

Moving to a system of support: using support brokerage

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A cursory review of current conference themes and agendas gives the impression that achieving a system of support is inevitable and around the corner. Words like choice and inclusion fall glibly from the tongues of managers. However, changes in practice have fallen far behind changes in rhetoric. During recent visits with agencies that say they are providing supported living, I have found managers whose language is impeccable but whose practices are still firmly grounded in program model services. While managers talk support with a convincing fluency and naturalness, when you talk to the people being supported and the staff doing the work you discover a better program, not supported living.

Real supported living requires that we learn how people want to live and then support them in the lives that they want (within the constraints of available resources and any issues of health or safety). It requires efforts that help people be supported by their communities and have opportunities to contribute to their communities. Real supported living requires that people with disabilities and the people providing the direct supports be empowered. It requires that agencies move from tidy organizational structures where people with disabilities "fit" into program vacancies to a fluid structure that changes with the desires of the individuals supported. It requires that control be shared rather than flowing from the top of a hierarchical arrangement.

The programs being represented as supported living typically fall short in several of these areas. They begin with a superficial understanding of choice. They do not focus on continuously learning how people want to live. They do not challenge themselves to help people get the lives they want. They encourage people to settle for what is readily available. Power is seen as a finite commodity. Sharing power with people with disabilities and the direct support staff is perceived as diminishing the power available to managers and directors.

Why have these clearly intelligent managers engaged in this elaborate self deception? They appear to be quite sincere, they appear to believe that they have made the necessary changes. Why are they "talking the talk without walking the walk"? In the challenge of organizational change, how companies experience it and leaders guide it the authors note that all change involves loss, that "...almost any action that disturbs the status quo or represents a threat to an individual's habitual way of doing things is likely to provoke defensive, and often counterproductive, behaviors - behaviors learned early in life."(Kanter, Stein, & Jick, pg 374) The loss that managers fear is their perceived power, perceived control, and sense of predictability.

This suggests that systems change is not going to arise just from promulgating new supported living rules or new ways to fund supported living. New "top down" rules results in a few real supported living providers and many agencies that achieve paper compliance but are only providing "sort of supported living" (sometimes known by its oxymoron, the supported living program). Agencies need a more powerful motivation for change and external assessment to insure that each person is supported as they wish to live. Where there are new "top down" rules they tend to focus on new process, not new outcomes, while the new ways to distribute dollars typically fund agencies rather than individuals.

Other "top down" efforts designed to change the system are not likely to be any more successful. Kanter, et al suggest that you need a combination of "bold strokes" and long marches" to change current practice and the underlying culture of an organization. "Bold strokes are those dramatic

changes that can occur in a short period of time while the long march refers to the myriad of small actions necessary to change belief." Because "...behaviors reflect beliefs: If you want to change someone's behavior, you must first change their underlying beliefs." (Kanter, Stein, & Jick, pg. 444)

It is clear that changing beliefs takes extended periods of time and requires that there are incentives for change. Getting real change started and providing real incentives for continuing change is the challenge for system managers. A "bold stroke" that would result in dramatic and immediate change is the creation of local "support brokerage" entities that would:

- empower people with disabilities to have real control over their lives;
- support the best use of limited public funding; and,
- move control (and decision making) as close to the people with disabilities as possible.

These are also characteristics that independent case management was to have. Yet, as several state directors of DD systems have noted, independent case management has not made the difference that they had hoped it would make. The effects that they had looked for were substantial improvement in the lives of individuals and changes in the system of services. They had anticipated that independent case management would move the system from being "provider driven" to "person driven", that the desires and needs of each individual would determine the nature of the supports provided. Instead they have found that the greatest determinant of quality of life has been the quality of the service provider. The presence of agencies that believe in (and practice) supporting each individual has been more important than the presence of case managers. While a number of systems report that the presence of case managers has positively influenced the system it has not caused the dramatic changes hoped for.

Why did independent case management not live up to expectations? The reasons for independent case management's "underachievement" are complex and vary from location to location. However, anecdotal reports suggest that the following apply in most areas. Independent case management has:

- had responsibility without authority;
- lacked the tools (e.g. person centered planning) needed;
- been independent only in name;
- been co-opted as just another compliance check;
- drowned in excessive paper requirements; and,
- had too many people for each case manager to support.

How would support brokerage be different? How could it avoid becoming another change in name without a change in practice? While there is nothing that can be done in design that cannot be undone in implementation, support brokerage can be designed to reflect the lessons that have been learned from case management. The first of these is independence. Support brokerage entities should be independent of any entity that provides services or has multiple responsibilities. Beyond the typical requirement that residential or day providers cannot provide support brokerage, county (or state) based systems, such as services boards should not be the providers of support brokerage either.

In outline, support brokerage entities should be locally based private, not-for-profit corporations which would:

- **be responsible for the planning for and the funding of services to all people with developmental disabilities within its catchment area;**

- have boards of directors where-

- people with disabilities (who are receiving services or are waiting for services) are a majority, with representation from both groups
- parents or other family members of those receiving services and those eligible for services are the second largest group
- people appointed by state and local authorities are present but represent the smallest group
- have an active mission statement which requires that people be supported in the lives that they want and that they be assisted in being a part of their communities;

- be required to -

- have "bottoms-up" rules which state that the primary goal is to support people with disabilities (not agencies) and where accountability is defined in terms of meeting the goals of the individual

- assure that support brokers have competencies in -

- learning how people want to live
- recruiting community resources
- supporting people in the lives that they have chosen

- demonstrate that each support broker knows the significant issues of every person with whom she or he does brokerage

- support people in their choices (within the limits of available funding and the constraints of assuring reasonable health and safety) including the choice to "fire" their support broker;

- have access to the resources necessary to assist agencies in changing from offering programs to supporting individuals.

Support brokers focus on assisting people with disabilities when they are:

- entering the system for the first time;
- in crisis;
- just unhappy with the life they are being supported in and;
- renegotiating plan implementation.

Individual support brokers spend the time necessary to learn how each person wants to live and develop an outline of what will be necessary to support that person. The support broker works with the person to arrange and negotiate the costs of the supports. While the supports are being developed and implemented the support broker maintains intense involvement. As the individuals and the support brokers are satisfied with the implementation of the supports the degree of involvement decreases. Unless there is an indication of dissatisfaction or inadequate supports the support broker's involvement is reduced to periodic monitoring, at a frequency determined by the desires and needs of the individual. The minimum frequency for contact would be twice a year.

How involved each support broker would be involved with each person would depend on the desires and issues of the person. In some instances people want simple things like an environmental modification or single services like respite. What these people want is only enough assistance to get what they want and not a flood of paper or a parade of officials. Other people need significant assistance in determining how they want to live, how they can get the supports, and on-going efforts to make sure that they are happy and safe. The degree of support that most people need will vary widely over their lives. We need a system that provides people who need assistance in negotiating services with the support they need while it empowers people who know what they want (and where to get it) to do their own negotiating.

Helping people achieve their desired lives will require changes in agency and system activities, practices, and rules. The changes needed can be classified as:

- those that only require local effort - "just do it" changes;
- those that require technical assistance to be successful; and
- those that require permission - a change in the practices or rules of those who fund and regulate.

Successful support brokerage will require that these change efforts be incorporated in a feedback process that identifies best practice, secures the technical assistance required, and gets changes in system rules on the agenda of the system managers. This requires that, while the brokerage agencies are local, there is a communication network where information is shared and distilled. Requiring and maintaining the network would be one of the responsibilities of those who fund and regulate.

The support brokerage structure and governance is designed to achieve a positive local balance within the competing pressures on the disability system. There is the pressure to simply buy people their lifestyles because it is easier than recruiting community resources. There is the confusion between helping people work to achieve a dream and funding their fantasies. There is the need to support people while they live at home to reduce the stress on families and to nurture community so that it is developed from a natural base. There is the need to help people leave home when they want rather than when their waiting list number comes up. There are pressures from agencies to receive a level of funding sufficient to pay their staff a decent wage. There is the reluctance for many agencies to leave the program model that they are comfortable with. There is the need for technical assistance for agencies to be successful in changing.

A positive balance between all of the competing pressures starts with the governing body. Good support brokerage will require an active, knowledgeable, and involved board of directors. Training is essential. All board members need training in their responsibilities and in what they should expect from the staff. Those members who have disabilities should have access to the training and support needed for them to fully meet their responsibilities. Systems that include coaching and mentoring should be considered. By having people with disabilities and their families in a strong majority position on the board there should be an on-going focus on the lives of the people who are receiving services. By including people with disabilities and family members who are waiting for services on the board there is an incentive to use community resources rather than public funds so that money is available to support those waiting.

Giving the brokerage agency the responsibility for conforming to the standards shown while simultaneously giving them control over how their money is spent should create incentives to maintain a balance between other competing interests. Rather than set a fixed ratio of support brokers to the number of people supported (e.g. 1 to 30), there is a requirement that support brokers know the significant issues of every person that they do brokerage with and that they see each person at least twice a year. If less is spent on support brokerage then more is available to buy services/supports. However, if too little is spent on support brokers then the quality of the brokerage and the assurance of quality and safety in the lives of those supported is diminished. Where that balance is struck will depend on local issues such as the quality of the agencies that provide supports, how well the agencies know the people they are supporting, and the demographics of those eligible (i.e. how many people are entering the systems and how their needs change over time).

From the perspective of the service providing agencies, support brokerage will introduce market forces that were previously absent. The broker will be saying this is how this individual wants to

live and ask how the agency can provide the support and at what cost. Where a satisfactory agreement can be reached, the person with the disability will receive supports from that agency. Although costs will be negotiated individually they would be audited against everyone receiving support from that agency. This would provide the agency with the flexibility to move resources around to meet rapidly shifting support needs. The costs would then be "rebased" annually. Where someone was not happy with the supports received they could move and the level of funding most recently negotiated would move with them. If an agency says that it is unable to accommodate the individual reduction in funding because it reduces the support for a house by a person then all of the people living in that house could have their supports reexamined.

The effects on agencies will depend on local circumstances. In rural areas, where there is only one provider, change will be slow. In areas where there are multiple providers change should be more rapid. In all areas, however, the emphasis need to be on supporting agencies in making change. Confrontation and people leaving agencies may be required but it should not be where things start. The development of additional community capacity will be essential in many areas. The development of new agencies will require a partnership between the brokerage agency and state, regional, or county authorities. Brokerage agencies may need additional funds and additional expertise to be successful in new agency development.

Support brokerage is not the answer. It is one of the possible answers. It will likely work where there is leadership that: understands the difference between providing support and providing programs; insures the presence of the on-going resources necessary for meaningful training of board members; enforces all of the standards outlined; and absorbs the "political heat" when the brokerage agency starts doing its job. However, without something like support brokerage we are likely to see the paradigm shift change our language without changing the lives of people with disabilities.

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Reference: The challenge of organizational change, how companies experience it and leaders guide it. Kanter, R.M., Stein, B.A., Jick, T.D. Free Press, NY (1992)

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