Investing in People

Periodic Updates from the Individualized Funding Coalition for Ontario 1:3

August, 2001

PERSONAL ASSISTANCE: WHAT IT IS AND WHAT IT IS NOT

Within the last fifty years society has realized that people with unusual abilities can participate fully in the community and contribute to society if they have the right support.

The right support is "personal assistance." Personal assistance is not being a nurse, a butler, a housekeeper or a warden. It is functional support provided through a personal relationship. Personal assistance includes completing the daily tasks that individuals cannot carry out themselves or that they find so time consuming as to interfere with other important activities. These tasks fall in the areas of hygiene, nutrition, dressing, mobility, finances and communication. Though the categories are the same for everyone, the actual functions that may be required depend entirely on the individual who is being supported.

One individual who uses a wheel-chair and is an accountant may require help with showering, food preparation, getting winter gear on, chauffeuring, filing and desk set up. A person who has cognitive differences and owns her own baking business may require someone to book appointments with the hairdresser, support with shopping for her home and business, coaching on clothing selection, budget assistance to afford bus tickets, and invoice and bookkeeping support for her baking business. A third person with extreme mood

swings, and is an artist may need physical assistance to bathe when depressed, coaching in food selection, reminders about the need to shop for clothes, support to recognize when not to drive, and assistance with advertising and selling their creations.

Like any good support, personal assistance is nearly transparent. Just like I want to remain unaware of the elevator that is transporting me meters above ground level, and I soon stop noticing the hum of the refrigerator that is keeping a week's supply of food fresh, a skilled personal assistant performs his or her functions without overshadowing the contributions and personality of the person who is being assisted.

Paradoxically, personal assistance is also like a dance. The dance is led by the person who stays active in the community by relying on his/her assistant in an otherwise inaccessible world. Both dancers must be fully committed to the dance. They must bring a willingness to be with each other, to be honest, straightforward and respectful. Both must take responsibility to make sure that the leader of the dance really leads.

Both the personal and the transparent aspects of the relationship must be maintained together so that supported individuals can be in charge of their own lives. Without this balancing act, all that is achieved is the presence of housekeepers and wardens taking care of helpless individuals.

Some common practices still prevail that diminish the potential of personal assistance. First, individuals rarely receive the money and the opportunity to hire their own assistants. Instead money flows to agencies, which hire the workers. Supported individuals have no choice over the identity of their assistants, their job descriptions, or their training. They have little opportunity to direct their support. The personal nature of the working relationship doesn't get established and support doesn't become transparparticipation ent. Community doesn't happen.

Secondly, the resources to create personal assistance are usually given only to individuals who show they can direct their own "care", or to family members of those who are deemed to have the "potential" to be self-directing. But without personal assistance, many individuals have no means to develop and demonstrate their ability. If access to personal assistance depends on first demonstrating capacity, many individuals will forever remain segregated and dependant.

Personal assistance is a powerful vehicle for building the capacity of vulnerable people, making it possible for them to realize Our communities will be stronger when we recognize, celebrate and adequately resource personal assistance as a mainstay of community living.

Judith A. Snow, M.A.

MAKING INDIVIDUALIZED SUPPORT AND FUNDING WORK IN ONTARIO

COMMUNITY WORKSHOPS

for self-advocates, families, service providers, and government.

Will be held between October and March in:

Belleville Toronto Brockville Windsor Perth County / Stratford

Watch the Coalition web page for dates and details

Additional workshops will be held later in 2002

The Individualized Funding Coalition supports the self-determination of persons with disabilities and their full participation in community life.

To become a member of the Coalition, please go to the 'Membership' section of our website: www.individualizedfunding.ca

Coalition co-chairs: Yona Frishman & Judith Snow