

## CHAPTER

## 2

## THAT NAGGING QUESTION

**WHAT HAPPENS TO MY CHILD WHEN I'M GONE?**

You know that question so well if you are the parent of a child or adult who experiences special needs. In some ways the question is more difficult to deal with today than it was in past decades when we knew that we couldn't depend on government interventions to the degree we expect today. Friends and family were more comfortable making commitments to be there when we could no longer take care of our loved ones. Now everyone has busier lives, and we are such a mobile society that family members may live so far away they never really get to know your adult child. The situation becomes more complicated. There are some government programs, but never enough to meet the needs of all of today's adults who experience disabilities. Even the closing of the large institutions makes the question more complicated. We may not have wished for placement in an institution, but at least it was a backup plan.

We have all heard horror stories about adults who are not properly cared for or taken advantage of after their parents die. It is scary to think of your adult child being unprotected after your death. Parents often express the hope to survive the child by at least 5 minutes so it won't be a problem. Some have actually taken tragic steps to assure they survive their child.

I can understand that because my own son, Billy Ray, now 26 years old, is very complex. He experiences multiple medical problems, developmental disability, and mental health diagnoses that include behavior problems. To compound these problems, the medical issues are often more the cause of his behavior than the developmental disability diagnosis or mental health diagnoses. It is difficult to find the right residential and vocational program for him. A program that can deal with his behavior may not be equipped to deal with his multiple medical challenges and vice versa.

In a perfect world, you would hire support staff that would remain with your child long after you could not provide direct care. Staff would be trained by you and pass that training on to the next person. According to the former brokerage that managed the government funding for his in-home supports, we generally keep staff for an average of one year. That's longer than the four- to six-month average.

We have tried having in-home staff for Billy Ray. In fact, if you have read my previous book, you know I wrote about how to train and maintain staff. That type of resource is important, but we haven't been able to do that for Billy Ray recently because:

- Finding employees—especially in-home support staff—is difficult in our area.
- Billy Ray's current medical issues require absolute consistency in care and monitoring. We have had much difficulty getting that with anyone but family.
- Billy Ray's aggressive behaviors usually result from medical issues. The response of staff can be fear or aggression; both are a concern.
- Billy Ray bonds to most of his support staff rather quickly. The loss of a staff person who moves on is very traumatic to him. Thus, we have been giving him a break from that trauma until we get him medically stable.

Billy Ray remains at home with his stepfather and me. We plan to have support staff with the idea that eventually Billy Ray will have his own home

with staff trained in place to help him maintain the environment he needs to be comfortable and less agitated.

We have Billy Ray's care sort of down to our own science and it works for us. However, at 57 years old with a family history of stroke and other health issues, it is a concern that crosses my mind often. I ask myself, *What if I can't set him up in an adult placement before something happens to me?*

This is even more worrisome because his difficult (sometimes explosive or aggressive) behavior is frequently interpreted as something that can only be treated with medication. I am not against medication, but have learned from my best teacher, Billy Ray, that it is not always the best answer. Billy Ray's explosive or agitated behavior may be related to a physical issue or a change in routine that confuses him.

While the following examples may seem off subject for this chapter, bear with me; it will become clear why they add to that nagging question. Billy Ray has had two incidents where his life could have been strongly impacted by misinterpretation.

Because he describes a horror-filled situation during bath time while in a treatment center as a teenager, he requires absolute consistency in the process of his bath. Once, I methodically trained a new staff person in his bath routine by providing her with instructions complete with pictures and by having her watch me do the routine with him for one full week and then watching her to do the routine with him for another week before allowing her to do it independently with him. The following week she changed part of his routine: It was a simple thing—she helped him put on his T-shirt earlier in the process. He seemed to accept this during the five days each week that she assisted him with his bath. She never mentioned the change in routine to me. And each weekend when I assisted him with his bath, I returned to the original routine. When I would not put his T-shirt on him at the same point in the process that she had been doing it, he became agitated out of confusion. As the weeks went by, he became increasingly aggressive toward me.

Another example was a time when his aggression toward me was reaching dangerous proportions. At the same time, he was also experiencing physical issues. His primary medical provider instructed me to take Billy Ray to the emergency room on a Saturday because he had done all he could to find the cause of Billy Ray's behavior and worsening health. The emergency room doctor stated clearly and repeatedly that there was nothing physically wrong with Billy Ray. He wanted to send him home on

psychiatric medication. I strongly advocated that there was something physical occurring and that he was in pain. When they finally did a CAT scan, they discovered that Billy Ray had a leaking appendix, an enlarged pancreas, severe acid reflux, and the beginning of an ulcer. He was rushed into emergency surgery.

Why do these examples add to that nagging question? For one thing, had I agreed to the emergency room doctor's plan to send him home on psychiatric medications for the behavior rather than finding the physical problem, Billy Ray could be dead now. In the bath routine example, the increasing aggression could have caused him to be placed in a facility for aggressive children or adults. It might have resulted in his being given strong enough medication to render him zombie-like had we not researched the cause and dealt with it. Because I understand his "communication by behavior" better than others, I worry more about what will happen to him when I am no longer here to interpret his behavior and try to find solutions.

This chapter was already written on New Year's Eve 2007, the day I experienced major breathing problems and was rushed to the hospital. During the ambulance ride, the EMT kept saying that if I didn't slow my breathing, I wouldn't make it to the hospital. All of the above ran through my mind. Was everything ready so that others would know what Billy Ray needs even if I didn't have everything in place for his transition? What *should* I have done but did not have time to finish? It turned out to be a minor heart attack, not life threatening. But the panic it brought on was a wakeup call for me.

After coming home from the hospital, I requested a meeting with the case manager. He reminded me that when an adult must be placed because his parents can no longer take care of him, the vacancy may not be in the area where he resides. The case manager mentioned the coast, which is approximately 200 miles from Billy Ray's community and his relationships.

Once, when I needed to be away from Billy Ray for a few weeks, this distance problem was dealt with. We wanted him nearby so he could see his friends, attend the school program we had struggled so hard to create, and go to church in as close to his routine as possible. It took strong advocacy and basic refusal to accept anything less. Now the nagging question is, *What happens when I am not there to advocate for him?* Thus, the importance of the next chapter, "Loneliness Is the Only Real Disability." Establishing relationships to prevent loneliness is vital. Establishing relationships with people who will assure contact even if it is not convenient and who you can

trust to stand up and advocate strongly for your adult child is the most important thing you can do for him.

I learned something else during my recovery that horrified me. Because of the way my minor heart attack had come on with no warning, I was nervous about my husband leaving Billy Ray and I alone for extended periods of time. We very much wanted him to be able to attend his daughter's graduation from college, but that would require Larry to leave Billy Ray and I for a few days. I talked to a friend about being available to come over with Billy Ray until the case manager could be reached in the event of an emergency.

I called the county case manager to ask if I could give our friend his cell phone number in case of an emergency. Having moved from a metropolitan area where I knew that there were temporary "crisis beds" in the event of an emergency, it was my expectation that this would occur until my husband or I returned. I learned that they have no coverage or crisis homes, etc., on the weekends. In the event of an emergency, the police would have to be called, and if Billy Ray had to be placed temporarily, it would be in a regular nursing home until the office was open, and they could work out some sort of placement for him.

The reason this was horrifying to me was twofold. First, Billy Ray would be totally freaked by the appearance of a uniformed officer and ride in the police car. He and his deceased father used to watch the television program *Cops*. Once, a uniformed officer came to the house on what was judged an unfounded child abuse complaint. Billy Ray thought he was a "bad boy" like from the theme song of the television program and was sure he was going to jail. It impacted him for months, even though nothing came of the complaint. I can only imagine his reaction if he actually had to ride in a police car.

Additionally, I can see that placing him in a nursing home would not work for either the other residents or Billy Ray. He would be frightened, so his behavior would intensify including noise and activity. He is not a typical runaway from home, but he did run away from an uncomfortable classroom situation once. I think that is a real risk. He could also become aggressive if he became afraid.

It is easy to become paralyzed from the fear of that nagging question. However, it doesn't have to be that way. You can experience the peace of mind that comes from knowing you have done everything you can to make the transition smooth.

## MAKING PEACE WITH THAT NAGGING QUESTION

There are so many unknowns, not only in your child's future but in your own as well. Fear of the unknown is very difficult to live with. There are many things you can do make sure your adult child gets the level of support he needs and that allows him to live a life that is fulfilling to him. As you arrive at the conclusion that you have done everything possible to document your knowledge of your child and help him to establish a quality adult life, you will feel much more at peace.

An adult who experiences disabilities and is able to live independently may still require followup by parents or part-time staff. Whether verbal or not, he may have difficulty communicating what he needs verbally. Programs that offer support come and go—as does the staff they employ. You wonder whether anyone will follow up on your son or daughter if you can't do it personally. Having the documentation and planning spelled out (as we will discuss in Chapter 11, “Implementing the Plan a Step at a Time”) will allow your training methods and involvement to survive your ability to be there personally.

Assisting an adult child to find a fulfilling life is more complicated when he experiences disabilities, but it can be done. The same pride of watching an adult child enjoy life is achievable if you adapt to what works for him and what he enjoys.

Even the most difficult issues can probably be adapted in some way to deal with the problem. For example, the horror I mentioned that Billy Ray might be moved away from the community relationships we have struggled to create might be dealt with by establishing his own home and setting up supports sooner. If that isn't achievable immediately, there could be a backup family who would agree to become specially certified foster parents in the event I am not available to him and until more permanent arrangements can be made. (See Appendix A for the Sample Emergency Backup Plan and Appendix B for the Sample Caregiver's Manual I have prepared to deal with that potential situation.) At the very least, family and/or friends can be taught to be advocates for him.

While waiting on service waiting lists, you can begin helping him discover what he wants in his life as an adult. You can try to get some training and/or provide other training at home toward both vocational and residential situations. You may even be able to create a life that is much less dependent on governmental agencies than you had expected.

As stated, it is best if your adult child is actually transitioned while you can still be a strong advocate for him. However, by doing the preliminary planning with and for him, having relationships in place with people who will advocate for him and documentation available, transition without your help will be further ahead than it might otherwise be. That nagging question is conquered—or at least quieted—by the preparation and planning we will discuss in subsequent chapters. There is more peace when we see that things are in place for the kind of life that makes our adult child as happy as possible.

There are some hard realities in dealing with nagging questions—including some you may not want to face. For example, Billy Ray's case manager is always reminding me that it is unlikely anyone will have the same commitment to Billy Ray that I do, no matter how noble his or her intentions. However, showing those who will advocate for him the principles of team-building advocacy, as opposed to the principles of combat-fighting advocacy, will increase the likelihood of their success. Helping them to understand what is important to your adult child and why certain things happen assures a greater understanding and commitment to your child than there might otherwise have been.

There may be things that will occur after you are not involved that you could not possibly have anticipated. Unfortunately, some of that is unavoidable. But there is also peace in accepting that you have done what you could.

Suppose you plan for your child to inherit the family home and have staff come in to provide whatever level of assistance he requires. Maybe you even hired staff and trained them while you are able to participate in the training. A few months or a year after the training has been in place you may think you have it all arranged. Then the staff leaves, and you get to start all over again. You may find it hard to keep good staff. You worry about what happens when you are not able to keep taking care of him. Starting over again will, of course, be frustrating, but you will do it because of your commitment to your child.

As we will discuss in the next chapter, building relationships between your child and others will bring you even more peace. These relationships may not be with future caregivers, but if they stay involved with him, there is a greater chance of maintaining the life your adult child and you envision.

## TRANSITION PLANNING EASES THAT NAGGING QUESTION

I recommend starting transition planning at about age 10 to 12. That is ideal because you can get necessary skills included in the IEP as goals for training. Of course, you may not have the luxury of time. Wherever he is, you can begin to set goals and make plans.

Parents are best able to work with their children to determine an effective transition plan. Yes, professionals will play an important role. But parental involvement makes things more secure for the adult child, and it adds to the chance of a successful transition.

Probably the hardest part of transition planning is that, to some degree, you are preparing for your replacement. It is much more emotional than training your replacement before retiring from a long career. It will also take a lot more people to accomplish it.

You have likely been your child's best friend, advocate, financial manager, caregiver, and more. And now you will need to assure that either he is trained to do those things for himself or that others are trained to meet his needs. It is hard to imagine someone else doing things for him that you have always done and hard to recognize that perhaps he can do some of it himself. At the same time, you recognize that you will not likely be able to do those things forever.

As you will see in the following chapters, there are many things you can do to help with the transition. You will be able to help ascertain what he wishes for his adult life. As his parent, you know him best and will be his most powerful advocate.

As you work through transition planning, the pressure of that nagging question will subside—but only to a degree. Realistically, the question is never far from our hearts. But again, there is peace in knowing that you have done everything you could do to assure a happy and secure life for him when you can't be there to provide it.