

Teaching Kids and Teens about Personal Assistants and Independent Living

By Carrie Smoot



A typical teenager, Ronny Kaye Tice of Stafford, Va., loves to listen to music, read and write. She uses voice recognition software on her computers at home and at school. When she's done with homework, she enjoys talking with her friends on the phone and going places, such as the mall or the library, with her personal assistant (PA). A person of strong faith, she is active in church, squeezes in as many after-school activities as she can and spends a lot of time with her family. "I'm glad that I have them all around me," she says.

Tice, who turned 18 in May, wants to be a teacher, but doesn't know which college she'd like to attend, yet. "I have to do more research on that, so I'd better get started," she says. Eventually, she plans to live independently in her own apartment. "I would probably have it painted purple, or with purple decorations. And I'd have a lot of things with sunflowers around," she says.

Tice has worked with paraprofessionals (paras) since kindergarten, and she's used to working with different people. She has cerebral palsy and needs a great deal of help with the activities of daily living. "I always had paras in school to help me during lunch, when I use the restroom and when I need assistance during class," she says. But when it came time to work with PAs at home, when she was 13, it felt different.

"I was very nervous, because I didn't know how it would work out and it felt strange," she recalls. "My mom had always helped me, and we worked together well. My family and I had always talked about these issues, and I knew I would have to do it eventually. It was nerve-wracking in the beginning, because I wasn't sure how people would react to or deal with me, but it got better."

The family lives in an accessible home and has a modified, rear-entry wheelchair van. At home, Tice has

an accessible bathroom with a roll-in shower and a shower chair. She plans to use her "DD Waiver" (i.e., Individual and Family Developmental Disabilities Support Waiver) funds, which she was just approved for, to obtain a special automatic safety door which allows her access into and out of her home through the attached garage. (Without this, she needs the assistance of another individual to open/close the door which could be very dangerous in the event of a fire or other emergency.) She uses a hospital bed for safety but it is decorated to look more like a "normal" bed than a hospital bed.

As she's grown older and more confident, Tice has taken more control over managing her PAs and making alternative arrangements in case someone doesn't show up—certainly not great experiences, but they teach her how to deal with the unexpected. Her mom gets her ready for school in the mornings, and her PA meets the school bus in the afternoon and is with her until 8:00 p.m.

"Working with PAs gives you and your child a chance to be separate," says Belinda Hurlburt, Tice's mom. "PAs can help the person with a disability with any limitations they have with activities of daily living, such as with dressing or needing assistance on outings. But if the person has

medical needs, such as tube feeding, these issues are managed by nurses and other medical professionals."

Letting go was a bit difficult for Hurlburt. "I love caring for Ronny Kaye. The mornings are 'our time,' and we enjoy it, but I also want her to be independent as much as possible. This can be a great experience. Some PAs will accompany you on family vacations. Some of Ronny Kaye's PAs have become lifelong friends. She still keeps in touch with some who have moved away," she says. "But that doesn't mean I don't worry every afternoon at 2:30 when the school bus is due. I'm always

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afraid the PA will be delayed or not show up. I'm relieved when my cell phone rings and it's Ronny Kaye, just checking in."

Mother and daughter work as a team to hire PAs, including backup helpers in an emergency. "I write the advertisement, and we both interview the PA," Hurlburt says. "I want to make sure that the person has good character and is doing it for the right reasons. I want to be sure that she will treat my daughter with courtesy and respect, and at the same time, be safe with what needs to be done. As we both explain the routines of Ronny Kaye's care, I ask the PA to shadow me-observing, practicing and asking any questions. "It also takes a lot of work to manage the PA schedules and time sheets," Hurlburt adds.

Tice says her questions deal more with whether her lifestyle, interests and preferences will mesh with the PA's, and that they are compatible. "Members of our church family have been great PAs," says Tice. "I've grown comfortable with asking people I know, and then running it by my family.

However even with this practiced team effort, things don't always work out as planned. "Sometimes we'll look at each other two weeks later and say, 'What were we thinking?'" says Hurlburt, chuckling.

Hurlburt mentions another key piece to Ronny Kaye's successful transition—a tool called PATH (Planning Alternative Tomorrows with Hope). "Ronny Kaye almost never gets discouraged," says Hurlburt. "She looks at her barriers in positive ways. I wish we had PATH before.

"Using a PATH, the teen with the disability and the family meet every three months or so with neighbors, friends, school and agency professionals and others in his or her support system to think about what life would be like with no barriers. The young person sets their goals, and then looks for people who can help them achieve them. For Ronny Kaye, this meant learning more about exercising and eating healthier, exploring college and independent living resources, and getting involved in more after-school groups. She enjoys occasional school dances and being involved with the disAbility Resource Center's Youth Leadership Team.

Hurlburt is a staff member of the disAbility Resource Center, the Center for Independent Living in Fredericksburg, Va. Staff members either have disabilities themselves or have family members affected by dis-

abilities. She helps people with Medicaid Waiver consumer-directed respite and personal attendant services, which Ronny Kaye also uses. "By being part of the Medicaid Waiver program, people with disabilities are waiving institutionalization in favor of living on their own in the community with assistance," says Hurlburt. "Eligibility is based on need and the individual's income and resources, not the family's, and an individual must meet the criteria of nursing home care. Consumer-driven services involve the individual being responsible for hiring, training, employing—and if necessary—firing PAs. This includes tracking employees' hours, ensuring that they are paid on time, scheduling vacations and backups, and other administrative tasks. It can be very overwhelming, but most people prefer consumer-directed Personal Assistant Services because they have control of who comes into their home. For those who prefer it, we can also arrange for people to work with agencies. The agency will do their best to match the person with the PA, but they send who is available and there isn't much flexibility," she says. The Center has a PAS registry available, and Hurlburt helps consumers learn the detailed training manual from the Department of Medical Assistance Services.

"Working with a PA is a challenge, but it's doable," says Tice. "For any family dealing with this, I say never give up and never take no for an answer. There are always resources, so keep moving forward, reach out and learn new things," says her mom.

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The disAbility Resource Center offers various services to people with disabilities of all ages in and around the Fredericksburg, VA, region. "Every Center for Independent Living in the U.S. is mandated to provide four core services-independent living skills training, peer counseling, information and referral, and advocacy. Each local center tailors other services to the community," says Kim Lett, Hurlburt's co-worker and the director of youth and transition services at the disAbility Resource Center. "Additional programs include help with benefits, a weekly exercise and nutrition class that everyone looks forward to, a durable medical equipment refurbishing and donation program, SibShops for the brothers and sisters of children with disabilities, and various support groups for people with disabilities," she says.

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Lett coordinates the Youth Leadership Team for teens and young adults, ages 17 to 21, and she works with the teens on transitioning from school to adult life. She says many of them are eager to get on with the next stage of their lives. They talk a lot about understanding their disabilities, their plans and advocacy work. Several lobbied the state legislature about personal assistance services, postsecondary educational opportunities, and the lack of employment and transportation opportunities for those with disabilities. "This was a great opportunity for teens who have disabilities to use their voices—something they may not have been taught before," she says. They also wrote letters to the local paper about the possible loss of some special education services.

Lett says more attention is placed on transition now. "Parents should be thinking about transition from day one," she says. "After all, the goal is preparing your child for adult life and the experiences it brings."

Independent living and personal assistants is also an area of focus for the ENDependence Center of Northern Virginia (ECNV). "ECNV is a community resource center run by people with disabilities. We provide peer-based services to people with disabilities who live and work in Arlington, Fairfax and Loudoun Counties and the Cities of Alexandria, Fairfax and Falls Church. We serve persons with all types of disabilities of all ages," says Doris Ray, ECVN Advocacy and Outreach Coordinator.

Doreen Solar is an ECVN peer counselor who works with people who are deaf or hard of hearing. She herself is deaf. To communicate, she uses a video phone, which looks like a small TV screen. She signs responses to questions. Interpreters from the relay service translate. It's a lively and pleasant conversation.

"Technology has really improved so much over the last 10 years," Solar says. "Cell phone pagers also have texting technology, which makes it easier for people who are deaf to communicate with people who hear."

Solar provides peer counseling at ECVN, both one on one and in groups. She helps with budgeting and other independent living skills, along with coaching and assisting with life goals. A Deaf Support Group meets monthly, on Thursdays.

"Depending on their circumstances, people who are deaf may have low self-esteem and difficulty communicating, because society has traditionally looked down on them," Solar says. "When they see me, it gives them a great sense of what is possible. Parents of deaf children need to let them be who they are, teaching them what their rights are, and how to advocate for them."

Says Ray, "We provide personal assistance management training to give consumers the skills that they need to be better employers of their personal assistants. Skill sets include how to recruit, select, hire, train and manage a personal assistant and the employer responsibilities that are entailed in being an employer. We provide this training usually on an individual basis to persons of all ages, including youth. We provide this training from a peer-based, self-help perspective, since members of our staff are persons with disabilities who are experienced in managing their own personal assistants.

"We have developed and maintain a personal assistance registry that we provide to consumers when they are recruiting personal assistants. I think that I can confidently say that we think that it is important for youth to begin to learn personal assistance management skills as early as possible so that they can become independent and in charge of their own lives. Some people may need a surrogate to help them with some of the personal assistance management tasks but we encourage consumers to take as much responsibility as they can."■

Carrie Smoot is a ree-lance writer living in Falls Church, Va, and is a longtime contributor to Celebrating Special Children. We value her unqiuie insights into the issues facing people with disabilities.

Resources:

- **Center for Personal Assistance Services**
www.pascenter.org
- **National Council on Independent Living**
www.ncil.org
- **Virginia Statewide Independent Living Council**
www.vasilc.org
- **Virginia Department of Medical Assistance Services**
www.dmas.virginia.gov
- **The disAbility Resource Center**
www.cildrc.org
- **ENDependence Center of Northern Virginia**
www.ecnv.org
- **Loudoun ENDependence**
P.O. Box 1284 • Purcellville, VA 20134
Voice/Relay: 703-342-7651
Voice/SMS: 703-485-7381
E-Mail: LEND@ecnv.org
Contacts: Bill Ward 703-485-7381 or 703-346-5521;
Elise Graves 703-342-7651
- **PATH**
www.inclusion.com/path.html