

FEELING THE STONES

In a different age and under vastly different circumstances, the late Chinese leader Deng Xiaoping once talked about crossing a raging river by “feeling the stones underfoot.” All of us—agencies serving the developmentally disabled, parents of children with special needs, and even the politicians—are in that river now, trying to feel the stones in this fiscally-challenged environment.

Feeling the stones underfoot, however, may not be a good enough strategy for parents who want their special needs child to have the opportunity to achieve his or her greatest potential. Government benefits will always be subject to change depending, among other things, on the political and fiscal environment. It is therefore more important than ever to plan for your child’s future, and to begin that planning as early as possible.

The landscape has changed dramatically over the past 1-2 years. Group homes are, with rare exceptions, no longer being built. That means most group home opportunities will occur upon turnover—when someone dies or leaves the home. These vacancies will usually be filled by those in crisis and by a “best fit” criteria—the agency will determine who is best suited to the current house population.

Budgets for Medicaid Service Coordinators (MSCs) and Day Programs are being cut. Medicaid and Medicare benefits are being scrutinized for opportunities to make them more cost effective (translation: fewer services).

These changes require an additional commitment on the part of parents to plan for transition from the school to the world of adult services, employment, and post secondary education/training. Your child’s transition plan should be reflected in his IEP at age 15. Collaborating with your child and your school district in the development of an IEP that includes the development of appropriate goals is an essential part of good transition planning. A coordinated set of activities aligned with your child’s goals will help to transition your child to a positive post school outcome. Other issues such as guardianship, Supplemental Security Income (SSI), and Medicaid will also need to be addressed as your child turns 18.

Parents who begin planning earlier have the best chance of creating the most opportunities for their disabled child. While we cannot know exactly how things will turn out when the dust settles—and it will likely not settle for many years—we can still plan. We can create a safety net for our child so that he or she can attempt to reach his greatest potential without fear of failure.

It is no longer enough to “be on the right track.” Stay on that track long enough, and you are bound to be hit. It’s time to get off the track and do something. It’s time to do some serious planning. And implement that plan. Remember, you are your child’s greatest asset.