IMPLEMENTING ORGANIZATIONAL CHANGE UTLIZING THE PRINCIPLES OF SELF-DETERMINATION

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Very recently there has been much discussion about the importance of self-determination as a guiding principle in assisting people with disabilities in control-ling their own destinies. The four basic principles outlined in the "Declaration of Freedom" include Freedom, Authority, Support and Responsibility. (Nerney, Crowley, 1993; Nerney and Schumway, 1996).

Because of this focus, there are some throughout the country who have begun to rethink the way that agencies are funded and how they operate. There are some people with disabilities who want to have complete control over budgets, staffing and other aspects of their lives. There are others who may continue to choose to have assistance in some or all areas of their lives. These varieties of choices must be respected and plans must be put into place to be able to implement these various choices.

It may be time for us to finally admit that the traditional agency as we now know it may be a dinosaur. The shift staffing pattern (24 hours a day, 7 days a week, 365 days a year) is highly problematic at its core. It is not only incredibly expensive but finding the volume of staff needed given the recruitment problems, demographic issues and other recruitment issues will only get worse as time goes on. There are many very good agencies who spend most of their time in a survival mode of simply trying to have enough people to cover the next shift which leaves precious little time for any long range planning, let alone focus on desires and wants of those they serve.

In addition, there is a growing recognition on the part of many states and others that there simply are not enough providers for the people they are seeking to serve. In many states, much time and effort is being spent in recruitment of new providers, often from other states who fit both their philosophical and financial mold of expectations that will allow them to meet their ever increasing need for services. There is also an underlying assumption that it may be easier to bring in a new "crop of providers" that will require less retraining and for whom the funders may have more direct influence over the outcomes that they desire.

There is also the issue of people with disabilities and families desiring a different system than is currently in place. **All the talk of waiting lists, tight budgets, Medicaid, etc. means very little if someone wants services now**. With the increasing focus on person-directed services and individual budgets, people with disabilities and families look around at a system that is entrenched, highly selective and, in many cases, unresponsive and often say that they want a whole different approach - not just a slot.

As many caregivers continue to age, this problem will only multiply. It should be absolutely frightening to anyone who looks at the demographics over the next ten years to see the number of families that are going to pass on whose sons and daughters lived at home for their entire lives. While they may have used some services (i.e., transportation,

workshop, recreation, etc.), they have not used the most expensive service that the government can buy except for medical - namely, residential.

Over the next decade, increasing numbers of people are going to go from the bottom to the top of the waiting list upon the death or disability of their caregiver. We think we have been prepared because we have seen increasing pressure on the system, however, as the saying goes, "You ain't seen nothing yet."

The system is already struggling and reeling from the continued graduation of individuals with disabilities from special ed and this will now be coupled with an increasing demand for services for which there are too few providers, too few funds and a system that has grown incrementally when a wholesale restructuring is needed.

Most of the problems occur in not only accepting some of the philosophical premises that drive such determination but in the actual implementation of person-directed budgets, Medicaid, staffing and other related issues. One area that has not received much attention except for a few writings by Nerney and others is not only the poverty of people with disabilities but the poverty of their caregivers.

How ironic it is that people with disabilities and their low incomes are most directly linked to the people within agencies that offer them the greatest amount of support. We have developed a system where the person who may be most important in the person's life (other than family) is often poorly paid, poorly trained and very often will not be able to stay in their position for very long for financial reasons. At the same time we commit ourselves to person-centered planning, individual approaches and speak of community and friendship as if it is something that automatically happens.

Many of the direct support staff who work with people with disabilities often have issues of survival and complications in their own lives as well. We know that a majority of the caregivers are female, may have children and in many cases must have a second job. We then say to these same individuals that they are supposed to not only provide support, direction, encouragement and training, but are also supposed to assist people with disabilities in becoming involved in their communities.

As previously mentioned, the whole issue of the poverty of the caregiver, not only the poverty of people with disabilities must be addressed as part of this equation if we are ever to get at the core issues that need to be resolved in order to offer true options for living a full life to people with disabilities.

Unless this fundamental issue is addressed, we will forever swimming upstream in trying to implement a system whereby people who need and choose support are able to receive it from people who are not living at the edge of poverty themselves.
Thus there is a radically different approach that is needed if we are truly to implement these principles.

What is needed is an approach whereby work is done with several groups throughout a state who are willing to truly commit not only to the principles of self-determination but in implementing them across the board including a review of:

1. Mission/Values/Vision
2. Implementing person-centered plans
3. Implementing personal budgets
4. Structuring supports in creative ways chosen by the individual
5. Looking at the elements in the supports person's life that would assist in enhancing their personal and financial status as well.

In order for this approach to be tried, there has to be a commitment on the part of the group to truly be committed to systemic and personal change by all concerned. Specific outcomes have to be determined that are desired by the individual and by those involved in such an effort.

In some states this approach may begin with existing agencies that are committed to this approach and are willing to stop and take a look at the services and supports they offer in a fundamentally different way. It may also be necessary to work with parents and people with disabilities who desire to form new agencies, microboards or other entities that will for the first time be offering supports. There is no right or wrong way to approach this. Each situation is different. It may also be possible in a state to offer a combination of both approaches.

When these outcomes are established, it is possible to set into place a work plan of activities and responsibilities that will lead to the projected outcome.

At the heart of this is remembering the five principles of freedom, authority, support, responsibility, and confirmation that must be the driving factors in any such effort. If these are kept in mind, it is possible to look at the linkage between persons with disabilities and their caregivers and how it is possible to achieve desired outcomes for both parties.

In order to proceed, the group has to commit itself not to study, evaluate and research, but to action.

A special set of outcomes, expectations and expected accomplishments has to be agreed to prior to working with each group.

The goal is to provide a path for systemic and group change fostering self-determination for the individuals it supports.

There are a variety of issues that must be addressed as this plan unfolds. Some of these issues include, but are not limited to:

1. Group commitment

2. Who will be involved?

3. How many people with disabilities will be included?

4. How will a personal plan be developed?

5. Resource allocation must be across the life span of the person, not departmentalized.

6. Resources must be flexible and directed by the individual through the person-centered plan

7. Part of the effort will likely involve funders and other parts of the system. (i.e. Medicaid issues, transportation, etc.)

8. There must be attention paid to citizenship, community, and the individual's desire to connect with others. There must be a commitment not only to internal change but expanding citizenship possibilities.

9. **Finally, there must be a realization that this is not a project, but a fundamental, longterm commitment to change, not only to beliefs, but to actions.**

One way to begin this exploration may be to bring together over a one or two day period, individuals with disabilities, family members, providers, funders, stakeholders, etc. who are interested in taking a look at this entire area and what its implications truly are.

It is far more complicated than simply restructuring how Medicaid payments are made or increasing recruitment and retention efforts. This discussion needs to focus on a whole range of issues that include but are not limited to:

1. How do we determine what people want?

2. How do we differentiate between wants and needs?

3. How do we ensure that services and supports are person-directed, rather than agency-driven?

4. How were individual budgets developed and how do they link with current funding structures?

5. How do we ensure a flexible approach to supports that change as individuals change?

6. How do we ensure that self-determination does not become another program?

As Dickens wrote, "These are the best of times and the worst of times". There lies before us a tremendous opportunity to offer a different set of options than currently are in place. Despite funding issues, staff issues and a whole host of other problems, there also lies within this approach a tremendous opportunity to rethink how we have done things.

Time is indeed of the essence.