High Anxiety: Addressing Family Issues in the Transition of Students with Disabilities from Middle Grades to High School

Nancy Brigham
Nancy Brigham Associates (NBA)

Cynthia M. Aguilar
Education Development Center

Abstract

This article documents the development of a protocol that addresses the anxieties and tensions felt by the families of students with disabilities when they face the daunting transition from middle grades to high school. The tool grew out of a study of schools that form meaningful partnerships with diverse families of students with disabilities, funded by the U.S. Department of Education, Office of Special Education Programs (OSEP). The article details the process of developing the transition protocol, which is based on the real life experiences of families involved in the study and their experiences with transition. It expresses the families’ fears for the social and academic success of their children and how schools can help to counter these. The complete protocol, including assistance with logistics, a sample lists of topics for the session and a scripted guide for facilitators are available free of change from the Inclusive School Network.

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Having friends, dating, driving cars, even just doing homework are all common teenage high school experiences but for families of students with disabilities, these everyday issues may become challenges magnified by their children’s disabilities. Will my child have friends? Will the teachers in a large high school understand the nature of my child’s disability? How will my child feel if the other students begin to drive and date and he or she cannot? Little wonder then that the transition process becomes a matter of anxiety and tension for these families.

The ICARE Schools study, funded by the U.S. Department of Education, Office of Special Education Programs (OSEP), focused on the families of students with disabilities and their connections with their adolescent’s schools. Over a 4-year period, ICARE staff worked closely with two middle schools and their families to unpack and describe some of the innovative approaches and strategies used by schools to engage all families in the education of students with disabilities. Transition issues were not on our radar screen when we began to identify and document middle schools that form meaningful partnerships with the families of students with disabilities, particularly families from culturally, linguistically, and socio-economically diverse backgrounds. However, soon we found ourselves engaged in conversations with families of soon-to-be-high-schoolers, and the team had nowhere to go but forward.
Early in the study, we held focus groups with families and talked about the concerns they had for their children. Although our discussion centered on the families’ relationship with their middle schools, we found transition to high school was a topic of high interest to our families. They convinced us that the typical transition activities, such as guided tours and family information sessions were not sufficient for their children to make this important and difficult step. Many students with disabilities are moving into high schools from a smaller, safe environment in middle school with systematic communications between home and school. We learned that these schools and all schools transitioning students with disabilities to high school need to recognize they are not just transitioning students, they are also transitioning families.

This realization led us to undertake the development of a family transition process, using one of our schools as a pilot site. First, we went back to the transcription of those early family focus groups and listed the transition concerns parents had expressed. These included:

- Homework
- Fear of children getting lost in the building
- Fear of children getting lost in the system
- Social concerns: dating, sex, driving, being shunned
- Will they be able to handle the work?
- How do parents interact with the system at the high school?

We reconvened some of the families who had expressed these concerns and whose children had gone through the transition process and were now finishing their ninth grade year at the high school. We discussed their’ previous concerns and asked how it had all worked out and we documented their responses. The next activity was to conduct a Family Transition Group from among families whose children were about to graduate from eighth grade and move up to the high school. The positive relationship between the school and its families facilitated recruitment for the Family Transition Group. Even so, we asked counselors to issue personal invitations to families whose children with disabilities would be transitioning to the high school in the fall. A total of 20 family members attended the session, including parents, grandparents and one older sibling.

We invited a high school representative, a case manager with extensive knowledge of programming at the high school as well as some middle school counselors to attend the session. These participants were asked to listen quietly until the end of session and then to provide information in response to parent concerns and make connections that would facilitate personal contact with them or others at the high school.

Preparation for the Family Transition Group included setting the place, the time and the tone. Since the families were comfortable at the middle school, we used a large classroom and scheduled the session for two hours beginning in the early evening. We asked families not to bring their children, so that they could speak freely about their challenges and concerns. In order to set an impartial tone, we decided that it was best for the facilitator to be a neutral party rather
than a teacher or administrator. In this group, one of the researchers served as facilitator, but a social worker or even a guidance counselor would also be a good choice.

We informally divided the session into three chunks. The first was devoted to families introducing themselves and telling why they appreciate the middle school. The following quotation is typical of what we heard.

> I have found that they are approachable. Sometimes educators are in their own little worlds and the parents are in their own little worlds. I find that here if I have anything that I want to discuss from the teachers to the principal. I can approach them, I can contact them, whatever, send emails and I get responses back.

The second portion of the session began with a discussion of the specific fears and concerns that families had about the transition of their children to the high school. Here are some typical family responses.

> I feel like I’m releasing my child into a different population and you know, to me, high school, you don’t have the same hands on as you had in middle school. I mean, I’m trying to give up some of my control and that kind of stuff, but at the same time, that’s such a new territory for me and for him. I have two children that are finished but to me, but for him because of special needs, I feel like I still need to have that little bit of control and I feel like I’m going to lose it.

I’m also concerned about the socialization because…in high school the kids are much, more, for lack of a better word, aggressive. You know, that concerns me because my son’s not like that. He’s very low key, very laid back and I’m concerned that because he’s going to be kind of isolated in a special education class.

Here the teachers always communicated with us and if my son is missing work or something they would tell me, you know, email to me, and make sure, and I know sometimes I hear from teachers you need to be independent, teachers don’t really care for this. It like, bothers me because my kid is in special education, he needs someone, maybe sometimes as a parent you always want to baby your child, its true because it’s a true concern that if I don’t support my child and care for him he’s going to fall apart. And my concern is how is the communication with teachers (going to work?)?

In all, the list generated by the Family Transition Group, included the following concerns, which we jotted down on chart paper as they arose in the conversation.

- Getting lost in the system
- Who are the “team” at the high school?
- Will child feel part of the high school?
- Getting lost (building size)
• Socialization: Will they be picked on? Will they be isolated? They are blossoming now, will it continue?
• How will I know if they are doing well in class? Will we get support? How do I communicate with the teachers?
• If I “release” my child or step back will anyone support them?
• The middle school “team approach” may not be duplicated? What is the approach at the high school?
• How will my child deal with opposite sex relationships

The third portion of the session was devoted to allaying the families’ concerns. We began by comparing the list they had just generated with the list that had been addressed the previous evening by families that had already gone through the transition process. Looking at the two lists side by side, we noted that with the exception of homework, family concerns were the same in both groups.

Then we shared the experience of the previous year’s families, which brought a sense of relief in the group. On the topic of getting lost in the building or the system, families reported, “Most of the kids within a week or two did find their way around the building”. Getting lost in the system, however, remained an issue for some students. As summarized by the facilitator, the problem is one of being willing to ask for help.

We talked last night about how there are two types of kids in this world. There are those who are kind of out there and it they need help the world knows about it, right? And then there are the kids who just as part of their personalities, they won’t ask for help. You know, they just won’t ask anyone for help. So no matter how many people there are around who would help them if they asked, they won’t ask. So that was a problem that the students and their families did encounter at the high school.

In terms of dating, families found that, in ninth grade, children are not ready yet to really get into the dating scene the way they will later. “In ninth grade kids still hang around together in groups. They don’t break off into relationships so much.” Driving too was an issue that families decided they could worry about later, focusing first on the problems that are really ninth grade issues.

The families experienced with transition had some advice for those about to undertake it. The first thing they said was to ask for help right away.

If you have a problem at home or you think your child is having a hard time with a particular thing, it is okay at the high school to call. If you get the wrong person, they will forward you to the right person. There is a responsive team at the high school…so get to know your support team right away.

One parent advised that families “work on the class selection with your kids. If they have particular interests as you fill out the selection forms with them, try to work on that with them right away.” Another mentioned that if the child insists on a particular class, you might want to
let him try it. “I mean, if you think it’s within reason, try it in ninth grade. That’s a good time to have that experiment. “

At this point, the high school representative was introduced and spoke directly to the scheduling issue. As a case manager at the high school, she is responsible for scheduling classes for students with disabilities and offered the following guidance.

If your particular child has trouble with transition (from one class to the next) I would take a look at the schedule and make sure he doesn’t have four major subjects in a row. Maybe your child should have two subjects, gym, an elective, lunch and then two other subjects… I don’t think there’s a problem with the transition. It keeps the day moving. But if your particular child does have trouble with that, with the amount of changes maybe we could design his schedule especially so that it doesn’t hinder him as much. A lot of kids take gym at the end of the day because they’re just done. When I do my schedule, I design the schedule, math first period English second period… get them when they are fresh in the morning. Some kids that are on medication, their medication wears off in the afternoon.

The high school representative, a woman with 30 years of experience in the field said later that she was struck by the depth of feeling and deep concern among the families in the group. She said it was an “eye opening experience” for her and she responded by offering special accommodations to the families.

I’m going to mail a letter out to every special education parent and have one day or two days set aside this summer just for us to meet, you bring your child and we’ll walk around. You have my phone number, call me any time, July, August; I’ll always get back to you. If you have a concern about the schedule, if you want to bring your child for a visit or to meet me, call anytime. It’s an open door policy.

As we watched families gather around the high school representative in the hallway after the meeting, talking about their children, taking her business card and generating a cheerful hubbub of conversation, we realized that creating a formal process for replicating this kind of experience would be a service to middle schools, high schools and, especially, families of students with disabilities. The complete protocol, including assistance with logistics, a sample lists of topics for the session and a scripted guide for facilitators are available free of change from the Inclusive School Network. Go to [www.inclusiveschools.org/resources](http://www.inclusiveschools.org/resources) and click on “Transitions.”