

...offering
information &
inspiration
to individuals with
disabilities and
their families
as they direct their
own supports and
services



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Transition from School to Self-Directed Services

A Vision & A Plan

Too often, the transition from school to adult life for students with developmental disabilities is marked by interruption in services and unexpected glitches. But for Aailya D'Sylva Lee, everything has gone according to plan. On June 14, 2004, the day she graduated from Warren Hills High School and began receiving DDD services, the only thing that changed was who paid for her services.

“Allowing families to take the responsibility for allocating dollars promotes more sensible ways of approaching goals.”

The key to this smooth transition was a clear vision and years of careful planning. Since she was twelve years-old, Aailya had been job sampling in the community. Now, at 21, she has options open to her, and trained staff in place to support her, at home and on the job.

Aailya, who has significant physical and cognitive disabilities, began her school career at the Warren County Day Training Center. While there, her mother, Lorraine, began to explore her vision for Aailya's future and realized that the highly segregated Day Training Center was not the way to get there. “She got out when she was 10,” declared Lorraine, “and has been in inclusive settings ever since.” She went to Brass Castle Elementary and then to Warren Hill High School. “She was fully supported every step of the way.”

“We did hit snags along the way,” admits Lorraine. “There were people who didn't appreciate why Aailya was there (in the general education classroom), especially because she was functioning on a different academic level. We were fortunate to have had a great case manager, Elaine. We locked arms and moved forward for Aailya. Elaine ‘got it’ and that made planning for Aailya's future a lot easier.”

After Aailya made the ceremonial ‘graduation walk’ with her class in 2001, she still had a few more years of schooling available before her 21st birthday. Returning to the high school was not the best use of Aailya's time since it would do little to prepare her for life as an adult. Instead, the district opted to contract with Allies Inc., a Hamilton-based non-profit agency, to provide community-based transition services. By the time Aailya left school in 2004, Allies, Inc. was providing all of Aailya's services.

continues on page 2

A Self-Directed Transition

(continued from the cover)

Issues that might normally present problems, such as insurance, licensure and teacher certification, were overcome. “If you look hard enough,” says Lorraine, “you can always find a stumbling block. We never took that approach. We just worked it out.”

“Just tell me what I have to plan with and I will figure it out.”

For Lorraine, being in charge of Aailya's supports meant making choices. “The school was spending \$86,000 a year to educate Aailya, but the adult services system would allocate only about \$26,000. You can't make that jump in a day. I knew we had to figure it out THEN, while she was still in high school.”

Lorraine believes that allowing families to take responsibility for allocating dollars for services promotes a more sensible approach to setting goals. “Now Aailya has basic goals with services incorporated into her daily routine, not highly specialized services that happen once a week.” Aailya no longer received daily related services such as occupational therapy and physical therapy. “Allies worked instead on life skills, such as increasing the functional use of her hands. She didn't need therapists to do that - just someone who had good training and was well supervised.” For that reason, Lorraine made sure that Aailya's IEP always included training and consultation for direct care staff.

Transportation was another challenge for the D'Sylvas, who live in rural northwest New Jersey where there is no public transportation. “I was ready to give up my own car to make it work,” says Lorraine. “School bus transportation costs are prohibitive. In those last years, I could have had the school just pay for all the bussing, but I said, ‘no, let's figure this out now.’”

“Good staff is all about relationships.”

Finding and maintaining staff in a field known for high rates of turnover did not present a barrier to the D'Sylvas. They looked close to home for people they knew and built a team from there.

“People ask me, ‘How can you do that? What if they quit?’ I have found that if you respect people, value their contributions and develop a relationship, they stay.”

“They are not just workers, they are people,” adds Lorraine. “Yes, they are professionals and yes, they are paid for their work and we have to consider things like benefits and sick time. But I believe people don't leave jobs, they leave managers. When there is a lot of turnover, you have to look at the management.”

“Its not perfect.”

Even with all these self-directed services in place, there are still some gaps. “I do all the over nights and we still do most weekends. It is hard, because I have to slowly move away from being the one who provides direct care for Aailya. My job now is to manage her support hours in a way that works for her and for our family.”

“There are always loose ends,” admits Lorraine. “I am still the one making things happen and coordinating things. It would be ideal to have a ‘community connector’ to put things together for us.”

While she values the fully inclusive life Aailya now leads, Lorraine has found Aailya's experience to be somewhat isolating. “We fought so hard to do our own things, now we have to look for chances for Aailya to be with other folks who have disabilities.” Adds Lorraine, “I think that could provide a sense of belonging; a chance to blend in and not be noticed. I need that community connection and so does Aailya.”

“A Highly Personal Solution.”

The D'Sylvas got involved with self-directed supports in 1998 when Self-Determination was introduced. “We were at a breaking point,” recalls Lorraine. “We would have had to place her.”

“It was perfect for us,” says Lorraine. “We could not have continued to support Aailya without the services in our home.” Even then, however, Lorraine was not sure if self-directed services were for Aailya. “I even took her with me to the initial meeting so that DDD staff could see who we were talking about; she has some very significant needs. I was reassured that self-determination was open to her.”

Lorraine sees self-directed services as a vital part of the adult service continuum. “This works for us, now. Yes, I'm still changing diapers and having to lift my daughter, but other families have heavy loads, too. The solution is highly personal.”

A Self-Directed Transition

(continued from page 2)

“I think self-directed services allow for natural progression - not one that’s determined by disability, but by age,” says Lorraine. “As our kids grow up, we will be making decisions that mirror typical families. When our youngest son leaves the nest, it will be time for Aailya to leave too. At that point, we will be looking forward to a more independent living situation for her.”

Lorraine knows that her family is an important part of Aailya's future. “Aailya is the oldest of my three children and I know her brothers will always be there for her - that bond is natural. They are the most critical of the direct support staff we have.” They can describe times in their lives when Aailya's disability has had a negative impact on their lives, such as when her seizures made them late to karate. “But,” adds Lorraine, “they can also describe times when she brings joy to their lives. She is their sister.”

“More challenges, more opportunities.”

“I am already planning the next transition - the ‘move’ I know she will make one day. I know the time will come when my other children are ready to move out; that time will come for her, too.

If the transition is to happen seamlessly, Lorraine knows that the planning must continue. “I hope to see her live in a college town where there is a steady supply of potential staff and young people. I envision a roommate, perhaps someone who has similar support needs, so we can pool resources. Lorraine knows that Aailya's supports will be built on relationships and friendships. Most of her staff have been people she either went to school with her, or met someplace.

“I know it will work,” says Lorraine confidently. “It has to. If I put her in a group home or developmental center, the little light in her eyes would go out. And I just can’t do that.”



Partners in Policy Making: Taking Self-Directed Services to the Next Level

Partners in Policymaking (PIP) is an innovative leadership training program for adults with disabilities and for parents of young children with disabilities.

The program provides information and training to help participants develop and build on the advocacy skills they need to obtain appropriate services.

Partners participants learn about current issues and best practices, and become familiar with policymaking and legislative processes at local, state and federal levels. The overall goal is to foster productive partnerships between people who need and use special services and those in a position to make policy and law affecting them.

Each session is devoted to specific topics presented by nationally known experts in their fields. Partners participants must complete assignments between sessions and commit to one major assignment, such as serving an internship, organizing a letter writing campaign, organizing special receptions or town meetings for public officials.

continued on page 4

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"I've always been interested in the movement for people with disabilities to have more rights," says Jorge Ortiz, a graduate of the 2001 Partners in Policymaking Class. "I wanted to learn how things work in government and how we can help influence the decisions that are made."

Mr. Ortiz, who has cerebral palsy, says he was looking for something to do on weekends that would increase his independence. "I learned how powerful a person with disabilities can be," Mr. Ortiz says. "I learned about the power of the voice and, if you put your mind to it, you can be anything in life. It was something I never thought I'd learn."

Partners takes place one weekend a month for eight months. Participants are reimbursed for travel and respite care expenses. Overnight accommodations, meals and personal assistance are provided at no cost.

PIP is now recruiting highly motivated people for the next session, which will begin in April 2005. The training will take place in downtown Trenton at the Marriott. Applications are due in March.

For more information, call Denni Todd 609-984-4519, or e-mail dennie.todd@njddc.org

"I learned that you can't just sit back and hope change will come.

You have to go out and get it yourself."

*- Jorge Ortiz,
Partners In Policy Making Graduate*

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