

Parent Perceptions of the Anticipated Needs and Expectations for Support for Their College-Bound Students with Asperger's Syndrome

Julie Q. Morrison
University of Cincinnati

Frank J. Sansosti
Kent State University

Wanda M. Hadley
Central State University

Abstract

Many students with Asperger's Syndrome have the cognitive ability and specific interests to be successful academically at the college level. However, these students often have difficulties navigating social systems, and higher education presents great challenges. The purpose of this study was to explore parent perceptions regarding the: (a) supports or accommodations college-bound students with Asperger's Syndrome need at the postsecondary level to successfully adjust to the academic and psycho-social expectations of the college experience, and (b) self-advocacy skills or strategies needed to increase the likelihood that students with Asperger's Syndrome be successful in college. Parents reported a variety of strategies that colleges can use to support students with Asperger's Syndrome within postsecondary settings and provided insights into their expectations for college-level supports. Implications for practice and recommendations for future research are discussed.

Asperger's Syndrome (AS) is a lifelong disability that is characterized by impairments in social interactions and restricted, repetitive, or stereotyped patterns of behaviors, interests, and activities (American Psychiatric Association [APA], 2000). In addition to formal diagnostic characteristics, many individuals with AS demonstrate a host of challenges that make everyday functioning difficult. For example, individuals with AS often demonstrate limitations with functional communication, or the use of language for communicative purposes (Landa, 2000; Sansosti & Powell-Smith, 2006). Moreover, individuals with AS often have difficulty recognizing and expressing emotions (Frith, 2003); responding to distracting sensory stimuli within the environment (Kern et al., 2006); and engaging in a host of executive function tasks such as setting goals; initiating a plan; and monitoring performance (Killiany, Moore, Rehbein, & Moss, 2005). As a result of such impairments, individuals with AS often do not interact with peers comfortably, possess poor appreciation of social cues, make socially and emotionally inappropriate responses (e.g., laughing loudly when another student gets hurt), and are at-risk for depression and other affective disorders. It is not surprising then, that only 12% of individuals with AS are employed full-time (Barnard, Harvey, Prior, & Potter, 2001).

Despite a myriad of impairments and a poor longitudinal outcome, individuals with AS often display average to above-average cognitive abilities and structural language strengths (Klin, Volkmar, & Sparrow, 2000). The presence of elevated cognitive abilities combined with the propensity of individuals with AS to have areas of special interest (e.g., computer science, geology, horticulture) may lead an individual with AS to demonstrate exceptional abilities and/or great expertise in a particular area. Because of these strengths, individuals with AS have incredible potential to be successful, productive members of society. Yet, realizing their full potential is hampered by challenges in meeting the more basic academic and social demands of college. Although great advances have forwarded our understanding of the transition and adjustment of

first-year college students with specific learning disabilities (Hadley, Twale, & Evans, 2003; Thomas, 2000), there has been only minimal discussion regarding the unique needs of college-bound students with AS (Dillon, 2007).

Successful Transition to College

One of the greatest challenges for students with AS and their families is transitioning from the familiar model of special education services at the high school level to a very different system of services at the college level (Madaus, 2005). Not only does the scope of services change, but also the means by which these services are provided. For example, student support in college is no longer guided by the Individuals with Disabilities Education Act (IDEA) but rather by the Americans with Disabilities Act (ADA). A primary focus of ADA is to provide accessibility and promote anti-discrimination (Rothstein, 2003), not offer an array of academic supports. Although many colleges and universities have begun providing more supports for students with academic learning difficulties (e.g., study skills, writing workshops), services that address the unique difficulties that confront students with AS transitioning to college are virtually non-existent.

Furthermore, college-bound individuals with AS are required to be more independent and responsible for self-advocacy. Specifically, students with AS are expected to deal with increased levels of personal freedom (Brinckerhoff, 1996); the unique challenges of their disability (Conyers, Schaefer Enright, & Strauser, 1998); the performance of acceptable social skills (Mellard & Hazel, 1992); and other variables such as organizational skills, time management, budgeting, and transportation. Students with AS in college settings also are responsible for securing services (i.e., augmentative equipment) on their own volition. Although these challenges present opportunities to practice and master independent living skills and self-advocacy, many individuals with AS are no longer entitled to resources and accommodations with the college setting that promote or enhance the development of such skills (e.g., teaching of functional living skills or social skills). Students with AS may need to seek additional support outside of the postsecondary setting, such as local rehabilitation agencies. Such agencies often have expertise for working with individuals with AS, yet their services tend to focus on vocational challenges and not college transition (Dillon, 2007). From this perspective, individuals with AS may be less successful in their college endeavors because they may not receive the specific services they need. Without considerable supports and accommodations to assist these students with their diverse talents, interests, and perspectives, their successful integration into the college environment may be in jeopardy.

Previous research has highlighted several strategies that are critical for college-bound students with disabilities that may translate into successful approaches for individuals with AS. For postsecondary students with disability-related needs for accommodations, effective disclosure of their disability and self-advocacy strategies are viewed as valuable contributions to success (Lynch & Gussel, 1992). For example, stating one's disability and identifying instructional accommodations with instructors are two strategies related to successful transition (Durlak, Rose, & Bursuck, 1994). To assist with this, Carroll and Johnson Brown (1996) proposed training in self-advocacy skills to enable students with disabilities to become more autonomous adults and avert social isolation. Regardless of the strategies that are employed, students with disabilities, and individuals with AS in particular, will need to develop a skill set that emphasizes not only self-advocacy, but also self-control and functional communication in a clear and concise manner in order to navigate successfully the transition to college.

A Model for College Student Development

Working knowledge of how students develop during their college years is important for understanding the skills needed for success in higher education. Chickering (1969) and Chickering and Reisser (1993) provided the major theoretical framework for understanding student development as it relates to successful development of skills and provides a framework for how supports should be aligned for college-bound individuals with AS. Specifically, Chickering's first three vectors of college student development describe the movement of the entering undergraduate toward greater competence, self-advocacy, and autonomy. The first vector, *Achieving Competence*, relates to the student's ability to develop intellectual competence and acquire new information and to expand interpersonal competence and work cooperatively with others. Development of skills in the first vector allows the student to manage a variety of social situations from talking in class to managing group activities. *Managing Emotions*, the second vector, involves focusing on the development of self-control and expression of oneself appropriately to a variety of circumstances (Reisser, 1995). It is within this stage that a student

develops skills to recognize his or her own feelings and how to handle emotional circumstances (e.g., roommate conflict, excessive academic anxiety). The third vector, *Moving Through Autonomy Toward Interdependence*, entails the student's developing freedom from the need for constant reassurance and approval from parents, peers, and others. That is, a student learns to trust his or her own abilities and feelings as valid sources of information.

Within the first three vectors is the foundation for successful transition. A student cannot simply progress through these vectors. Rather, the student requires stimulation through challenge and positive support. In order to provide challenges and support, Chickering and Reisser (1993) suggest that colleges and universities encourage student development by: (a) clarifying institutional objectives and ensuring consistency of policies and practices, (b) disallowing institutional size to restrict opportunities for student participation, (c) providing frequent student-faculty relationships, and (d) providing varied instructional styles that encourage active student engagement. It is within these suggestions that the foundation for college success for individuals with AS is forged. However, it remains unclear as to whether these suggestions align with perceptions of how to best support and accommodate students with AS on the college campus.

Understanding Parent Expectations

The role of parents in advocating for their college-bound student with AS is notably absent in the literature regarding the need to support students with disabilities at the college level. Parents frequently serve as powerful advocates for their students with AS at the elementary and secondary school levels. Yet, like the parents of non-disabled college students, the active, overt role of parents in their students' education is diminished severely at each level as the expectations for student autonomy increases. Parent expectations are highly influential and an understanding of these expectations is particularly important when fostering support for college students with AS.

Purpose of the Study

The purpose of this study was to explore parent perceptions regarding the: (a) supports or accommodations college-bound students with AS need at the postsecondary level to successfully adjust to the academic and psycho-social expectations of the college experience, and (b) self-advocacy skills or strategies needed to increase the likelihood that students with AS obtain the supports and accommodations they need to be successful in college. To this end, parents from a local chapter of the Autism Society of American (ASA) provided their perceptions of the supports and strategies needed for college-bound students to increase competence, manage emotions, and develop autonomy. As awareness of the number of students living with the AS diagnosis increases, so does the need to provide meaningful supports to ensure they have every opportunity to realize their potential in the college setting. The findings from this study are intended to inform and guide professionals in the fields of special education, college student development, school psychology, and school counseling who advocate for full participation of students with AS in higher education.

Method

Focus group (qualitative) methodology was used to investigate parent perceptions of the supports and accommodations that college-bound students with AS need at the postsecondary level to be successful. Focus groups are defined by the use of participants who have a specific experience with or opinion about the topic under investigation, the use of an explicit interview guide, and the exploration of subjective experiences of participants in relation to predetermined research questions (Gibbs, 2007). A focus group approach was selected because of the exploratory nature of the study coupled with the desire to uncover common themes and opinions (Krueger & Casey, 2000; Vaughn, Schumm, & Sinagub, 1996).

Participants and Setting

Potential participants for this study were recruited through a network of professionals associated with a local chapter of the ASA. A total of four parents of sons with AS expressed interest in this preliminary study and agreed to participate in a focus group. The participants included: (1) Ms. Peters, (2) Ms. Harrison, (3) Ms. Clark, and (4) Ms. Vincent. Ms. Peters' son was 16-years-old and in the tenth grade at a college-preparatory, public high school. Ms. Harrison's son was 15-years-old

and in the tenth grade at the same college-preparatory, public high school. Despite their children attending the same school, Ms. Peters and Ms. Harrison had not met before their participation in the focus group. Ms. Clark's son was 14-years-old and in the eighth grade at a Montessori, public middle/high school. Ms. Vincent was the mother of two sons with Asperger's. Her older son was 12-years-old and in sixth grade at a Catholic elementary school. Ms. Vincent's younger son was 8-years-old and in the second grade in a special program for students with Asperger's located in an urban, public elementary school. All of the parents participated equally and without reservation, expressing interest and empathy through their spoken words. In addition to the parent participants, one professional from the Student Services Program of a local, private, four-year liberal arts University hosting the focus group was a participant and one faculty member from the Department of Counselor Education of another local, private, four-year liberal arts University served as the facilitator of the focus group.

The focus group was conducted in a meeting room of the student union on the campus of a private, Catholic University located in a city in the Midwest. All of the participants were residents of the city and its surrounding suburbs. The focus group lasted approximately one and a half hours and beverages and snacks were provided.

Data Collection and Procedures

A questioning route (see Appendix) was developed by the authors to examine information related to two specific research questions:

- What supports or accommodations do college-bound students with AS need at the postsecondary level to successfully adjust to the academic and psycho-social expectations of the college experience, and
- What self-advocacy skills or strategies will increase the likelihood that students with AS obtain the supports and accommodations they need to be successful in college?

Specific prompts for the focus group were based on Chickering's (1969) and Chickering and Reisser's (1995) initial three vectors of college student development: (a) *Achieving Competence*, (b) *Managing Emotions*, and (c) *Moving Through Autonomy Toward Interdependence*.

Each focus group session was recorded using a digital audio recorder. Following each focus group, the audio file on the recorder was downloaded onto a computer as a .wav file. In an effort to keep files small, each .wav file was converted to .mp3 format. In all cases, the audio recording from the recorder was used for transcription. The transcription involved creating a written record of all words spoken throughout the session.

Data Analysis

The method used to identify themes was adapted from Jehn and Doucet (1996). Two reviewers independently reviewed the transcript from the focus group and identified segments from the focus group that pertained to each of Chickering's three vectors (*Achieving Competence*, *Managing Emotions*, and *Moving Through Autonomy Toward Interdependence*). Segments were coded as either an area of need or potential support. Statements representing similar themes were grouped and counted to show the concept's weight relative to other less common themes evident in the transcripts. After independently analyzing the data from the transcripts, the two reviewers compared their findings. Themes agreed by both reviewers to be general themes were reported in the final analysis. Two primary themes were defined as (a) *supports and accommodations*, and (b) *self-advocacy needs and supports*. Supports and accommodations included services that could be provided by an external agent (i.e., a college's Student Services Program, a high school's guidance department) to assist a family seeking a smooth transition to college. Self-advocacy needs and supports involved a description of skills a student with AS would need to demonstrate in college and included services that would increase the probability of the student performing these skills. Representative quotes from various categories were selected and presented to exemplify the descriptive summary of the qualitative data.

Results

Matching Students with Accommodating Professors. The parents of students with AS participating in the focus group identified a need for careful consideration when scheduling college courses. Ms. Harrison described a role for a professional in a college's Student Services Program in which that person could:

...look at the schedule and they can say, well we know that this particular Latin teacher is not going to tolerate a kid that, you know, doesn't look at him, doesn't make eye contact, won't take notes. You know, that won't work for the teacher. But this teacher is very concrete, has handouts, he can follow along with the handouts, that kind of thing.

The parents identified professors that permit alternatives to group work, are open to independent study arrangements, and provide accommodations for note-taking to be better able to meet their students' needs. Parents also discussed a need for professors who have an understanding of the strengths and weaknesses of students with AS. The mode of instruction preferred by the students with AS varied, according to their mothers, with some of the students preferring independent, hands-on activities and others preferring instructor-led lectures.

Advocacy. Related to support for scheduling courses, the parents of students with AS identified a need for a professional in a college's Student Services Program who would serve as an advocate for their college-age child. This professional would gather information from other students with disabilities regarding the professors' willingness to provide accommodations and tolerance for individual differences in learning and communicating. In recommending this course of action, these parents drew on experiences attaining positive outcomes when working one-on-one with individual instructors to meet the needs of their student, rather than trying to affect change through broader-reaching efforts, such as staff development. Information such as this could be compiled to assist all students with disabilities, not just the students with AS. As articulated by Ms. Clark, this professional would serve as "a resource person ... the interpreter for the student. You know, and can also be the advisor and go-between and so when that student is starting to struggle, is having trouble working things out with the professor ..." this college-based advocate could provide support. A college-based advocate might also assist students with AS identify intramural clubs and activities that are well suited to their interests (e.g., band, chess club, video gaming).

Alternative Routes. Parents of students with AS discussed the possibility that alternative routes to a four-year college education may be the best avenue for their college-bound child. A student with AS may pursue a successful transition to college at a two-year college or community college setting prior to attending a four-year college. For some students with AS, a technical institute might provide the best match. The parents' voiced considerable consensus regarding the need for their sons to live at home and commute to college or possibly live in a dormitory room designed for a sole occupant.

Self-Advocacy Needs and Supports: Disclosure

All of the parents agreed that their sons would be most successful in college in an environment where they feel understood and supported by professors and peers. Developing this level of understanding will require students with AS to disclose their need for supports and accommodations and to advocate for themselves. The parents participating in the focus group expressed considerable concern that their sons did not have the self-advocacy skills needed to obtain supports in the college setting. In the words of Ms. Harrison:

"I know he knows that he perceives the world in a different way. And I've tried pretty hard not to put a value judgment on it – it's not a good thing or a bad thing, it just is. But um, I don't know. I think at least he's more open to talking about it occasionally. But he's not somebody who wants to really disclose it."

In response to the need for strengthening their sons' self-advocacy skills, the parents identified supports a college's Student Services Program could provide to help develop these self-advocacy skills. Specifically, the parents identified the need for: (a) prompts for their sons to seek support from a professional in the college's Student Services Program, (b)

regularly scheduled meetings with a professional in the Student Services Program, and (c) a channel of communication from professors to a professional in the Student Services Program for instances when the student with AS starts struggling. All of the parents agreed that their sons would not likely struggle with the course content, but they would need accommodations and support with organizational skills (i.e., note taking, breaking down tasks to meet deadlines) and interpersonal skills (i.e., interactions with professors and peers).

Parent Involvement. All of the parents agreed that their sons would continue to require higher levels of parental involvement and support in college than do their neuro-typical peers, particularly with daily living skills (e.g., laundry, money management, scheduling doctors appointments). The parents expressed an on-going need to maximize their sons' capacity to live independently, while maintaining a watchful eye for potential struggles. According to Ms. Harrison, "the biggest thing I've seen is just as he gets more independent, there's still like big gaps. All of a sudden, oh yeah, I guess we really didn't go over that exactly, what you should do in that situation." The parents identified a possible role for themselves in helping their sons when trouble arose in the dormitory or another social context. Given that students with AS do not typically recognize the intentions of others, the parents expressed concern that their sons would be taken advantage of by ill-intentioned peers. "They're just the perfect victim," said Ms. Clark, "And they are going to be the ones that are going to be left holding the bag, because they are a little slower on figuring out, oh, we better be careful not to get caught."

The parents also saw a role for themselves in helping their sons manage the daily living demands outside of the college classroom (e.g., paying bills, doing laundry). In addition to parent involvement, one parent suggested that her son could be well served by a job coach/life coach to assist with the daily living demands of on- or off-campus living.

Discussion

The present investigation provides a preliminary examination of parents' perceptions regarding the anticipated supports and accommodations needed for their college-bound child with AS to adjust successfully to the expectations of the college experience. This study is viewed as a first step toward understanding parents' perceptions of needs and expectations for support for their child at the college level.

The first major theme that emerged from this investigation was the need for reasonable and appropriate supports and accommodations. Supports and accommodations included collaboration with the college's Student Services Program/Disabilities Office (SSP/DO) for scheduling considerations and advocacy. Participants expressed a desire for SSP/DO to carefully match students with instructors who understand the characteristics of AS and who naturally employ best-practice teaching strategies within their courses (i.e., using handouts, guided notes, prompts). In addition, participants expressed the need for increased advocacy for students to assist through difficult moments and provide networks for social support. Information about alternative routes (e.g., two-year college, technical institute) was also expressed and is critically important for college-bound students with AS and their parents to consider. Pursuit of this information should be a focus of educators and guidance counselors at the high school level.

The second major theme generated by the focus group was the need and challenge of self-advocacy among college-bound students with AS. This need for effective self-advocacy skills represented an on-going challenge for the parents who recognized that their sons could not maximize their chances for success at the college level without advocating for themselves. Specifically, parents expressed concern with separation versus supervision. Recognizing that their sphere of influence will change when their child leaves the familiar K-12 school environment, parents of students with AS will need to collaborate with the college's Student Support Services, while experiencing a diminished role as advocate for their adult child.

Implications for Practice

The results of this study underscore the need for parents, high school guidance counselors, other student support personnel, and professionals serving in Student Services Programs in colleges and universities across the country to anticipate and plan accordingly to address the challenges of students with AS at the college level. Although the findings of this study must be considered preliminary and tentative, several recommendations seem warranted. First, it seems likely that

professional development will need to occur for both high school staff and postsecondary faculty. The content of professional development will vary with the role expectations for each level. However, there is certain content that personnel at *all* levels should receive. Content should focus on awareness of: (a) the unique characteristics of individuals with AS (e.g., weak central coherence, executive dysfunction, poor social cognition), (b) the specific social, behavioral, and academic needs of individuals with AS, and (c) the approaches for remediating difficulties within each of these domains. Regardless of the approaches employed for providing such professional development, the end result should be a strengthened support staff. Second, it may be helpful for middle and high schools to develop programs for successful transitions for college-bound students with AS. These programs may want to emphasize the teaching of skills related to complex social interactions, self-advocacy, and organization. In an effort to provide optimal skill building, such programs may want to partner with Student Services Programs at colleges and begin a comprehensive transition plan to occur the semester prior to the student's enrollment. These collaborations would allow for the student to not only visit a campus and ease lingering anxieties, but also identify a person who would be available to coach him or her through difficult moments. Finally, counselors within high schools and postsecondary campuses will need to consider carefully how to advise individual students with AS. From a high school counselor perspective, careful advisement should occur regarding a student's options for postsecondary education (e.g., small college or large University, technical school). It is important for advisement at this level to be realistic in order to ensure the greatest probability of success for the student. For advisement officers/counselors within colleges and universities, considerations for advising should focus on areas related to academics (i.e., careful matching with supportive faculty members) and social networks (i.e., clubs that align with specific interests of the student). In addition, it would be important for advisors to provide the student with resources on campus and within the local area for support.

Limitations

The results of the current analysis examining the supports and accommodations that college-bound students with AS need at the postsecondary level are limited by several factors. First, parents who participated in the focus groups were those willing to attend a scheduled meeting and discuss their experiences with, or perceptions of, the supports needed for individuals with AS who are college-bound. The extent to which the participants' reports are representative of all parents or individuals with AS in this region and other locales is not known. Second, the number of participants was relatively small and may have reflected only those who were actively participating in transition planning or possessed a higher level of insight regarding their child's experiences with AS. Attempts to conduct studies with larger samples of parents and/or with individuals with AS regarding their expectations of college may identify broader perspectives and allow for a direct comparison of those process variables that are facilitative or inhibitory within successful or unsuccessful schools respectively. Alternately, a case study methodology could have been employed to explore the unique experiences of each family, however, the opportunity for the parents to interact with one another in the context of a focus group yielded valuable information that would be lost using a case study approach. Third, the use of a qualitative analysis only measures perceptions of participants and does not allow for more direct measures of the actual presence or absence of factors within school environments that are supportive of a positive transition to college.

Recommendations for Future Research

Additional research approaches are required to provide a more detailed picture of the specific supports and strategies that will promote success for individuals with AS seeking a degree in higher education. Although focus group methodology is useful for conducting exploratory studies such as the one reported in this article, this approach tends to be expensive (i.e., providing incentives for participants), time consuming (i.e., sorting and analyzing data is often complicated and protracted), and of limited experimental control. Future research endeavors may wish to employ methods that provide more detail regarding specific factors that contribute to the success or failure. Specifically, it may be useful to explore the perceptions of college-bound students with AS regarding the supports and accommodations they find to be most useful. Such research could employ self-report measures or surveys. In addition, longitudinal analysis of the college experience should be employed. That is, future research should identify the variables within a variety of colleges and universities that have contributed to successful experiences and identify development for individuals with AS. Identification of such variables may

assist in the growth of effective professional development components and models for faculty and staff at higher education institutions, as well as generate specific programs or strategies that could be implemented as part of a preparatory program for individuals with AS who are interested in attending college.

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About the Authors

Julie Q. Morrison, Ph.D. received her B.S. degree in Psychology from St. Louis University, her M.A. in Experimental/General Psychology from Xavier University (Cincinnati, OH), and her Ph.D. in School Psychology from the University of Cincinnati. Her experiences include working as a school psychologist for Cincinnati Public Schools District and serving on the multidisciplinary Autism Spectrum Support Team for the district. Dr. Morrison is currently an assistant professor of school psychology at the University of Cincinnati. Her research interests include evaluating the effectiveness of universal supports and targeted interventions to address academic and behavioral needs of school-age children and youth. She can be reached by email at: Julie.Morrison@uc.edu.

Frank J. Sansosti, Ph.D., NCSP received his B.S. degree in Psychology from the University of Pittsburgh and Ph.D. from the University of South Florida. His experience includes working as a school psychologist and district autism consultant for the District School Board of Pasco County in west central Florida, providing coaching and technical assistance for intervention and best practice approaches for students with autism spectrum disorders (ASD) in inclusive settings. He is currently an assistant professor of school psychology in the Educational Foundations and Special Services department at Kent State University. His research and professional interests focus on the development and implementation of behavioral and social skills interventions for individuals with ASD, as well as best practice approaches for the inclusion and transition of individuals with low-incidence disabilities. He can be reached by email at: fsansost@kent.edu.

Wanda M. Hadley received her B.S. and M.A. degrees in Education from Ohio State University and her Ph.D. from the University of Dayton. Her experience includes working as an administrator for the University of Dayton and Central State University. She is currently an administrator and adjunct professor in the College of Education at Central State University. Her research interests include the academic adjustment issues first-year college students with learning disabilities experience in their transition to college. She can be reached by email at: wandamhadley@yahoo.com.

Appendix

Prompts for the Focus Group Discussion

Developing Competence

- 1.1 Describe some of the challenges your son/daughter (or student you work with) will likely encounter expanding interpersonal competence in the college setting.
- 1.2 Describe some of the challenges your son/daughter (or student you work with) will likely encounter working cooperatively with others in the college setting.

Managing Emotions

- 2.1 Describe some of the challenges your son/daughter (or student you work with) will likely encounter managing his/her behaviors in the college setting.
- 2.2 Describe some of the challenges your son/daughter (or student you work with) will likely encounter expressing him/herself appropriately to circumstances among peers, faculty, and staff.

Developing Autonomy

- 3.1 Describe some of the challenges your son/daughter (or student you work with) will likely encounter in reducing his or her reliance on parents, peers, and others to meet needs and accomplish personal objectives.
- 3.2 Describe some of the challenges your son/daughter (or student you work with) will likely encounter in reducing his or her reliance on parents, peers, and others for approval and reassurance.

A prompt to discuss the supports or accommodations needed to address these challenges was provided for each of these six initial prompts.