

## Guest Commentary

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### Editor's Note

We are delighted to have this Guest Commentary as a part of this PAS Issue of the JVR. Todd Vaarwerk and Barbara Knowlen, two regional coordinators from the New York State Council on Independent Living, not only use PAS to successfully live in the community, but also use it in their respective workplaces. Their commentaries will set the stage for many of the issues and concerns that address the importance of PAS as a workplace support. I am very grateful to Todd and Barbara for their willingness to share their personal and sometimes difficult experiences in using this very important support.

### Comment from Todd Vaarwerk

As the community advocate for a large independent living center, I get to work quite often with consumers on issues related to getting them to employment. If the true goal of Vocational Rehabilitation is to “level the playing field” for persons with disabilities, then the use of Consumer Directed Personal Assistance Services in the Workplace is a critical player in a consumer's arsenal.

When I first began my employment, I had little understanding of PAS services in the workplace. However, over the years, I have had the opportunity to watch the ability of persons to get, hold, and expand their employment due to the valued work of readers, sighted guides, drivers, and so on. As my job itself expanded into larger areas, I have had the opportunity to employ persons to assist me in many things in my position: driving, filing, assistance with personal care issues away from home, and many other things too numerous to mention.

Without a doubt, these synergistic relationships mean more to the individual employees than just the tasks that are assisted. In using PAS services on the job, I learned how to better prioritize time, communicate with others, and evaluate success. Not only did using

them make me a more efficient employee, but in the long run, also a more effective one. Clearly, these benefits have yet to percolate amongst the business community. More must clearly be done to emphasize the benefits of the use of these services, and not just in a wage/cost vs. result way. Valuable resources, in the skills and experience of persons with disabilities, can be brought to bear with very little effort by the use of these services.

Clearly, I wouldn't be the person I am today without them.

*Todd G. Vaarwerk is the Disability Rights Advocate for the Independent Living Center in Buffalo New York, and is currently a Coordinator for the Statewide Systems Advocacy Network in New York State. He has spent over 17 years in the Disability Rights Movement, working with students, businesses, and other stakeholders to improve access for citizens with disabilities in Erie County.*

### Comment from Barbara Knowlen

I have had a disability since 1965, when my older 2 children were 4 and 5, and the youngest wasn't born yet (1967). Because my disability is progressive (MS and a Spinal Cord Injury at T-10), I did not really need assistance in Activities of Daily Living or work activities until around 1978–1979. I would not have needed help then, except that the bathroom where I taught math in high school was inaccessible. I was resolved that my own children were not to be my caregivers, so I trained and paid one of the senior girls to help me use the bathroom at noon. For assistance in writing, such as preparing materials and entering grades in book, I used student helpers provided by the school.

I began hiring paid attendants in 1981. I did not live in a state with a Medicaid program to pay personal attendants until 1991. The attendants assisted me mainly with ADL's and housekeeping, since secretarial staff met most of my needs at the jobs I had in those 10 years.

That was also about when I began using a computer at work and at home, which greatly reduced the need for clerical assistance. The jobs I had were in the field of independent living and required travel. My attendants accompanied me to conferences and did a lot of driving for me.

My life at these jobs was anything but routine, so I could not use attendants who wanted routine, or even attendants who placed medical needs or routine over job performance. I needed someone who would get me to the conference on time, regardless of whether I had taken my pills or had breakfast first. I needed people who were adaptable. I was also unable to pay much. I usually bartered a place to live, food, use of my van, etc., in addition to cash pay. I usually paid more than half my take home pay for attendant services. I bartered something else too – protection.

I am not very impressed with authority, have little fear and probably less common sense, and have an excellent knowledge of law and bureaucratic systems. I am very good at what I do, so being fired was never a worry. I would say the biggest problems with attendants and work were 1) I was poorer than my colleagues due to the money I had to personally pay attendants (all were covered by workmen's compensation at my expense, and those who could go on record by FICA and MP

deductions, and 941s filed), and 2) the type of person I could afford, and the type of person I needed for attendants, plus my own poverty, reduced socializing and social acceptance among my colleagues. However, I always had friends so I was happy.

As of 1991, due to severe illness, I did not work, and had recently moved to Minnesota, where a number of consumer-controlled assistant services options are available and paid for by Medicaid. I started my own business in 1991, which is still going. My business is home based. I conduct the business with the indispensable support of a man (he asked me not to use his name, not knowing where this would be published) who was one of my attendants in the late 80's. I also have Medicaid paid attendants. When I travel for my business, the attendant/driver is usually paid by the organization hiring me for the workshop, training, etc. At home, my significant other does the most helping with business activities.

*Barbara Knowlen is currently a regional coordinator for the New York State SILC. She has had almost forty years of experience using PAS to work, live, and be a parent in the community. Barbara had to be creative and use self-determination to be able to fund this vital support in her life.*