

This study was the second in a three-part study of Onondaga Community Living (OCL) in Syracuse, New York. This report is being prepared for the OMRDD Search for Excellence on Person Centered Planning Committee. This part of the study revolved around OCL's closure of a group home in pursuit of more personalized arrangements. The process OCL took and what was learned from the experience. This report was reviewed by members of the OCL Board of Directors, some OCL staff and peers from the community before formal presentation to OMRDD. It is our desire to give to OMRDD or any one interested any information that they feel to be useful about this particular exercise. Questions from this report should be directed to:

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An Organizational Study of OCL's Pursuit for Improved Lives

Introduction

What is described in this paper is an outline of one agency's sense of what it takes to keep focused on meeting the distinct needs of each person they serve; what some people might call the challenge of staying "person centered". The agency, Onondaga Community Living (OCL) of Syracuse, New York, has come to these insights through a wide variety of influences; many of which are difficult to adequately acknowledge. The formal theory which most adequately captures their overall sense of reality is social role valorization theory, yet most of those associated with the agency have had very little formal instruction in the theory nor are they particularly conscious of it as a day to day matter. Yet, in their practices, in interactions with the people they support, and their commitments, they function consistently within its directions.

What is described here are rather the insights of practitioners who, on a daily basis, attempt to live out a commitment to the people they support that they hope will leave the "clients" (a word not used by this agency but one they would use only with great reluctance), with improved lives. They seek not to fulfill a theory so much as to gain ground daily on the matter that appear pressing to the daily lives of the people they support. Even so, like any "work in progress", they have had to settle on some conclusion and principles as being provisionally true at least insofar as these insights have led to tangible benefits for those they support. They seek in this paper to outline where their thinking has come to, at this point in time. This is provided not as a dictum to others, but more as a sharing of what they have come to trust and value in the hope that this will help others as much as it has been instructive for them.

A1. The Outlook Needed to Keep Focused on Persons

The crux of supporting people properly is to recognize that it is people's lives which are to be optimized not particular human service models or methods. On the face of it, this may seem straight forward, but the reality is that it is very hard to go about supporting people in such a way that it is their needs and wishes that are driving things. The common tendency seen in the field has been to fit people into the patterns and models of service preferred by the server and service system. It is much more difficult, but necessary, to adjust the system around people's lives such that it is the inherent needs of their lives that ultimately define the support that people will get.

The task facing the supporter and his/her "service" organizations is to create a way of working with individuals that both permits and enables a pattern of supporting (a "model", if you like) to emerge from the person's circumstances. In order for this to occur, it then becomes a necessary obligation for the supporter(s) to recognize and counter those instances where the interests of others might inappropriately prevail over those of the person to be supported. In other words, that there be no confusion or lack of clarity as to whose needs the service organization ought to ensure come first.

This might be more clearly seen initially in the contrast between what traditionally is seen as helping a person get as good a life as possible given how the person would hope to live, even if that meant living under entirely different circumstance than at present. The task is not to have the group home "work" for the person, but rather to undertake a process of "dreaming" or exploration such that the person and their supporters be enabled to evolve a unique sense of their wants and needs; even at the expense of support roles. Conceivably this (ongoing) process of "dreaming" has lead to lives and lifestyles that are simply not possible given the normal operation of the group home the person is now a resident in.

For OCL this challenge has led to many key insights which set the stage for their day to day operation. One of these is the recognition that the people they support are people who are at great risk of being misunderstood and devalued and that it is therefore very important for their supporters to appreciate this vulnerability. One particular aspect of this is the awareness that a central part of the struggle of people with disabilities is to be seen and be treated as a person with the same human needs, frailties, and hopes as any other person in the community whether they are disabled or not.

This recognition derives from firsthand experience of the ways in which the people being supported have had their humanity and personhood denied to them even by those who care a great deal for them. This insight

is not unique to OCL, but it is taken to heart that a core part of their commitment must be to struggle to ensure that, as much as it can be achieved, there needs to be a focus kept on the person; without this there will inevitably be the risk that the needs and identity of others will prevail at the expense of the emergent personhood of the people being supported. In this sense, OCL sees itself as being a potential threat to the persons it serves insofar as it might behave in ways which diminish the humanity and developmental potential of those they support. Similarly, it sees the value and necessity of there being an ethic whereby they try as consciously as possible to not do the things which might undermine or ignore the person and his/her needs as being central; in a positive sense, to continually seek to enable the person and their needs to come first.

This outlook has led to many routine practices that OCL believes to be helpful but even these are to be seen as a potential barrier if they become more important than the people being supported. OCL's belief is that trying to stay centered on the people being supported is not a specific methodology, formula or "cookbook", but rather a day to day struggle to treat people well. Further, OCL does not see the premise that they are right and correct, but rather that they are in all likelihood quite capable of not being so and thus, must struggle with themselves constantly to continually search for the ways in which the people they support can emerge as central to their efforts.

A2. The Safeguarding Mentality

The premise of OCL, as has been stated, is that they do not have things "right" and that the lives of those they support are not in any way so perfect that they can relax and maintain things. On the contrary, they believe the lives of the people they serve are dynamic and can get much worse very quickly even if they are being careful in how they support people. In that sense, there is a recognition by OCL that it is a good assumption to believe that things in people's lives do "fall apart" routinely and that as a day to day matter, one has to always be alert to seeing this and responding to it.

This responsiveness to where people are at, at a particular moment in time is not unique to OCL. Neither is their emphasis on not seeing their current patterns of supporting a person as beyond question. Nonetheless, it is a matter they labor hard on for fear that they might be "fast freezing" people into particular models of support that might suit OCL but in the process not advance the person.

One aspect of this ongoing process of safeguarding the person is to not look at where people are currently at as being satisfactory even where this is substantially better than has been so in the past. This is not meant as a way in which there is a lack of gratitude and appreciation for progress, but rather as a responsibility of OCL

as a support of people to look beyond the present for both how things might yet improve or worsen for the person and to anticipate what can be done on both counts. In this instance their safeguarding mentality encourages them to see the fragility of their efforts and supports even when things appear to be going well for the person.

The actual creation of intentional and specific safeguards is a natural consequence of this more primary recognition of the imperfection of all support arrangements and the ceaseless need to both safeguard what is nevertheless good and valuable and to proactively do what can be done to recognize and anticipate harm to the person and to prevent it. Many of these safeguards are attitudinal in that the view of OCL, of itself, may conceivably be a routine risk factor in how the people they support get treated.

One such attitude is the willingness to doubt that OCL has got things right for people as this may lead to the very complacency that is to be avoided. OCL's view is that modesty and humility (about OCL) are more adaptive if people are to advance because of the ability it gives OCL to question and change its practices if that is what is advantageous for the people it supports.

A similar attitude is to not "blame" the people they support for things not working out for them through the practice of looking for deficits within that person. Rather, they look to see the potential explanation for why things aren't as they could or should be to extend well beyond the person to include the many others in the person's life circumstances. As OCL would put it, they try not to "fix" people so much as to change the way people are supported and perceived such that remedies do arise as much by the responsibility others take for moving things along as what the person themselves can do about things. In this, OCL and what it does or fails to do, is a central focus in devising new patterns of support. Underlying this is the mentality that OCL itself needs safeguarding both to diminish its negative tendencies and to strengthen its possible positive contribution as a critical supporter of peoples' lives.

A3. Some Illustrative Practices Which Enable the Person to Come First

OCL has found it advantageous to not offer group-programming models of support. This refers to arrangements of support that include more than one person to be supported such that the group needs overshadow and dominate decision making and support practices rather than the person. OCL has historically operated such support arrangements and still does, but increasingly these become fewer and fewer as ways are found to develop supports for people one person at a time. This constitutes a bias not against group-programming so much as a positive preference for support arrangements that are individualized to the extent

that it is clear that the particular person being supported does not have their needs and priorities become subordinated to those of others being supported. This is very difficult to do, in OCL's view, in group-support arrangements.

OCL does not, however, believe that simply because a support arrangement is developed around a person solely that is, by definition, a good arrangement for the person, as it begs further questions as to whether the arrangement properly addresses the person's needs and best interests even if it is individualized in how support is provided. Nonetheless, OCL does see the value of being able to focus entirely on what would work for this person unconstrained by the considerations of the impact on others being supported and the constraints their needs might place on what is now possible for the person who is to be the focus.

In both its employment services and in its residential services, OCL has consistently developed support arrangements "one person at a time" and has not, as yet, found it necessary to do otherwise in that it has always proven possible and feasible to develop individualized arrangements and supports at cost levels comparable to those of group-support arrangements. This is not meant to suggest that people are supported "all alone", thereby intensifying their social isolation as all of OCL's support arrangements are socially integrative to the extent that the person either shares a home with non-disabled persons or works in a regular business alongside others who are not disabled. OCL has simply not found it necessary or advantageous to group the people it supports and it is wary of never doing so as a prerequisite of optimally supporting people. This in no way constitutes a prohibitive against the person voluntarily seeking out the company of their friends and acquaintances who might also live with a disability. It is just that mandatory group-support arrangements have not yet had to become an integral feature of support.

OCL will not develop supports based on a particular fixed dollar amount. This is not to say that OCL won't adhere to a budget, nor that it does not take into account fiscal limits, but rather that it starts, as a matter of planning, with what it believes is the more important question of who is this person and what do they need irrespective of what or might not be allocated now (or ever) for the person by funders. This is not a mere semantic distinction but rather a very practical effort by OCL not to have its thinking about a person, unnaturally constrained by the impositions prematurely, of the necessity to fit the person into a dollar amount such that that becomes the focus.

OCL does believe that it is necessary and unavoidable to have to negotiate budgets and to find both the fiscal and human resources that make it possible to support people in their lives. In fact, OCL, like everyone

else who operates within the formal service system(s), is forever searching out ways in which helpful forms of funding can be tapped in the interests of those they support. Rather, their point is that they believe it to be preferable to start with the person as the focus and work ones way through the needs and priorities before getting to questions of accessing resources. Starting with a particular dollar amount, would in their view, tend to preempt the quite necessary and perhaps extended exploration and discussion of what it is that this person's life directions ought to be or could be even if funding levels were adequate.

A related point is that OCL is averse to fitting people into funding streams as this normally has the effect of starting with fixed service approaches and the inevitable fitting of the person into them. OCL's preferred method would be to start with the person and to "bend" the funding streams to accommodate the person rather than have the person accommodate to the funding stream. Again, this view is not unique to OCL, but OCL has found it critical to how they can best support people.

OCL will not "chase dollars" in the sense of creating supports simply because there is money to do so. Again, their preference is to start with what the people they currently support need and to only utilize the amount of resources this task will require of them. They want to be led by the people not by other influences such as the temptation to access resources. This reflects for OCL its continuing struggle to be certain that it's the needs of those they serve that is driving things, rather than some external factor.

Keeping people first is also reflected in the practice that OCL has consistently resisted enlarging itself for fear that it will no longer be small enough to stay close to the people it now supports such that its responsiveness to them is not compromised. It is not at all sure where such a point in the size of the numbers it serves is that is optimal, but it has consciously chosen to both limit its current size and eventually spin off a portion of its current support arrangements to ensure that the collective effect of serving too many people does not compromise their ability to optimally support people on at a time. If agency size is not a detriment to keeping people first, then there is one less thing to worry about.

OCL is not convinced that an enlarged organization is in the best interest of those they support, even though expanded size may otherwise have advantages for the organization. It is their experience and conclusion that the needs or wishes of the organization must be secondary and subordinate to the needs of the people being supported. Like many others, they have seen what can happen when the needs and wants of the support organization become more important than those of the people being supported. OCL does not believe

that being a small agency assures, by itself, that the person will come first but it does see it as an advantage on an overall basis.

It still remains for there to be people in the support role that indeed put people first and the less that agency size interferes with this prospect the more likely it is to occur. OCL is not, in principle, anti-organization or any other formality either required by “the system” or otherwise, insofar as it believes that a good support organization ought to be well administered. It has found that formal and bureaucratic practices are actually helpful to ensure this. OCL has not found it possible or necessary to dispense with its identity as an agency in order to keep its attention on the people it serves. What it has found is that it is possible to largely keep agency bureaucracy out of the lives of the people it supports though certainly not out of the lives of the supporters themselves.

In this, OCL recognizes that it is itself not a “natural support” but rather part of the formal service system and the public and private bureaucracies that are intrinsic to these systems. What it has concluded is that the people it supports need both “natural support” i.e. support not derived from services that comes “naturally” in ordinary ways from ordinary people in the course of daily life and (some) of the support that service agencies such as OCL can provide. This is due, in part, to the recognition that “natural” supporters are limited intrinsically as well as in numbers for some persons and there are constructive contribution that can come from (paid) human services. It would prefer that people not be reliant on formal support systems in favor of support coming more naturally, but OCL, thus far, has not been able to arrange things such that OCL could withdraw from peoples’ lives even though many “natural” supports have been fostered by OCL.

OCL is aware of many planning systems that call themselves “person-centered” and has no objection to their use. It believes that it has probably incorporated many ideas into their practices that may have come originally from people associated with various planning systems that aspired to be “person-centered”. What they have discovered is that what keeps them focused on the people they support is not individualized planning systems per se, but rather the attitude in itself of focusing on the person. OCL does plan with individual persons, but finds that it does not rely on a standardized methodology nor does it sequester planning into being an annualized event. Like in other practices, it incorporates its plans with people when planning appears to be needed by them.

When OCL does plan with people, it prefers methodologies that are “natural” in style and that come out of the involvement of people and relationships that are present in the person’s life. While planning in OCL is

often referred to as the necessity to “dream” in regards to a person, it could also be called “exploring what might be possible” or even “casual discussion of needs and wants over time”. OCL sees planning with people as an ongoing discussion that requires a considerable amount of genuine listening and discernment from those involved. OCL does not see this as requiring unanimity amongst those involved though, in the end, some consensus is needed in order to act. Even so, much has come in OCL’s judgment, from those many (and often painful) times in people’s lives, where disagreements as to what is best have arisen both amongst those around the person and with the persons themselves.

OCL does not start from the premise that the person automatically always knows what they want or need or can recognize their own best interests. Similarly, it does not assume that OCL necessarily know what people really want, need and is in their best interest. More commonly, it is something that can be elusive enough to require a considerable amount of searching to discover even when people know each other quite well; thus, the emphasis on OCL’s unhurried (and perhaps endless to some people) exploration or “dreaming”. OCL does not interpret its role of focusing on the person as being that or merely responding to peoples’ current wishes or wants, though these clearly matter. Similarly, OCL does not see that it has a responsibility to seek to clarify what will be in people’s best interests even in those instances where this question is currently of no interest to the person. Even so, OCL is highly reluctant to impose its vision for people on the people themselves and have evolved a preference for proceeding from mutual agreement wherever this is possible.

OCL does not believe that even where it is being highly centered on the people it supports that this inevitably equates to a good life for the people themselves. The supports people receive from OCL and elsewhere are certainly important but only to the extent that they actually help people get a good life for themselves. Thus the critical question in the end is not whether OCL is “person-centered” but rather whether any of this has actually helped people get lives that meet their needs.

OCL is acutely aware that the lives of the people it supports are far from ideal and that OCL continues to be unsuccessful in many matters in supporting people to get lives that are deeply satisfying for them. In fact, OCL recognizes that they often stand between people and better lives because they fail to do things well in their role as supporters. Equally, many needs in people’s lives are long term and enduring and that years may be involved in making progress.

A4. The Costs of Keeping the Focus on Persons

It is not surprising that there is always a price involved in making progress. So it is with trying to keep supports centered on persons. Perhaps one of the most obvious is that the more that is required of the supporter the more it costs them. Yet, there may be many beneficial effects when supporters push themselves to do better. OCL recognizes that keeping the focus on people is a commitment that the supporters will be expected to struggle with because it is inherently challenging, difficult and demanding. Yet this is what it takes to make progress and this has to be accepted as a “given”.

If supporters are not realistic and reconciled about the price this kind of support work exacts, it is predictable that they will not bear up well with their responsibilities to the person. In fact, there needs to be, in OCL’s view, a very real sense that staying focused on people asks something of supporters that goes well beyond the normal demands of a “job” to a kind of personal commitment that is unlikely to be commonly made. In this, OCL recognizes that this kind of commitment comes from people and attracting and supporting people to make it is a continuous struggle.

It is not easy to continue to make special and extra efforts on behalf of people yet those contributions are essential in “being there” for people and cannot easily be reduced to routinized job descriptions of the kind that are common in many bureaucracies. A willingness on the part of the supporter to endure some measure of stress and difficulty is a basic prerequisite for hanging in there with people. Part of this is the expectation that OCL has that supporters ought to set high standards for themselves on all sorts of levels such as their values and ethics, their sensitivities to people, their imagination for what is possible, the quality of their relationships, their attitudes, their effort, their sacrifices, their creativity and so on.

In the end, being “person-centered” comes not from OCL but more fundamentally from the people themselves who are in support roles and thus derives from who they are. OCL’s role is to demonstrate that such a commitment is possible to those who have not yet considered it and to model this such that those who work at OCL are encouraged and strengthened to manifest this commitment. OCL recognizes that indeed it is possible for people to have a loving concern and belief in/for the people they support and that this tendency needs constant cultivation and support.

OCL also recognizes that the task of “walking the walk” is only as good as what happens today and that better futures will only come from what is done each day and every day. Yet, it is not possible for people to maintain high standards without at times failing to live up to them. OCL would be paralyzed if it could not

pick up after its (many) mistakes and try again and again. Thus, it has concluded that it has no choice but to see mistakes as part of the learning that comes with trying to be there for people. As much as it seeks to safeguard the people it supports, its own shortcomings and the inherent limitations of (human) efforts, leave it with the awkward role of seeking to be both simultaneously willing to set high standards and to be realistic about itself.

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