

For instance, in a traditional residential institution, it recently emerged in an independent review that the staff had virtually never recommended that the residents obtain any options for their habilitation program that were not already available in the institutions program offerings. This included the option of permanently leaving the institution and pursuing a life within the community. Yet, each of these persons had a “person centered plan” that was signed off by all of the professionals in this facility without any record of officially registered dissent from any of them. Yet, this occurred at a time when, throughout the world, people with disabilities by the near millions were taking up new lives within the community, and governments and agencies everywhere were reducing institutional options, including in the state where this occurred.

On one level, they did have a degree of personally targeted activity opportunities *within* the institution, but even these were only modestly relevant to the person’s needs, given that much better options in the community would have had comparatively more beneficial developmental results. For instance, people with the same degree of disability had already acquired “homes of their own”, that they actually owned, while the people in the institution were still living on custodial wards. In matters of formal supports, almost their whole lives were lived out in group contexts and group programs.

To be fair, many of these group programs were largely similar to those offered in the community and, in some instances, the institution residents and community clients shared the same day programs. So, the question is not resolvable in terms of “community” and “institutions”, since personalized options may be equally unavailable

in each. It is also true that both communities and institutions may equally be susceptible to simply adopting the language of “person centeredness”, while largely still failing to really address people’s needs and potential to the degree they deserve and that is feasible.

To complicate matters somewhat more, to say that games done in a group, such as checkers, bingo or cards are “individualized” may be accurate insofar as the person enjoys bingo more than cards, and can sometimes have this preference respected. Yet, that may be one of the only features of a formal service program that grows out of, and is meaningfully linked to addressing the potential and needs of that person. Yet, when we claim that a whole program is “person centered”, it suggests that more than one feature is individualized. In this regard we might be expecting something more approaching comprehensive individualization.

Obviously, when we consider what precisely is “person centered”, we need to be open to a continuum from minor individualization to perhaps profound and dramatic life changing individualization. They both qualify as valid, but differ in degree and existential importance, assuming that each advances the person’s address of their needs and potential. Yet, while most of us can sense these qualitative differences at an intuitive level, in terms of the degree to which some conditions are exceptionally beneficial to a person’s life and fulfillment, the words “individualized” or “person centered” cannot, in themselves, capture it.

For instance, there is a young man in Europe who has spent many of his recent years in a group living residence in the community. He was living there, not because he or his family wanted him to move from the family home and the small community he was from, to a group home facility in a major regional city an hour away. This option was simply the only one the agency could offer at that time from within its portfolio of existing options. The choice of creating something “from scratch” had either not occurred to anyone, or was judged to be impractical or inexpedient, including the family.

The young man had, in fact, a person centered plan that presumed that he would continue to live in the group home. This was because the agency planned on the basis of what was presently available, not always what was actually needed or ideal for the man. The people involved were not indifferent to the man’s needs at all, nor were they unconcerned with his potential, but the possibility of him having a home and lifestyle that was uniquely his own had not arisen in their minds as a practical possibility. This was due to the fact that their imagination had been so completely bracketed by the channeling of their imagination of “better” into an evaluation of existing and familiar agency options, that they had foregone their ability to design an entirely unique option around the man.

When this young man and his family gave themselves permission to ignore what was on offer from the agency at that moment, they were then better able to begin to picture a more ideal life and lifestyle. He was freed to the possibility that he could develop dreams for his life that were uniquely his. In a sense, they were able to return to seeing the young man as a person with potential, as opposed to a being a man with autism that needed a “service”. As it has turned out, this young man will soon have a home of his

own quite near to his family, and any detail of his new life can be changed by him as it may be needed, given that the support arrangement is his to guide and steer with the help of his friends, family and support staff. It is also noteworthy that the involved agency is now fully supportive of this new chapter in his life, despite the fact that they had previously not encouraged it.

When there is such a potentially profound engagement of a life defining need, such as getting a real life or home of one's own, then it reveals that there is a remarkable difference between a person being able to make some minor choices of their own in a group home, and redesigning one's life in an overall sense. This distinction is further accentuated when there is also the deliberate intent to do this in the context of asking about and seeking ideal or optimal answers to what is precisely needed by a given person, rather than attempting to secure minor personalized adjustments within existing service models.

While being able to eat one's favorite foods, have your preferred choice in clothing and setting your own bedtime may be, on one level, a genuine expression of one's personhood, it may also be that these may simply be indicators of deeper and more fundamental needs in the person that possibly may not be addressed solely through a minor expansion of ability to make some selected choices within an existing service situation. If this distinction is real, then it raises a dilemma, because it asks us to look at "person centeredness" as possibly ranging from minor examples of it to something more significant.

This recognition would call for us to be better able to qualitatively distinguish between greater and lesser versions of "person centeredness." This would also require that we more frequently put adjectives in front of the word, such that the varying degrees of achievement of person centeredness become more apparent. For instance, we might describe "trivial" individualization from "profound", or "significant" versus "insignificant" individualization, or perhaps "superficial" versus "deep", or "partial" or "selective" individualization versus "pervasive" or "thoroughly comprehensive" versions. The words themselves ought not to be the focus, but rather what is or is not happening with and within people's lives.

All of these distinctions can help point out that a continuum may exist in the quality and relevance of the type of individualization being experienced by the person at a given moment. It can also help illuminate that a given response to a person's needs may conceivably be inhibiting and preempting a deeper and more relevant address of a person's needs, because the existing form of individualization is relatively minor, but is mistakenly judged to be profound, optimal or near ideal.

If for some reason the people involved, including the person, cannot properly appreciate and understand the person's more profound existential needs, and true long term potential, then they may simply settle for much less than might well be possible. Given the pervasively low expectations that have historically shaped the lives of people

with disabilities in our culture, it should not surprise us that a few crumbs might well be taken to be an elegant meal, if the bar is set too low.

We might all be aware of instances where rather shallow and largely minor changes in people's lives are heralded, by those involved, as evidence of considerable person centered success. This is actually quite understandable, as most of us would like to believe that we are doing the right thing, and making a useful difference in people's lives. Also, many of these minor achievements are both valid and relevant in themselves, and ought to be savored for whatever benefits they may bring. Nonetheless, what makes these claims of significant person centered success problematic, is that they may serve to block or delay the recognition that much of what is, or could be, better for the person will not be explored. This, in turn, will mean that the person's true potential will neither be recognized nor pursued.

Nonetheless, if we are not more willing to be critical of superficial individualized responses to people's needs, we may then be functioning as agents of keeping people's real potential hidden and ignored, while we address needs and wants that may be comparatively easy and convenient to address. In this regard, we will be colluding in a possibly unconscious process of dampening expectations for people's lives through a tacit unwillingness to vigorously explore what might be optimal or ideal in relation to a person's potential.

If we imagined that a contest existed within society as to whether a person's scope for extensively having and enjoying a good life if being amply supported and upheld, then a choice exists between expansive visions for people's lives and truncated ones. If there is too little vision, then the person will do without, whereas with more generous levels of vision, we could well anticipate a greater prospect of enriched lives.

An example of this can be seen in the premise that many people may have encountered, where it is believed that obtaining an individualized support arrangement is simply a matter of assisting people to leave group support arrangements. This can often be seen in services that are no longer center based, or congregate, and in which each person supported apparently is ensconced in some manner of individualized support arrangement. Yet, one can often see that, despite the obvious physical distinctness of "one person at a time programming", there may well be people whose personal needs are not at all well met by the precise individual option they have obtained. It is conceivable that some people's actual needs may even be ignored, neglected and even worsened by arrangements that are admittedly organized on an individual basis. In a sense, one could have organizational or programmatic individualization, yet fail in delivering relevant existential results, given what the person actually needs.

Though it seems rarely done as yet, one could say with some legitimacy, that these new individual options might actually be a novel kind of "rip-off", insofar as the largely irrelevant, or even harmful individualized option, is serving to keep people entrapped in a lifestyle that is now holding them back, but perhaps in different ways than had been the case in the (prior) congregate era. This conclusion is obviously predicated

on the assumption that “good” or “preferred” individualization involves helping people meet their needs and life purposes and achieve their inherent potential, and “poor” individualization would be where the person is held back or deprived in regards to these. In a shorthand way, good quality is “life giving”, and poor quality is “life denying.”

It should also be recognized that this is not in any way an argument against celebrating the genuinely beneficial outcomes of individualization, as even small gains are still gains to be thankful for. It also does not mean that modest benefits should be forsaken for profound ones, as that would set them up as being opposed when, in reality, both can be achieved in a person’s life simultaneously. Rather, it is simply a call both for greater clarity as to what constitutes actual progress in people’s lives, and a decided preference that people not be cheated out of the long term potential in their lives through our lack of proper consideration of it.

Naturally, we are all tempted by the tendency to equate symbols of individualization with its actual achievement. Yet, we must be careful in doing this. It would be unwise to equate service system practices that are labeled as “person centered” with actual enriched lives, as we would be succumbing to treating the presence of “means” as being equivalent to the achievement of “ends”. Genuine results and outcomes are revealed in people’s lives, not in the bureaucratic or rhetorical artifacts of either formal systems or informal ones.

Yet, we will all be constantly confronted by claims that something is “person centered” because of the presence of suitably “person centered” symbols that are taken to be a sure sign that actual personalized achievements are taking place. This can be seen already in the widespread adoption of the language and vocabulary of “person centeredness”. For instance, in the example of the “person centered” institution already mentioned, that had insisted it was a champion of a person centered approach, it was most certainly true that they had experienced a considerable shift in their routine service related vocabulary towards person centered buzzwords. The institutional staff in this example are no different from most of us, in that they equated a genuine intention around expanding person centered options as being equivalent to actually achieving them.

We can see similarities in another example of the use of symbols to convey the impression of substantive results if we consider the tendency to equate the presence of person centered plans, or individual planning processes, as being the same as actual results in people’s lives. After all, the plans may not be implemented, or they may be intrinsically inconsistent with people’s actual potential. Yet, their presence is apparently widely believed to be evidence of a person centered outlook and outcomes.

These symbols are many, and may include various seemingly beneficial things like individual “success stories”, the decline of group models, the existence of individual funding, the growth in personal control over aspects of services, the existence of support circles, the existence of “dreaming”, the presence of individual home ownership, the person having notable peak experiences, the person or agency having been cited as a leading example and so on. These sorts of suggestive symbols are commonly taken as

signs of success and progress, and may actually contain many positive elements. However, this may not be the same as certain proof of progress, as they are simply indicators that are being relied upon to serve as proxies for success. Even if these serve as a catalyst, true results can only be determined by a close examination of what has really transpired, or not, in a given person's life.

Given that success may be a continuum, by settling for too little we may risk strengthening the lesser or shallow end of this continuum at the expense of the better end. However, if we take the undoubtedly harder road of struggling to define and pursue "better", as being what ultimately substantively benefits a person, then it is quite foreseeable that what we will come to witness is seemingly miraculous breakthrough after breakthrough. Naturally, as the artificial constraints imposed by too low or pessimistic expectations gradually yield to the actual truth of people's potential, then a breakthrough is both logical and predictable.

It is also likely that the harder this task may get, of trying to deepen our grasp of what is authentic person centered results, the less interest will be shown by people who really want what might be called "easy" or "easier" person centeredness. Equally, the more that many people will be tempted by shortcuts, cutting corners and the passing off of "fakes" or deceptions as if they were the real thing. After all, it is not unheard of for people to cheat if the going gets tough enough, and the rewards are substantial.

It could also be the case that the needs and preferences of other involved parties might be gradually substituted for those of the person, but be misrepresented as being only those of the person. Instances where that which is done is undertaken to principally benefit people other than the person, can easily be portrayed as being entirely "person centered", yet it may actually involve a sabotage of the persons interests if the benefit that is gained for other parties comes at the price of the person not getting what they really need.

There may be no harm "*per se*" in other parties benefiting from a person centered initiative. Still, it is important to be able to evaluate what is really behind person centered success claims in order to be as sure as one might that a new kind of exploitation is not underway. After all, quite unseemly things could be done in the name of person centeredness, or any other legitimating slogan for that matter. This would not be the first time in history that something questionable was concealed and disguised by creating the appearance of moral or virtuous conduct. It could make some of us wonder whether things are not what they appear despite all of the right notes being hit.

So, for advocates, change agents, progress minded leaders, innovative service providers and many others who seek a better world, the challenge of authenticity in person centeredness is ultimately a question of truth and discernment, coupled with an increased willingness to become a great deal more demanding and principled as to what we will settle for. The dangers in unduly trusting in appearances and symbols can only be offset by paying much closer attention to the realities of people's lives, and less to claims of success that are not upheld in practice.

We most likely will need to be more on guard, more skeptical, more doubting, more challenging, more testing of our cherished illusions and wishfulness, and more questioning of the new orthodoxies and vested interests that are gradually appearing and entrenching in the “person centered” universe. Paradoxically, at the same time, we will also need to be more willing to dream bigger dreams, to hope with yet more vigor and courage, and to persevere in raising the bar a little higher whenever an opportunity appears.

We will not likely enable matters to get better because we avoid painful realities and difficulties, but rather because we solve the problems we encounter properly, and with the solidity they deserve, and with the integrity that comes with trying to be faithful to demanding but worthy principles. We must be wary of those who claim to have easily surmounted the many perplexities that are involved in assuring that people’s lives are fulfilled, as that which is authentic and good is not likely to have been achieved quite so effortlessly, and at such little cost.

We most certainly have the assurance of knowing that it is quite feasible, and hardly beyond the pale, to have real hope that the lives of people could become better, as the evidence that this is so can be seen in the genuine accomplishments already made by thousands of people with disabilities in their lives, despite the fact that they and their allies had faced and overcome unrelenting pessimistic prognoses. Countless lives most certainly hang in the balance, and it is important that we seek and support all that brings and enriches life. Authenticity in person centeredness need not be forsaken as an illusion, as life can and should be good, particularly when it has been earned and gained through sound efforts.