

Health Care for a Young Woman with Complex Needs: A Mother's Perspective

The following was written by the mother of a young woman with intellectual and developmental disabilities. It is intended to provide users of this module with some personalized insight into the experience of individuals with complex disabilities and their families, and to provide strategies for ensuring patient- and family-centered care.

My daughter has received lots of medical support in her 18 years. Typically, as parents, we accept each new need, analyze options, and quickly make the appointment just as if we are spokespeople for Nike's "Just Do It" campaign. Dealing with the issues around women's health is a much slower, deliberate process for us.

I'd love to say that there has only been one challenge or even none, but that would not be realistic. Challenges have included Dad's fears, Mom's fears, and fear of our daughter's fears by family and medical professionals alike. It is easy to worry about the logistics of how to maneuver a wheelchair in and out of a tight exam room. We know that an effort to provide medical care without a transfer from the wheelchair may mean that we are probably not accomplishing all that we need to. Other times, the barriers are in paperwork and insurance. Unessential complications in the juggling of resources can give the patient and family the feeling that their patient should transfer to another healthcare provider!

Accustomed to a certain number of obstacles in obtaining necessary services, we are willing to work at it. As a family, we identified some of the things we could do to make women's health care for a patient with complex needs as successful as possible. We worked to identify ways to increase our teen's participation in responsibility for her health. Partial participation is better than no participation. It was also important to start early. For example, a caring artist in our community created a beautiful glass bead 28 day scheduling system for my daughter that enables her to anticipate her monthly cycle.

Other things can make the actual appointment more smooth and efficient:

- Schedule a preliminary visit to the office, as a rehearsal for the real appointment. A frank discussion about whether extra time is required for an appointment may be needed. As a parent, I appreciate professionals bringing up this question. While extra time may be needed for the first appointment or two, the time required can diminish after the first few appointments.
- Practice a transfer. Each transfer in and out of the wheelchair calls for attention to detail and valuable exam room time. Practicing this on site without impacting the healthcare provider's schedule makes sense.
- Practice positioning. Identify and share the language that will help to reduce muscle tone and ease positioning.
- Allow time for the patient to explore any educational models. The familiarity with them will pay off in actual appointments.
- Discuss options that allow for appropriate health issues to be fully addressed with the minimum invasiveness.
- Identify and discuss how to increase the patient's realistic expectations of the appointment. Avoid surprises.
- Consider scheduling the actual appointment when the best assistant (not just any assistant) can attend.

Finally, even with preparation and troubleshooting, issues may arise that need to be addressed. To keep healthcare progressing, we need to be ready to communicate. The idea for a minor tweak that improves the medical outcome may come from the family, the medical office, or the patient. This teamwork makes great women's healthcare obtainable for all.