

World Health Organization Releases International Perspectives on Spinal Cord Injury

Joan L. Headley, Executive Director, International Ventilator Users Network, St. Louis, Missouri

It was through my colleague David Gray, PhD, Professor of Occupational Therapy and Neurology, Washington University, St. Louis, Missouri, that I joined the advisory committee for a major project of the World Health Organization about perspectives on spinal cord injury. The document is written for the world in which every year between 250,000 and 500,000 people suffer a spinal cord injury, with road traffic crashes, falls and violence as the three leading causes.

People with spinal cord injury are two to five times more likely to die prematurely. I had the opportunity to review chapters looking for information about the option for ventilator use and to pass along the opinions of users of home mechanical ventilation. IVUN was specifically asked, “Do you think attendants of ventilator users should be required to have some medical training and should there be a method of certifying them?” We asked the question in February 2012 via internet posting to two ventilator user listserves. Respondents were those who used a ventilator as a result of disabilities such as SCI, post-polio, ALS, muscular dystrophy, etc.

Long-term ventilator users responded, with the following comments:

“How to train a new attendant/caregiver is a tough question. I’m sure you will get many answers. Most often, the old attendant trains the new one. A family member may be available to train.”

“Some of us vent users can and do train the new person. As far as what specific training to give the new person, just train for the specific person’s needs, and don’t overwhelm the attendant with stuff that’s irrelevant.”

“Of course an RN or LPN would be nice, but too expensive and some training with the vent might be needed. Everybody needs to be flexible because there is no international standard.”

“The agency that provides two of my caregivers provides specific ventilator training followed by a competency exam. My privately hired caregivers receive their training here by my most experienced caregiver. I personally believe certification is not necessary.”

“The training and licensing of a personal assistant regarding ventilator use can well be false security regarding competence and ability to meet the needs of a ventilator user. I nearly died once because a so-called ‘qualified and licensed’ nurse decided I was just anxious and did nothing when I was having difficulty breathing. It was my long-time personal assistant (who had been shown how to suction at the hospital before discharge)



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International Ventilator Users Network's mission is to enhance the lives and independence of home mechanical ventilator users and polio survivors through education, advocacy, research and networking.

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who arrived, encountered difficulty, and in front of the nurse picked up the phone and called 911. As it turned out, a huge granuloma was blocking the airway below the trach tube. I could have died!”

“I look for maturity, interest, basic intelligence and an ability to listen and take directions, well before I even consider any credentials, references or experience with ventilator users. If anything, credentials are a red flag to me and I redouble my efforts to determine the qualities of character I need before hiring a new attendant.”

“As for training a new personal assistant, it’s a combination of having my experienced attendant showing them what to do and my also directing. The interplay between me and a trusted, experienced personal assistant during this teaching process gives the new employee a ‘loud and clear message’ that this is a team effort.”

“Absolutely NO to certification for home care workers. It goes against all tenets of consumer direction for people with disabilities and will force many into institutional settings. I live in a state where we have consumer-directed attendant services (Colorado). We get to screen, hire, train, fire (if necessary) our attendants. We set their duties and decide on their qualifications. In my state it is impossible for a home vent user on Medicaid to find adequate home health services through the agency system. The staff simply is not there. If it wasn’t for consumer direction, we would all be living in acute care hospitals.”

“I can only speak from my experience. I can’t speak for the parent of a non-verbal child who is vent-dependent. I’m fairly independent, with the use of a scooter, limited walking, and I drive a van. I’ve had personal assistants in the past and none were certified, they were trained by me to do simple tasks.”

“I’ve had medical doctors tell me how to suction, adjust my vent settings, even force an adult trach into my pediatric stoma, so I can say the qualifications don’t always match the competency. Personal assistants are just that — personal, not professional. A good relationship with the person is all that is needed.”

“As a resident of California, I have had the responsibility of training my attendants to perform my daily necessary attendant care tasks. Personally, I wouldn’t have it any other way. If I should ever hit a snag regarding ventilator training, (which has never happened in 31 years), I have a very competent RT available to help me. I also rely on a type of training using a more experienced attendant helping to train a new attendant with my oversight. This system has always worked really well for me. I believe if it ain’t broke, don’t fix it.”

“Yes, of course, they need training! I would want them to know what to look for if the vent alarmed, without panicking, how to reset the vent, how to talk my son through breathing off the vent until other help could arrive, if necessary, etc.”

“‘Medical professionals’ always have a tendency to assume that disabled people are naive, ignorant or just plain stupid. They always seem to undermine our knowledge and skill about knowing what our needs are, and how to attend to them.”

“That is a very hard question. I’d say it all depends on the competency of the caregiver. My son is on a vent 24/7, and I can take care of him very well even though I am not a nurse. He does have RNs and LPNs caring for him now. If I could not find a nurse and had to rely on a personal assistant, I would want them to have training. The question is: Where would they receive it? I don’t know of any place here in New York that does such training (which doesn’t mean there isn’t, just that I don’t know about it).”

My personal opinion is that I think personal attendants (PAs) are “the hands” that people with significant disabilities can’t use. The person with the disability instructs those hands to do what they want done when they want it done. I suspect that the relationship/understanding between the two parties, ultimately, is more important than certification.

The vent user understands that the PA comes with some training and skills and the PA understands that the vent user is unique and has certain ways of doing things and should honor that.

My observation has been that new vent users (including families) need and want the attendants initially trained about vent use (e.g., use/care of the vent and the interfaces [masks], trach care, and how to trouble shoot and handle emergencies) by the professionals. For those who use a vent 24/7, it is a matter of life and death.

But, veteran vent users have acquired practical knowledge that most professionals have not had a chance to acquire. It makes perfect sense that they train their own attendants and have past attendants train the new ones. The general fear (in developed countries, too) is that if the task is “medicalized” too much, vent use will become too costly and unavailable as an option. Paying an RN for 24-hour care is prohibitive for most, and in many cases unnecessary.” ■

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