

DYNAMIC LEARNING MAPS

The Arc Parent Focus Groups

Final Report

November 12, 2013

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Table of Contents

Introduction

Overview.....	2
Methodology and Participant Characteristics.....	2
Domains of Inquiry and Research Questions	3

Parental Expectations of Students and Post-Secondary Goals

Academic and Nonacademic Skills	5
Post-Secondary Education and Transition Planning Goals.....	8
The Role and Formation of High Expectations.....	12

Parents' Experience and Perceptions of Alternate Assessments

Knowledge of Assessments	15
Perceived Purpose of Assessments.....	17
Information Received About Assessments.....	18
Relevance of Assessment and Use in Planning	22
Reporting and Resources to Support Understanding	26

Parents' Attitudes toward Special Education..... 29

Conclusion 35

Introduction

Overview of Report

This report explores parents' perceptions of alternate assessments in the context of their experiences with the special education system. It describes the way parents view their children's education and the goals they have set for their children after high school, and the role that alternate assessments play in helping them work toward these goals. Special focus is dedicated to using the alternate assessment as a planning tool and how this can be further encouraged. Parents' use and understanding of alternate assessments is couched in their broader views of special education as a system, which helps explain why they hold the attitudes they do and what can be done to increase knowledge and use of alternate assessments.

The report is divided into five major parts: an introduction; an exploration of parents academic, non-academic, and post-secondary expectations for their children; their reported knowledge and experiences of alternate assessments their children have taken; background on their other concerns and frustrations with school systems; and a conclusion that explores possible changes in communication and reporting to address parents' concerns.

Methodology and Participant Characteristics

This report is based on an analysis of responses to 15 research questions by 44 focus group and interview participants. Focus groups were held in person in four states, and a group of participants from a fifth state participated by teleconference. Follow-up interviews were conducted with seven individuals representing all five states, six by telephone and one in person. In total, more than 17 hours of recorded feedback were transcribed and analyzed.

All of the participants were parents of children that participated in their state's alternate assessment. Parents were recruited through their local Chapter of The Arc, except in one state in which recruitment also included the Exceptional Family Member Program at a local military base. All parents were provided with a \$50 gift card to support their travel and participation in the group. Focus groups were held on weekday evenings and hosted by local Chapters, except in the state where the group participated via telephone from separate locations. Follow-up interviews were scheduled individually and conducted by phone.

Groups ranged in size from six to twelve participants. Most of the participants were mothers of children with disabilities; about 15% of participants were fathers. In three states, both the mother and father of at least one child attended the focus group. Although parents of different ages, educational

levels, and cultural backgrounds were represented in the groups based on voluntary self-report, demographic data about participants or their children was not solicited or systematically tracked.

Due to the method of recruitment and the content of discussions, participants were likely more engaged with their child's education and more knowledgeable about special education in general than the average parent of a child with a disability. Some participants had experience with alternate assessments in multiple states, and many had more than one child taking alternate assessments as well as other children taking the standard state assessments. In addition, many participants were employed as advocates or educators working in the disability and special education fields. Participants mentioned working or volunteering in the following areas:

- At a UCEDD or other university center focused on disability issues
- As a nurse or paraprofessional in a school
- As a teacher, teacher's aide, or educational administrative professional
- As chair of The Arc's education committee at a state chapter
- As a member of the Statewide Special Education Committee
- As organizers in state-based family advocacy organizations or parent coalitions
- At Protection and Advocacy agencies
- At Chapters of The Arc, as coordinators of parent training and support programs
- Working with families whose children with disabilities are facing out-of-home placement
- As an Education Ombudsman in the governor's office

At least three participants had been involved with administering alternate assessments, or had seen them being administered. Many had also participated in trainings or workshops around special education through The Arc or another organization. Parents noted that "probably everybody here is really involved in their child's IEP [Individualized Education Program] and communicating with the school," and that "none of these people [in the room] are the average parent of a kid with an IEP." Many, though not all, participants were engaged in advocacy professionally or as volunteers specifically in the area of special education, beyond their engagement with their own child's education. As one mother said, "I've always been on the teachers' tails. I don't let anything slide. I'm always-- well, the Board of Education knows me." This engaged and critical perspective was reflected in many responses, including reactions to the research questions themselves. For example, while parents voiced appreciation at being asked their opinions, they were skeptical of questions about their expectations for academic versus functional learning, and self-critical in their responses about seeking more information about assessments and evaluating their own knowledge and understanding.

Research Questions

Fifteen research questions were asked in each of the focus groups. They were developed based on six domains of inquiry provided by the Dynamic Learning Maps team.

Domains of Inquiry:

1. Parental academic expectations of student
2. Parental post-secondary education (career and college readiness) goals for students
3. Transition plans
4. Alternate Assessment: parental experience and information received
5. Reporting: how parents want/need/expect to know about their student, and how that information is presented or should look
6. Parent resources

Research Questions (in the order they were asked):

Domain 4: Parental Experience and Information Received

1. Tell us about your experience with alternate assessments for your child.
2. What do you think the purpose of the alternate assessment was? Do you feel like your child's alternate assessment served this purpose?
3. How informed do you feel about alternate assessments for your child? Can you rank yourself on a scale of 1-10, 1 being not at all informed and 10 being very informed?
4. If you received information about the alternate assessment process beforehand, what kind of information did you receive? Where did it come from? How was it presented?
5. If you received information about the alternate assessment process afterward, what kind of information did you receive? How was it shared or presented to you?
6. Do you feel like you understood this information? If so, what (if anything) did it tell you about your child?
7. Do you know how this information was used, or if it was used? [For example, in IEP planning, transition planning, at home?]
8. Do you know where to get more information about the alternate assessment process or results? If you do, have you ever accessed this information? Did you find it helpful?

Domain 5: Reporting

9. As a parent, what do you think an alternate assessment should tell you about your child? How would you like this information to be presented to you? What changes would you make to the reporting process?

Domain 6: Parent Resources

10. Do you feel like more resources and supports for interpreting the results of the alternate assessment would be helpful? If so, how should this information be presented in order to be most useful to you?

Domain 1: Parental Academic Expectations of Students

- 11. What academic skills do you expect your child to have at the end of high school? What do you expect them to know and be able to do? How did you arrive at these expectations?
- 12. What skills and abilities unrelated to academics do you expect your child to have at the end of high school? How did you arrive at these expectations?

Domain 2: Parental Post-Secondary Education (College and Career Readiness) Goals for Students

- 13. Do you have post-secondary goals for your child? What are they? Does your child have post-secondary goals? What are they?

Domain 3: Transition Plans

- 14. Does your child have a transition plan? What is it?

Domains 2, 3, and 4:

- 15. Is the alternate assessment process and reporting useful to you in planning for or achieving these goals?

Parental Expectations of Students and Post-Secondary Goals

Academic and Nonacademic Skills

Parents were asked similar questions (11 and 12, above) about their academic and nonacademic expectations (referred to below as functional skills, after parents' usage) for their child's achievement before completing high school. The responses recorded are detailed in the table below:

Academic Skills	Functional Skills
<ul style="list-style-type: none">• Reading• Counting• Understanding sameness and difference• Basic math including addition, subtraction, multiplication, division• Write legibly / penmanship• Compose a letter or e-mail• Critical thinking and reasoning• Technology skills• Using language appropriately• Computer research	<ul style="list-style-type: none">• Communicate• Ride the bus• Handle money or make change• Make choices / say yes or no• Develop social skills• React and adapt to surroundings• Numbers in the real world (math literacy)• Read street signs• Balance a checkbook• Fill out a job application• Read food labels• Know own name, address, phone number• Tell time• Use a cell phone• Google something• Hail a cab• Shop for own food• Eat by himself

	<ul style="list-style-type: none"> • Shower and brush teeth • Dress and put on shoes • Be a self-advocate • Turn on the TV • Cook
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For the most part, in their responses parents did not separate academic and functional skills: “I think it’s very hard to think about just academics, as you can hear it. Most of the parents couldn’t just strictly state the academics because there’s so many things affecting the academics and the learning.” This quote illustrates the view, shared by many participants, that thinking of their educational goals in these terms was not easy or that they did not think this distinction made sense when applied to their children. This was also a point of tension for parents who felt that schools disproportionately focused on one aspect or the other of their child’s learning, in contrast with parents’ own priorities.

Many parents did have stated academic goals for their children that they saw as realistic based on their child’s ability. Reading and math were the areas that received the most emphasis. For some parents, this meant math skills including multiplication and division:

“By the time they graduate high school, I expect the state to have taught my children how to read, do basic math like addition, subtraction, division, and multiplication. It doesn’t have to be trigonometry and algebra.”

For others, “numbers in the real world” were of more importance. Parents emphasized being “able to do a checkbook....or handle money.” Making change or understanding how to count money was a frequently stated math goal, and was often linked to a desire to make the student “employable.” Filling out a job application was also repeatedly indicated as an educational goal.

A similar emphasis on reading and literacy was almost always directly linked to a desire for students to be able to go out into the community by themselves. This included learning how to use public transportation, shop for themselves, prepare their own food, and arrange and follow their own schedules. Many parents had the stated goal of helping their son or daughter learn to ride the bus. However, parents discussed these skills primarily in terms of their importance for employment potential:

“...Functional literacy all the way across the board is the minimum that we should expect. They can get on a bus and be able to read what the name of the streets are and fill out a job application and make change at Walgreens and read

the can that says green beans versus corn without having to look at the pictures.”

The only other specific area of academic emphasis was on learning to use technology. Several parents said their children currently used technology, especially computers and smartphones, to make up for some of the difficulty they experienced communicating verbally. One mother discussed texting with her daughter when she had difficulty articulating her thoughts, and said, “for my daughter in particular, the gaps that exist in her everyday learning are just covered with technology.” Computer use was also linked to developing job skills in areas not historically open to individuals with significant disabilities. As one mother mentioned, “a lot of our kids have a real affinity towards technology and I think that’s something that’s really exploding now.”

However, many parents did not express an interest in academic goals when faced with what they described as much more pressing needs:

“I’m not talking about the academics-- more about the day-to-day living. I want him to become independent. I think actually that’s a far-reaching goal; that we will be able to get that or not, I think it has a big question mark there, but we are trying our best actually to get him to that prospect.”

For some parents, the focus on academic goals was a source of frustration. Often, they described a major disconnect between their perceptions of their son or daughter’s needs and the schools’ priorities. One mother became emotional when asked about her academic expectations for her child:

“My problem is they’re always wanting to teach them how to read or do math. I don’t care if he knows what $2 + 2$ is. It’s not going to help him. He’s not going to be able to communicate that. I want him to be able to bathe himself when he’s 20 years old, so I don’t have to do it. I’m going to get emotional. Sorry.” *[Crying]*

Other parents expressed hope that their children would learn to dress themselves, feed themselves, and perform other activities of daily living like brushing their teeth and tying their shoes.

However, emphasis on a group of goals related to appropriate social behavior, communication, and choice-making was nearly universal. Almost all parents expressed the conviction that their children “have to be able to communicate with people and interact with people and work with people,” and that these skills were a primary educational outcome. Parents hoped that their child’s high school experience would be socially formative, providing “friends, a social life, and other things that are important to their day....School can help prepare them for what would be valuable to their day after they’re out of school.” For many, this included soft job skills, because “if we’re talking about our kids working, behavior has to be right up there with reading.”

Especially for children whose parents felt that many strictly academic goals were not attainable, and for parents of older children who were nearing or had reached the end of high school, social and behavioral learning, including better communication, took precedence. For example, “learning more and more language and, you know, using it more appropriately,” was mentioned as a goal and echoed by other participants. Choice-making was another popular response.

“It would be nice if he can understand that he himself can make a choice— be a change agent. I think that would be really good....Just the fact that he can be that causal agent to say yes or no, or make a choice of which one he wants or something. I think if he gets to that level just understanding that he can make a choice can put him on a level of understanding literacy or number concepts or things like that as well. And I think that would open the door for him for other much bigger things.”

Safety was another concern that seemed to underlie many of the responses about educational expectations, especially goals related to appropriate behavior and articulating choices. Parents expressed a desire that children would learn “how to adapt to [their] surroundings,” and “how to think on [their] feet, take information and then decide what to do with it.” One mother and father began discussing goals by talking about teaching their son to take initiative within their own household:

“We kind of asked the teacher, you know, if can teach the initiative; go ahead, grab the water, open up your own fridge, grab your own food, if you want to turn the TV on, go ahead; turn the TV on. Even if he’s wanting to get up, want to do something, he just look at me, ‘Can I do something?’ I say, ‘Go ahead, do something. This is your house. Do what you want. Go get anything you want.’”

But the mother concluded her response by saying, “One of the things that I am really for is to be an advocate for himself; to be able to say tomorrow, when I’m an old lady, ‘I don’t like this,’ or ‘Don’t touch me,’ or whatever it is – to be an advocate, and that’s a big goal; I want to see that.”

In general parents expressed reluctance to separate their academic and functional educational goals for their children, and opinions differed on which aspect of teaching and assessment should take priority. One mother whose daughter had graduated high school articulated her feelings this way:

“I have this love-hate thing with the whole life skills and inclusion. We really worked hard for my daughter to be included and we wanted real academic goals. But now that she’s 24 I know how important those functional life skills things were....It doesn’t have to be either or, but we need both pieces there.”

Parents stressed that they “want the life skills, but also want a lot of focus on academics.” Concern for their children’s post-secondary prospects, whether this included employment or

continuing education or not, was evident in the goals described. Very few responses, whether they were in response to the ‘functional’ or ‘academic’ question, were offered without reference to the parent’s hope that their child would eventually live or work independently.

Post-Secondary Expectations and Transition Planning Goals

When asked about their post-secondary goals or transition plans, parents most often indicated a preference or existing plan to help their child secure community-based employment. College or continuing education was frequently discussed, although parents expressed hesitation about whether this goal was appropriate for their child and a lack of knowledge about resources to support this. In general, parents believed that the benefits of college for their children would be “social” rather than “academic.”

With few exceptions, parents expressed strong opposition to day programs or segregated settings, even while they acknowledged that resources for other options were not always readily available. Parents often saw themselves becoming the primary support system for their children’s community participation. Many parents had not yet begun transition planning or had not thought in detail about post-secondary goals, and in certain states serious dissatisfaction with the planning process was expressed almost uniformly within the group.

Responses to questions 13 and 14 above, about hopes or expectations for post-secondary goals and transition planning, included:

- Trade school or vocational school
- Work-study program, job sampling or volunteering at a job
- Lifelong opportunities for learning
- Community college (academic participation)
- Community college (social participation)
- Art or music classes
- Auditing college classes
- Getting a job on a college campus
- Working at The Arc or at a thrift store
- Volunteering at a therapeutic horseback riding center
- Traditional day program
- Work as a greeter
- Work as a model
- Become a self-advocate

Reflecting the concerns described earlier in parents’ descriptions of educational goals, attaining employment was the most often stated post-secondary goal. In some cases parents stated a preference

for trade schools or vocational programs instead of two- or four-year colleges because of their belief that this would develop more valuable job skills:

“We are hoping to get our oldest into a trade school program where he can learn a trade to move on, because honestly with him, I don’t believe he would be college material. He just doesn’t have the want-to or desire to really go on.”

In this case, the mother speaking expressed her preference for vocational school as a choice between job training and the “academic” experience of college:

“I thought about the college end of it but I don’t think that– I can reassess it as he gets older, but I think he would need more vocational and life skills in order to ever set him up for the opportunity to live independently.”

Even for parents who had not done any detailed planning for their children yet, their hopes for the future often centered on whether or not their child would work. One mother expressed her thought by saying: “I don’t know what he can do, but he can do something. So I do think that he can be employed.” And for parents who had been through transition already with at least one of their children, employment continued to be a primary goal:

“He goes three days to a day program, and then the other two days he’s volunteering at a job. Because he’s not employable, unfortunately. As smart as he is he’s highly distracted and so he needs supervision too, and so he needs to be redirected constantly. But I always hope that, you know– he’s 22– that maybe in ten years he will. So there’s always that...hope that he’ll get there.”

College was frequently mentioned as a possibility, though parents seemed to have fewer ideas about how to incorporate this into planning. Many parents expressed concern that their children would not be allowed to go to college because they were receiving modified diplomas or certificates of completion. Several parents discussed being unable to organize services to allow their child to take college classes especially those who indicated that extremely limited resources were available to support any kind of transition in their state. However others said they had connected with colleges that would include students with disabilities in auditing classes:

“So I just had good luck talking with community colleges that will include students. You have to provide the support they need, but they will include students in the classrooms for auditing purposes. You don’t have to pay the tuition. They can be in that experience. Sometimes they can get jobs on campuses– and that’s the type of transition kids should be doing, not sitting in a segregated facility.”

In many cases, parents were able to provide one another with information on programs in their area or strategies for organizing supports during and after the focus groups. Parents who had children without disabilities entering college indicated that this had influenced their expectations and planning for their children in special education:

“We have several other children— we have her basically on the same track, which is college-bound, with the expectation that she will enter community college. I know there are pilot programs that offer great assistance and great programs for children with disabilities, and I’ve heard great success stories.”

College was mentioned as an option for students with a wide range of disabilities, and parents indicated its value as much as an environment for social development as continuing academic achievement. However, many parents expressed doubt that their children would be able to participate academically or indicated that this was not a reason for choosing college as a post-secondary goal:

“I’d love for him to go to college in the sense of the extension of just the social. I think it would be great. I don’t know-- I don’t think he can do anything academically in the college. But maybe he could participate somehow in some other courses like music or I don’t know. And it doesn’t have to be in a university but maybe at a community college or something like that.”

Music and art were both specifically mentioned as areas in which students might take college-level classes. In contrast to parents’ stated academic goals for high school, where reading and math were prioritized and other subjects were not mentioned, reading and math were not mentioned as post-secondary goals. Some parents specifically denied this as a possibility, describing their expectations as, “not for them to go [to college] and take an algebra class, or anything like that, but take classes that they would enjoy, getting to further their education in those areas that they really like.”

Both college and employment were discussed as desirable options in contrast to mainly negative perceptions of segregated day programs. Even parents who did not have other transition plans in place expressed strong opposition to day programs, and they were prepared to provide the needed supports themselves if services were not provided to them. These parents were usually supported by the others in their focus group:

Mother 1: So I have no idea really where he’s going from this school, because he’s not going to a 18 to 26 center base [day program]. That’s not gonna happen, unless I am no longer alive and somebody else permits it to happen.

Mother 2: And then you’ll reach out from the grave. *[Laughter]*

Mother 1: I will do that no doubt. So where he's going I'm not sure, but I have a feeling that it's gonna be me and my husband making the plan to go out and do some searching and either finding an independent job coach or becoming that job coach or that support. Otherwise— well he's not gonna be sitting home.

A few parents did indicate that their child would be going to a day program after graduation, and in some cases were already attending one. Even when these parents expressed dissatisfaction with their situation, barriers were cited to finding alternatives—in particular, the need for one parent to stop working in order to support the child's employment or other activities:

“My daughter has transitioned. And – you know, and she actually had a pretty good transition planning process and did job sampling and community-based instruction and we ended up not going the self-directed route but going the traditional day-program route— mostly because I work full-time and I just couldn't be home enough to kind of help manage that. I needed her to be someplace that she could go every day and have transportation and –she needs one-on-one supervision, you know, so it's not like I can drop her off without supervision.”

The only mother who said that attending a day program was part of her child's transition plan cited differences in the quality of the programs in different areas of her state, and mentioned that the location of her particular program would allow her daughter to visit other family members more frequently, which accounted for her satisfaction with the plan. Dissatisfaction with transition planning was also cited as a barrier to meeting postsecondary goals, and this was concentrated in states where resources were characterized as minimal and schools and other participating agencies as resistant. In describing her son's transition plan, one mother in a state where complaints were frequent said:

“He has his state ID, he has his telephone, it's just-- stuff that parents would do anyway. Transitioning from there to, say to higher ed. or to true employment, we can't even talk about that [in his transition meetings] because the people are not allowed to be in the room that would be paying for that or would be a part of that.”

Parents universally indicated an expectation that their children would be engaged in at least some inclusive community-based activities after high school. Paid employment was the most often stated preference, but both employment (paid and unpaid) and post-secondary education were mainly understood as alternatives to segregated programs. Parents placed much more emphasis on the “social” benefits of continuing education than the “academic,” and did not express any expectation that college would continue to build on the academic goals expressed when they were asked about elementary and high school (reading and math in particular). For parents who had begun or completed a child's

transition, resistance on the part of schools and service providers to offer community-based options was described as a major barrier to meeting post-secondary goals. For children with more significant disabilities, the intensive supports—including those provided by parents—needed to participate in community-based activities was an added barrier.

The Role and Formation of Parental Expectations

Parents indicated that they found it very normal to have high standards for their children. When asked how they arrived at their expectations (questions 11 and 12, above), parents expressed both surprise at what seemed a very obvious question as well as awareness of the historical impact of expectations in special education that provides the backdrop for this line of questioning. This area was one in which parents pushed back against the researcher, reading between the lines and offering countering questions.

In general parents found it normal to have what they understood as high expectations for their children. This attitude was often expressed as wanting to “push” students, or help them achieve “their full potential.” Many parents reiterated a focus on educational achievement, saying “we’ve always focused on pushing the academics with her as far as we could go.” Parents seemed to understand having high expectations of their children as part of what it meant to be a parent—whether this was of a typical child or a child with a disability:

Moderator: I’m wondering what kinds of things led you to these expectations. Why is it that you have the expectations that you do of your child?

Mother: We love our children.

Father: [Laughter] I’m sorry. That’s funny to me. I have five children, four average children, and then [my daughter]. And my expectation came the same way with all of them. You get to know them. You have a sense of where they are and where they ought to go, and you push them that way.

Mother: If you love your child, you want them to succeed.

Father: It’s called being parents, I guess. I don’t know.

Parents also had strong and sometimes suspicious reactions to questions about their academic expectations and how these expectations took shape. These parents felt that posing this question in the context of special education could put forward a double standard for their children with disabilities. In response to the question about what academic goals she had for her son, one mother responded:

“My answer is I want him to learn everything everybody else is coming out with, okay? I don’t know but to ask that question, what academics do you expect them to come out with, I expect him to come out with everything. Now will he? I don’t know, but if you get what I’m saying there’s something interesting about asking that question and not assuming that we want the kids to come out with what the kids without disabilities come out with, you know? Because I doubt a Gen Ed kid’s parents get asked that question.”

During this part of the discussion several parents reflected on their belief that schools and teachers had lowered their expectations as their children got older, and their perception that schools’ expectations for their children did not match their own.

Mother 1: I hate to say it but that goes back to expectations when our kids are in elementary school....Speaking from our own experience, the expectations were so low– what was your quote? [to *Mother 2*] That if you have high expectations...

Mother 2: He’ll meet your high expectations but he will also meet your low expectations.

Mother 3: Isn’t that true of any child? I mean –

Mother 1: Educators don’t know that. In my experience they don’t practice that.

This topic was another area where tension became evident between parents who were frustrated with schools’ low expectations and parents who were frustrated with schools’ continued emphasis on teaching and assessing academic skills. Many parents who expressed the latter frustration had older children or children with more significant disabilities. In each focus group, at least one parent took the position that based on their child’s experience in special education they were more concerned with having what they perceived as “realistic” expectations than with “high” expectations. Some of these parents expressed frustration with their child’s lack of progress in terms of academic measurement, even when these parents felt their children were acquiring valuable social or functional skills. For example, one mother responded by saying: “Of course I’d like to push her as far as she can go, but I don’t even know how far or how to push her– I’m just so overwhelmed and exhausted after all these years of dealing with it.”

A concern that was raised in response to several questions about goals and expectations was the effect of a focus on academic standards on children with different levels of ability. Several parents said they had difficulty addressing what they saw as their children’s most pressing needs with schools in the context of conversations about high academic expectations:

“It’s very hard for me to talk about that in these conversations when people are talking about standardized tests and students with disabilities, because I feel like often the interpretation is either I don’t have high enough expectations for her or I’m...or there’s a risk of kids who can learn being swept up in a tide of low expectations that has I think been part of the history special education.”

This mother, whose daughter had recently completed high school and was currently attending a day program, continued to explain her position this way:

“You know, we didn’t start out saying that we didn’t have expectations for her; we thought she’d be able to learn how to read and do math– so it’s not like, you know, so somebody has a significant intellectual disability, so automatically there are assumptions made about what they should or shouldn’t be tested on or expected to learn, you know. But over time as you try and try and try and start realizing it’s just not going to happen, then I think the testing and the expectations need to be adjusted....I am in no way trying to speak for anybody other than myself, but for students like my daughter, with the more significant intellectual disabilities, high academic standards are not meaningful.”

Other parents of children at or near the end of high school expressed similar sentiments. Several talked about their concern that too much emphasis on academics made their children “invisible” in conversations about special education. While they did not state that an academic focus had negatively affected their child’s learning of life skills, they struggled to express the relevance of life skills over academic skills in this discussion and in light of the historical conversations about high and low academic expectations for students with disabilities:

“How can I honestly say ‘these are my daughter’s limitations’? I really love her. I really have expectations for her. I have hopes for her, but the reality is she does not know her colors, numbers, letters; she can’t read, she can’t write. We have tried every which way she...has not learned that and we need to talk about her education and her future in ways that recognize that without it being dismissed. I feel like children like [my daughter] become invisible in a lot of conversations. I feel sometimes both in the realm of education and the realm of adult services it’s just hard to talk honestly about the reality of an intellectual disability.”

The theme of struggling to articulate the value of social and functional skills without being seen as undervaluing academic skills or having harmfully low expectations of children was a major factor in parents’ perceptions about the relevance of alternate assessments. While many parents did indicate their desire for better supports, better coordination, and more options, both within schools and after transition, the emphasis on gaining independence after high school was paramount.

“When we say college and career readiness what does that really mean? In my mind I interpret that as I want her to have skills that help her to live a productive and meaningful life in the community.”

Although parents stated the belief that high academic attainment was possible and desirable for their children, academic skills tended to be valued as a complement or addition to functional skills while functional skills were deemed valuable in themselves. For parents, especially those of children with more significant disabilities, academic skills were seen as important but functional skills ultimately took priority. Because of the close relationship among these skills, but also to avoid the risk of being perceived as underestimating their children’s potential, parents often would not discuss academic and functional skills as separate goals and struggled to describe the importance of learning goals labeled “non-academic” to them and their children.

Parents’ Experience and Perceptions of Alternate Assessments

Knowledge of Assessments

Although parents in the focus groups voiced strong opinions about alternate assessments, they described themselves as having little knowledge of them—far less, they said, than other aspects of special education. When asked to rate their knowledge of alternate assessments on a scale of 1 to 10, with 1 being uninformed and 10 being very informed, participants rated their knowledge an average of 2.5. Only two of the 44 participants rated themselves higher than a five, and both of these individuals acknowledged that their involvement in special education as part of their professional lives had likely affected their responses.

Mother 1: I’d probably say around a 7, but— I’m chair of the Education Committee for The Arc [in this state] and we’ve had people come in and talk to us about the testing so.

Mother 2: Mm-hmm. I’d probably say the same thing [7], but it’s more because of stuff like that and work-related, and just because I was curious and I looked ‘em up.

Most participants rated their knowledge a zero, one, or two. Even otherwise very well-informed participants identified the alternate assessment as a weak area in an otherwise strong knowledge of special education.

Mother: It’s really an interesting question because when I look at all the aspects of special education I feel very well informed and this is an area I do not. I would say 4.

Participants were aware that their knowledge of alternate assessments was probably higher than most people's because of their advocacy work. Some found it hard to rate themselves, because while they knew they could learn much more about assessments, "if you compare it to a lot of the other families, they probably don't even know that, you know, [the alternate assessment] exists."

Parents made it clear that they did not rely on schools to provide more information about assessments or their relevance for their children. While several parents said that they could have or should have asked more questions of the school, others indicated they did not know what questions to ask or, more often, that schools would not answer them. Even after rating themselves very low on the scale of 1-10, some parents felt that their knowledge at least equaled that of school staff:

Mother: Actually I have to say I've sat at IEP [meeting]s where I think I understand the tests more than the people who are... [pause]

Moderator: ...Giving the test?

Mother: Giving the test.

Most agreed that "the communication [with schools] hadn't been very good." Only parents that worked in schools had any knowledge of how the assessment was administered, and this was a major source of confusion for parents—especially those whose children were nonverbal or had the most significant disabilities. One mother whose three children were all nonverbal said,

"I wasn't given any information about how the test would be performed, or what kind of questions...I know they can't go by basic questions, but what they were going to do in order to...to provide this test to my children, and how they were going to get my children to take this test."

A few parents were engaged in ongoing struggles with schools at the time of the focus groups to try to learn more about how their children were being assessed. One mother who had previously engaged an attorney because of a separate issue with the school recalled that she had asked for a year to see her daughter's portfolio, and the day she withdrew her legal complaint she was informed that she could come in and review the portfolio and scores. Another mother, whose son is nonverbal and has multiple disabilities, recounted:

"So what I ask them is, 'Okay, so can you tell me some of the things that you're – you know, what you're doing?' And they said that they can't tell me. I asked them– 'Okay so then don't videotape the alternate assessments but why don't you do a mock alternate assessment to show me how are you testing my child [and videotape that]?' And then they said the district will not allow for videotaping."

Although these parents expressed concern that they were not able to learn more about their children's assessments from schools even after asking, other parents had not known until the focus groups that they were supposed to receive scores at all. A few had requested scores from the school for the first time in preparation for the focus group, and during some of the groups it became evident that scores were not shared uniformly with parents across or within school districts in some states. Parents' perception that schools were reluctant to share information with them regarding alternate assessments may also have colored their responses about the purpose of the assessment.

Perceived Purpose of Assessments

Parents did not perceive the alternate assessment as something that was meant to help them. Most expressed frustration that the alternate assessment also did not seem to them to be intended to help their child. Parents differed widely on their knowledge of the assessment's purpose based on their use of legal and technical terminology; only a few offered responses such as "I know it's required for the district to make AYP [Adequate Yearly Progress]— you know, [my son] has to be included." Much more common were responses such as "It's for the state; it's not for the child." One or two parents did demonstrate awareness of the alternate assessment in the context of trends in special and general education:

"I mean I think it's part of the whole movement around high-stakes testing for all students, and this is a way to include students with, you know, the most significant disabilities....I've certainly heard parent advocates say they feel, you know, including our kids in the high-stakes testing has forced schools to sort of pay more attention to our kids, that when they weren't included in testing they could just sort of not pay attention because nobody cared about the outcome and this sort of forces them to change perspective."

But even these parents felt that the primary audience for results were schools and "the state," and that "The alternative assessments and the standardized assessment are really meant to look at the schools as a whole...they're being used in more aggregate ways than measuring the individual child."

Many were more direct. Some parents stated that since the assessments did not seem to measure anything relevant to their child's learning, academic or otherwise, and that since results had not been widely shared with or explained to parents, they could not discern any purpose beyond meeting some unspecified requirement. As one mother said, "I know it's like required and that's the reason they do it....But it's like they have to do it, so they do it. The results aren't shared, so it's hard for me to even know or to suggest what a purpose would be." Another agreed: "I don't know what the purpose is and I

don't know that it actually helps my child other than the fact that I know his teacher has to do a whole lot more work and a whole lot more paperwork to get it done."

The overwhelmingly dominant impression of alternate assessments was that they were administered to "grade the teacher" and are "a hoop that the school has to jump through." Much discussion of the assessment's purpose also included complaints about standardized testing in general, both in terms of the stress placed on students and teachers and the disruption of regular teaching and learning. Several parents complained about their children in general education classrooms "wasting time" on standardized assessments as well as complaining about the alternate assessment, but many reiterated that the results of the alternate assessment had not even been shared with them or were not explained to them in a way that demonstrated how they would be used.

In addition to engendering suspicion about the alternate assessment in particular, the lack of information or perceived resistance to sharing information supported parents' broad conclusion that the purpose of the assessment was to get money for the school. By far the most common response to questions about the assessment's use or purpose included reference to school and state funding structures, and occasionally to teacher employment and compensation as well:

Father: It's a process for funding.

Mother: It is.

Father: And that's what we see.

Even when debate took place among participants about the benefits of having children with significant disabilities included in testing, parents agreed almost unanimously that the assessment's primary purpose was to help schools get and keep money. This was true whether or not parents demonstrated an understanding of why and how assessment results could impact funding.

Information Received About Assessments

Parents reported receiving little or no information about alternate assessments ahead of time. The most common response to this question was that nothing had been given or explained to them. A common exchange around this question went like this:

Moderator: If you received any information about the test beforehand, before it was administered, what kind of information was it? Where did you get it, or how was it presented to you?

Mother 1: Nothing.

- Moderator:* Okay.
- Mother 2:* Nothing.
- Mother 3:* Nothing.
- Mother 4:* Mm-mm.
- Mother 5:* Nothing.
- Mother 6:* No.
- Mother 7:* I sit on the statewide Special Education Advisory Committee so it gets talked about on there and through our work with the [Parent Training and Information Center]....But from the actual school staff not a word.

This response includes all but one of the participants in a focus group of eight. As was typical for many of the questions, one or more parents had received information from a source other than the child's school, such as from an advocacy group or through their work. As one mother, an employee at a university center working on a disability project, said:

"I don't think they even tell me that it's called alternate assessment. I think they just say like, 'Oh, we're going to do general testing. The school is all doing testing during this time.' So yeah, actually they don't tell me it's alternate assessment. I just know it's alternate assessment."

The most common response for parents who had received information ahead of time was that the school sent a letter or flyer home with a schedule of test times.

"We would get information from the school saying the assessment was going to be these days, please make sure your child is at school, please make sure they get a good night's sleep, please make sure they eat a good breakfast. But no real information on the test itself."

However, some parents were unsure whether the general testing schedule outlined in these letters applied to their children taking the alternate assessment. In at least one state, notices were mailed home to parents with general testing schedules that did not apply to the alternate assessment and parents of children taking the alternate were not provided with a separate notice:

"My experience to me is a double standard... I have three other children, and I have notices when we're gonna have the [state standardized] test. We have prep days.... My daughter, she likes order and schedule. I need to know a few days before when you sit down with her and do the [alternate assessment]. I need to prepare her for what to expect the next day at school, so I had to have it written into her IEP as part of accommodations to notify the parents when

you administer the test to her. So I feel it is a double standard and no – it's not even on the school calendar where they [show dates of] the other tests....That's making our kids invisible."

Other parents did have information shared with them by their child's teacher or in an IEP meeting. This was usually described in terms of deciding whether or not the child would participate in the alternate assessment or the general assessment, or in some cases which version of the alternate assessment the child should take. Although these parents did report that schools brought the assessment to their attention, the terms and outcomes of these discussions varied. Although she said this is "nobody's fault," one mother described how:

"When my daughter was younger and we've come to that part of the IEP...you know there's like two or three different kinds of it, and nobody really knew what was the most appropriate choice and a couple of times we looked at sample questions and it just seemed totally unrelated to anything that she'd ever done in school."

A few other mothers described talking with teachers or other parents, outside of IEP meetings, and hearing their perspectives on the assessments. In the cases that were described, this discussion often influenced how the assessment was viewed by parents. Even parents who did not receive any information from schools directly, for example, indicated their perception that alternate assessments create a lot of work for teachers. One mother recalled her daughter's teacher "going on and on about how time consuming and how much work it is and how much effort, and it was really going to be meaningless when all was said and done, and it really wasn't measuring [my daughter]." Another mother from the same state said:

"In junior high, [my daughter's] teacher showed me examples of portfolios, and I had heard from other parents that it was a waste of time and really critiques the teacher more than the students. In seeing the examples, I could see how much work it was for the teacher, and not really reflective of where students were, so I opted out. I said, 'I don't think there's any reason for you to spend time on this, when you could be spending time on instruction and other things,' and she said, 'Thank you.'"

Parents reported mainly the same range of responses when discussing information they received after the assessment. "Nothing" was again a frequent answer, especially in certain states, although many parents did indicate they had received a score report or letter. These reports were described as "not very explanatory," and parents did not always know how to interpret their child's scores. Even for parents who received scored portfolios,

“There’s no information about how they got to the scores, so if my son was advanced proficient, advanced proficient in what? ...Scoring-wise, there was no detail as to how they came to the fact that this is what he got, this is how they gauged him, this is what his percent was.”

IEP meetings were the second important way that parents received feedback on their child’s scores, and at least for some IEP meetings provided more useful information than the score report. However, the degree of difference this made varied widely. One mother who described meeting with her child’s IEP team said that she “understood what they were talking about pretty well. The teacher is very good and she was trying very hard to make it applicable or show how to tie it in. I think it was a valiant attempt.” In other cases, however,

“They talked about results and the teacher did a little bit about how he performed on this or that. But they didn’t talk about, “We use this to do this,” or anything like that. If that’s what you mean. They didn’t talk about if that assessment drove their instruction. I never heard that.”

Not understanding if or how results could be used to change teaching practices or provide additional supports to their child was a frequent complaint. Reports on the alternate assessment were seen as especially frustrating where children did not perform well in contrast to other types of assessments that resulted in clear-cut recommendations. While parents did indicate that specific data was most helpful, several felt that alternate assessments seemed too focused on children’s deficits and not enough on their progress:

“All it said was she needs too much help with this, she need too much help with that, she need too much help with that, and I said well no kidding. I know she needs too much help so how do we get her past that?”

The lack of connection to relevant material or future instruction in some cases seemed to frustrate schools and teachers as well, and parents picked up on this frustration. One mother who had a good relationship with her child’s teacher and IEP team remembered that they “sat around the table and just agreed– they too agreed– it had been a complete waste of time. So they did include us; they included us in agreeing that it had been a waste of all their times.”

A few parents did not enjoy this rapport with school staff and were told they could not see their child’s results. In some cases these parents had also been told they could not know how their child was being assessed or what the assessment would cover. One mother described several iterations of this conversation with school staff:

“I’ve asked them several times, ‘Could you show me— like how are you assessing him? Are you giving him choices? Are you doing eye gaze? Like what are you doing?’ And they won’t even tell me. They said, ‘Well we already submitted it and we can’t replicate it and I don’t exactly remember what it was.’”

A concern that came up in two of the focus groups was a lack of information provided for parents whose first language was not English or parents who did not speak any English at all. Several participants in these groups explained that written materials were not provided in their preferred language, technical terms in English were not explained to them, and qualified interpreters were not provided. In one instance the school janitor was called in to interpret at an IEP meeting. Mothers in these groups stressed the need to provide written materials, certified interpreters, and knowledgeable bilingual advocates to help them through IEP meetings and, in some cases, court proceedings. Previous requests for translation had not been met:

“I request over so many years to get the IEP translated to me, and they never have. Even say, ‘I have the right to ask.’ Yeah, I have the right to ask, but I don’t have anything, even I ask. Since I ask, since elementary school until now—that’s been over 10 years.”

Although this mother and others did say she had received assessment results from a score report, she was unfamiliar with the terminology around the alternate assessment and found the report difficult to translate. No additional communication or in-person explanation was provided.

“Usually, they mail it to us, and as the minority, I’m not really get much about the portfolio, because they are not translate in my language. I try to understand a little bit better, but it’s a stumbling, special terms or whatever that is. To tell you the truth, my son is 17, so he’s in the special education almost over 10 year. I still stumble about the IEP things....So for the portfolio or whatever that is, it’s that the teacher not really sit down explain to us, what’s that about. Only the paper sent to us. And a lot of times we have no ideas and we have to sign it anyway, because that’s what they ask you to sign.”

Only one participant used another mother as an interpreter throughout the focus group discussion, but several participants whose first language was not English expressed their concern that large populations of parents in their state or city were less able to communicate than they were. The same mother quoted above described learning English as an adult as “a huge challenging thing.” She continued, “I really understand the other people, they still have the language barrier. How can they overcome to advocate for their child? It is impossible.”

Relevance and Use of Assessments in IEP or Transition Planning

Parents unanimously said they were not using alternate assessment results to inform transition planning, and in almost all cases results were not tied to IEP goals or even brought up in an IEP meeting. A typical response from a focus group when asked if results had been useful for planning was:

- Mother 1:* It's not used at all.
- Mother 2:* I never seen it used.
- Mother 3:* Mm-mm.
- Mother 2:* I don't have a record, either.
- Mother 4:* Never used.
- Mother 5:* Never even mentioned.

Many parents reminded the researcher when asked this question that they still had not received any assessment results, but this was not the only reason that parents did not seem to value the assessment as a planning tool. Most seemed surprised to be asked about using the results in planning and were not sure how that might be done:

- Moderator:* And so if you got the information, do you know how it was used, or whether it was used in IEP planning, in transition planning? [*silence*] Do you use it at home? [*silence*] Does anybody use it?
- Father:* Yeah. It's right on the refrigerator.
- [*Group laughter*]
- Mother:* Well if we don't get them, how can I use them?
- Mother:* Even if you do get them, how can you use them?

However, during the course of the focus groups parents mentioned several other sources of information that they did use and felt were more helpful in planning for their child's future:

- Progress reports
- Report cards
- Schoolwork sent home
- Communication with teachers
- Neuropsychological evaluations
- IEPs
- Vocational assessments
- Job sampling programs

Parents found these sources more descriptive and more detailed. One mother described her son's progress reports as "phenomenal—they're like 20 pages long, and breaks down every single thing. It breaks down the reading comprehension, the math, the music—it breaks down all the subjects." Neuropsychological evaluations were noted as helpful for understanding a child's learning style, and direct interactions with teachers provided an opportunity for parents to ask questions and get detailed feedback. Job sampling programs and vocational assessments were described as providing concrete ideas about how to "move forward."

In contrast, parents did not feel that alternate assessment results were trustworthy, were relevant to their goals and plans, or were valued and used by teachers for instructional purposes. Some parents, after seeing score reports or portfolios or conferring with the IEP team, simply felt that the assessment "was not an accurate portrayal of what [a child's] abilities are, or what he knows or understands." In other cases, parents provided more reasons for their doubts:

Mother: [Our daughter] and [our son] took it, but...I have no idea how they took the test. They have scores of mastery and partial mastery. All three of my children are non-verbal. How they came to that conclusion, I don't know.

Father: And our kids, they don't communicate, and they've never been able to-

Mother: I mean, they don't communicate verbally.

Father: Right, but [the school has] never been able to come up with any type of communication device or anything, so how they think that [our son] and [our daughter] are reading something, or are answering mathematical questions...or if they're just judging it off of their listening while someone else is reading it to them?

Other parents recounted similar stories that, over time, had led them to discount the alternate assessment. Several said they were unable to replicate tested skills at home with their children, and some pointed out that the assessment results seemed to contradict other documentation provided by the school:

"At first, I really look at how that grade is, if that reflects of what he is, but actually it's not. And now, I'm not even want to look at what the number is when they send it to me, because it just does not make sense. It's not talk about my son at all. Plus, when you look at the IEP, the teacher have been saying, 'He's not doing this. He's not meet the goals. He's not independent.' It's just reverse things going on. So it looks like the paper is somebody else. It's not my son."

As described earlier in this report, parents saw themselves as having high expectations for their children's academic achievement and in most cases expected their children to be employable, engaged

in learning, and included in their communities as adults. However, no matter what parents indicated their expectations were or what their child's ability level was, alternate assessment results were not seen as relevant to helping their children move toward these goals. Some parents simply rejected it as part of a movement toward testing that they felt was unproductive overall. One mother who expected her son to pursue post-secondary education said "this isn't going to help my child in college. And it sure can't help my child in the real world." However, another mother whose daughter was at a very different skill level explained her disregard almost the same way:

"I don't even look at the scores because I enforce to [the teachers], "Don't prepare her for it. What's to prepare?" You know five minutes in front of something studying is not my solution to her life-long situation."

As this quote illustrates, while no parents were deeply invested in the alternate assessment as a planning tool, it was the parents of children with the most significant disabilities that objected most consistently. One mother, who worked in her son's school and had seen the assessment given to other children, explained:

"His [alternate assessment] last year was learning about planets. What is he going to do with that? Nothing. I'd rather him learning [to] go to the bathroom or learning to play. He cannot play; he doesn't know how to play, interact with other kids. I'd rather he do that than learning about planets or making a narration story."

As was the case during the discussion about expectations, these parents were grappling with the tension between the benefits of inclusion in testing for children with significant disabilities and the frustration they experienced during their own child's alternate assessment. One mother who made this point several times summed up her position by saying:

"I always am really very careful to say that it's different for kids who are making academic progress, but in [my daughter's] case to be looking at math skills that supposedly were linked to grade level core content standards when she's in high school and she's doesn't know how to count to three; what are we measuring? It just felt so meaningless.

I struggle with it because I do understand that school's an academic environment and there are educational needs related to academic skills. But somehow it just felt like we had lost sight of...any meaningful view of [my daughter] and what she was learning, and what we were moving towards in terms of her future."

The final reason given for not using assessment results in planning was that they were often not given to parents or brought up in IEP meetings. Some parents gave this as a reason for their surprise in being asked about assessments as a planning tool, and others indicated that this told them even schools did not find the results useful. Parents oscillated between being angry at a lack of interest in the results on the school's part and ambivalence about whether results should be incorporated into planning at all. In many cases this ambivalence was again underscored by a lack of knowledge about the process of assessment or a lack of communication about the results. In the discussion around tying results to IEP goals, one mother explained:

“Usually when you take a test, the data from the test, then you take action, right? It shows the child does or doesn't know something and if it's an area they're weak in, then you know you support them in that area. But I get these test results back and they mean nothing to me.”

However, participants in this group did not think it was impossible to incorporate assessments into planning. Mothers in this group offered the opinion that if schools treated the tests as important for something other than funding, “the significance of it will then be translated to the parents.” Although in almost every other area of discussion parents were more likely to disagree with schools than agree, in this respect they relied more heavily on the behavior of teachers and staff. Especially due to a general lack of knowledge about assessments, parents' perception of their possible uses was limited by their sense that assessments “are not being presented in a way that lets us know this is a valuable piece of information.”

Although parents offered many reasons for not using assessment results in planning, the most significant was that results were not given to them at all or that they were not introduced in the context of IEP planning. Beyond this, many parents did have serious concerns about the trustworthiness and relevance of results for their children. However, it was clear that across all of the groups, parents had not really considered using the assessment results in this way. They did not understand the assessment as something that was for them or their children at all, as described earlier. As one father put it, “Whatever they're doing for the purposes of doing it, bless them. But what's that got to do with me and my world and my daughter and her world?”

Reporting and Resources to Support Understanding of Assessments

During the focus groups parents discussed how they currently learn about alternate assessments, what resources they would find helpful, and what changes can be made to the reporting process to

better support their understanding. This table provides an overview of the resources parents indicated they currently use to help them learn about and interpret alternate assessments. The right-hand column summarizes suggestions parents made for additional resources they would like to see in response to questions 5 and 6, above.

Resources Currently Used	Resources Suggested
<ul style="list-style-type: none"> • State Department of Education website • Conversations with teachers • Call State DOE Office • OSEP website • Information / resources on score reports • Center for Educational Networking website • Advocacy groups providing special education advocacy (The Arc) 	<ul style="list-style-type: none"> • Post information on child’s personal school information page (personalized portal) • Meeting to discuss assessment results • Paper and electronic score reports • “Assessments for Dummies” handbook • School district website—not just state; provide school and district AA numbers • Workshops and trainings (like for IEPs) • Guide to helping parents work on goals not mastered at home • Q&A website about legal rights • Structured responses for addressing resistance from schools

The resources above were described as helpful in understanding alternate assessments. However, many parents had not sought additional resources or said they would not know where to look for help interpreting score reports. Some parents admitted that they “probably should ask more questions,” but a few made the point that:

“The problem I think we’re all expressing is it feels like these tests are measuring stuff that is meaningless and not helpful, so it’s not even like we care enough to have it all explained to us. I think we’ve all said the same thing; we just take it and push it aside. So the problem wasn’t not understanding. Right?”

Many parents did say they disregarded the alternate assessment results. But others either expressed or demonstrated a lack of understanding about how assessments were related to educational goals and core curriculum content standards, and many indicated that more resources would be helpful. Parents expressed a consensus that it was the school’s responsibility to provide them with context for understanding their child’s scores. While parents said it would be helpful to get this information in a meeting, such as a parent-teacher conference or IEP meeting where they could ask questions, it should be “on their backs” to call these meetings.

Parents stated a desire to access information both in print and online. While the most commonly cited resources being used were state and advocacy group websites, parents acknowledged that not everyone had access to the internet and that they would still prefer to receive a paper score report and supporting information as well. One resource that was mentioned in two states was the schools' personalized information portal for students, which parents of general education students were using to view their child's day-to-day work and communicate with teachers. However, use of this tool was not uniform across states or even across teachers within a single school. Differences were also cited between use by general and special education teachers in a single state or district.

Parents emphasized that "resources" to them included materials to help them advocate for better use of the results and better communication about the assessment. One father mentioned using resources from his state Chapter of The Arc and working with their advocates:

"I think [the Director of Education Advocacy at The Arc] helped us a lot and— in a formal approach to some of these things, to have a separate body whereby you could get some information or know what your rights are —I think that's very helpful. The Arc has a structured response to some of these things. For example you have a right — a legal right — to get this result within this period of time and [The Arc] will give you a letter or [The Arc has] a website that you could point the school administrator to indicating you want to exercise this right."

Other parents also spoke highly of trainings or workshops they had attended on other issues, such as IEPs, and suggested that similar trainings be conducted around alternate assessments.

Based on what parents had indicated about their knowledge of the test, its content and relevance for their child, one mother summed up what any supporting resource would need to provide:

"For myself what I need, I need to know first the purpose of the tests, and what it is intended to show. Then as the result of that what I need is now that we have the results of the tests, how is this information going to be implemented and implemented in such a way that it will enhance my child's learning."

While the emphasis on legal rights and training indicates existing suspicion or anxiety about alternate assessments and working with schools to improve communication and make significant changes, parents focused their suggestions for resources mainly on understanding the purpose of the test and tying the results to planning for new educational goals. Conversation also indicated that most parents did not understand the way that existing score reports communicate scoring criteria or how the skills assessed were related to grade-level core curriculum content standards, which often led them to conclude that results were not important to their child's education.

When asked specifically about changes to the reporting process or what they want the alternate assessment to tell them, parents offered the following suggestions for what any score report should explain:

- What was the baseline measurement to compare this score to?
- What were the goals selected and how much progress has been made toward them?
- What was the tool used to measure this, or what does the test look like?
- How much exposure has the child had to the content included in the assessment?
- What is the child's relationship to grade level (i.e. reading on a third-grade level)?
- How does this child's test fit into the system of accountability?
- How will the school will be accountable, and what resources they will provide to address unmet goals or areas of weakness?

In order to learn as much as possible, parents felt "the more specific the data is, the better." They wanted to be able to tell the difference between academic progress and developmental maturation, and also to get a sense of their child's growing abilities in addition to any areas that need work:

"I want it to not just be about what my kid can't do, but show what they can do as well. There's nothing worse than getting something where it's just doesn't, doesn't, doesn't; I want to know what they can do as well."

Parents also wanted a better sense of how their child's test fits into the system of accountability for the school, and what specifically schools would do to address identified deficiencies or unmet goals. One mother pointed out that when another one of her children's standardized tests indicated she needed help in math, the school provided access to a "Mathnasium" support program for students in general education to bolster her skills. This mother made the point that "if they have resource services there for other kids without disabilities, our kids should have access to that as well."

The final suggestion parents made was to offer more avenues for parent feedback. Several told stories of their favorite and least-favorite teachers, schools they had loved and schools that refused to communicate with them, but all indicated that their relationship with the school was perhaps the most important factor in their perception of their child's education. Noting the sometimes drastic effects of changing states, districts, schools, teachers, or paraprofessionals, one parent made the suggestion that assessments contain "some type of feedback from the parent about how the child was...instructed over a period of time." A few parents went further, stating that if the purpose of the assessment was really to assess the quality of the schools, then a better method would simply be to survey parents:

"You will get some parents who are going to complain no matter what, but if you see a consistency where this school really is nothing but complaints from

every parent, you're going to know there's a problem that needs to be fixed. But if a majority of the parents are happy, and things are going well in the school, I think that would give better results than testing children."

While this parent survey approach may not provide the desired benchmark for planning purposes that an assessment of the child could, it does reflect an important factor in parents' perceptions of alternate assessments: their perceptions of the special education system as a whole. Several questions asked during the focus groups, especially those related to transition planning, elicited strong responses from parents about their relationships with the educational system that probably colored their views on the alternate assessment.

The way parents perceived their own knowledge of alternate assessments and how they expressed their understanding of scores affected the use of scores in planning. More resources are needed to support parents' learning about alternate assessments, including changes to reporting that better support the interpretation of scores. In addition, resources need to frame the assessment as a tool for parents, children, and teachers to use in planning and instruction and encourage parents to insist that results be discussed in IEP and transition meetings. Parents said schools should provide more information and opportunities to ask questions instead of parents having to seek that information on their own. The fact that schools are not currently presenting assessment results as a tool for planning and not distributing results to parents consistently makes the case for providing additional resources that are not distributed to parents through the school.

Parents' Attitudes Toward Special Education

Interpreting parents' comments about alternate assessments in the context of their broader interactions with the special education system is crucial. As described in the Introduction, many of these parents were engaged with this system as parents but also as professional and volunteer advocates. It is reasonable to assume they had more frequent, and perhaps more vocal or oppositional, interactions with schools than the average parent. Some of their comments about alternate assessments can be helpfully understood in terms of their frustration with their child's school or district; however, some of those comments also stem from a lack of understanding about how assessments are conducted and used, which has not been communicated clearly to them.

Many parents expressed fatigue with the level of engagement required by their child's support needs, both within the classroom and in general. Many also acknowledged that they did not have the time or the desire to make learning more about the alternate assessment a priority. However, a few

parents expressed ongoing concern for their child's safety at school, and cited this as a reason for not paying more attention to the assessment:

“When you have a child with high needs— support needs— sometimes you have to pick your battles. You can't go in fighting for every single thing. So sometimes I'm fighting just to keep him healthy at school. The school says, 'We want to double up on all of his feedings.' He's tube fed. And I'm like, 'No. You can't double up. Why would you give him two feedings at once?' So I'm fighting for just his health sometimes at his IEP meetings. So I say, 'You know what? I will let you do whatever you want with his educational goals.'And those are things that I'm fighting for at these IEP meetings.”

Another, more common source of mistrust was the school system's perceived lack of investment in transition planning. Especially in certain places, frustration with transition planning overshadowed much of the other conversation about the possible relevance of the alternate assessment. It was these locations in particular where parents noted that alternate assessments would remain irrelevant, no matter what the form or content, as long as the overall quality of transition planning was poor. And parents made it clear, unanimously in some groups, that they were dissatisfied:

Moderator: And the last question, well, the two last questions are about transition planning. I just want to know, does your child have a transition plan and what is it?

Female: Should we all start laughing at once? *[Laughter]*

As one mother said, “I can apply absolutely nothing to that plan as much as I want and I will still be left with absolutely nothing...‘cause that's all we've ever gotten is nothing.”

Parents reported they were not offered a reasonable variety of resources for transition, and did not perceive that schools were making a sincere effort to help their children meet their post-secondary goals. Concerns were voiced multiple times that process took precedence over results for schools: “The transition planning here consists of having the parents fill out an ESTR [Enderle-Severson Transition Rating Scale], checking boxes on an IEP, and really no more than that. There are no other agencies at the table.” Another mother in this group agreed, saying “They're all about compliance. They are not anything about results, not really. It's just making sure the boxes are checked.”

As described earlier in the discussion on post-secondary goals, parents often reacted to perceived inaction by the school by taking transition planning into their own hands. At one group, mothers shared tips about how to create their own family transition plans, resumes, and portfolios to support their children's job searches and how to push back against the traditional options offered by schools. When asked about transition, one participant responded:

“Well my son has a transition plan, at least that’s what it says at the top of the paper, and it was a struggle to get to what it is. If I had accepted what the resource person was offering me when she first wanted to convene this transition IEP, it would be even less than it is now.”

Another shared that since she was not satisfied with her daughter’s transition plan, her family had gotten together to write a separate one independently.

“My daughter doesn’t have too bad of a transition plan because I wrote it. I said this is what she’s gonna do. These [are the] community places she’s gonna go and so, but if I would’ve taken what they had she’d just be sitting in a segregated building doing nothing.

When offered no inclusive postsecondary options for transition planning, parents were prepared to opt out of working with schools entirely. One mother who had not yet begun transition planning for her 16-year-old son said matter-of-factly:

“I’ll put the plan together, and I’ve got two years to do it and to work him toward that to be successful in that. Left to the school it would not happen— it won’t happen.”

Although many parents did describe difficulty coordinating services for the postsecondary options they wanted, this was not the primary source of frustration with transition planning as they interpreted it. Across groups, some parents indicated their feeling that middle and high schools were less concerned with their children’s progress than elementary schools had been. Parents wondered aloud whether the accountability alternate assessments were supposed to support was being helped or hindered by the increased emphasis on testing:

“There’s something about all of that I did not feel at younger levels; there’s something that has changed at the high school level, and that’s a very significant sense of feeling of less importance. ‘We’re getting this child through school; they’re not getting a diploma, they’re not really helping our school, let’s get them through school’....This makes me question are we really working hard for those transitional services to help this child be a contributing member of society, to be the best person that they can be even based on whatever disabilities that they are working with.”

This mistrust of schools, even where it was unrelated to alternate assessments, came coupled with cynicism about how they were administered and interpreted and what the intent of the testing was. Most parents cited a connection between testing, accountability for teachers, and funding for the school; but “accountability” was not often described as yielding any benefits for students in special

education. For the most part, the history of advocacy in the disability rights movement to include students with disabilities in standardized testing was not brought up. Several parents expressed their wish that their children not be assessed at all.

Different factors contributed to this sentiment. Combined with very little communication about how assessments were administered, parents' inability to replicate what they interpreted as the results of the assessment led to suspicion that data was faked.

"It's more amusing and entertaining...than believable. And I feel like when I'm asking you, 'I'd like to see— how are you testing him, how are you really doing the data collection' and I don't see— you're telling me he's doing this but I can't replicate this at home."

In a few cases, direct observation or conversations with teachers that were described during the focus groups supported parents' suspicions that tests were not being administered fairly or according to requirements. One mother, when detailing the high rate of turnover in special education teachers and paraprofessionals working with her son, recounted this conversation with a new teacher:

"She said, 'I'm new to this state.' This was two teachers ago, when we first started in third grade. And when I was asking about [the alternate assessment] she said, 'I'm learning. I'm from a different state. I just moved to the state. They told me to pick certain complex—I guess the [state standards]— to pick those that we can test for.' And she had to pick something. She would say like, "I gotta see which one he can do, that he can master."

In another instance, one of the participants who had worked in the schools described witnessing different teachers compile portfolios for an alternate assessment:

"I used to work in schools and I used to help teachers implement the [portfolio]. And I was just thinking, how many teachers have I worked with? I can think of at least five. And the worst teacher was the one who straight-up lied, and her kiddos passed. Like, I watched her falsify data, set it all up. She took pictures the day the portfolio was due, and turned it in, and they passed. The best teacher I've seen was the one who really tried to tie it into IEP goals, really tried to find ways to match it. Sometimes they didn't pass—there was no rhyme or reason."

Parents' suspicion of the alternate assessment was reinforced by the fact that it was not used to set goals or in transition planning. This practice seemed to support the perception that the assessment was an instrument for schools, not for children, and that schools had a financial interest that could encourage them to manipulate results. A common opinion was that "the school's plan is not to actually do work to...help the children progress in those areas [measured by the assessment]. They actually find

ways to change the testing so that they can make it look better on their end, make it look better for the purposes of them rather than for the purposes of the children.”

Parents’ attitudes in this regard were summed up by one mother who asked, “How does this work in the face of the school district not wanting to pay attention to these students?” Several parents complained, along these lines, that their children had been assessed on material they had never covered or that their children were not provided enough access to the general education curriculum to be assessed fairly. These parents’ feelings of frustration and sometimes betrayal by the school system were expressed clearly by statements such as this one:

“Assessing the Gen Ed curriculum with kids who haven’t had the same access or very limited or no access is like handing us all maps with an X that says you aren’t here and expecting us to get someplace with it. We’re all gonna be wandering in the wilderness, which is pretty much where I am at this point anyway.”

Alternate assessments became a lightning rod for parents’ anger in the focus groups, but served as a means for them to discuss related concerns pertaining to special education. Parents were nearly unanimous in their conclusion that the assessments were not useful for measuring student progress, and this was often tied to the perception that their importance for school funding made the results untrustworthy. Given widespread agreement on this point, some parents questioned whether or not the tests were fair to special education teachers.

“Is this the right tool to assess how our teachers, how our hard-working teachers are being judged? And how we can help them to do a better job? Is this the right way? How we can come up with additional ideas? I know feelings don’t count, because that don’t give you money.” *[Laughter]*

However, despite general suspicion and a few specific anecdotes about manipulation of data, most parents retained favorable views of their children’s teachers. When they spoke of difficulty they usually referred to “the school,” or sometimes “the district” or “the state” (although state offices and resources were also seen as a trusted source of information). Many parents spoke of having “great, caring teachers,” and several cited their teacher as their most valuable source of information—even information they didn’t think the school wanted them to know. A few offered stories, such as this one, of teachers collaborating with them behind the school’s back:

“The regular teacher and the Special Education teacher, we would sit the three of us around a table and figure out what to best to do for my daughter and we can’t let the Principal know because of everything above the teacher’s levels.

You know there are teachers who will bend over backwards in that way but you can't let anyone know 'cause they will get in trouble."

Many parents expressed sympathy for teachers because of the perceived burden placed on them by "schools" and "the administration," especially in regard to alternate assessments. As one mother said, "I don't blame much on the teacher. I just blame more about how the administration has to be doing it, how funding works." Perhaps because of their frequent contact with teachers, and the fact that teachers served as their primary source of information as well as having frequent contact with their child, parents had positive perceptions of teachers' character and abilities:

"It's not the teacher's fault. I really don't believe that. When you sit down, talk to that teacher, very well-educated, has a heart, compassion, would love to do this and this and this, has all these great ideas—it's really frustrating as a parent."

As noted earlier, teachers themselves did not express enthusiasm for the alternate assessments. This may have been a factor in statements such as the following, in which parents seem to understand alternate assessments as a hindrance to the child's education precisely because of their effect on the teacher:

"I really believe [teachers] got into teaching Special Ed because of their love and their compassion. They want to make a difference, they want to see [our kids] make this big progress this year, and they're like gung ho to do this. Then all of a sudden, they have all these rules and regulations and bleh bleh, it just squeezes the life out of them. Because they have all these checklists they have to meet, and all this data that is not even meaningful for the teaching experience, for the learning experience, and it's just like it sucks the life out of them."

While teachers were often described as heroic, or at worst as ineffective or ignorant about assessments, "schools" and "districts" were vilified by parents in statements such as, "for me the underlying issue of this whole conversation is trust. I just don't trust the school to do anything with my son. Not a thing." While teachers were described as working on behalf of students, these larger entities were most often seen as conspiring to work against parents to further their own interests:

"I don't trust that the district will care one inch whether my kid falls off the face of the earth the day after they're done with high school. You know it just doesn't matter to them— I think that parents that feel like the district cares about a transition plan are just fooling themselves. I mean as soon as your kid's not on their property they're not gonna care."

Parents very rarely talked about specific school personnel or administrators with whom they had problems, while they often mentioned individual teachers with whom they enjoyed good relationships. The most frequent complaint they voiced about teachers was inadequate communication with parents, and this was just as often a complaint about the “school” or “district.” But they were clear that the link between funding, school administrative structures, and the alternate assessment was problematic in their view even where it was not especially well understood.

In the broader context of their relationships with the special education system, which often included conflict, suspicion and mistrust, parents did not view the alternate assessment as a particularly important area of concern. However, the alternate assessment was seen as less reliable than other sources of information because of its importance for school funding, which in parents’ responses was a major motivation for schools to make results meet their needs instead of the students’ needs. Parents widely assumed that alternate assessment results were manipulated or faked, or that children were not provided adequate access to the content covered by the assessments.

Potential use of the assessment in educational or transitional planning was overshadowed and undermined by negative attitudes toward special education in general, and the perceived absence of quality services in areas like transition planning where the results might be used. This was the case where parents had actually received the results of the assessment, and receipt of the results was very inconsistent across and within discussion groups. Parents did not express faith in the ability of the educational system in general to meet their needs or expectations for their children. As one mother said at the conclusion of her group discussion, “It’s just broader even...than the [alternate assessment]. There’s so many little broken pieces.”

Conclusion

The results of the focus groups indicate that parents do not see academic and functional skills as separable, and consistently frame their articulations of these goals in terms of their postsecondary goals for their children—employment being foremost. The goal of employment or the quality of “employability” is a thread that runs throughout parents’ thinking and planning about their children’s social and educational development, even for parents who have not yet actually begun transition planning for their children.

In contrast to employment, post-secondary education was a less familiar option for participants. Though parents expressed awareness of college as an option, they were much more hesitant about whether or how their children might participate than they were in discussing employment. Some

parents preferred vocational training to traditional college, anticipating that this postsecondary option would be more productive for their children in terms of securing employment; other parents had not been able to find a college program that would include their children or organize services to support their child's attendance. Parents who said they did or would want to see their children attend college tended to frame this desire in terms of social inclusion or social development rather than continuing academic attainment. Reading and math, the two academic areas stressed in discussing academic goals for high school students, were not mentioned in relation to post-secondary education.

However, almost all of the parents in these focus groups expressed strong feelings that day programs were not preferred or were not an acceptable post-secondary option. Parents whose children attended day programs largely cited dissatisfaction with this outcome and continued to seek ways to arrange services (or rearrange their family schedules) to support more community-based activities for their children.

The relevance of high academic expectations for children with significant intellectual disabilities was hotly debated in many of the groups. Especially for older children whose major goals were not academic in nature, parents expressed frustration that assessments continued to focus on reading and math and failed to capture significant social or functional skill development. This focus was a major reason cited for not using alternate assessments in planning, and the perceived inflexibility of the assessment in this regard contributed to generally negative perceptions of it among parents.

Parents stated that they did not have a great deal of knowledge about the alternate assessment. Despite being a highly engaged and educated group around disability and education advocacy, parents cited alternate assessments as a gap in their knowledge. This gap was at least partially due to a lack of communication from schools, which varied widely in parents' descriptions and was not uniform across or within states, districts, and schools. In some cases parents described an outright refusal on the part of schools to communicate with them when they sought more information about their child's assessment. Because of the alternate assessment's connection to school funding, this perceived reluctance to share information created an enormous amount of suspicion and cynicism around the assessment.

This confluence of factors—lack of knowledge, difficulty getting information, inconsistent communication, and the assessment's known importance to school budgets—contributed to parents' perception that the alternate assessment is a tool for evaluation of schools and teachers, not children's learning or achievement, and that the audience for results are schools, districts, and state governments instead of parents, children, and educators interested in instructional or educational planning. This was compounded by the fact that schools did not seem to regard the assessment as a planning tool either—

it was rarely introduced in IEP or transition planning as a planning tool, according to parents, even when results were communicated in the context of an IEP meeting. None of the parents participating in the focus groups were using the results of the alternate assessment to plan their child’s future.

In general, parents did not perceive the results of the assessment as trustworthy or meaningful. During the focus groups, they often expressed or implied their belief that schools manipulated results to protect funding. This perception was especially the case where parents of children who did not speak or use symbolic language could not get details on how assessments were administered to their children or how scores were generated. Parents’ lack of knowledge about testing procedures as well as little available information on how to interpret scores encouraged them to heavily discount the results of the alternate assessment.

When asked how they would want to learn more about alternate assessments, parents offered many promising suggestions, including resource guides, trainings, and materials to help them approach resistant schools. A frequent and straightforward suggestion was that a meeting be held to discuss results with educators, so that parents could ask questions and get one-on-one feedback from teachers. In addition to receiving paper score reports, several parents also mentioned that they would like to be able to access their child’s results and more details about the alternate assessment online, either through a personalized web portal for the child or the school district website, instead of state or federal government education websites.

Parents were emphatic that the burden should be on schools to provide them with more and more consistent information; however, resources from third parties such as parent groups and advocacy organizations was also described as helpful. The demonstrated lack of consistency on the part of schools in providing basic information, including notice of the assessment and score reports, thus far strongly supports a case for offering information to parents through an avenue other than schools in addition to bolstering the current methods of dissemination.

Parents’ views on the alternate assessment must be understood in the context of their broader views on special education and their history of interactions with the school system. As described in the introduction, focus group participants were highly likely to be very attuned to their child’s educational progress and engaged in the details of IEP and transition planning. Many cited their unhappiness with their child’s transition planning process in particular, and others explained that alternate assessment results paled in significance compared to the concerns that took up time at IEP meetings. Many parents spoke dismissively of “schools” and “districts,” which were portrayed as entities acting to protect their own interests rather than those of children—especially children in special education.

However, parents were less consistently negative in describing their children’s teachers. Although stories were told about resistant or ineffective teachers, and the high rate of teacher turnover was cited as a problem, parents seemed to trust the opinions of teachers with regard to the alternate assessment. They also told stories that portrayed teachers as co-conspirators looking out for their child’s well-being, and lamented the effects they saw alternate assessments having on teachers as well as children. Many parents couched their comments about alternate assessments in a critique of the educational system, and explicitly exempted teachers from blame. A few suggested taking the money used to administer assessments and funneling it to teacher training and support; some also expressed concerns that teachers bear the brunt of poor assessment results instead of school administrators.

Although parents did not often speak about themselves or their experiences as caregivers in detail, it was also clear that they saw themselves as finally responsible for their children’s success. As described throughout this report, parents saw themselves as parenting their children with disabilities the same way they did their other children, and therefore expected schools to educate their children with disabilities with the same care as other children. Often, critiques of the schools were described not simply as experiences of frustration but of discrimination. Parents did not understand the alternate assessment as a means of inclusion for their children, and in some cases speculated that it was in fact perceived by schools as an instrument of segregation rather than inclusion.

Developing the understanding, of schools and parents, of the alternate assessment as a tool for planning that can support a variety of postsecondary goals for students can help change this perception. Parents expressed eagerness to share the work of helping their children progress academically, including in their suggestions for resources tips on how they could help support their children in areas of weakness identified by the assessment outside of school. However, they also expressed a desire that schools would meet them halfway. As one mother explained, “You know, I’m not expecting the school to do this by themselves. It’s going to take both of us, all of us....I push him like I want them to push him.”