



Texas School for the Blind and Visually Impaired

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When Planning for Adult Life, How is a "Lifestyle" Different than a "Program"?

By David Wiley, Texas Deafblind Outreach, TSBVI

A few years ago, I made a videotape for families and teachers helping young people who are deafblind and making the transition from school to adult life in the community. The tape depicts several deafblind young adults. One is a young man with Congenital Rubella Syndrome, who is deafblind with additional disabilities, lives with his mother and has the support of an intervener who comes to his home to work with him for several hours per day. The intervener is paid for through a Medicaid "waiver."

When the intervener comes to the home, he uses a tactile symbol calendar made of poster board, Velcro, and homemade tactile symbols to inform the young man of the day's and week's events. He then helps the young man take part in meaningful activities in the community and at home. These activities include making a grocery list, going to the grocery store, making fresh-squeezed juice, doing strength and flexibility exercises, chopping raw vegetables in a food processor, and taking a ride in the neighborhood on a tandem bike. The tape mentions that they often go to a swimming hole in a local creek.

Recently, after showing the videotape to a group of teachers in a rural area, I was asked where the young man lived when I made the tape. I answered that he lived in Austin, our state capital, with more than a million people in the metropolitan area. To this, a teacher replied, "You can find programs like that in big cities, but we don't have any of those kinds of programs in small towns and rural areas."

This comment made me stop and think because I am conscious of the fact that resources are often not distributed equally in all areas. But as I thought, it occurred to me to ask, "What 'program' is not available in small towns?" A local man was hired to serve as an intervener, and he and the young man's mother got together to plan daily activities. The intervener went to the young man's home to work with him. From there, they went to stores and swimming holes, rode bikes in the neighborhood, and did enjoyable activities surrounding food and physical movement in his home and yard. All of these activities were chosen because they are meaningful activities based on the young man's preferences, which kept him active, motivated, and content. The young man's support is funded by a Medicaid Waiver available in all the rural counties I visited.

What part of that situation couldn't be done in a small town? All that is needed is a posterboard, Velcro, a grocery store, juicer, food processor, exercise mat, bicycle, road, and swimming hole. It could be anywhere.

I think this misunderstanding arose because we have been conditioned to think in terms of programs, a system-centered approach, rather than lifestyles, a person-centered approach when thinking about adult lives for people with disabilities who need extensive support.

System-Centered Programs

In the past, it was usual to think about support for adults with significant disabilities in terms of getting into a "program" and going to the program, a place, to get needed services. These programs might include day-activity centers, sheltered workshops, residential facilities, supervised recreation centers, therapy centers, supported-living apartments, etc. These programs are created by the "system" of service providers to meet the needs of clients or consumers in the area. Programs that now exist certainly fill a vital role in meeting some people's needs.

However, programs are usually created to meet the needs of groups of people. Consequently, they are most often found in larger population areas and often are designed to meet the common needs of most people rather than focusing on individual needs. As a result, in order to gain services, people must qualify as eligible and fit into the agenda followed by the group. Consequently, some people are unable to get the kind of services they need in the place they want because there are no programs in the area or the existing programs, and the individuals are not a good fit.

Person-Centered Lifestyles

Rather than planning by starting with what programs are available, I prefer to start by asking what kind of lifestyle and activities the person would like as an adult. The creation of new ways to fund services in the community allows us to plan by discussing preferred lifestyles rather than available programs. For over ten years now, support for adults with disabilities can be provided to individuals through Medicaid "Waiver" services. In Texas, some of these "Waivers" are called Home and Community-Based Services (HCS), Community Living Assistance and Support Services (CLASS), The Texas Waiver for Deafblindness and Multiple Disabilities (DBMD), Community-Based Alternatives (CBA). Waiver Services are designed to be flexible in developing a plan to meet individual needs.

This allows a person-centered, rather than system-centered, planning approach. Rather than asking what programs might be available, transition teams can start by asking, "What are the person's abilities and preferences? What would the person like to do with their time? What kind of support would enable the person to do these things?"

This can lead to solutions like those in the videotape. The young man's preferences lean toward food and physical movement. On the other hand, unpredictable events (having no schedule or not knowing what is happening) lead him to become frustrated, agitated, and sometimes self-abusive. Preferred activities include getting, preparing, and eating the foods he likes, as well as exercising, swimming, and riding bikes. He needs emotional support in the form of consistent routines and being informed of what to expect so he can anticipate and look forward to things. He needs guidance and physical support to stay active and accomplish the activities he likes. He needs these activities to be planned for him in a schedule that keeps him interested and involved and at a pace that leads him to be successful. There is no preexisting program that meets all his individual needs in any large city or small town. Instead, the people who support him created the lifestyle.

It Can Happen Anywhere

I recently made a videotape of another young man who is deafblind with additional disabilities. He lives in a small west Texas town. His parents had applied for him to get services from the Texas Department of Human Services through the DB-MD Waiver. They planned together with his case manager, who works for a service provider organization in the nearest city and developed an individual plan of care.

The service provider hired an intervener in their small town. She comes to his home, does activities with him there, and takes him out into the community. With her support, he keeps a garden in his yard, helps out with domestic chores like laundry, enjoys music-related activities for fun, goes to the park and stores, and volunteers his time at a regional VA medical center, helping his grandfather with Bingo games for older patients. He takes swimming lessons at the local YMCA. He visits with friends at the hospital and in his intervener's neighborhood, as well as often running into acquaintances at the Walmart or the pool. This is a lifestyle he enjoys based on his abilities and preferences. As his Dad says in the video, "We made our own program."

Starting with a lifestyle: that is how transition planning becomes person-centered. Sometimes, the plan may involve taking part in existing programs if they are available and provide a good fit for an individual's goals. Sometimes, teams will need to "make their own program." It can be done anywhere: large cities, small towns, and rural areas. It starts by thinking about lifestyles.

When this talk of programs came up, I remembered a poem written by the keynote speaker of one of our workshops many years ago. At the time I first heard it, I enjoyed the poem, but I think I didn't fully appreciate it because I was still too close to the system-centered approach to planning. I recently reread the poem with a new appreciation. It is called "Beyond Programs".

Beyond Programs: A Parable

By Michael McCarthy

In the beginning, there was placement, and lo we were happy when it happened, as placement was not mandated for adults who happened to experience severe disabilities.

And so, we said, this is good.

And placements multiplied and filled the earth.

And then we said, let us make programs, which focus on serving clients.

And clients were defined and labeled, and grouped according to their labels and assigned to programs based on their label.

And programs created services for each label, and state agencies developed unit costs for each service.

And programs prospered and multiplied, and we said, this is very good.

And as programs multiplied, a cry arose: Let us evaluate these programs to see how good they really are.

And program evaluation, state regulations, quality assurance, compliance plans, and other program measures were created.

And they multiplied and filled volumes.

And in those times, a person arose who was a client, but who was also a prophet, and said:

"I don't want to be a client,

I want to be a person.

I don't want a label,

I want a name.

I don't want services,

I want support and help.

I don't want a residential placement,

I want a home.
I don't want a day program,
I want to do meaningful and productive things.
I don't want to be "programmed" all my life;
I want to learn to do things I like, and go places, which I like.
I want to have fun, to enjoy life and have friends.
I want the same opportunities as all of you:
I want to be happy."

And there was a long silence.
And lo, everyone realized that they must look beyond their programs.

But they were troubled, and they asked:
"How can we do this? Would not each person need their own unique program and system of support
and his own individual measure of its quality?"

And the prophet replied:
"Even as you say, so should it be done-
Just as you do for yourselves."

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