

ASPIRE Case Management

Promoting Readiness of Minors in Supplemental Security Income

The Achieving Success by Promoting Readiness for Education and Employment (ASPIRE) project was one of six model demonstration projects funded under the Promoting Readiness of Minors in Supplemental Security Income (PROMISE) Initiative. PROMISE projects were funded by the U.S. Department of Education, in collaboration with the Department of Health and Human Services, Department of Labor and Social Security Administration, with the goal of improving the employment and education outcomes of youth enrolled at ages 14-16 receiving SSI and their families. Each model demonstration project was organized differently, but all projects delivered a common set of services including case management, self-determination training, transition training for parents, financial literacy training, benefits counseling, and pre-employment services to prepare youth for employment in integrated settings with competitive wages.

ASPIRE

The ASPIRE project consisted of a consortium of states including Arizona, Colorado, Montana, North Dakota, South Dakota, and Montana who worked to deliver services using common methods. One of the cornerstones of ASPIRE was delivery of intensive case management services. Specifically, ASPIRE Case Managers were tasked with helping youth and their families to identify and work towards goals in education, employment, and independent living domains, link families to various ASPIRE and non-ASPIRE training opportunities, and to make referrals to various community based services. Case Managers were expected to conduct monthly face-to-face meetings with every youth and/or family enrolled in ASPIRE services.

Despite Case Manager intentions, face-to-face monthly meetings fell well-below established targets of one meeting per month. Across the last three years of the project, the average number of in-person meetings was about five meetings per year. This was unfortunate given regression results that showed higher numbers of face-to-face meetings between the Case Manager and family predicted improved youth employment outcomes, after controlling for youth age, gender, race, ethnicity, and disability (Ipsen, Kurth, McCormick, Hall, & Chambless, 2019).

Methods

To better understand delivery of ASPIRE case management services and strategies to engage families, we conducted two focus groups with ASPIRE case managers to learn about their experiences. Teams of two researchers conducted each meeting in the fall of 2018 with case managers (n = 15) from all participating ASPIRE states. Focus group discussions were recorded, transcribed, and analyzed for emerging themes.

Focus Group Interview Questions

The following focus group questions focused on better understanding the unique aspects of ASPIRE case-management.

- In what ways did the case management you conducted for ASPIRE differ from case management you have done for other projects, agencies, populations, etc.?
- What discussions, linkages, etc. did you feel were the most useful when you had opportunities to meet with youth (families)?
- How did you adapt services for hard-to-reach groups (e.g. families in very rural areas, with more severe disabilities, etc.)?
- How did youth (and families) respond to the goal-making process (SMART goals)?
- For those of you who utilized the “MyFile” or similar tools for helping youth and families organize important documents, what are your thoughts on the usefulness of these tools? How have youth/families continued to use them?
- How did case management change as youth neared or reached age 18? What paths seemed to work the best and for whom?
- What do you know now that you wish you had known earlier in the process as it relates to case management services?

Results

ASPIRE Services and Delivery

Participants described ASPIRE case management as distinct from past case management experiences in terms of three primary themes including the holistic nature of services, delivery characteristics, and the optional aspect of participant engagement.

Holistic services. Respondents described ASPIRE services as holistic in terms of service to entire families and types of services offered or explored. One respondent stated “You worked with their parents, grandparents, extended family, whoever else may be involved in their life, their teachers, their support people....more as a team rather than in some areas of case management that are very targeted to just that one person you’re working with.” Another case manager stated “case management felt a lot more like multi-systemic therapy...that was pretty impactful when you’re able to see what’s happening with a sibling and be able to contact their teacher and work with them also.”

The comprehensive aspects of ASPIRE services were described both in positive and negative terms. On the plus side, Case Managers appreciated the opportunity to work in areas that resonated with individual families, rather than having to follow a more narrow focus. As one Case Manager described, if someone had employment and VR covered, then he could work in another area that seemed more relevant or pressing to the family’s situation. The broad nature of services, however, also left some Case Managers feeling ill-equipped to provide quality

services. One informant stated “because there is a larger scope...there was more room for a lot of things to change and we’d have to adapt...it gave interesting challenges in certain situations.”

In addition to specific APSIRE services, informants addressed a range of crisis issues such as unanticipated pregnancy, issues with SSI, homelessness, and incarceration. A negative aspect of family crisis was that is sidelined forward progress in the APSIRE domains of education, employment and independent living. A positive aspect was the trust-building that resulted from the Case Manager helping a family through a crisis situation.

Delivery characteristics. Informants shared that ASPIRE case management was very accommodating to family needs and desires. Case Managers met families at various locations and hours to meet family preferences. One Case Manager stated “We met the family where they were at. So if they felt comfortable meeting in their homes, we went to their homes. If they felt comfortable meeting at our offices, that’s what we did. If they felt comfortable meeting at a McDonald’s, that’s what we did. We also went outside business hours and on weekends. I know a lot of agencies don’t do that. It’s you need to come to my office 8-5. So I think that was the big difference that I saw from this.”

Respondents also described the duration of ASPIRE services as a contributing factor to effective services. For one Case Manager, service duration was an important difference. In her words, “[it’s] just the long-term relationships we’ve built. Just having the families for 4 years. That’s made a huge difference.”

Optional Attendance. A defining difference between ASPIRE services and other case management was the optional nature of participation. Case Managers often came from systems where participation in services was mandated or required. One Case Manager described “I’ve always had a job where the clients were required to meet with me monthly or whenever, or that there was some incentive that was kind of huge enough that they did meet with me regularly. So having a significant part of my caseload that doesn’t want to meet with me, doesn’t seem interested in meeting with me, or even that will occasionally just flat out say I don’t want to meet with you every month, that’s been different....it’s, you know, a little discouraging or disheartening sometimes, especially when you feel like you have so much to offer...”

Promoting Attendance

Case Managers describe strategies for reaching families, particularly in the face of optional attendance. Strategies focused on persistence and flexibility.

Persistence: Case Managers often took extraordinary lengths to stay in contact with youth and families. This included rescheduling appointments multiple times to accommodate sporadic schedules, visiting youth in juvenile detention centers to ensure continuity of services, and visiting families in their homes to overcome transportation or other caretaking barriers. One

Case Manager described a good example of this commitment for a youth living in a very rural location. “There’s nothing in this little town. The family doesn’t have a car and they frequently don’t have a phone that works. So, we kind of have a set time. I’m going to stop by the first week of every month so I don’t have to call or set up or text to set up a meeting....And, it’s worked out pretty well. If the kid’s not there, mom’s usually there so I can get a meeting in and get stuff figured out.”

Case Managers were diligent in figuring out ways to deliver services to families. This included keeping on top of signed releases as youth transitioned between systems, such as between the juvenile and adult corrections systems, so they could continue to hold appointments. They also figured out alternative delivery strategies, including delivering some of the training content themselves, when contractors were unwilling to serve certain rural and reservation locations.

Flexibility: Case Managers also described flexibility in terms of how and when they delivered services. Case Managers often addressed family needs rather than pushing mandated ASPIRE services. For instance, they helped families connect with counseling services, social support groups, food pantries, Section 8 housing resources, to name a few. They also served other family members. One family felt their ASPIRE child with a severe disability got all the services he needed, but were concerned about another child who was falling through the cracks. In this case, the Case Manager helped find resources for the non-ASPIRE youth. Case Managers described focusing on family interests first, and then gradually incorporating ASPIRE services and goals into the discussion, as a means to engage the family. Other examples of flexibility included helping family with transportation (both in terms of bus passes and mobility training).

Overall, Case Manager persistence and flexibility translated into trust-building with the family. According to focus group participants, when youth and families concluded that Case Managers were there to help them, and did not give up on them, they were more willing to make time for appointments and other ASPIRE services.

Case management tools

SMART Goals: ASPIRE case management centered on goal setting activities in the areas of employment, education, and independent living. In particular, Case Managers were tasked with helping youth and families understand how to develop and accomplish specific, measurable, attainable, relevant, and timely (SMART) goals. Case Managers provided both positive and negative feedback about the SMART goal-setting requirements.

In general, they described difficulty getting the SMART goal process rolling, including family reluctance to set goals, and confusion about the SMART goal requirements. Additionally, because many youth were required to identify goals for their IEPs and other disability related services, they did not understand why they were being asked to develop yet another set of goals. Some Case Managers adjusted to this feedback by breaking goals into between-meeting task lists, which were easier for the youth to deliver and see tangible progress on.

Over time, Case Managers reported that families grew to tolerate and often appreciate the goal setting process. Goal setting also helped Case Managers frame their meetings with families. Specifically, revisiting goals was good at giving meetings traction or focus, and helped establish a system of accountability. As one Case Manager described “it helped me to stay on track and really start to see movement and progress in our meetings as opposed to just checking in and how are things. And then also, help all of us stay focused and now we can look back and review things that they have accomplished.”

MyFile: Another meeting tool used by several Case Managers was called MyFILE. MyFILE was developed by the South Dakota Parent Connection as an organizational tool for maintaining important information. It consists of an expandable folder with tabs for keeping a variety of documents, such as school transcripts, health records, provider contact information, social security numbers, etc. Case Managers provided MyFILE folders to youth and used it as a discussion point about confidential documents and the importance of keeping them safe, organized, and available for medical or other important appointments.

Case Managers reported that less than half of their youth and families used the MyFILE folder. Use often depended on Case Manager enthusiasm for the tool. One stated, “I think you have to keep revisiting it, and I think the ones that didn’t use it were probably because I didn’t keep it at the forefront of our conversation or they just kind of stuck it aside and forgot about it.” Another felt that the tool included enough cues about what was needed that even if it didn’t get used right away it could become a useful tool later.

Case Managers reported that the tool was amazing if youth used it. One case manager said, “I have a girl who religiously uses hers. Every meeting she brings it, she takes it in her backpack everywhere she goes. She’s kind of experiencing some homelessness, so it’s actually been really beneficial that she can take all of her documentation, have it organized, and have it be small enough where she can tote it around...If you use it, it’s an awesome tool. And if you don’t, I mean hopefully it’s just a place for organization at home. But a lot of my families have asked for more for other family members, or parents have used them. So the MyFILE was a total hit with my families.”

Another Case Manager shared that many of her youth were not interested in using the file, but probably because they were too young to recognize its usefulness. Building on this, one Case Manager said, “I think as kids turn 18, giving it to them rather than their parents when they’re younger would be a good idea...Because I can say now you’re an adult, you need to keep track of all of this stuff that your parents once kept track of for you, and in a safe place.”

Youth into Adulthood

Pre-18. Case management changed as youth aged. When youth were nearing age 18, Case Managers reported that families began to see more value in ASPIRE services and a greater

sense of urgency to figure out their child's next phase. One Case Manager put it this way. "I actually felt like when they were about 17, 17 and a half, was the perfect age to start getting more involvement with families because all of a sudden it was real. It's not this distant thing, and...people wanted to know where the parent trainings were about guardianship, or how do they do a power of attorney, or how do I ask the school to keep my kid in school longer, or what about college, or what's my kid going to do now. And obviously the age 18 redetermination [for Social Security] was huge."

Case Managers highlighted that many parents were over-protective of their youth, and nearing age 18 sparked conversations about planning for next steps. As one Case Manager described, "But a question I've had to pose to them as we're planning for the future, one planning for me not to be here, and planning for them [youth] to become adults, is a lot of the parents are so involved they have this mindset that they're always going to be there...So I think getting the conversation started and giving them [youth] more independence and reaching out to more places so that their kid has a plan, if heaven forbid, something happens to the family. "

Age 18 and Beyond. Case Managers described situations where family involvement faded and they had more direct contact with youth. Although youth were sometimes left unsupported, Case Managers described less parent involvement in positive terms. For instance, one Case Manager said "And once the youth is 18 and the parents just sort of said, just deal with them directly, I have found it to be so much more productive. That the youth actually want to be engaged and involved and go to classes and do the interventions where I feel like some of my families, the parents, are actually standing in the way of that happening." Case Managers also highlighted that it was easier for youth to express their voice more openly without their parents, and that they met more regularly, since parents often had competing demands which made scheduling more difficult.

One Case Manager stressed how important case management became for emancipated youth, particularly if they had less severe disabilities and were not transitioned into post-high school services. He stated, "They move off, and they're their own guardian so they just kind of try to find their own way. And I think that was the most challenging but also the group that really needed the case management the most. They're couch surfing, they're just kind of out there looking for a place. They rarely have the same phone number for a week at a time, so they're pretty difficult to track down. But I really think that's the population we can serve the best."

Lessons for the Future

Procedures: Case managers provided feedback about things that would have improved their case management experiences. First, there were several comments about confusion regarding specific procedures. Rules evolved over time about where case management meetings could occur, the types of supports Case Managers could offer, and how ASPIRE interventions could be delivered. While these changes were often seen as improvements, Case Managers described frustration with evolving policies and procedures. This same issue applied to case records,

where expectations for AIMS data input were not clearly understood until later in the process, which created confusion and back work for the case managers.

Case Management. In terms of case management, informants said that ASPIRE’s focus on goals in employment, education, and independent living, sometimes undermined family engagement. They described needing to adjust strategies to “client-centered or client-directed approaches” to build stronger relationships with families. They also highlighted that parents were often able to provide better contacts for initiating services. One Case Manager put it this way “I think maybe in our conversations with parents...that would’ve been the first place to start. Rather than going to the school and talking to the special education director and saying ‘ok, we’ve got this project,’ I guess knowing a little bit more about where are these students at. Are they in this particular special education department at this high school? And going there and talking to all those teachers and explaining. I think maybe starting more at the ground level rather than going through administration.”

Training. Informants highlighted specific competencies that would have helped them support families better. For instance, they wish they’d received more background in SSI, Medicaid waiver programs, and local resources in more rural areas. They also desired more continuous training opportunities to meet different needs as youth were getting older. A few Case Managers were also benefits specialists, which they saw as a huge advantage in supporting the family.

Cross-site sharing. Informants also wished there had been more opportunities to share strategies across sites. As one informant said, “it’s interesting listening to what other people did, because I feel like we all did very different things with our families. Like I’ve really barely had any contact with schools at all. Just for whatever reason it hasn’t even been a thing. And so I’m like, how could I or should I have done that... I just wish I’d known more about what other people were doing, especially in other states that are just kind of outside the box for me.”

Discussion

Like all PROMISE projects, ASPIRE practices evolved over time to better address emerging issues. As highlighted in other ASPIRE research articles (e.g. Ipsen, et al, 2019; Hall, et al., under review) engaging ASPIRE families was more difficult than initially anticipated. This lack of engagement stemmed from a variety of factors, including family crises which disrupted service continuity (Hall, et al., under review), present-thinking orientation or decision making-making based on immediate needs (Ipsen, et al, 2019), and the optional nature of ASPIRE service delivery. Together, these factors made it hard to deliver a consistent set of services over time.

Data indicated, however, that ASPIRE youth experienced better employment outcomes when they had higher rates of face-to-face case management meetings (Ipsen, et al., 2019). In part, provision of these services was amplified when Case Managers were able to develop strong

relationships with ASPIRE families, offer flexibility in terms of meeting locations and times, and provide incentives for engaging in services (Ipsen, et al, 2019). In particular, focus group informants highlighted that relationship building was enhanced by the duration of ASPIRE services, client-focused approaches, case management support through crises or other family situations, and flexibility in service delivery strategies.

The full impacts of ASPIRE services will not be available for years to come, when youth have transitioned to full adulthood. Preliminary data, however, supports the important role that case management plays in the road towards economic self-sufficiency. Strategies to replicate or incorporate case management services into standard practice delivery should build on lessons learned from frontline ASPIRE case managers. It was the aim of this factsheet to provide these.

References

Hall, J., Ipsen, C., Kurth, N., McCormick, S., and Chambless, K. How family crisis may limit successful transition of youth with disabilities from SSI to self-sufficiency. Manuscript submitted for publication to *Career Development and Transition for Exceptional Individuals*.

Ipsen, C., Kurth, N., McCormick, S., Hall, J., & Chambless, C. (2019). Engaging SSI youth and families with ASPIRE services. *Journal of Vocational Rehabilitation*, 51(2), 211-224.

Disclaimers

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