

# The International Journal for Direct Support Professionals

## Without Direct Support Professionals in My Life, I Don't Have a Life

By: Robert Peterson with John Raffaele

### Bob

Self-determination is a funny thing. As a person who lives with cerebral palsy, I have had, and continue to have, a wonderful life. I have experienced many awesome things, and I try to live my best life every single day. However, I also happen to be significantly physically compromised. I rely on people to assist me with many of my daily personal functions. Back to self-determination. I direct the course of my own life. No one tells me what to do or has control over me. I make my own decisions. However, it is impossible for me to be that self-determining person without the daily assistance from competent and ethical direct support professionals (DSPs). That is the reason for this article. I want to share how the professional partnership and relationships with direct support professionals has impacted me. I owe my self-determination to the work of direct support professionals, and this is seldom discussed.

### John

The National Alliance for Direct Support Professionals Code of Ethics states the following:

**"Self-Determination** - *As a direct support professional I will assist the people I support to direct the course of their own lives. Furthermore as a DSP, I will support the rights of individuals to lead self-directed lives, working with other members of the person's support network. I will promote self-determination in physical, intellectual, emotional, social and spiritual pursuits. I will honor a person's right to assume risk in an informed manner. I will recognize that each person has potential for lifelong learning and growth. I will celebrate, accept and learn from life's experiences with people through triumphs and failures."*

When followed and honored by direct support professionals, self-determination can enhance and expand the possibilities for people with disabilities. Self-determination ensures that there is constant growth and opportunity.

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## Bob

Let's look at the list of what direct support professionals do with me every day. This is not a complete list but, without these actions, I literally cannot have my life.

- Getting me out of bed
- Transferring me to my wheelchair
- Helping me in the bathroom/shower/personal grooming
- Assisting with preparation of food
- Helping me communicate with people via phone, Zoom, etc.
- Taking me places in my vehicle
- Assistance with shopping
- Looking after me when I am sick and communicating with physicians
- Helping me coordinate holiday times
- Listening to me when I am having a bad day

This is a list of things that are vital. If I don't have a direct support professional to help me with these things every single day, I am stuck. I would be in a hospital bed all day long. Literally.

Now, let's discuss Self-Determination. I cannot direct the course of my life unless these basic things are met. Think about that for a moment. My life's work is all about advocacy. I have been a self-advocate for as long as I can remember. Furthermore, I am involved with so many organizations as a professional advocate, I cannot imagine my life if I was unable to do my mission. I have served on boards of directors; I have been in many state-level legislative hearings; I lobby; I speak, and I am passionate. But back to direct support – I completely depend on direct support professionals to be self-determining.

Direct support professionals are under-recognized and often misunderstood. They are my lifeline to my career, as much as they are critical for my daily physical and personal well-being. I am reminded of Maslow's Hierarchy. Abraham Maslow, a famous psychologist, had a theory that, if the most basic of human needs are not met (food, shelter, clothing, self-care), then human beings cannot become actualized. That means, humans cannot have a full life unless they are well taken care of. This is exactly where my relationship with direct support professionals becomes so important. I rely on the competence and ethics of those that I invite into my life to assist me. They are paid for their incredible work. I should then expect professional services.

Too often, the world sees the role of direct support professionals as that of being angels, heroes, or saints. This is upsetting to me as a person who depends on highly skilled people to assist me with the physical tasks of my life, as well as being my partners in my daily work as a professional advocate. I do not want a saint or an angel helping me in the shower. As much as I advocate for disability rights, I also am beginning to see my advocacy work turning to working towards advocating for and with direct support professionals. I have seen many of these professionals come and go. They will often leave because of low wages and a lack of respect. I am here to say that this workforce deserves so much more than being recognized as some type of heroic group of patient people. They deserve to be treated as professionals.

## John

The last 30 years have seen people with intellectual and developmental disabilities becoming more empowered and living in their respective communities versus living warehoused in institutions. This is a wonderful evolution and continues to grow. However, there is an invisible workforce that has enabled this movement to happen. Direct support professionals, for the last

thirty years, have worked side by side with people with disabilities and their families to discover, integrate, and become included in the community. This does not happen by accident or luck. Direct support professionals are skilled and ethical when they are doing the functions of their craft with competence. They rely on a body of knowledge, a set of competencies, and a code of ethics. So, the logical conclusion is that this workforce should be recognized and visible.

The National Alliance for Direct Support Professionals (NADSP) founded in 1995, by John F. Kennedy Jr., along with a host of other disability and direct support advocates, exists to elevate the status of direct support professionals throughout North America. NADSP values the full participation of people with disabilities in all aspects of community life through the provision of person-centered supports. We believe that high quality support requires all professionals to follow the individual path suggested by the unique gifts, preferences, and needs of each person they support, and to walk in partnership with the person, and those who love them, toward a life of opportunity, well-being, freedom, and contribution. Our operating principles are clear:

- All direct support professionals benefit from access to well-constructed educational experiences (e.g., in-service training, continuing and higher education) and lifelong learning;
- Certifying highly qualified workers incentivizes continuing education, increased compensation, and access to career pathways for direct support professionals, thereby, improving retention;
- Values and ethical decision making can be learned and infused into daily practice, and
- Strengthening relationships and partnerships between direct support professionals, self-advocates, and other consumer groups and families improves the quality of support.

Bob's quality of life is made possible through the work of direct support professionals.

## **Bob and John**

The time is now for direct support professionals to be recognized and treated better. Wages are important to address. That is clear. However, there are many other things beyond improved wages that can be done to elevate the profession of direct support. Here are a few practical and realistic actions that can improve the status of direct support professionals.

### **Recognition**

Direct support professionals need to be celebrated and given the utmost respect as the people who are integral in creating self-determining lives with people they support. This recognition can come in so many forms but, what most direct support professionals appreciate is heart-felt and specific gratitude for outcomes that have been achieved. When a direct support professional receives thanks and acknowledgement about a specific task in which they have helped someone achieve a positive outcome or experience, the rewards are palpable. Direct support professionals often feel invisible and anonymous. When they have direct gratitude given to them, it can be an enormous ego boost.

### **Professional development opportunities and improved training**

Most direct support professionals are required to have mandated training. Often, those required trainings are based on health, safety, and regulatory requirements. Most direct support professionals want to learn more person-centered topics. They appreciate trainings that address the concerns and needs of the people they support. For instance, if a direct support professional is supporting someone in end-of-life care, the logical and practical assumption is that the direct support professional(s) who is/are involved should get hospice/palliative care

training. This can improve the levels of support and the quality of care, as the direct support professionals can take such training and directly apply it.

### **Involvement in decision making**

If a direct support professional is employed by an organization, it is critical that they have involvement in organizational participation. Too often direct support professionals are unaware of how their organization operates. They see through the lenses of their “shift” and focus on the people they support. This is great. But it is also important for direct support professionals to understand funding, policy development, and the broader operations of their provider organization. Direct support professionals should feel completely involved in the mission of their organization. This empowers direct support professionals to realize their vital function. The point of interaction between people supported and direct support professionals is the most important activity in any organization that serves people with disabilities. When direct support professionals understand their role in a more global perspective, the results are often a more confident and motivated workforce.

### **Career ladders and lattices**

Retaining direct support staff is a challenge for most organizations, as well as a challenge for those people with disabilities who hire and maintain their own staffing schedules. One reason is wages. But the other variable that plays an important part in retention is the opportunity for professional advancement. Direct support professionals are treated as “entry-level” workers in the North American system. The importance of capturing interested direct support professionals who discover the enjoyment and excitement of practicing direct support cannot be understated. Most people who do this work came into it by accident; often they needed a job, applied for a direct support position, and fell in love with the profession and the work. Anything that can motivate these workers to stay and advance is important to consider. Career lattices can offer direct support professionals positions in specialty areas, e.g., dementia support, positive behavioral support, supported employment, etc. Often, the only method for retaining good direct support staff is to advance them into supervisory positions. That is fine but, generally, being a good supervisor does not necessarily equate with being a good direct support professional. Organizations can benefit greatly by creating ladders and lattices based on the aptitude and competencies of the staff.

### **Certification/credentialing**

The ultimate goal for a professional is certification and credentials to illustrate the demonstration of the skills of the profession. All valid and recognized professions demand that one needs to be qualified to practice the specific professional tasks. This is done through licensing, certification, and credentialing via a third party of some sort. Often, a state or province has departments of education or ministries of professional certification. These authorizing bodies create the standards and requirements to be allowed to practice the respective profession. Also, when a person practices a certified or licensed profession, there is likely remuneration and compensation associated with the acquisition of a credential. At this point in our intellectual disabilities service system in North America, there is no specific requirement for certification or licensing. There are certification programs available for direct support professionals, but no standard and universal accepted credential. If this could be addressed at a policy/funding level, the profession of direct support would likely become less invisible and more recognized.

## Final thoughts

### Bob

It is clear that direct support professionals can help create lives of self-determination with the people they support. The fact that I rely on them for so many aspects of my life is evident to me. I am proof. However, I am just one person with a disability. There are millions of people with disabilities around the world who also rely on the knowledge, skills, and values of direct support professionals. I want to help others understand their value and importance. Direct support professionals working with self-advocates can be a powerful partnership for advocacy. Please consider advocating for and with direct support professionals for a better future for us all. The suggestions we have outlined in this article are only some of the things we can do to improve the status of this profession. As the title of this article states, without direct support professionals in my life, I don't have a life.

## Resources

[www.nadsp.org](http://www.nadsp.org) National Alliance for Direct Support Professionals

[www.sabeusa.org](http://www.sabeusa.org) Self Advocates Becoming Empowered

## About the authors

Robert (Bob) Peterson is well known in Illinois disability circles as a seasoned and impassioned advocate for community living. He served nine years on the board of The Arc of Illinois, is now an Arc Mentor, and is an officer for the Arc's National Council for Self-Advocacy. He has been involved with many advocacy organizations, including Partners in Policymaking, The Self Advocacy Alliance, the Going Home Coalition, SABE, and UIC. He has served on advisory committees, testified at hearings, and spoken at rallies and press conferences. He can be found at numerous events talking to legislators and other movers and shakers in the disability field. Bob has been interviewed, quoted, recorded, and filmed by a number of media outlets. Bob likes movies, eating out, socializing with friends, time on his computer, and always advocating! The struggle for higher wages and real respect for direct support professionals is very important to Bob. As he says, "Without direct support professionals in my life, I don't have a life."

John Raffaele is the Director of Educational Services at the National Alliance for Direct Support Professionals. His career spans over three decades, and those years have been spent teaching direct support professionals and the people they support, including those with IDD, at-risk youth, and people with chronic and terminal illnesses. John has also worked as a Director of Training and Education for a developmental disabilities service provider and taught at The State University at New Paltz, NY and for the City University of New York City. He founded his own international direct support professional consulting company in 2012 and has developed many exciting and informative training programs and helped propel the NADSP into national prominence. John became NADSP's Director of Educational Services in December of 2016. John has educated tens of thousands of people in the NADSP Code of Ethics and Competencies and most recently, the NADSP Informed Decision Making curriculum and Frontline Supervisor Train the Trainer curriculum.

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