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Personally Speaking: A Critical Reflection
of Factors Which Blur the Original
Vision of Personal Assistance Services
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What a dilemma. What a sense of dissonance I am experiencing. For the last 20 years or what seems to be my last lifetime, I have personally and professionally expounded the principles and even the sacred virtues underlying independent living (IL): values such as self choice, personal autonomy, the right to risk, in essence general personal liberation for people with disabilities. Tragically however, within the last few years, I am having serious questions and doubts about this concept actually being realized in many peoples' every day lives. My disillusionment continually emerges from the tension between a philosophy of liberation and self-autonomy and the actual implementation of IL. I guard the reader against thinking that in any way I am suggesting the philosophy is flawed or unrealistic. It is, rather, my purpose to identify and possibly invoke some thinking around the reasons as to why there exists incongruence between an essential and practical philosophy for people with disabilities and the way it has been filtered down to the experiential level.

Support services as conceptualized by founders with disabilities of the Independent Living Movement were and still are a pivotal element of independent living. Although there are a variety of natural and formal supports which function as a dynamic construct to assist people in the actualization of independent living, this article will be confined to a discussion of the support service known as personal assistance services (PAS).

For many people with severe functional limitations, PAS is the catalyst around which the IL Movement philosophy was built and more importantly the necessary vehicle in the actualization of individualized independent living for people needing logistical help in carrying out personal care and daily life affairs. PAS, a seemingly simple and logical solution to people with disabilities exercising their self autonomy and individuality in their daily lives, has become corroded in an abyss of policies and regulations, many of which still have their roots in the medical problem-centered paradigm.

The intention of this article is to identify some of the major issues, which, in my perspective, have over time been responsible for the diluting of the initial impetus and concept of PAS as it was so passionately envisioned and advocated for by the founders of and subscribers to the Independent Living Movement. Those readers who are familiar with PAS are all too aware that there are unlimited permutations in the way in which this support service could be viewed and examined. This article, by no means, is comprehensive in reviewing even all of the many major considerations rooted in a study of PAS. This paper is intended to invite the reader along with myself to look at this issue through some of the different lenses here put forth.

If there is a pre-conscious state of knowing how life should be for people with disabilities I definitely experienced it in terms of feelings and concepts rumbling around in my soul and spirit even before I was literate and sophisticated with the rhetoric. My memories of learning from and advocating side by side with leaders with disabilities still cause my throat to clench with emotion. Ever since I came to the of age of reason, even before I knew the right words or lingo to articulate my rage and passion, I knew there was something wrong with a person not being free or enabled to live according to their choices and capacities.

In 1949 I was physically born but it was not until 1988 that my true identity was born. It was when I heard a speech by a brilliant insightful woman with a disability, Sieglinde Shapiro. In her speech, Sigi talked so passionately about our rights and responsibilities to grab hold of what was rightfully ours, societal as well as in terms of personal choice and control. Her words had to compete with the throbbing emotions that flooded my entire being.

It only was the fact of my being at a public gathering that held me back from breaking down into a soulful, purging type of weeping. I just wanted to keep saying "yes!" in the style of an evangelical revival meeting. I remember Sigi ending this epic speech by expressing the sentiments that we need not ever wait for anyone to give us our empowerment, that it is something that is intrinsic within each of us. We need only to become more and more comfortable and confident in acting upon it. The bonding, the camaraderie, the oneness with all my brothers and sisters with disabilities who were and even those who were not in that conference room that day, catapulted me into aggressively and undauntingly following my dreams and desires. PAS, for me as a person with a severe disability, has been and remains one of the primary ways in which I portray these dreams and desires, the way in which I can claim and express the many colors and shapes of my identity.

In reflecting upon the issues intrinsic to the multi-dimensional nature of PAS I am increasingly overwhelmed at its complexity and its paradoxical and multiplicity of factors. There are so many ways of looking at this Rubick's Cube of personal assistance services. One can, by the twisting and turning of

angles, identify some of the components that may be considered illusive and pervasive, but nonetheless influential, in the persistence of PAS being trapped in a web of tenacious strands of difficulties. This entrapment is probably embedded in a constellation of cultural and social determinants which have not been resolved to the degree that we, the disability community, might like to think they have.

Consider the conflicting duality of just one of the principles on which this phenomenon of PAS is built. We, people with disabilities, need and want PAS to be viewed as an enablement or facilitatory type of service, one in which ideally the person who is accessing it has maximum control over it. It is, for most of us a way of achieving our cherished personal rights of self-empowerment and autonomy. This reasoning, this precept has indisputable integrity and rationality. The faltering of it arises when it is positioned side by side with the fact that by retaining personal assistance as a supportive capacity, it has not been able to attain the prestige and economic status as those of more socially acknowledged and valued careers. Many of these ramifications are of a negative and disincentive nature the least of which obviously is not the economic consequence. This has profound implications on those considering or actually serving as personal assistants.

The fact that American culture pairs prestige and success usually with some type of academic or formal training conferring credentials upon the candidate is another juggernaut. People with disabilities, because of our abhorrence of always being seen in the context of medical or social service spheres in which we have been subjected to "experts" who know what's best for us, have been adamant in contriving PAS as a service in which the leadership and control is in the minds and wishes of those accessing the service. It is for this reason that it has been a general consensus that a person who performs PAS should not receive formal training, but rather be trained by the individual consumer according to his or her preferences and style of PAS interaction. Not wanting PAS to be formalized in the traditional sense of professionalism, but definitely needing and wanting it to be a position that attracts people who will be invested in their jobs and provide quality service, is an issue which I think needs to be seriously looked at and grappled with by people with disabilities. Until there is an effective resolution of these conflicting factors, problems with retention of good, qualified people and quality of service will persist.

PAS in most cases is a very one-on-one intimate relationship. It demands of the person who is the assistant to have a variety of personality traits and practical skills which must operate in unison in responding to the request and needs of the consumers. I know that activists promoting national uniform policy of PAS are always aware that a paradigm shift needs to continually take place regarding the thinking about people with disabilities. I also think we who are personally involved with and knowledgeable about the services realize more than ever

before that unless there are inherent incentives built into the system of PAS for those working in the field, the service will be a stunning reflection of the lack of incentive and the lack of public awareness and valuing of this most critical accommodation.

Unless PAS can truly be a win-win situation for both employer (consumer) and employee (assistant), it will always be "a nice idea," but one which is unstable in quality due to lack of incentive needed by those who probably would be proficient at performing PAS but who need, as in any employment context, attractive wages, benefits and some type of opportunity for personal and professional advancement.

Another issue for consideration is that, as people with disabilities, we genuinely embrace the concept of self-choice and control over our lives, but we have not yet given ourselves permission to, in actuality, boldly be liberated from the paternalistic model of thinking. Even if mentally we have indeed rejected this proverbial mentality we may still be awkward about expressing our assertiveness and still a little "apologetic" or overly "grateful" about receiving needed assistance or accommodations. It is not uncommon that when a person with substantial needs for assistance asserts themselves in a powerful way they are often perceived and actually labeled as "demanding" to put it politely.

The need to please, the need to be liked, and the need to belong can be among our greatest opponents in effectively and efficiently managing and attaining high quality personal assistance services. The fact that we are acutely aware that the person who we are directing and from whom we are requesting services is in many cases being paid below minimum wage is another very powerful source of reticence and reluctance in our exercising assertive managerial skills. On the other hand if we as consumers fluctuate in our styles and degree of assertiveness this can create a montage of problems, including mixed messages, for both us and assistants. Truly managing personal assistance in the purest sense of consumer direction requires even more than good communication skills. There are many emotional, psychological, and practical factors which comprise the choreographing of the consumer-personal assistant interaction.

Personal assistance services have a most unique and sometimes challenging character. Technically it is and should be intended as a structured business relationship. Keeping it in this type of defined context is thought by many to insure the power dynamic, as well as, casting it as a formal legitimate service which demands the respect and seriousness that are associated with positions of importance and economic valuing. Seeing personal assistance as a business relationship has definite advantages. Expectations and boundaries of the assistant and consumer are in some respects easier to maintain. Keeping it as a business arrangement it is less likely to become clouded with personality distractions. In other words the quality of services should not depend totally upon the congeniality or charisma of the consumer. Also the business framework is a way of

reminding us, the consumer, that our independence is in our minds and will always be within our claim regardless of the changing of assistants. In other words it is very tenuous if we the consumer over identify the effectiveness of PAS and independent living in general with one assistant with whom we have bonded and have become personally and intuitively synchronized. PAS must be broader than personalities, broader than rapport. It must be a consolation of management skills.

Having said what I have about the necessity of maintaining the business like quality of PAS I also firmly believe that there should not be a rigid, even if unspoken, bias that those people who choose to engage in a friendship with their assistants are in some way violating a sacred edict. Many people are able to very effectively flow back and forth in the relationship from that of business to that of friendship and vice versa. This choice, however is a little more demanding of both parties having a clear understanding of expectations and how the relationship will manifest itself in different contexts.

Another issue which has a multitude of complexities, in and of itself, is whether a person is using an assistant from an agency or whether the person has recruited a person, on their own, from the general public. There are some advantages to having an agency affiliated assistant. A major incentive may be having the agency help, at least in theory, provide a replacement person, if need be, in a timely manner. Being a user of both the agency model and the consumer model, I have learned that thinking the agency will be able to respond promptly with a qualified person for different consumers' needs and lifestyles often in reality is more within the realm of false security.

Without intending to dismiss or degrade the services provided from an agency affiliated assistant, I want to address the fact that often assistants who are filtered through agencies come to a consumer directed orientation with more biases and notions that are rooted in the medical professional model of care giving. Even if a person is proficient in their skills as an assistant, they more than likely are operating under some umbrella of policies and regulations which are explicitly or even implicitly promulgated by the agency hierarchy of administration. Home help agencies, although marginally more community based minded, are still very within the notion of "caring for" thereby medicalizing a normal daily living situation.

The consumer model in which the person with the disability is solely the employer and subsequently the one in power of training and negotiating time scheduling, etc., has challenges. There are many demographic variables which contribute to the success of identifying, recruiting, and retaining personal assistants on one's own. Even if a person lived in the ideal area, one in which there was the likelihood of a population from which to pull people who might be more likely to be attracted to serving as assistants, other variables such as economic, transportation, weather, not to mention life events of the assistant may all factor into how smoothly the consumer control

model may be actualized.

Regardless of the model or combination of models that one utilizes, the effectiveness and the satisfaction of the consumer reverts back to people with disabilities being ever vigilant about informing, educating, advocating, call it what you like, about the paradigm shift of power. This educating or advocating can and should be done on a micro as well as macro level. I think that we who fought long and hard for PAS may have been a little too confident that the paradigm shift would be easily received and adopted by all of the support systems.

Even the Centers for Independent Living have become, in many ways, for different reasons, very bureaucratized and are not as responsive as they need to be to individual needs which may require extra flexibility and creativity in helping a consumer configure a personal assistance system that is truly effective and practical for their particular needs and living issues. When I think of Ed Roberts, the father of IL, I know with absolute certainty that he envisioned people with all types and degrees of disabilities living independently according to the types and degrees of supports they individually required.

PAS and independent living is a phenomenon which must be individually customized to each person. Even if two people have exactly the same functional limitations there may be other factors in their lives such as social supports or other resources which may influence how they are able to accomplish their daily living demands. Many times there is an implication that because some people can manage, given the supports they have, all people should be able to rise to that level. I do not think independent living when it was initially conceptualized by the beloved mothers and fathers of the Independent Living Movement was ever meant to cause people to feel inadequate or inferior if they were not able to live according to some arbitrary standard definition of independent living.

Another issue is that while we genuinely embrace the concept of self-choice and control over our lives, I think we have not yet given ourselves permission to, in actuality, be liberated from the paternalistic model of thinking. Even if mentally we have indeed rejected this proverbial mentality we may still be awkward about expressing our assertiveness and still a little "apologetic" or overly "grateful" about receiving needed assistance or accommodations. It is not uncommon that when a person with substantial needs for assistance asserts themselves in a powerful way they are often perceived and actually labeled as "demanding" to put it politely. The need to "please," the need to be liked, and the need to belong can be among our greatest opponents in effectively and efficiently managing and attaining high quality personal assistance services. Truly managing personal assistance in the purest sense of consumer direction requires even more than good communication skills. There are so many emotional, psychological, and practical factors, which comprise the choreographing of the consumer-personal assistant interaction.

As with any social rights movement, those who are totally immersed in the momentum sometimes lose sight of how the movement is really being viewed and interpreted by those on the periphery and especially those who are outside onlookers. While we have an intrinsic inbred awareness of the integrity and benefits of the paradigm shift, especially in regards to PAS and independent living, we must be equally as tirelessly passionate about helping others to genuinely understand and become invested in the precepts and practices of independent living and in PAS within the construct of the paradigm shift. This paradigm shift, which is a political statement that the power of authority for one's life must be firmly within the grasp of the person with the disability, has not been as readily received or assimilated as I think we would like to believe. In all of our fervor and enthusiasm of beating the drum to the PAS anthem I think we did not fully realize that not everyone, even those we thought would be, is marching to the same paradigm shift rhythm.

In thinking about and writing this article I was suddenly struck by the notion that the whole purpose of independent living and PAS is to experience and enjoy life on our individual terms. While we must, each of us in our own ways, continue to deal with our personal as well as systemic demons around PAS and IL, we must also be intentionally dedicated to the enjoyment of liberation which these movements were intended to release. If we are not claiming and embracing the personal pleasure and satisfaction of these movements we are doing a disservice not only to our history and to ourselves, but we are also sending an ambivalent message to society that PAS and IL is all about struggle and effort and not that much about emancipation and enjoyment. Let us seize the vision, seize the struggle, and seize the joy of living.