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Greetings,

Thank you participating in the research project "*What's Working and What's Needed? Parent-Professional Collaboration in Postsecondary Education Settings*," funded by the George Mason University Summer Research Award. The purpose of this report is to describe the nature of the research conducted, report the results of analyzed parent and professional data, and provide recommendations based on these results. This report includes five sections:

I.   Introduction
II.   Participants
III.   Findings
IV.   Recommendations
V.   References

Please feel free to contact me to express how the data did or did not capture your experiences or provide any suggestions to better inform the findings and recommendations.

In addition, should you have any questions regarding the study, this report, or future research opportunities, please do not hesitate to contact me.

With sincere thanks and kind regards,

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What's Working and What's Needed? Parent-Professional Collaboration in Postsecondary Education Settings
White Paper prepared by Grace L. Francis
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PART 1: Introduction

Need

Young adults with disabilities are among the least likely to gain competitive employment, live away from their families, and attend college following high school (Wagner et al., 2005). However, parent-professional collaboration significantly influences positive transitions from school into adult life among young adults with disabilities (Francis et al. 2013; Griffin et al., 2010; Martinez et al., 2012; Neece et al., 2009). Despite the importance of parent-professional collaboration, parents frequently report being uninformed about and uninvolved in the transition planning of their young adults in high school (Francis et al. 2013). Further, there is a paucity of information on how to develop these relationships as individuals with disabilities age (Hirano & Rowe, 2015). This lack of information is significant because parent-professional collaboration enhances outcomes for parents, professionals, and young adults, including goal attainment, reduced levels of stress, and family well-being (Bryan & Henry, 2012; Giovacco-Johnson, 2009; Tschannen-Moran, 2014).

Purpose of the Project

This qualitative research project was designed to investigate the perspectives and experiences of postsecondary education program (PSE) professionals and parents of PSE graduates to learn about barriers and promising practices to parent-professional collaboration during transition to adult life. This research was guided by three primary research questions:

Research question 1. What factors do PSE professionals and parents of PSE graduates identify as barriers to parent-professional collaboration?

Research question 2. What methods do PSE professionals employ to develop meaningful parent-professional collaboration in higher education settings?

Research question 3. What strategies or suggestions do parents of PSE graduates have to enhance parent-professional collaboration in high school and higher education settings?

Method

Recruitment. The primary investigator recruited parent participants by contacting PSE program directors with an invitation and prepared email to distribute to the parents of young adults who graduated between 2013 and 2016. Interested parents completed a brief demographic survey and contacted the primary investigator directly to schedule an interview or focus group.

The primary investigator recruited professional participants by asking the director of each program if they would be willing to share a prepared email describing the study and offering an opportunity to participate in an interview or focus group. Interested participants completed a brief demographic survey and provided contact information that the primary researcher used to schedule interviews. Program directors collaborated with the primary investigator to schedule focus groups for those who elected to participate.

  Parent focus groups and interviews. We used a semi-structured interview protocol to conduct a total of two focus groups and 21 interviews. In only one interview did both the mother and father of a PSE graduate participate. The majority of interviews and one focus group were conducted over the phone or via Skype or Facetime. Two focus groups and one interview were conducted in-person at local libraries, and one interview was conducted at a restaurant of the participant's choice. On average, focus groups lasted approximately 95 minutes and interviews lasted approximately 105 minutes.

  The primary investigator started interviews and focus groups by explaining the purpose of the study and associated risks/benefits of involvement before seeking informed consent from participants. The parent interview protocol included questions related to participants' (a) experiences with high school professionals, (b) experiences as their young adult graduated from high schools and PSEs, (c) experiences "letting go" of primary caregiving responsibilities once their young adults entered college, (d) experiences interacting with PSE staff, (e) suggestions for ways in which professionals and parents can better collaborate to support positive student outcomes, and (f) recommendations for families to enhance positive outcomes for their young adults as they enter into adulthood.

  Professional focus groups and interviews. As with the parent participants, we used a semi-structured interview protocol to conduct focus groups or interviews with a total of 23 PSE professionals. All but two focus groups and three interviews were conducted over the phone or via Skype or Facetime. Those conducted in-person occurred on university campuses or in the community (e.g., public library). The primary investigator also conducted two in-person focus groups from one university that they were unable to transcribe because several participants did not consent to audio recording. Although the primary investigator took field notes during the focus groups, they did not feel confident that the notes accurately reflected all key information participants shared and, as a result, did not analyze those data. On average, focus groups lasted approximately 110 minutes and interviews lasted approximately 55 minutes.

  Again, the primary investigator started interviews and focus groups by explaining the purpose of the study and associated risks/benefits of involvement before seeking informed consent from participants. The professional interview protocol included questions related to participants' (a) procedural experiences interacting with parents, (b) barriers related to parent involvement in higher education, (c) positive experiences

partnering with parents, and (d) suggestions for improving parent-professional collaboration.

    Analysis. Demographic survey data were de-identified by the primary researcher and entered into SPSS by a graduate research assistant. We used SPSS to calculate and report frequencies for each survey question for both sets of participants. All qualitative data were transcribed and de-identified by the primary investigator prior to analysis to protect participant confidentiality. The primary researcher and two graduate research assistants used NVivo software to perform basic interpretative qualitative analysis (Merriam, 2009), first for the parent and then for the professional data.

PART 2: Participants

    We report data from two sets of participants: parents of PSE graduates and PSE professionals.

Parents

    In total, 26 parents of PSE graduates (22 mothers and 4 fathers) participated in this study. The majority of participants identified as White/Caucasian (75%), followed by Black/African American (14%), Hispanic or Latino (7%), and multiple races or ethnicities (4%). All participants identified English as their preferred language. Approximately 85% reported their domestic status as "married," and the majority of participants lived in suburban area (75%), followed by urban (21%), and rural (4%). Over half of participants reported annual household incomes of $95,000 and higher (58%) and indicated earning a college graduate degree (68%). The majority of participants' young adults graduated from a PSE between 2015 and 2016 (74%) and were 24 years old or older (46%). The disability label of graduates varied, with the majority participants reporting autism (29%), intellectual disability (29%), or multiple disabilities (18%). Due to confidentiality assurances made to participants, we are unable to disaggregate participant demographics by PSE program.

PSE Professionals

    In total, 23 professionals participated in this study. Participant roles varied, with 48% of participants identifying as a program administrator, 19% identifying as a program instructor, another 19% identifying as "other" (e.g., case manager, university liaison), and 14% identifying as residential support staff. The number of years working with the programs ranged from less than one year (5%) to six or more years (14%). A majority of participants identified as female (62%), 71% reported being between ages 26-35, 42% reported being a master's or doctoral students, and 76% of participants reported their race or ethnicity as White. Further, 95% of participants reported a close relationship with an individual with a disability outside of their work with the PSE (e.g., parent of an individual, sibling of an individual, other family member of an individual). Of those participants, 52% reported various relationships with multiple individuals with disabilities (e.g., a sibling *and* a close friend of an individual with a disability). Table 1

provides additional demographic information for universities and PSEs included in this study.

Table 1
Demographic Information for Universities and Programs

	University 1	University 2	University 3	University 4	University 5
U.S. region	Northeastern	Eastern	Southern	Midwestern	Western
Total university enrollment	~12,000	~35,000	~20,000	~17,000	~24,000
University students living on campus	~5000	~6,000	~6000	~1000	~1000
Total program enrollment	~10	~50	~60	~30	~30
Length of program	2 years	4 years	4 years	2 years	2 years
Program students living on campus	Off-campus	On-campus option	On-campus option	On-campus requirement	On-campus requirement
Number of parent participants	2	9	6	7	2
Number of professional participants	2	4	6	5	6

PART 3: Findings

We report findings of three research questions related to (a) barriers to parent-professional collaboration in high school and higher education, (b) methods to develop meaningful parent-professional collaboration in higher education settings, and (c) strategies or to enhance parent-professional collaboration in high school and higher education settings.

Research Question 1: What factors do PSE professionals and parents of PSE graduates identify as barriers to parent-professional collaboration?

PSE Professional Perceptions of Barriers

Professionals identified five primary barriers to parent-professional collaboration, (a) parents transitioning roles, (b) parent fears, (c) conflicting expectations for programs, (d) parent overinvolvement, and (e) parent underinvolvement.

Parents transitioning roles. Participants indicated that difficulty transitioning from a deeply involved advocate (e.g., doing for young adults) to a new role of a less involved advisor (e.g., doing with young adults) resulted in many "overbearing" parents. Participants fully acknowledged how difficult it must be for parents who have "suddenly become a person without a job" after "years of fighting [with] schools."

> *We recognize that families have had to fight for a long time, probably the entire life of their son or daughter, just to have access to inclusive education and experiences. Being that parent advocate is such a huge part of their identity and I think that's what we kept bumping up against.*

Parent fears. Participants reported that families fearing that "someone is going to take advantage of [their] child" at an unprotected, inclusive campus resulted in a great deal of anxiety among parents. Further, because many parents did not seek or receive support to "talk through things," participants indicated that "they don't know the root of [their feelings]...so [the fear] festers."

Conflicting expectations for programs. Participants noted that parents sometimes expected staff to secure young adults "a fulltime job with full benefits and vacation and retirement" and "get really mad" when that did not occur. Several participants also discussed parents expecting program staff to enforce specific cultural or religious practices (e.g., prohibiting young adults dating outside of their race, religion, or ethnicity; mandating young adults attend worship services).

Parent overinvolvement. Participants described overinvolved parents "contradicting" or "bypassing" student choices because they "are used to making the

> *The bottom line is that we do have their son or daughter's best interest in mind… we're really passionate about what we do…*

choice [for their young adult]." Participants observed that young adults who "contact [their parents] a lot" end up not "addressing [issues] with anybody except their parent," which perpetuates parents feeling the "need to be [the young adult's] voice" and the "wheel" of dependence and parent overinvolvement. Many participants described difficulty determining what information they should and should not share with parents "when young adults have issues:" "there's that that line about [staff] trying to facilitate an environment where the young adults are [treated as] adults," while also keeping parents "in the loop."

Parent underinvolvement. Participants indicated that sometimes they "wished [parents] were… a little more available or present" because it "would be helpful" if they "advocate[d]" for services and supports provided by adult service systems and other community organizations after graduation.

Parents of PSE Graduates Perceptions of Barriers

Parents identified six primary barriers to parent-professional collaboration in high schools and PSEs, (a) parent exhaustion, (b) a lack of information, (c) communication breakdowns, (d) disagreement, (e) disappointment, and (f) a lack of trust.

Parent exhaustion. Participants described feeling "so worn out" after decades of "relentlessly" searching for information, seeking resources, and advocating for services and supports. Several participants described the overwhelming stress of being "on that frontier" of navigating services, supports, and inclusive experiences for their young adults with disabilities. Participants recalled having to constantly "show [professionals] inclusion works" and the effort it took to "pull people" along to expect that their children would grow to live meaningful, inclusive lives in their communities.

> *We are running a marathon and [parents of children without disabilities] are running a relay race. They're passing the baton so they're all fresh and we're like - we're really tired.*

A lack of information. Even participants with knowledge of available supports and resources admitted that they were "flying blind" during transition from high school and college, "had dig and dig" for information, and felt "like nobody tells you what resources are available." Participants indicated that the "very time-consuming and exhausting process" of locating resources to support their young adult after graduation from high school and college often made them frustrated and despondent. While appreciative of and sympathetic of

> *Is the team stepping in? Is mom stepping in? Do we contact a peer and have the peer step in? Is that appropriate?"*

"overworked" professionals, participants felt especially frustrated when professionals did not "do a good job telling" them about "great resources" in the community or were unaware of resources entirely.

Communication breakdowns. Participants felt belittled when professionals rejected or ignored information or suggestions they offered (e.g., strategies to best motivate or teach their young adults). All participants described feeling "frustrated" "in the college setting as a parent [being] more hands off…[and] not having as big a rapport with the teachers and the administration as [they] did in high school" as a result of "FERPA or whatever the laws are." This change in communication especially made participants get "bent out of shape" when "struggling" "students speed dial the parents" and participants did not have the ability to "pick up the phone and talk to [PSE professionals]" to "dialogue" about the circumstance and determine a "logical" response to "smooth things out."

> *We did not get very much support from the supervisor of the program…I think she was more upset that he didn't do well in the program that she had created…it was her baby.*

Disagreement. Participants disagreed with segregated educational placements throughout primary and secondary school and overwhelmingly noted that "the wheels came off the bus in late middle school and high school." Participants also advocated against professionals who simply "parked [young adults] on a couch" at school or placed young adults in specialized, segregated programs without considering their needs or preferences. Many participants disagreed that "as parents [they] weren't allowed to know what was going on" with their young adult in college.

Disappointment. Participants described feeling "a little bit disappointed" when their expectations for programs or vision for their young adults' futures were not realized.

However, several participants also admitted that their expectations were sometimes "unreasonable," especially with regard to PSEs: "…like degree-seeking students, your hope is that they're ready to go [after graduation from a PSE] and there's a naiveté in that." Although many participants highlighted benefits of attending a PSE (e.g., "The program was worth its weight in gold just for the confidence [Young Adult] got and the feeling that we got that [Young Adult] will be okay down the road"), some participants also reported feeling "short-changed a little bit" and did not "think it would have been worth it in the long run to have put forth all that money" because their "understanding of what the postsecondary program was wasn't quite what it ended up being."

> *It was your fault and you tried to put it back on the parents. Admit your fault. Admit your lack of success or admit when you're wrong and I'd have a heck of a lot more respect for you.*

A lack of trust. Participants described some professionals "giv[ing] a rosier," inaccurate portrayal of student progress and well-being, providing "convoluted answers" to pointed questions, and "making up [student] data." Participants also lost trust when professionals deflected poor outcomes or programmatic failures back to parents. Further, several participants believed that professionals did not trust their judgment as parents and one participant speculated that, "although it sounds terrible," some professionals purposefully "try to keep [parents] separate" from each other because they "fear that [parents] might talk too much" and create turmoil.

Research Question 2: What methods do PSE professionals employ to develop meaningful parent-professional collaboration in higher education settings?

Professionals identified three primary strategies for developing parent-professional collaboration in higher education including, (a) providing parents support, (b) establishing expectations, and (c) engaging in on-going communication.

Providing parents information support. Some programs created workshops and activities to (a) teach parents how to help their student transition to college life, (b) help

> *We stepped back and said let's acknowledge that [advocacy] is an important role that [parents] have and perhaps they need some support in figuring out what their next role is in their adult son or daughter's life."*

parents cope with stress that they may experience, and (c) connect parents with current and alumni parents as a source of support. Participants described supporting parents to transfer responsibility to young adults by thanking them for the "heads up" when contacted staff about a young adult issue and responding with comments such as, "It might be helpful the next time you see your son or daughter to have them come speak to me so that we can work this out together."

Establishing expectations. Participants explained program expectations during admission interviews, as well as asked parents interview questions about their expectations for the program. For example, one program asked parents about how they would react if their student engaged in sexual activity, decided to drink alcohol, or attended late-night events in the community to determine if their reaction was consistent

with program expectations. Creating detailed parent and student contracts outlining expectations, responsibilities, and obligations that they must sign and return before the young adult may enroll in classes was another strategy. University and PSE orientations and program webinars also served as a "really good time" to "start to build that relationship [with parents], answer their questions," and discuss polices such as the FERPA.

> *We've just gotten smarter and smarter…from year one to where we are today. We've changed our verbiage. We've articulated our expectations. We're better at putting [expectations] out there [to parents] immediately.*

       Engaging in on-going communication. In addition to person-centered planning meetings, participants described the importance of on-going communication with parents throughout the year: "It's just really important to keep parents in the loop because… they're more supportive of the program when they know what's going on and because it's easier for them to be your ally." One program created a dedicated position for communicating with parents who responds to parent emails, provides immediate support (e.g., listening, providing reassurance), and documents questions and concerns in a log that staff and young adults review and respond to together.

Research Question 3: What strategies or suggestions do parents of PSE graduates have to enhance parent-professional collaboration in high school and higher education settings?

       Participants identified eight strategies to strengthen parent-professional collaboration in high schools and universities, (a) recognize the need for interdependence, (b) maintain high expectations, (c) demonstrate commitment and care provide information, (d) provide emotional support, (e) foster parent networks, (f) operationalize and align expectations, (g) provide information, and (h) collaborate.

       Recognize the need for interdependence. Several participants agreed that "we keep talking about independence like it's this plateau that you reach [and] at some point you're going to be completely independent" when, in reality, "that's not the way the world works for these [young adults]." A participant noted that for individuals with disabilities "independent living" involves "do[ing] most things on your own but you also have to have the wherewithal, if there is a problem, you can talk to somebody who can help you create the wise solutions."

       Maintain high expectations. Some participants had "amazing" and "fabulous" experiences with professionals who treated their young adults "like whole person" and a "smart person." Professionals who participants described as "excellent," "phenomenal," a "godsend" or "wonderful," were "very supportive," "very involved," and encouraged young adults to "to go as far and as wide as [they] could go." Professionals with these characteristics also "worked really hard" to help participants "visualize [the] future [for their young adults], rather than feel sorry [for themselves]" and focused on identifying and maximizing strengths. Participants forged partnerships with professionals who

maintained the "attitude" of "let's keep going" and "helped with transition," instead of creating a "go it alone situation for a parent or a family."

Demonstrate commitment and care. Participants signified that "people [who] were definitely caring and wanted [young adults] to succeed" thought of "very creative" ways to teach young adults "at the beginning" of their lives. Specific examples of creative approaches included the use of universal design, "work[ing] really hard to create accommodations," and developing innovative ways for young adults to be included in school and the community. Participants noted that professionals who "took time" to make personal connections with young adults demonstrated "compassion" and understanding. This was especially true for young adults who were "very difficult to establish a relationship with because of social skills."

Provide emotional support. Participants reflected that they "just forget sometimes that [they] don't have to fight everybody" and often felt "scared to death" for the well-being of their young adults. During times of heightened stress, participants "need[ed] to know number one that their child is safe" and that young adults "are not going to be left alone." Participants also believed it "very important" for professionals to "share [young adult] successes…even tiny successes where they made an attempt" in order to help parents feel more confident about their young adult's safety and progress. Another strategy included asking the question "Where do you want [young adult] to be in five years?" when parents are not in crisis and reminding them of their answer when parents "try to stand in [the young adult's] way."

> *Remember that conversation we had? You promised you would never stand in his way because of something you were fearful about. Well, is it [Young Adult's] fear or your fear about getting on that bus?' I was like, "Grrrrrrr. Fine! He'll get on the bus tomorrow!*

Promote parent networks. Participants indicated that promoting parent networks should be a professional "priority" because "parents are hungry for parent-to-parent interaction." Participants made suggestions for facilitating such networks, including "connecting parents" to existing parent support groups, encouraging local parents to "get together and network [to] learn things from another parent with a similar problem," and creating local "mentoring program[s]" consisting of parents "who know the ropes or would be a good fit to support another parent."

Operationalize and align expectations. Participants suggested that professionals could more easily "get parents [to] buy-in" by establishing expectations about how parents should resolve conflict, such as "talk[ing] to [professionals] in a clam way" when they "see something [they] disagree with." Participants suggested that professionals reinforce that "students are going to make mistakes" and programs "are going to hit some roadblocks" and establish "expectations for working through roadblocks." Another expectation participants suggested professionals establish is for parents to "not come with [complaints] without solutions." Although they noted the importance of parent-to-parent

support, several participants also suggested that professionals establish expectations and procedures so that parent groups serve as a way parents "can support each other" and do not "end up a bitch session."

Provide information. In addition to the importance of aligning parent and professional expectations, participants also highlighted the importance of professionals providing information to parents and "talk[ing] to the parents to find out what they want to know." Participants also found it helpful when professionals shared "what was successful for other students," as well as information about what to expect "at each stage of school and development and steps to make [positive outcomes] happen." Participants expressed other areas in which parents commonly need information, including "help[ing] parents understand changing roles of kids making more decisions [for themselves]," learning how to keep "[Social Security benefits," and "guardianship options."

Collaborate. Participants offered numerous recommendations to tap into "underutilized parent power to get things done" and to not "be afraid of parents," but rather to "really join forces to support individuals [with disabilities]." Participants described how they would have liked more "behind the scenes" conversations with professionals to discuss "the game plan" they developed with their young adult.

> *You want to be an advocate for your child but it's easy to take the barriers personally and to kind of flip out and be mad and bring in the lawyer…but if you can just kind of get your point across but not be mean. If you go in with your guns all blazing and mad you lose your credibility.*

Participants described "that fine line between independence and enabling" young adults and the importance of parents and professionals acting as "a team so one of those team members can say this is the time to back off [or] this is the time you need to put that hand out and help [young adults] up." Participants also described how they successfully collaborated with professionals by giv[ing] [professionals] information," "reformat[ting]" materials for young adults or "help[ing] with job applications," and "phra[sing] sentences in a fashion where you're not attacking" professionals.

Part 4: Recommendations

Recommendations related to (a) establishing and enhancing expectations, (b) permitting risk and failure, and (c) building trust emerged as a result of this research.

Establish and Enhance Expectations

- PSE Professionals
  - Collaborate with primary and secondary professionals to discuss skills young adults and parents need in higher education, as well PSEs strategies to develop these skills
  - Establish program, student, and parent expectations prior to enrollment and reinforce throughout each year
  - Facilitate parent-to-parent connections, including alumni support groups and parent-led meet-ups
- Parents

- Support young adults to learn about their strengths, needs, interests, and goals in order to promote self-awareness and advocacy and decrease dependence on parents
- Institute household responsibilities and establish family goals related to interdependence that supports positive outcomes for the family unit
- Connect with other parents as a form of information and support

Permit Risk and Failure

- PSE Professionals
  - Increase rates of inclusion in order to better prepare young adults for meaningful employment, socialization, and participation in the community (and encourage other professionals to do so)
  - Collaborate with community and university departments to provide in-service trainings about topics such as universal design, effective communication, and crisis intervention to increase comfort with risk and failure among young adults and parents
  - Scaffold opportunities for young adults to experience failure at the university, provide increasingly latent support and guidance, and collaborate with young adults to communicate their process to parents

- Parents
  - Explore and address roots of fear and anxiety to become more comfortable with young adults taking risks and experiencing failure
  - Scaffold opportunities for young adults to experience risk and failure in the home and community, provide increasingly latent support and guidance, and collaborate with young adults to communicate their process to professionals
  - Collaborate with young adults and professionals to create a plan(s) for addressing student failure, as well as parent anxiety and stress related to risk and failure

Build Trust

- PSE Professionals
  - Communicate commitment to student outcomes and seek family expertise about young adults
  - Provide ongoing assurances about the safety of young adults and highlight young adult accomplishments
  - Reinforce interdependence by collaborating with family units (e.g., caregivers, parents, siblings, extended family members, close family friends) to develop long-term strategies for generalizing and enhancing progress at home and in the community

- Parents
  - Communicate fears and seek advice and support to cope with anxiety and stress

- o Reinforce young adult skills developed in PSEs in the home and community
- o Express concerns, in addition to gratitude and recognition of young adult progress

Part 5: References

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