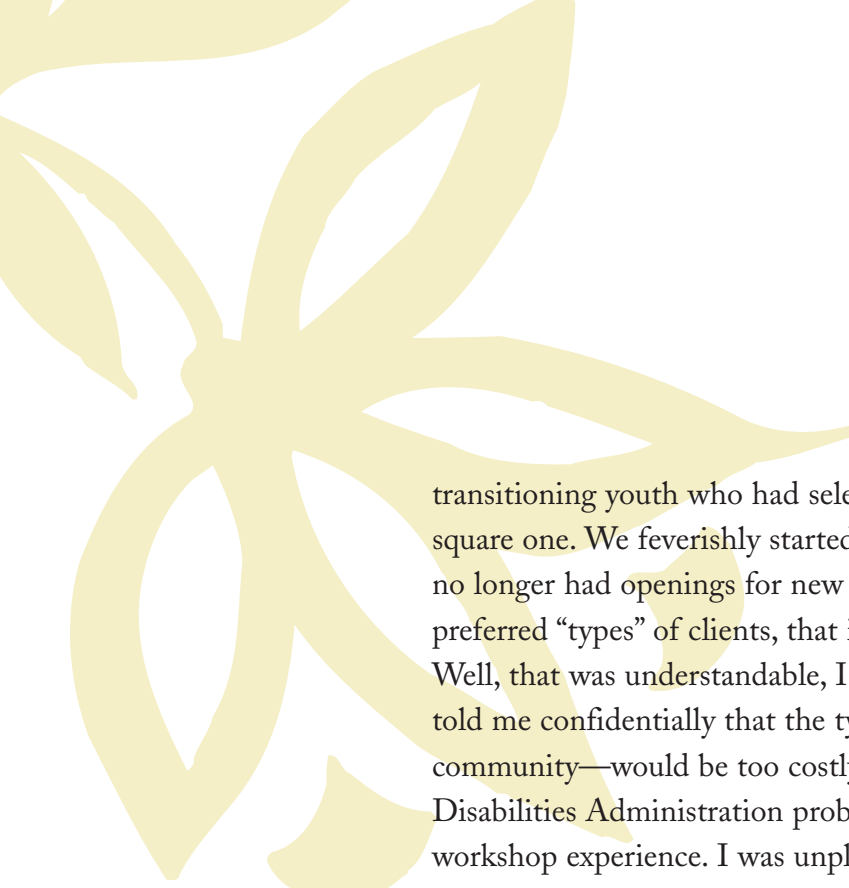


Transition

B“BE CAREFUL WHAT YOU ASK FOR BECAUSE YOU JUST MIGHT GET it” is a saying that I recite frequently. When my daughter was in high school, I couldn’t wait for her to “exit” because the 6:05 a.m. school bus “pick up” was torturous and I thought that she/we were ready to leave school and enter the “adult” world. We were ready for transition. The entire experience of leaving school and moving on to adult activities is called transition. Transition involves planning, identifying the student’s strengths and interests, information gathering, interagency collaboration and relevant services while the student is still in school. However, little did I know that the 6:05 a.m. schedule was the easy part of keeping my daughter’s life meaningful and stimulating.

While she was in school, I thought I did what I was supposed to do for her transition. She had “transition” goals and services in her Individualized Education Program (IEP), I attended informational meetings about transition, I shopped around for “provider” agencies and visited many, and I worked with her to figure out what her interests and goals were. This last task had been an on-going dialogue for many years. Her response at that time was, “I want to work in radio or television.” I knew that this field was very competitive for everyone, and that it would be especially limited for her—a young woman who uses a motorized wheelchair, needs assistance with most activities of daily living, whose speech is somewhat hard to understand for most people who don’t know her and whose reading and writing skills are no where near her chronological age. However, she is intelligent, articulate, opinionated, fun and beautiful—to name just a few of her assets. And, besides, this was her dream.

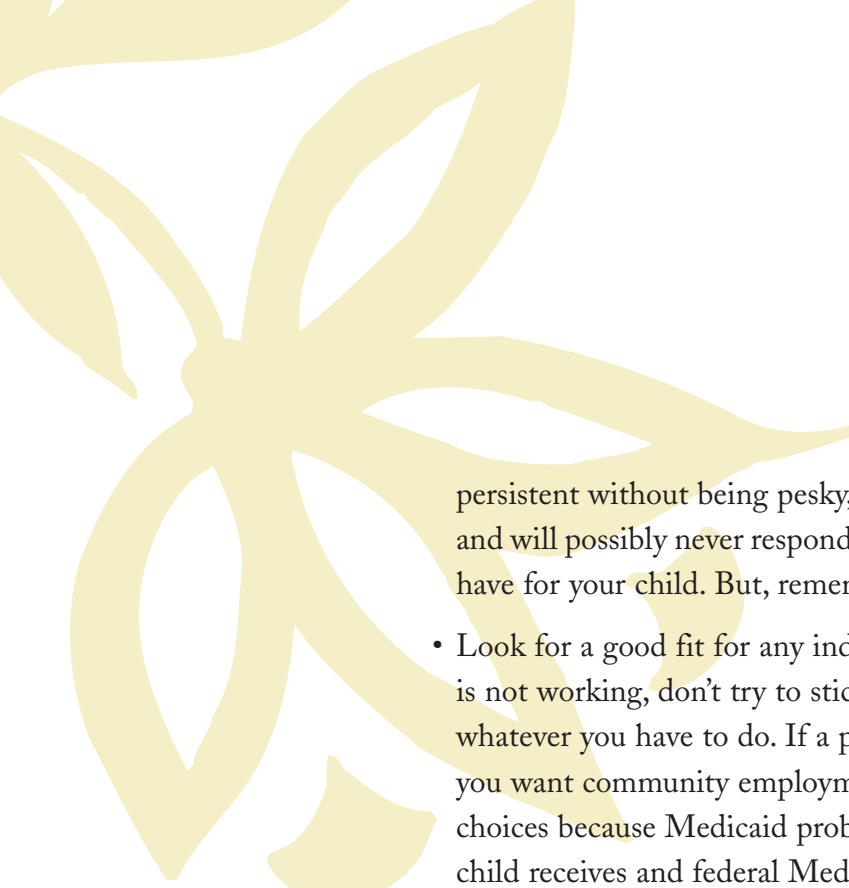
Several significant things happened as we were searching for the right provider. The first provider agency that we selected had a staff change which resulted in us learning five months later that we had “fallen through the cracks”, along with five other



transitioning youth who had selected them as their provider agency. We were back at square one. We feverishly started visiting and calling agencies, again, many of whom no longer had openings for new clients. I next learned that agencies tend to have preferred “types” of clients, that is, they want people with certain types of disabilities. Well, that was understandable, I guess, except that one person who interviewed us told me confidentially that the type of services we wanted—employment in the community—would be too costly for her agency and that the Developmental Disabilities Administration probably wouldn’t fund it. They offered us a sheltered workshop experience. I was unpleasantly surprised and said no, but thanked them for the info. We went to another agency to interview. When my daughter said that she wanted to work in radio or TV, the interviewer laughed at her and said something like, “well doesn’t everybody?” My daughter and I looked at each other, pulled our dignity together and prepared to leave. We thanked them for their time and told them not to deliberate about her since they weren’t a good match, because we wanted an agency that would support her dreams, not squelch them. We finally ended up with another agency. They thought my daughter was a good candidate for community employment, but it really didn’t work out after the program manager left. In fact, this agency did nothing positive, and only showed up to get paper work and reports signed when they submitted quarterly invoices. We finally went to our regional DDA to complain about this fraud, and to reiterate that we wanted an alternative to the provider agency route. We were partially successful—the same agencies are still providing (or not providing) the same services, however, my daughter was accepted into the pilot “New Directions” Waiver program in Maryland. More on this waiver next month and other services that we found...

In closing, here are a few tips, from me to you:

- Take advantage of the transition process—ask questions, get answers, and talk to other families that have been through the experience.
- Be clear about your responsibilities as a parent. Understand the process for transitioning into services provided by another agency. Learn the deadlines, and application and eligibility processes. Call or email the designated contacts. Be



persistent without being pesky, since most of these people will have large caseloads and will possibly never respond with the level of speed, intensity and passion that you have for your child. But, remember, everyone wants to have examples of success.

- Look for a good fit for any individual or agency that's working with your child. If it is not working, don't try to stick it out. Ask for a change and follow through with whatever you have to do. If a provider only offers you a sheltered workshop and you want community employment—it's not a good fit. You should have other choices because Medicaid probably pays for some or most of the services your adult child receives and federal Medicaid regulations require that states offer free choice from among qualified service providers.
- Be patient and look for alternative options (on your own) to ensure that your child's life is as meaningful and stimulating as possible. For example, my daughter is our official "paper shredder" and gets paid for her services. She's proud of her work and often offers to treat us to dinner with her earnings.
- Decide that you are going to make this work. Don't let your child waste his or her gifts and talents, even if it seems like an insurmountable task.