

Personal Agents and Independent Brokers

The Center for Self-Determination

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For a variety of reasons, the transformation of case management to support individuals in building lives full of opportunity and relationships, rather than placing in programs, has not occurred as so many had wished. In the past several years, the name case manager has been changed to support coordinator, just as teams are now called circles, but little in the work or the process has been changed. The reasons vary place to place, from lack of will to lack of leadership to lack of resources to lack of trust to lack of knowledge. There are many in current unchanged systems, however, who very much want to get away from desks and paper in order to spend a maximum amount of their time doing something different have the time and support necessary to help people with disabilities build lives, but are unable to get out from under the administrative/monitoring functions within the traditional system. Creativity and spirit become stifled in many situations and once again people who have disabilities remain in their perpetual state of waiting—waiting for change, waiting for friends, waiting for a place of their own, waiting for life. The years lost will never be regained.

For those who work in the system and who have made a commitment to major change to support self-determination, this situation needs resolution. For those who have disabilities, the situation is unacceptable. It is time to think outside of current systems and to commit to necessary changes within those systems.

Proposed Remedy/Action

Systems change and responsiveness to people with disabilities must be put onto a faster track. To model the structures and culture which need to be in place, there are a variety of directions into which systems can choose to go.

- **Personal Agents:** a true transformation of case management, most effectively based outside of the system, under contract to provide a variety of supports. The Personal Agent is a hybrid of support coordination and brokering. Personal Agents should work in a unit, preferably one which is a private, not for profit, and has a contractual agreement with the funding agency. In some instances, parts of the support coordination work of case managers may remain (primarily paperwork and monitoring) with case managers who provide those services to a larger number of individuals. In these situations, the development of Personal Agents who provide the other aspects of support, beyond paperwork and policing, may also move the agenda for change along quite quickly. A Personal Agent may work independently, but feedback from those who have done so illustrates several issues which impede success in a completely independent environment: 1) staying abreast of changes in what is available can be limited; 2) training in a variety of

skills may not occur as needed; 3) isolation can impede creativity and energy; 4) understanding and influence on the funding mechanisms diminishes.

- Independent Brokers: individuals who work independent of the system to provide linkage with needed support or information in the community. In some instances, a broker may provide expertise in only one area; others may have expertise developed in a variety of areas. Brokers may charge hourly or daily or in a lump sum for providing their services. Being completely independent may bring up the same issues listed above (1 through 4). However, a strong working relationship with case managers, etc., can bridge these voids. Brokers can remain independent, but work together as a collaborative, sharing clerical and bookkeeping services, etc. Brokers may also work as a unit, similar to that described below for Personal Agents. In addition, and perhaps most importantly, brokers should not necessarily be human service focused. If you want to know about buying or finding a home, use a realtor as your broker. If you want to find a job, try a job locator on the internet. If you want to break into the world of art, ask an artist for help. We cannot continue to create our own multi-task systems within, yet separate from, vibrant communities. In addition, it is ludicrous to believe that one person can be all things to all people. This is, indeed, one of the reasons a disconnect from community is so prevalent in the lives of those currently served in human service systems.
- The development of these roles will be an opportunity to provide positive change more quickly, with more personal connection and interaction. It is also an opportunity to create a learning laboratory from which changes in the system itself can occur.

Necessary Elements

What follows, though it is written specific to Personal Agents, is also easily reflective of the environment needed by Independent Brokers.

The responsibilities of Personal Agents include implementing the principles of self-determination in the way in which they do their work and in the lives of those they support.

The structure in which Personal Agents work and individuals with disabilities are supported must respond to the following imperatives:

- that people with disabilities are living the lives they want to lead, are happy and healthy, and have solid relationships
- that people with disabilities have opportunities for generating income
- that people with disabilities are participating citizens of their communities
- that approval of individual budgets be in the hands of individuals and their Personal Agents, as long as the bottom line is not exceeded
- that Personal Agents and their Coaches (mentor/supervisors) are getting the kind of information, support, and training they need
- that communication is clear and consistent

- that there is a buffer between the unit and the difficult, complex systems issues which will still be covered by traditional case management
- that the Personal Agents operate within a line item budget which is controlled by them for the performance of their work
- that authority over the expenditure of dollars allotted to this unit lies in the hands of those who work in the unit
- that the dollars allotted be used more wisely and that they help build a positive future for the individual—an investment in one's future
- that evaluation of performance includes input of those receiving support

I The Essential Characteristics of an Effective and Committed Personal Agent

Personal Agents are very important people working in the system, second only to those who provide direct support. This is not because of who they are as individuals or as workers. It is because of whom they represent. "The closer you are to the person, the more compelling your arguments and the greater your authority." Because the commitment to helping people build lives is so deep in Personal Agents, they will not always be liked. They will have to be willing to take a stand against anything that will diminish the possibilities for the people they support. They may find themselves under attack periodically, which does not feel good to anyone. Yet they need to have the ability to stay focused. They will get supported when they cry and are distraught on behalf of people they support. They need to have the capacity to laugh, to be joyous, to have fun, because these things, and the support of their coaches and peers, will help sustain them. Their peers will celebrate with them collectively even the small steps forward in fulfilling their mission.

It is not exaggeration to say that their characteristics are the most important element. If people are found who embody much of what is written below, they can be taught the skills and the job responsibilities. If skills are emphasized over characteristics, it is very difficult to manage. You can teach someone how to facilitate a gathering; but you cannot teach a person to have a heart.

The most important characteristics of a Personal Agent are:

- Has a strong sense of social justice
- Is committed to and understanding of self-determination, freedom, civil and human rights
- Capacity for profound empathy with the people supported
- Feeling compelled to ACT
- Ability to develop close relationships with those who receive support and all of the people who are important in that person's life
- Understands through personal experience the nature of human relationships
- Believes in the value of every human life, despite disability
- Has courage to take a stand on behalf of person supported
- Has common sense
- Is connected within her/his community

- Is a clear, concise communicator and facilitator
- Makes a personal commitment to those supported
- Knows how to lead
- Knows how to listen
- Has respect for the cultural values of others
- Has a sense of humor
- Is willing to transfer control
- Has authority and power within the system on behalf of those receiving support
- Has a sense of joy
- Is flexible and can work in an environment of ambiguity

II Job Description of a Personal Agent

A Personal Agent provides the leadership, ideas, commitment, and coordination in the life of the person they support. Personal Agents have a clear focus on helping the individuals they support build lives, not programs. A Personal Agent does whatever it takes to ensure quality in the lives of those they support. In system speak, the Personal Agent is a hybrid, fulfilling the responsibilities of support coordination and, as well as having extensive duties to bring relationships, freedom, and the other principles of self-determination into the lives of those they support.

Job responsibilities may include:

- Performs their work using the principles of freedom, self-determination and civil rights, and the operating principles of CLS, as their guide
- Developing close relationships with the people they support
- Developing relationships with everyone who is important in a person's life
- Act as the primary advocate for the person within the system
- Will work with a flexible number of people depending on the needs of individuals receiving support (start up # will be 16; will increase as individuals connect with their communities and develop relationships and circles of friends))
- Has authority to take action when necessary
- Acts in a leadership capacity with regard to designing and coordinating support
- Facilitates gatherings held with the individual (unless another facilitator is asked to do so)
- Builds circles of friends
- Elicits dreams of people they support
- Develops cohesive, relevant annual plans with the person and their circle
- Develops an individual budget for each person they support
- Provides follow-up and coordination of plan
- Researches resources in the community
- Has a discretionary budget (\$2500) to manage in order to assist individuals as needed
- Keeps abreast of all aspects of the individual's life and works with others to ensure people are getting continuity of support

- Works flexible hours
- Provides for health and safety issues to be addressed in a person's life
- Provides creative problem-solving by by-passing traditional services
- Does minimal paperwork and receives a great deal of clerical and administrative support
- Works collaboratively with those who provide support whenever possible
- Negotiates with providers of service
- Stays abreast of all issues important in the lives of people they support Reviews monthly reports from fiscal intermediaries and provides leadership to the circle to manage individual budgets Maintains an intense, focused level of advocacy which drives the system

III Other Configurations

A system may choose to transform current case management/support coordination by gradually building a unit of Personal Agents, and assisting in the development of Independent Brokers in the community. This is an approach which can provide safeguards for the freedom of individuals, since the development of a Personal Agent unit requires the development of a new culture and the identifying of new leaders. It is the change in culture and the training of new leaders committed to social justice which can provide safeguards to individuals in the future, if leadership no longer supports self-determination in their lives. The cultural change needed is vast and deep, but quite doable and enjoyable to those who step out in front to try this new way of providing support. To ensure that a new culture takes root, it is necessary for the unit to be autonomous and separated from the system physically. It is difficult to work with one foot in the old system and one in the new, i.e., working within the principles of self-determination. However, the development of a new culture is even more complex. Thus, the necessity to have physical separation for the culture to take hold and sustain itself.

One of the most powerful aspects of developing a unit of Personal Agents is the requirement that those currently working within the system must interview for the positions. Other powerful aspects include a team approach to providing support, e.g., a team of 10 Personal Agents with one Coach (mentor/supervisor), and three Administrative Assistants, has the responsibility of supporting 200 to 250 people. Whatever configuration makes the most sense, whatever specialization makes sense within the unit, can occur easily because decision-making lies in their hands since they know best how to help those 200 to 250 individuals build the lives they want.

The configurations are endless, but some things remain the same:

1. a cultural shift which is readily evident is the most fundamental requirement
2. problem-solving and decision-making in the hands of individuals and those who support them is essential
3. working within a line item budget and understanding how the money flows is necessary
4. characteristics of Personal Agents as noted in this paper are imperative
5. connections in the community on the part of Brokers and Personal Agents is necessary

6. expertise in one or more support areas by Brokers, many of whom are generic to the community must be identified
7. a deep belief in the possibilities and a sense of urgency are the underpinning of success in rebuilding, since the work of change will be so demanding.