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ABSTRACT

This essay uses a question-and-answer format to examine issues of concern to persons with mental retardation related to personal assistance or support services. Questions include: "What do people with mental retardation or others in the field of developmental disabilities know about personal assistance?"; "How is personal assistance defined?"; "What aspects of personal assistance are particularly of relevance for people with mental retardation?" (such as user definition and determination of services, the person with a disability as expert, personal determination and family empowerment, and informal or paid services); "What are issues that are not currently well addressed in personal assistance designs?" (includes common flaws in existing personal assistance services and the importance of personal assistance and decision-making support); "What about the issue of entitlement or case subsidies for people who need assistance with decision making?"; "What are some fears of professionals and advocates in the field of developmental disabilities?" (considers the fight over who knows what is best for people with mental retardation, integration of people with mental retardation into an inadequate service system, and rights versus mutuality); and "Where can we go from here?" (DB)

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**THOUGHTS AND REFLECTIONS ON
PERSONAL ASSISTANCE SERVICES:
ISSUES OF CONCERN TO
PEOPLE WITH MENTAL RETARDATION**

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Everybody in this world today needs support of one kind or another. People need support to go ahead and do things whether this support comes from a good friend, parents, a social worker or guardian. There is no person so independent that they don't need anybody. We all need support, but with that support people don't want someone coming in and taking over their lives.

Michael J. Kennedy, 1990

As eloquently explained by Michael Kennedy, who lived over fifteen years of his life in institutions, all of us need support, which may at times, come in the form of paid services. This essay will explore several issues related to personal assistance (also known as support services), including the need for further discussions directly with people with mental retardation about their perspectives and viewpoints.

This essay draws primarily on our experiences in over 25 states in the US on how support services might be organized to better assist people with mental retardation in their efforts to lead fulfilling community lives. It particularly builds on the relatively new perspective that all adults, no matter how severe their disability, can live in typical homes in the community, if adequate support services (such as personal assistance) are made available.

What do people with mental retardation or others in the field of developmental disabilities know about personal assistance?

Generally, I have found that people associated with the field of developmental disabilities across the US, whether individuals with disabilities, family members, direct service staff, or administrators, often shared one or more of the following views regarding personal assistance:

First, many people simply had not heard the term personal assistance. Even if obtaining or using similar types of support services, these services may be described in different language (e.g., follow-along staff, come-in staff) and are often agency-controlled. Even state and local administrators in the field of mental retardation may know relatively little about the generic personal assistance system in their states.

Second, those who know about or who use personal assistance, typically view it as a service to assist people who have physical disabilities with such daily activities as going to the bathroom or eating. Most people with mental retardation do not see this concept as applying to their lives, unless they also happen to have a physical disability.

Third, the term personal care is used in some states in the field of developmental disabilities to refer to a funding stream that supports group homes (i.e., agency facilities) and traditional foster care (i.e., where a person with a disability resides in the home of another), thus bearing little resemblance to personal assistance as a user defined and determined service.

How is personal assistance defined?

In practice, personal assistance in most states appears to be defined very narrowly. Often people with mental retardation seem to be excluded from the generic options in a state, being referred back to the mental retardation/developmental disabilities service system, which is considered more appropriate to fit their needs.

A broad definition of personal assistance could include many of the types of assistance typically used by people with developmental disabilities. For example, personal assistance is:

Whatever a person needs to live fully within the community (as defined by the individual), to ensure dignity, self-determination, respect and full participation, throughout her or his lifespan.

This could include personal services, such as assistance with dressing; assistance with self direction, safety and decision making (if desired); assistance with a variety of daily activities, including eating, cooking, shopping, working, transportation, leisure, speaking and reading, medications and health needs.

What aspects of personal assistance are particularly of relevance for people with mental retardation?

People with mental retardation have been traditionally confined to life in agency facilities, if they needed intensive support services. They are also often viewed as not being able to speak for themselves, and instead representatives, who usually hold different perspectives, have spoken for them. (This is part of my own discomfort in writing this essay.)

With both the growth in the self advocacy movement internationally, including the 1991 election of a national (US) self advocacy steering committee, and a movement toward supporting people to live in their own homes, this is beginning to change. However, organizing around personal assistance offers at least four important opportunities.

User definition and determination of services.

Personal assistance services are typically user defined and determined. In contrast, most services for people with mental retardation assume that the agency or others knows best. In fact, our review of the literature on choice, indicates that people with cognitive

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disabilities are usually presumed in practice to be incompetent to make their own decisions. If making values decisions in conflict with prevailing norms, they are in particular jeopardy of social control.

Personal assistance services, including the option to hire, fire, and manage attendants (with support, if desired or legally required), can help to shift the decision-making power back to people themselves, placing agencies again in their proper supportive role. While the option must be available for people to choose to obtain assistance with coordination of personal assistance services, such an option should be available regardless of a person's disability label. A good example of an organization that is assisting people with developmental disabilities to work with their staff is Options in Community Living in Madison, Wisconsin.

The person with a disability as expert.

Users of personal assistance have strongly held that training should be done by the person with a disability, with the underlying premise that each person is unique. Since training in the field of developmental disabilities has been moving toward competency based training, irrespective of the individual, this aspect of personal assistance philosophy may help to stem the trend in this direction. People with mental retardation are not even regularly involved in prevalent group based training, and there is still resistance in some circles, to even having people participate in their own service planning meetings.

Personal determination and family empowerment.

Family empowerment has rightfully become recognized, and family support programs are now available in virtually every state. These programs, however, are typically constructed from the parental point of view (i.e., relief of the "burden" of caring), and seldom take into account the perspectives of the children. As one person I interviewed recently said,

This is practically heretical to say at this point in this state, but I happen to know there are a substantial number of people who are probably living at home who do not want to be there...I worry that we are supporting families to the point that we are encouraging behavior that is not fostering growth and independence in people with disabilities.

Several critical issues of concern to people with mental retardation, and I believe to all disabled people, revolve around children's rights and the rights of adults to determine their own destinies. Discussion about making personal assistance available for children, instead of thinking about the service as respite for caregivers, is still not occurring, even though the concept itself is sound and has been around for many years. The idea of helping people maintain the natural "breaks" from each other that typically occur as a child

grows up is not part of the way people typically think about family support, instead taking a specialist approach (e.g., converting recreation to recreational respite).

Informal or paid services.

In the field of developmental disabilities, there is a growing interest and acknowledgement of the important role that friends, neighbors, coworkers, and other community members can play in the lives of people with disabilities. While an important development, the new assumption seems to be that it is better to use natural, informal supports and concomitantly, that services will not be provided until the informal options are exhausted.

While there are many positive aspects of this rediscovered interest in relationships (see for example, Judith Snow's account), the general trend appears to be headed in a direction opposed to the personal life experiences of people in the independent living movement. Most people with disabilities want the option in place of having paid services, and then themselves choosing whether to involve family, friends or others in personal assistance services. In the field of developmental disabilities, it is the agency that typically is doing the choosing and playing a major role in deciding how formal services can be replaced by informal supports.

What are issues that are not currently well addressed in personal assistance designs?

These issues fall under two major categories: those that apply to people across all disability groups, and those that may be of particular importance to people who need assistance with choices and decision making.

Common flaws in existing personal assistance services.

In a number of different states, we have worked with people with mental retardation and their allies to try to access generic personal assistance services to support people to live in their own homes. We experienced the following common problems, all well known to PAS users:

- * limited availability of assistance compared to the needs of an individual;
- * low wages and benefits (or lack of benefits) for attendants;
- * inadequate or nonexistent back up systems, which leave people with disabilities stranded;
- * control of some personal assistance systems by home health agencies;
- * rigidity in how and where assistance is made available;
- * inadequate funding within the states for this option compared to the needs;

the medicalization of this option and the continued referral of people to options such as nursing homes, if they have need for more intense support services.

As one example of these myriad problems, Michael Kennedy explained one of his experiences in trying to keep the same work schedules as other people in his office:

Aides' hours need to change when a person's schedule changes, which is often a problem for the aide service offices. They are not used to having someone whose schedule changes, and it can create a problem for the agency. I ended up needing to have set hours (at work) instead of changing the hours around because the aide service didn't allow for flexibility or arrange for backups when aides were sick.

Michael said while the situation in New York State was difficult, in states such as Georgia, it was practically impossible.

Personal assistance and decision-making support.

Personal assistance designs have not always taken into account the needs of people with mental retardation for support with decision making. Much greater discussion is necessary about the role of allies and supporters, and how assistive decision making can occur, still retaining the people first orientation of the independent living movement.

Choices and decision making are very complicated issues, and many people have not had opportunities to exercise even basic choices about their daily lives. The rhetoric of choice has also been used to justify neglect; and in the opposite vein, the need for support in decision making has been used to justify full guardianship and together with that, procedures such as sterilization.

Setting up a flexible personal assistance system will also be of benefit to people with mental retardation. For example, the option needs to be available to have choices to manage one's own personal assistance; to share responsibilities with an agency or other person selected by the person with a disability; and/or to have another, whether an individual or organization, perform all these functions.

What about the issue of entitlement or cash subsidies for people who need assistance with decision making?

Entitlement or cash subsidies paid directly to the person with a disability are critical in a number of ways. Compared to a voucher that flows through an agency, such an approach removes some of the cost of asking for help, enables people to plan the use of financing on a long term basis, and removes some of the social control exercised through the requirement of worker involvement.

People who desire assistance with decision making should still have the option to obtain such support. Most people with mental retardation who need

support with money management already have mechanisms in place or that can be put in place, such as payeeships or caseworkers. Instead of using the need for support as a rationale to force worker or agency control, entitlements and cash subsidies offer an important opportunity to rethink the current systems of case management and payeeships that typically allow for little input by people with disabilities.

What are some fears of professionals and advocates in the field of developmental disabilities?

Since discussions about personal assistance often take place with representatives of people with mental retardation, it is important to recognize some of the fears of professionals and advocates in the field of developmental disabilities.

The fight over who knows what is best for people with mental retardation.

Though this will not be publicly acknowledged, one of the deepest fears is that people with mental retardation will not have an equal voice in any coalition with groups such as people with physical disabilities. In other words, people in the developmental disabilities field view themselves in a better position to listen to, support, and encourage people with mental retardation to come into their own. Regrettably, this ends up at times, taking another form of protectionism.

However, these fears are not totally invalid. People with mental retardation have often been on the bottom of a disability "pecking order" and the wording of the Americans with Disabilities Act (ADA) itself indicates their marginality in the movement. Also, the growing self advocacy efforts have often been and are still most supported by people who are in some way connected with the developmental disabilities systems.

Integration of people with mental retardation into an inadequate service system.

Personal assistance systems have been tenuously constructed in most places, with many problems besetting stability, flexibility, security and quality. People involved in the field of developmental disabilities generally do not wish to simply see people with mental retardation participate in such inadequate systems, and yet also do not view it as their role to help with the changes that would be necessary to improve these efforts. Expanding the role of the ILCs will not be adequate to address the challenges. Systems aspects, such as having a city emergency backup aide service, are not even known as options among developmental disability agencies, who instead are moving toward developing their own specialized systems.

Rights versus mutuality.

One important area of concern in the field of developmental disabilities is that rights cannot and will not insure that people will have a good quality of life. As one ally described, "people are dying with their rights on." This is an area of mutual concern with people in the independent living movement, yet meaningful discussions about the kind of society we are hoping to achieve (e.g., a power reversal or a more mutual way of

coming together) and the relationship between self-determination and mutuality, are seldom taking place.

Where can we go from here?

This essay introduces some issues for further discussion. I believe such grassroots discussions are necessary if we are going to have fundamental change at the local level as well as a political victory in creating a civil right to personal assistance. To further pursue these efforts, we can work together to:

- * Create more opportunities for exchange, such as ADAPT's recent workshop on personal assistance, at the national self-advocacy conference.
- * Seek opportunities to include people with mental retardation as part of national discussions on personal assistance, instead of relying on organizations with other, sometimes competing interests, to speak for people.
- * Overcome the language barriers between different disability groups by describing better what we mean when we use words such as independence.
- * Seek common issues to organize around. One good example is the issue of the nursing practices acts which have been problematic in several states for people to live in their own homes; another issue is the use of fire codes and requirements that may prohibit people from living in their own places.

Personal assistance, like housing, offers one visible opportunity for people to come together in creating some of the changes that can lead to better community lives for all of us.

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