

Personal Assistance : What It Is, and What It Is Not

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

“Personal assistance” is the right support. It 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 an individual 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, 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 wheelchair and is an accountant may require help with showering, food preparation, getting winter gear on, chauffeuring, and 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 who has 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 metres 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 can perform 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 their 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.

The personal and the transparent aspects of the relationship must be maintained together if the supported individual is to be in charge of their own life. 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 and schools which, in turn, hire the workers. Supported individuals have no choice over the identity of their assistants, their job descriptions, or their training. The personal nature of the working relationship doesn't get established - support doesn't become transparent. Community participation doesn't happen.

Secondly, the resources to create personal assistance are usually given only to individuals who can already show that 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 helpless.

Our communities will be stronger when we recognize, celebrate and adequately resource personal assistance as a mainstay of community living.

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