

## **A Life Like Yours**

by

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A short while ago, David Pitonyak asked if I would share some thoughts about why I believe smaller is better in terms of organizing services and supports for people with disabilities. He asked me to share my thoughts from my perspective as the director of a community based organization in Vermont (Upper Valley Services, Inc.) that offers a wide range of services and supports that are based upon an individualized support model. Given a career spanning nearly 40 years, covering a wide variety of services and experiences, he thought I might be in a position to comment on the role that size of place might play in the design and implementation of successful community based services. This seemed at first to be a simple task, and perhaps, for someone more eloquent such a paper would be quite easy. However, for me, my difficulty is in explaining what I feel should be the obvious. Often that which is clearest becomes the more obscure?

### **The World According to .....**

First a little contemporary context is in order. The worsening economic times are proving daily why such explanations are critically important. As things deteriorate economically, the quiet biases of some against community inclusion of persons with disabilities become more audible. For others, the lure of believing that larger is a cheaper and acceptable alternative, has begun to shape policy debates at all levels of government. Slogans such as “the system is not sustainable,” while devoid of a values foundation, are increasingly being used to galvanize policy positions. Places such as Virginia are planning on spending millions of dollars to rehabilitate large and ancient institutions, arguing in part that the safety of its residents justify the expenditure, even though the amount of money that will be spent is more than sufficient to create an individually designed community based alternative for each current resident. In my own state of Vermont, discussions are increasingly focused on returning to group models as replacements for the current array of individualized community supports that have been slowly created over the past thirty years. The fact that we as a state previously rejected group models for both financial and non-financial reasons seems to have been forgotten. I haven’t heard anyone in a significant position of authority and power comment about the importance of best practice (as applied to persons with a disability) for months and months. Previous learning has been forgotten it seems, as we plunge backward into a time spiral that may replicate past practices that were at one time judged to be public policy mistakes.

## **Individualized Alternatives are Realistic**

Upper Valley Services (UVS) is a non-profit community based provider located in Vermont. UVS is by no means a large organization by national standards, and is considered a mid sized agency by Vermont standards. Nearly all of the services and supports provided by UVS are paid through the State of Vermont's Medicaid program, and are organized around individual support budgets that define the parameters and costs for each individual's services. This individualized budgeting process results (for the approximately 200 people supported by Upper Valley Services) in support plans for individuals that range in cost and complexity based upon the needs of individual consumers and their families. Collectively, all of these individual plans result in an annual operating budget for UVS in the vicinity of twelve million dollars.

Organizationally, UVS provides services, for the most part, in the central part of Vermont through three similar but distinct program offices located about an hours drive from each other. Each of these offices offer individualized supports for a wide range of persons and their families, each of whom have unique needs and interests. While many services may look the same organizationally, the content of each individual's service plan are unique to the needs of the person being served. No two plans are the same, and in fact, no two support budgets are the same either.

From a resource perspective, UVS has a core case management staff in each of its three offices. These case managers are responsible for coordinating with each consumers support team in order to develop an individualized service plan. Once this plan is developed the case manager is responsible for supporting team members as they put the elements of the service plan into action. At UVS, as with other developmental services agencies in Vermont, most of the residential service providers are private individuals who are contracted to provide these supports within their own homes. Day supports (vocational and non-vocational supports) may be offered by UVS staff, by staff hired and supervised by the contracted home provider, or in some instances by an individual's family. Irrespective of the resource mix, it is the role of the case manager to support and monitor the implementation of the individualized service plan.

Over my career, I have worked in a variety of capacities ranging from the large 1970's institutions as chronicled so dramatically in print and photo by Burton Blatt (see Christmas in Purgatory, and Exodus from Pandemonium), and on film by Geraldo Rivera (see Willowbrook: The Last Disgrace). Large public institutions were (and still are) the extreme examples of non individualized service models. Throughout the 1970's and

1980's, I also have been part of developing and funding other congregate settings that were community based including group homes, sheltered employment settings, and day activity programs. As with anyone in this line of work, some of these efforts were far more successful than others. Among the design mistakes that I have been a part of, I would rank the establishment of a group home for six men with significant behavioral challenges among my worst examples of forward thinking.

Over the years I have come to recognize that non congregate settings provide an opportunity to focus on the specific needs of the person without having to mediate these needs against the needs and interests of many others. With an individualized support model it is possible to move away from program structures that are rules driven, that out of necessity, inject a compliance requirement on people who were not inclined to follow or respect such expectations. The outcome has been an ability to create a model of service within which team members could truly concentrate on the unique needs of individuals. In those instances where a person had a history of challenging behaviors, teams became more empowered to explore with the individual the reasons underlying the excesses in behavior. This, in turn, led to an ability to alter the environmental parameters (again in an individualized fashion) to become more supportive and encouraging of adaptive behaviors, along with the development of lifestyles more similar to the lifestyles enjoyed by people who were not disabled. In some instances the serious behaviors of certain individuals simply disappeared once they were in a setting that was individualized to their particular pattern of need. In all other situations the very challenging behaviors greatly improved over time.

While size of place is certainly a key variable, it is the relationships that are formed that make the biggest difference. Most of us recognize that people act differently depending upon who they are with and how comfortable they are. At the core are the relationships that go a long way towards shaping the extent to which an individual is socially interconnected at levels consistent with personal needs and expectations. In large measure this interconnectedness with those who are important contributes greatly to the sense of safety, security, and satisfaction.

Relationship patterns and needs differ greatly from one person to the next. Most of us have a significant ability to make real choices with whom we form these relationships. Persons with disabilities, if they need significant supports, typically have far fewer opportunities to make these choices. Instead the persons with whom they spend a great deal of time, are ordinarily selected by someone else. In many instances, these relationships are not able to develop to the extent where they play the critical social

role that relationships play in the lives of non-disabled persons. This is true irrespective of the size of program, although I think long term enduring relationships are more likely to occur within small program supports than in large ones. This becomes increasingly possible the more a person can be an active participant in the process of choosing who their primary support people will be. Within the framework of small individualized service models, this level of participation and choice is increasingly possible, and long term enduring relationships begin to emerge. Fostering these types of relationships and finding ways to help sustain them over time is a difference maker in helping a person to achieve a high quality of life.

Within most service providing organizations, a disproportionate amount of time, energy, and resources are directed towards the small percentage of people who are at times extremely difficult to get along with. For most organizations this is not the majority of the people who are served, but they are the ones that can change a programs agenda in a hurry if their support needs go unattended for very long. The larger majority, who tend to be easier going, may fall more comfortably into the daily routines of the program in which they participate. While the smaller number of more challenging people, sort of force an individualized response due to the nature of their behaviors, the compliant and easy going people may never get this opportunity, unless of course the program models themselves become reoriented to respond in an individualized fashion to everyone.

Being able to look at people as individuals, and working towards crafting life style opportunities that consider each person's unique needs has become our normal way of doing business. Surely we struggle as does any system, but overall the approach taken in this small state has given us the ability to support almost everyone who is eligible for services under Vermont statute. Once the shackles of "funding by model" were removed, we were able to think about organizing services in ways that supported people to have real lives in real communities.

The move to individualized service models in Vermont has occurred slowly over the past 20 years. In the mid 1980's Vermont still had a state institution and a number of group homes provided by community provider organizations located in many regions of the state. Day supports (other than the initial foray into supported employment) were large group based models operating as day treatment or work activity centers. Over time, individualized supports began to replace these group based service models. A major enabler of this process was the approval of a Medicaid Waiver which opened possibilities that were not allowed under the previous restrictive funding mechanisms.

Smaller more individualized residential models were proving to be far more cost effective than the larger group based models. The most common residential model in Vermont is a placement into a private home rather than in staffed residential options. The use of this model, from a fiscal perspective, virtually eliminated overtime (in the residential system) from the budgeting process while greatly reducing the annual cost for residential care overall. Additionally, and of significant importance, these contractually based placements resulted in much higher levels of satisfaction overall from consumers and family members alike.

With a better and less costly residential model, it was possible to focus more funding effort on needed day support services without driving the overall individualized expenses to an excess. From a system perspective, people were being supported more successfully in a dynamic service model that was designed to support people according to their individualized preferences and needs; even in those (many) instances when those needs changed over time. In most cases it has become possible to alter service intensity and approach when a person's needs change (even when these changes may be dramatic), instead of needing to find an alternative program when these changes occurred. People bouncing out of programs when needs change has been a long standing characteristic of many service models. In Vermont, and certainly at UVS, this phenomenon has been greatly diminished. The focus has remained on the individual at the core, and not on the limitations of a particular service model.

### **Now Enters the Economy - from Stage Right?**

In today's world, contemporary discourse seldom includes value statements other than basic health and safety – sort of the custodial floor that people feel obligated to include when discussing budget worries. Concerns that the unique and differing needs of individuals with disabilities must continue to be met, even in deteriorating economic times, has been lost; at least for the moment. The stated goals of policy leaders are overwhelmingly directed to cutting expenses, and there is precious little conversation about the implications the ensuing actions and policy decisions might have. **The poor economy is the rationale, and for many the consequences of making budget cuts are secondary to the fundamental need to make them.** Waiting lists are growing everywhere, and no one seems to have a plan to address this looming national crisis. Few people speak about the rights of the people being affected through the budget cutting process. Rarely does a conversation about budget reductions include the concept that if we have limited money we really should spend it in ways that make sense. Where is the logic in spending precious dollars to achieve outcomes that have

already been rejected? How is this effective stewardship of hard earned public dollars? If we have less money to spend should we not be more careful of how we spend it?

Few people, it seems to me, take the time to look back on our history to assure we don't move to service approaches and models that have already been rejected as poor quality choices. The progress made over the last 30 plus years has not been accidental but has been based on the realization that community services were far better, and yes, far less costly than the large group based counterparts that preceded them. Yes, 2009 is indeed an interesting and I think very dangerous time in the lives of persons who have a disability. Retrenchments made now in the way services are provided are not likely to be better. They will be worse. And given the economy we are in, it seems likely that such retrenchments might well change the structure of community support systems in ways that will be unrecoverable for decades to come.

### **Does Size Really Matter?**

So back to the question David originally posed concerning the advantage of small versus large service models. I am drawn to a statement made by a Virginia parent when interviewed about spending millions of dollars to upgrade a large institution serving more than 400 people. When asked by the interviewer what people with disabilities and their families wanted her reply was "a life like yours". This response was profound in its simplicity and provides for me the means to explain what otherwise might be considered unexplainable. For to answer otherwise, we would need to accept as the premise for our service models, that as a matter of public policy, we will provide services and supports for people with disabilities that create lives which differ significantly from the lives that most people without disabilities enjoy. Such a policy would inculcate a dual set of "life expectancy standards", one for persons without disability and the other for persons with disability. Is it possible that our society has devolved to a point where persons who need public support lose the ability to hope for a quality of life because of this reliance? Is this the trade off one must make as a consequence of disability? I wonder.

In general then, unless we can answer that a component of our proposed service model structure lies within the general framework of what typical people living typical lives experience, we probably are creating artificially contrived configurations that have no normative referent. So to me this rules out most congregate models and structures. These are not sustainable because they have no connective tissue to the everyday fabric of our culture. They cannot be defended it seems to me, on any logical basis. These

settings make community connections and relationships more difficult to establish and sustain. These settings contribute to stigma rather than lessen it. People get placed into these settings, not because they will benefit from them, but because they exist. People's lives are affected in permanent ways because of "bed space" or "available slots". Success is defined by the ability of someone to stay in these settings for long periods of time as seldom do they move on to more independent and fulfilling alternatives. These settings are almost always full, as people do not move on, unless their own behavior or deteriorating medical condition results in the congregate setting being unable to keep them.

If services and supports are individualized, then there is, at the very least, the potential to control many aspects of one's own life. Most of these aspects are quite simple, however, they are ones that have caused non-disabled people to wage wars when some authority has seen fit to restrict them. What you eat, and when. Who you live with. When you want to move to a new home. When you want to sleep. What music you want to listen to, what you might like to watch on TV, and when you want to change the channel. What time you get up in the morning. Where you worship and when. When you choose not to worship. Where you go for work. How you spend your money. How you spend your non-work time. When you want time alone, and when you want to be with someone else. When you go to the movies and what movie you will see. What video you rent. Who you do not want to spend time with. Who you want to go visit. When you shower/bathe. All so very simple, but so subtly elusive.

### **Sneeches, Stars, and Thars**

As the size of place gets larger, the potential for making personal life decisions that are important to you diminish. Once the government, or its sub-contracted partners, through their policies and practices determine that congregate models are what can be afforded, the ability of participants to make these basic quality of life decisions is greatly diminished. Is this the trade off for being disabled?

Most of us want to be known for who we are and for what we have accomplished. It is important for us to be seen as unique, as being an individual. We accomplish this by the things we do in life, the associations that we keep, the values we hold, the contributions we make to our families, our friends, and to our communities. Most of us would not accept a society where our individuality was defined by others on the basis of some personal trait or characteristic that separates us from other community members. Even Dr. Seuss has lessons about this (see *The Sneeches*). When our service models grow in size to become recognizable to those not a part of this clustering (not to be confused with normative community institutions such as churches, etc.) these become the

distinguishing characteristic that defines the persons who are served by them. In Seussian terms, these models become the “Stars upon thars”. People without disability for the most part will shy away. Old stereotypes will become more prominent, and interpersonal associations will become less likely. In my opinion when this happens everyone is the loser. Certainly with small individualized models, a different outcome is not assured, but at a minimum, a different outcome is at least possible.

Sometimes it becomes more necessary to articulate what you (or in this case a state or a system) believe in, and then to hold fast to those principles even (or most especially perhaps) in difficult times. In terms of what is happening to people with disabilities, I think we are on the precipice of seeing 30 years of slow and meticulous social progress being unraveled in a period of a few short months. The reason, or the excuse, is the poor economy. Among the problems however, is that while the economy will recover, the changes that are on the verge of being made in the lives of people with disabilities will likely not recover in their lifetime. For this segment of our population, these changes are likely to be permanent. Are we on the verge of imposing yet another tragedy on the lives of the most vulnerable among us?

### **Summary**

Certainly economics are important and thus far in this paper I have perhaps suggested that dollars don't matter, when in fact I believe quite the contrary. My call instead is to avoid the knee jerk responses during this time of economic retrenchment and instead embark on a careful discussion to define options that will not violate the values that have previously been defined as essential. Further, for places that have not defined core values, it is urgent this be done so as to provide guidance to the decision making processes ahead. Is it no less important to honor and respond to these values in bad times than it is in good times?

My belief is that the standard should be the simple value articulated by this parent in Virginia – “My son wants a life like yours”. Nothing more, and nothing less. How we spend our money as a community, or as a state, or as the Federal Government, should continually move us towards the accomplishment of this simple value. We can, and should argue about cost. We can and should find the most effective and efficient ways possible to move towards this value, but we should not allow ourselves (and our policies) to move further away from this profoundly simple view. I am not sure of the originator of the statement that goes something like, we will be measured and remembered for how we treat the most vulnerable among us. I think this statement, however, was meant for times just like these.