

Self-determination & Person-Centered Planning

I was once told that my daughter would probably never learn to write. Now she's completing her program here at George Mason and getting involved in decision-making about the future. What do I think of that? My first reaction is that it is breathtaking. Look how far we've come. My second reaction is that we can still improve upon the process. We need to start involving students with intellectual disabilities in decision making sooner. Also, we have to remember that, as the student becomes more involved in decision-making, the parent's role must also evolve. It is sometimes hard to step back and let a student make her own choices. But such a decision can turn out to be surprisingly successful.

Jenny has had the benefit of person-centered planning at Mason LIFE. It has helped her to come into her own and to start taking an increasing role in decision-making about the future. Of course, when Jenny entered Mason LIFE, I thought I knew what person-centered planning was. I had been through years of IEP meetings in public school and at Paul VI Catholic High School, where Jenny was part of an innovative special education program. But in all these situations, teachers and administrators met with parents to determine what a student's goals would be and how to implement them. If Jenny was invited at all, she had observer status, like a non-member state at the UN. She was able to choose her electives, and even joined an introductory journalism class. But self-determination was never truly attempted.

That changed at Mason LIFE. I first noticed the change in the middle of Jenny's second year – winter break was long, and I was working. Jenny was at home on her own, watching too many movies. I was afraid that she would lose her focus. I requested a meeting to help get Jenny motivated for spring semester. Dr. Graff asked me to have Jenny make a list of her goals, and to have her bring it to the meeting. She also told me that she wanted to talk directly with Jenny at that meeting. I would take a lesser role.

The meeting was different from any other we'd attended. We met in a classroom. I sat in toward the back. Jenny was up front in the driver's seat. Dr. Graff was at the blackboard, and Mrs. Ingram, the academic program coordinator, was in the middle, making occasional comments and taking notes.

Dr. Graff compared Jenny's list of goals and with a list that I had made and with Jenny's instructors' assessments. Then, she and Jenny had a lively discussion about why one goal was more important than another. The meeting was a challenge for Jenny. She was required to think for herself and to put her thoughts into words. As they talked, Dr. Graff used the blackboard to diagram the relationship of short-term goals to long-term goals and to success in the future. Dr. Graff posed some questions that Jenny had not considered, and it was occasionally hard for her to answer. But Jenny clearly enjoyed her new role.

Dr. Graff told Jenny that they would choose one or two goals to concentrate on during the next semester. They decided that Jenny would work on her ability to start conversations, and keep them going. Dr. Graff gave Jenny an ongoing assignment. She would read news or magazine articles, and write down at least three facts and three questions about them. I worried that Jenny would be overwhelmed by the additional work. But Jenny was motivated. She had helped choose the goal she would work on, and she looked forward to bringing work to Dr. Graff. In other meetings, Jenny and Dr. Graff selected other goals and created activities for working on them.

But that first meeting was empowering. Jenny learned that her views mattered. It got her to think in more specific terms about what she wanted out of school. Jenny spoke to Dr. Graff about getting more involved on campus, and community participation became a major part of her program. Jenny became a student ambassador for Best Buddies, and the liaison for the Mason LIFE program to the university's student senate. These activities work on many of her educational, community and independence goals.

In fact, Jenny's involvement in student government highlights one important characteristic of successful student-centered planning – keeping an open mind and not ruling things out because they haven't been tried successfully before. In her sophomore year, members of GMU's student senate met with the LIFE Program students and encouraged them to get involved and run for office. Jenny decided she wanted to do so. She collected about 300 signatures from GMU students during lunch hours and after school. However, neither Jenny nor the student senators realized that a student has to be in a degree-conferring GMU program to run for office. The LIFE Program does not qualify. But the faculty advisor to the Student Senate called Dr. Graff and, with some flexibility and creativity, found a positive solution. They created a new position, LIFE Program liaison to the student government. It was a way to achieve a good outcome for Jenny and to further integrate the LIFE Program into the school community.

When a student makes the choices, parents have to accept that sometimes the path chosen is not the one they would have taken. Moreover, the student learns about tradeoffs and that it is impossible to do everything. Dr. Graff and I had encouraged Jenny to consider auditing a public speaking class last year. But to fit the class in her schedule, Jenny would have had to eliminate at least one extracurricular activity such as student government or Special Olympics. Jenny did not want to do so. So instead, Dr. Graff and I worked with Jenny this year to structure her participation in student government so that it works more clearly on the writing and public speaking skills that the class might have addressed.

So what do I think of self-determination and person centered planning? If I would change anything in Jenny's experience, I would say that she should have been involved in the planning process even sooner. It is good for students to work with parents and administrators on setting long- and short-term goals, and in outlining how to implement them. But they need to have time, before exiting school programs, to become comfortable with making choices and to learn that each decision has further ramifications. I think that in the best of all situations, students would actually start to take a role in the educational planning while they were still in middle or high school.