

# The Limits And Vulnerabilities Of Individualized Support Arrangements: Some Dimensions Of Quality That Must Be Monitored Carefully In Individualized Options

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Many people have very decidedly emphasized the advantages of flexible individualized supports, as a core strategy, for responding to the unique needs of individuals. It would be dangerous and irresponsible to advocate for these without also providing some precautionary warnings of the risks associated with practices of this kind. Such risks and limitations as do exist can be addressed by responsible people, such that the individualised options themselves remain valid whenever they are undertaken responsibly. What follows is a brief attempt to identify what quality issues must be attended to. This will be done under several broad categories of concern..

## **The Possibility of Irrelevant But Nonetheless Individualized Supports**

Though it is rarely intended that individualized supports be only partially or wholly relevant to the actual needs of a given person, it is quite possible that the supports are badly conceived at the outset. There may be any number of contributors to such an outcome, but they would all likely derive from one of ten common and recurring 'core' errors. These are the errors of:

- ◆ Attempting to meet the needs of other parties or interests at the expense of the persons;
  - ◆ Utilization of incorrect assumptions or theories about what people might actually need, thereby leading to false steps;
  - ◆ Misjudging the relative degree of fundamentality of what needs are most important or crucial, relative to other needs;
  - ◆ Paying attention to only some of the needs of the person;
  - ◆ Confusion of the relative priority of the needs and wants of the person relative to some responsible standard of 'best interests';
  - ◆ Failure to give authoritative standing to the person and people close to him or her who know the person well and are authentically committed to the person;
  - ◆ There are insufficient external safeguards put in place that could reliably discern crucial irrelevance and thereby challenge the possibly faulty design decisions.
- These errors are usually undertaken by well - motivated and generally honorable people, so even good people with very good intentions can be present in situations which end up producing supports that prove to be irrelevant and even harmful to a person. For this reason, it is best that people look beyond the people involved in
- ◆ Not properly and deeply understanding the person being supported and their actual needs;
  - ◆ Not caring to understand the person sufficiently to deeply and correctly understand their needs;
  - ◆ Uncritical reliance on, and faith in, habitual or overvalued ways of supporting people i.e. 'fixed' models and practices, as well as panaceas;

designing supports to the actual support decisions and the inherent merit of these.

It is also very important to consider the prospect that calling something ‘individualized’, ‘person centered’ or whatever other term is used to denote its apparent value to the intended person, does not at all mean that it is, just that someone believes it to be so. Consequently, it is useful to consider that such undesirable outcomes as neglect, harm, indifference and even degradation can be and are routinely ‘individualized’ as is the damage done by them to the affected person. Ironically, many such harmed persons usually have in place a Bureaucratically sanctioned personalized plan that adamantly asserts that the person’s unique needs will be paramount.

### **Otherwise Valid Supports Are Not Implemented Properly**

It would not be all that unusual for people to ‘drop the ball’ when it comes to implementation. This can come about whenever there are multiple people involved who do not share the same understanding of the person and what needs to be done. It can come about simply due to flawed communication and the intervening effects of the service system itself. Thus, it is very useful to start from the premise that all implementation of supports, even those of an informal nature, are vulnerable to error, breakdown and even perversity. As a consequence, the agile and perceptive organizer of supports would hold to a set of disciplines that enabled implementation errors to be discovered and corrected as early as is possible. Even better, errors are foreseen and preventively dealt with before they have any effort.

It is useful to examine implementation from the vantage point of the various aspects of putting things in place that ‘must’ occur properly. If these ‘musts’ are undertaken well, then much of what is important has been addressed. Therefore it is useful for people interested in the ‘doing’ to keep the following points in mind as they struggle with their responsibilities. These points, while not exhaustive, cover much of what commonly can get poorly addressed in the implementation of individualized support:

- ◆ A “right relationship” or ethical partnership is established and maintained with the person to be served and their allies and supports;
- ◆ There is clarity about who is responsible for doing what, and the responsible person accepts their duties or roles;
- ◆ The ‘right’ people are selected for the task;
- ◆ There is a capacity in place to easily change the support arrangements as might be needed;
- ◆ The attitudes and values that are crucial to the day to day decisions are constantly scrutinized for their quality;
- ◆ There is clear designation of overall quality leadership responsibility, even if this is shared in some collective way;
- ◆ There is substantial attention paid to the person’s well-being and circumstances at all times, i.e. they do not get ‘lost’ or forgotten in the process;
- ◆ The interests, motives, behaviors and thinking of all the ‘vested interests’ involved are constantly evaluated in terms of their effect on the person’s well-being
- ◆ There is a struggle to ensure that an overall ‘coherency’ and balance of considerations of the different aspects of implementation occur relatively to the person;
- ◆ There is adequate attention given to the renewal of the supports situation, such that the person does not settle into a custodial routine and existence.

The task of ‘walking the walk’ is so easy to underestimate in terms of the many difficulties involved. It is likely that even the very best practitioners are constantly enmeshed in

dilemmas and limitations that greatly strain their ability to get things right. In fact, it is surely one sign of probable impending poor judgment and incompetence when key people become too complacent. The very best tend to have a more humble view of their abilities to keep things in good order, as they are aware and respectful of the endless fragility of what is, after all, human service.

Perhaps a key source of eventual problems with implementation stems from the failure to properly appreciate how very hard it is to really understand someone and to support there optimally. Given that many people may not really be sure about what or who they are, it should not come as a surprise that others might well miss crucial things. On the other hand, it is also important to recognize that much can be done that is highly useful if the effort is carried through over time. Time offers the great advantages of people being able to get to know people and achieving the trust that comes with passing the tests that lead to 'peace of mind'.

### **The Realities Of Personal and Community Life Even When Being Supported Well In Individualized Arrangements**

Life goes on, even when much of what a person needs is on hand. Persons who are largely satisfied with the supports they are getting may still, nonetheless, struggle with the many aspects of life that others also have to contend with. This would normally include living on a budget, wanting, making and keeping relationships, finding and sustaining one's interests, facing hardships and losses, making mistakes, bearing up with responsibilities, facing difficult choices, making sense of one's life, getting one's life in balance and so on. These are normal, and often tedious, aspects of personal life that are mixed in with the many joys and pleasures of life.

People who live with a disability share these aspects of life, as well as the further task of having to face whatever may come with the absence,

quality or manageability of the supports they receive. Additionally, they may do this in the context of a community that may misunderstand or even fear them, reject involvement with them, look down upon them and so on. None of these difficulties are entirely avoided, even when one receives reasonably sensible and ample individual supports. Nevertheless, they are to a significant degree less burdensome, if one has the security and satisfaction of getting the assistance and support one might need in a suitable way.

It is also true that individualized supports may actually create some problems for the person that might not have occurred quite in the same way in more conventional services. This might include any of the following (as well as many others):

- ◆ Onerous and overwhelming responsibilities for managing their own supports;
- ◆ Extreme personal social isolation, even though one is in a 'place of one's own';
- ◆ Difficulties in finding and evolving one's identity;
- ◆ Vulnerability to predatory interests in the community;
- ◆ Chances of being 'lost sight of' because one's life is now 'out of sight';
- ◆ High discontinuity due to the unrelieved rotation of casual and itinerant staff;
- ◆ Insecurity relative to the uncertain dependability and quality of service agencies, bureaucracies, professionals and managers;
- ◆ Expanded freedom and choice without much support in managing it.

### **Final Remarks**

Yes, even with the preceding concerns, it is still desirable to have flexible personalized supports available for people. Nevertheless, these are, at best, just an aspect of what constitutes

getting and keeping a good life for oneself, even if they are important. For this reason, it is best to undertake the provision of personalized support arrangements with the same wariness that many now feel towards 'conventional' services. The state of the art may be changing, but much of life will remain as it has always been - a challenge, no matter what.

What must not be lost sight of is that it is not the individualised options that are the source of quality but rather the foundation of commitment to the person that must animate them from the inside out. This is an ethical commitment at its heart and arises and expresses itself in a regard for the inherent value of the person and the need to do whatever it may take to uphold the potential of that one life. People who are to undertake individualised supports need to be cautious to place the emphasis where it is most needed. It is not the individualised arrangement that will predict good outcomes, but rather the quality of the people involved in creating its essence.

Note: This paper is a slightly modified extract from a lengthy independent evaluation by Dr. Kendrick of the entire Nova Scotia, Canada community-based options residential system completed in early 2001, and can be obtained in its entirety at [www.gov.ns.ca/coms/kendrick.pdf](http://www.gov.ns.ca/coms/kendrick.pdf)

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