Teaching self-determination to youth with disabilities: The ASPIRE model

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Abstract.
BACKGROUND: As one of the PROMISE projects, ASPIRE sought to enhance education and career outcomes to reduce long-term reliance on SSI. Self-determination training was offered to transition-age youth with disabilities receiving SSI as an evidence-based intervention to improve employment and post-secondary outcomes.

OBJECTIVE: To investigate the implementation of self-determination training for transition-age youth with disabilities, and provide lessons learned to inform future programs.

METHODS: Researchers used grounded theory and qualitative methods to obtain data on challenges encountered and successful strategies for delivering self-determination training to youth with disabilities. Informants were case managers and trainers in a six-state demonstration.

RESULTS: Challenges encountered included low attendance and adapting training for groups with a range of disabilities. Successful strategies included scheduling other events in conjunction with the self-determination workshops and adapting the curriculum to be more interactive and relevant to the interests of teens. Youth outcomes were enhanced by increasing self-awareness and skills for disability disclosure.

CONCLUSION: Considering the wide variety of training content and delivery formats, self-determination training can prepare youth with disabilities for post-secondary education and employment.

Keywords: Transition, disability, employment, SSI, self-determination

1. Introduction

Self-determination training was a key intervention provided to transition-age youth receiving Supplemental Security Income (SSI) through the Achieving Success by Promoting Readiness for Education and Employment (ASPIRE) project. Self-determination is a key concept associated with educational achievement and employment success for transition-age youth with disabilities (Shogren & Ward, 2018). Self-determination refers to characteristics of individuals that lead them to make choices and decisions based on their interests and preferences (Shogren & Ward, 2018). Self-determination skills allow a person to monitor and control their own actions to be goal-oriented and self-directed (Davis, 2015).

1.1. The ASPIRE Project

ASPIRE is one of six Model Demonstration Projects (MDPs) funded through the U.S. Department of Education’s Promoting Readiness of Minors in Supplemental Security Income (PROMISE)
initiative. PROMISE is a joint federal research demonstration of the US. Departments of Education (USDOE), Health and Human Services, and Labor, with evaluation support for the demonstration from the Social Security Administration. As the lead federal partner, the USDOE funded model demonstration projects in Arkansas; California; Maryland; New York; Wisconsin; and the ASPIRE consortium, to address barriers and obstacles to economic independence and promote successful education and employment post-school outcomes for youth who receive SSI. Youth SSI recipients between the ages of 14 to 16 were eligible to enroll in the PROMISE demonstration.

Designed as randomized control trials, PROMISE projects are testing the education and employment outcomes for youth SSI recipients assigned to the treatment group. The ASPIRE consortium consists of six states: Arizona, Colorado, Montana, North Dakota, South Dakota, and Utah. ASPIRE states worked collaboratively to deliver a consistent set of services to intervention group youth and their families across a wide geographic area. Self-determination training was offered to ASPIRE participants in the intervention group to improve youth’s skills in self-awareness, self-advocacy, goal-setting, and problem-solving. Intervention group youth were encouraged to attend up to six hours of self-determination training per year. Other services provided to the youth and family members in the ASPIRE Services group included: case management; transition training for parents/guardians; pre-employment services to prepare youth for employment in competitive, integrated settings; financial literacy training; and benefits counseling. Participants in the Usual Services group received the same services they would have received in their respective state transition and education systems.

1.2. Self-determination literature

There are two main theoretical models of self-determination. Wehmeyer’s functional theory suggests that self-determination emerges throughout childhood as individuals are exposed to a number of decision-making and problem-solving skills (Wehmeyer, 2007). This exposure, in turn, promotes self-monitoring, self-advocacy, self-awareness, and self-knowledge, which enables individuals to be conscious agents in his or her own decision-making. Mithaug’s self-determined theory focuses on the process by which students become self-determined. This theory depends on student capacity and opportunity to make self-determined choices, where capacity refers to knowledge, ability, and perceptions and opportunity refers to chances provided to students to apply their knowledge (Mithaug, 2003). Regardless of definition, both models posit these skills can be taught through education curriculum (Shogren, Wehmeyer, Palmer, Soukup, Little, Garner, & Lawrence, 2008).

Empirical studies have shown that youth with disabilities who demonstrate greater levels of self-determination are more likely to have a job, attend post-secondary education, and live independently in the community. Assessments of teens with disability demonstrate that current levels of self-determination predict future levels of self-determination. Consequently, the earlier that self-determination is integrated into the adolescent curriculum, the greater the impact on adult employment (Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2013).

People with different types of disability respond to self-determination training differently. For example, students with learning disabilities showed higher levels of self-determination than those with intellectual disabilities (Chou, Wehmeyer, Palmer, & Lee, 2016). This difference may be attributable to IQ, but also may relate to opportunities to practice self-regulation skills. Due to this variability, educators focus increased attention on the role of the environment both at home and in school in promoting skills to enhance self-determination. Parents can increase overall instruction opportunities for youth with disabilities by practice at home (Seong, Wehmeyer, Palmer, & Little, 2014).

1.3. Purpose

One purpose of the study is to describe the content and delivery methods of the self-determination training used in the ASPIRE project to permit future replication and effective implementation of this type of training with a similar age-group of SSI youth. A second purpose of the study is to identify specific components of the ASPIRE self-determination training which appear to affect behavior change in participating youth. The research questions that guided the study were: 1) What was the content of the ASPIRE self-determination training and what delivery methods were used? 2) What challenges were encountered in implementing the training in various
sites? 3) How was the training adapted over time to address these challenges? 4) Did the intervention appear to impact behavior change in the participants? If yes, describe examples of the changes. To answer questions 1, 2 and 3 the researchers conducted interviews with the ASPIRE project director, site coordinators, trainers and case managers from each ASPIRE site. To answer question 4, researchers conducted focus groups with ASPIRE case managers.

1.4. Preliminary quantitative results

Preliminary results from the ASPIRE formative evaluation showed that only 26% of the intervention group participated in two or more hours of self-determination training in the first two years following enrollment (Ipsen, Kurth, McCormick, Hall, & Chambless, 2019). Low participation rates in self-determination training may explain why measures of self-determination using the AIR Self Determination Scale did not show significant differences over time between the intervention and control groups (Ipsen, et al., 2019). However, further analysis of case management records for intervention group youth showed self-determination training during the first year of ASPIRE was positively associated with second-year employment outcomes (Ipsen, et al., 2019). Thus, early results from the ASPIRE study demonstrated evidence of the benefit of self-determination training prior to work opportunity. The number of in-person case management meetings between families and case managers was also positively associated with employment outcomes (Ipsen, et al., 2019). Interventions provided by ASPIRE case managers often included self-awareness, goal setting, and self-advocacy discussions. These activities also created both capacity (knowledge) and opportunity (experiences) for self-determination skill-building. While the focus of this article is on the ASPIRE self-determination training, the effect of case management is discussed as a factor in explaining the outcomes.

2. Method

Researchers used qualitative methods to obtain data on self-determination curriculum content, delivery methods, challenges encountered, successful strategies for delivering and its impact on youth with disabilities. Informants were the project director, site coordinators, case managers, and self-determination training contractors representing all six sites.

2.1. Participants

Researchers first interviewed the ASPIRE project director followed by interviews with site coordinators in each ASPIRE state (n = 6) to understand the challenges of defining content and procuring trainers to deliver self-determination training. Secondly, researchers conducted one-on-one telephone interviews with self-determination trainers (n = 5) and case managers (n = 4) to identify challenges, successes and strategies. In one state the trainer was also a part-time case manager. Following analyses of these interview data, researchers conducted two focus groups with ASPIRE case managers (n = 13) to gain their perceptions of training effectiveness and impact on participants.

2.2. Instrumentation

The ASPIRE evaluation team developed interview questions to address the research questions. Interview questions for the project director asked about establishing training requirements and writing contracts to ensure consistency of self-determination training across all ASPIRE sites. Questions for site coordinators asked how they procured qualified providers of self-determination training to fulfill contract requirements. Interview questions for trainers asked about their experiences in training youth with disabilities, curriculum they used, challenges they faced in implementing the training, and adaptations made to address the challenges. One-on-one interviews with case managers asked questions about challenges in getting youth to participate in self-determination training, observations on content and delivery, and recommendations for improving the effectiveness of the training. An interview guide for case manager focus groups included questions about challenges in engaging youth in the training, case management strategies they used to reinforce self-determination skills, changes they observed in youth behavior and stories that illustrated self-determination skills.

2.3. Procedures

The ASPIRE sites delivered self-determination training through independent contractors in five of the six states. One state chose to combine the trainer and case manager role into a single position. Contracts between the ASPIRE project and self-determination training providers contained a standard scope of work for the training. Contracts specified the train-
ing be delivered face-to-face with six contact hours of training per year expected for all ASPIRE youth. Decisions about specific content, format and locations were left to state-specific site staff to select. Contracts defined core self-determination training elements through a list of thirteen broad concepts:

- Choice-making
- Decision-making
- Problem-solving
- Goal-setting and attainment
- Independence, risk-taking, safety
- Self-observation, evaluation, reinforcement
- Self-instruction
- Self-advocacy, leadership
- Positive efficacy, expectations
- Self-knowledge, awareness
- Understanding one’s disability, ability to talk about disability
- Disability disclosure, ability to request accommodations
- Obtain and use effective assistive technology, as appropriate

Interviews and focus groups for this study were conducted with the ASPIRE staff and training contractors over a 10-month period during the fifth year of the project. At the time of data collection, self-determination training had been established and was being provided in all six sites. Researchers obtained the curricula used in the sites and compared curriculum elements with required content in the ASPIRE self-determination training contracts. Interviews were conducted via telephone and recorded by contemporaneous typed notes. Focus groups were conducted by web conference, audio-recorded and transcribed.

2.4. Data analysis

Analyses of the data followed a grounded theory approach (Strauss & Corbin, 1998). An initial list of descriptive codes was developed based on the research questions prior to analysis. One researcher coded the interviews of project director and site coordinator and assigned additional interpretive codes. Themes emerged such as “trainer qualifications” and “poor youth attendance” that were incorporated into questions for a second round of interviews with trainers and case managers. These data were then coded and salient themes emerged such as “self-awareness” and “disclosing disability” which were incorporated into the third round of data collection with case managers. A second researcher reviewed and independently coded the data. Differences in interpretation by the researchers were discussed and interpolated.

3. Results

3.1. Content and delivery methods of ASPIRE self-determination training (Research Question 1)

Content. In general, self-determination training was provided outside the school setting. The sites with the largest populations (Arizona and Colorado) developed new curricula to fit the contract requirements. The remaining four sites chose to build curricula from existing free or low-cost source materials available through the Internet. Table 1 lists the names of the curricula and source materials adapted to fit the ASPIRE self-determination training for each site.

All curricula met the 13 skill requirements outlined by ASPIRE contract, yet they varied considerably in content. Trainers adapted curricula to fit the requirement for ASPIRE youth to attend six hours of training per year. Sites also adapted activities on an ongoing basis to suit the needs of the participants and improve effectiveness. Most training activities had a clear relationship with ASPIRE employment goals, such as practicing job searches, interviewing, and requesting accommodations.

Three sites used curricula that demonstrated a clear focus on developing participant understanding of their disability or health condition. These curricula focused on developing youths’ skills in describing their personal challenges and strengths through practice. Training activities used scenarios involving school and employment settings. The Colorado curriculum titled, “Know Thyself” has a theme of self-discovery that runs through every session. The curriculum used in both South Dakota and North Dakota employed worksheets and homework for youth to understand themselves and how others perceive them. Personal disability awareness served as a key discussion point in all three sites’ trainings. The curricula notably reflected the perspective that each youth is a unique human being who needs to understand and articulate his/her own interests, needs and capacities to be successful. This perspective laid the foundation for participants to address the sensitive
Table 1
Source Curricula for ASPIRE Self-Determination Training

<table>
<thead>
<tr>
<th>Site location</th>
<th>Number &amp; type of provider organizations</th>
<th>Source curricula</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arizona</td>
<td>1 University Extension 4H Program</td>
<td>• ASPIRE Self Determination Curriculum developed jointly by AZ Governor’s Office for Youth Faith and Family and University of AZ Cooperative Extension</td>
</tr>
<tr>
<td>Colorado</td>
<td>1 Parent Training and Information Center</td>
<td>• Know Thyself, developed by PEAK Parent Center, Colorado Springs, CO</td>
</tr>
<tr>
<td>Montana</td>
<td>3 Centers for Independent Living</td>
<td>• Building Advocacy and Learning Leadership Skills (BALLS), developed by Summit Independent Living, Missoula, MT</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Living Well with a Disability, University of Montana Rural Institute on Disability.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Wellness Recovery Action Planning (WRAP), Advocates for Human Potential.</td>
</tr>
<tr>
<td>North Dakota</td>
<td>1 University Center on Excellence in Developmental Disabilities (UCEDD)</td>
<td>• ME! Lessons for Teaching Self-Awareness and Self-Advocacy (Cantley, Little, &amp; Martin, 2010)</td>
</tr>
<tr>
<td>South Dakota</td>
<td>1 Non-Profit Human Services Provider</td>
<td>• ME! Lessons for Teaching Self-Awareness and Self-Advocacy (Cantley, Little, &amp; Martin, 2010)</td>
</tr>
<tr>
<td>Utah</td>
<td>6 Centers for Independent Living</td>
<td>• ME! Lessons for Teaching Self-Awareness and Self-Advocacy (Cantley, Little, &amp; Martin, 2010)</td>
</tr>
</tbody>
</table>

issue of disability disclosure as they transitioned to environments outside high school and family settings.

Interviews with trainers and case managers revealed that in a couple of instances trainers did not focus the training on the goals of improving education and employment outcomes. In one site, a trainer reported that when he was hired, he received little direction about the purpose of ASPIRE. The organization did not have a self-determination curriculum, so the trainer borrowed activities from a curriculum on emergency preparedness. As part of the unit on decision-making, participants were directed to develop “72-hour survival kits” for emergencies. In a different site, during a lesson on self-advocacy, the trainer asked participants to suggest an issue they would like to advocate for at school. When the trainer was met with silence, she suggested advocating for having sushi served at the school cafeteria. Case managers expressed concern that these activities did not advance the intended goals of ASPIRE.

**Delivery.** The length and frequency of trainings varied from one hour per week to six hours in a single day. Each site experimented with varying length and frequency to meet the needs of the participants. In general, the delivery formats were adjusted to fit the geographic challenges of each region. In rural areas, the sessions were held for longer periods to decrease the number of times participants would need to travel. Urban areas held shorter trainings more frequently. One rural state held training workshops on a Friday-Saturday at a hotel in which families would stay overnight to attend an all-day (6 hour) workshop.

One ASPIRE site opted to deliver self-determination training with internal staff. The remaining five ASPIRE sites contracted outside their own organizations to deliver self-determination training. A total of twelve different organizations within the six states provided the training: Centers for Independent Living (8), University Center on Excellence in Developmental Disabilities (UCEDD) (1), Parent Training and Information Center (1), University Extension 4H Program (1), and a not-for-profit human services provider (1).

3.2. Challenges Encountered in Implementation (Research Question 2)

Results from in-depth interviews with site coordinators and trainers revealed details about implementation challenges and the strategies used by ASPIRE staff and training contractors to address them.

**Attendance issues.** Low attendance at self-determination trainings was a significant challenge in all sites. A decision was made at the start of ASPIRE to offer self-determination training outside
of the school setting to eliminate the chance of control
group youth receiving the intervention. Thus, fam-
ilies had to plan transportation to reach the training
locations. Low and sporadic attendance made it diffi-
cult for trainers to sequence lessons for skill building.
With inconsistent attendance, trainers were chal-
 lenged to adapt the session’s lessons for individuals
who were at different points in their understanding.
Trainers reported feeling obligated to cover the
basic content each time a new person attended, with
the risk of returning participants becoming bored
or disengaged. Boredom also contributed to lower
attendance in subsequent sessions.

Scheduling issues. All sites confronted barriers with
scheduling trainings to be accessible for all partici-
pants. For example, case managers explained: “Most
of the self-determination starts at 3:30 and it has been
challenging for parents who work to have their child
attend. Or if they don’t work, they don’t have trans-
portation.” Sites experimented with holding trainings
at different times and days of the week, but no sin-
gle solution worked for everyone. ASPIRE offered to
reimburse parents for transporting youth to the train-
ings, yet case managers reported this was not enough
of an incentive to make up for the logistical difficulties
many parents experienced.

Different types of disability. Another highlighted
issue was the wide range of cognitive abilities of
participants. Participating youth were all within a 3-
year age range (14 through 16 at enrollment), yet
they had wide-ranging types of disability. One trainer
described: “It was difficult to reach all the academic
and functioning levels of the teens [within a single
group].” Preparation to meet the needs of differ-
ent learners was exacerbated by little to no contact
between the trainer and the youth prior to the first
training session. ASPIRE did not have procedures to
communicate special needs of the youth to the train-
ers. Trainers were unaware of participant cognitive
levels or needs for accommodation prior to the first
session. Thus, initial time in the training was spent
getting acquainted with the instructional needs of the
youth. One trainer stated, “the biggest challenge for
us is not knowing who is coming” and not being able
to prepare for accommodating needs of participants.

3.3. Adaptation of training to address challenges
(Research Question 3)

Trainers and case managers collaborated in
addressing the challenges of self-determination train-
ing. They each had a role in increasing attendance,
 improving the relevance of the training, and commu-
nicating the needs and reactions of the youth involved
with the training. Case managers who attended some
or all of the trainings benefited by observing the cur-
riculum and reactions of the participants. Trainers
adapted training with feedback from youth, case man-
gers, and parents. The following strategies were used
to improve the quality of the training over the life of
the project.

Interactive training. Several trainers and case man-
gers stated that training sessions which encouraged
group interaction among all youth were the most
engaging and effective. One trainer who had been
a soccer coach, stated that movement around the
classroom was an effective strategy for maintaining
engagement. This trainer stated: “Our curriculum
is based on group activity—getting up and moving—
because having kids sit for hours doesn’t really work.”
Training sessions that were scheduled for several
consecutive hours had the challenge of keeping the
attention of teens. One trainer was opposed to ses-
sions that went as long as four hours: “My feedback
was that four hours is just too long.”

Trainers who reported success in engaging youth
were tuned-in to the interests of participants. Dis-
cussion content would revolve around issues brought
forth by participants themselves and not dictated by
the trainers or the curriculum. Trainers cited an ex-
ample of obtaining a driver’s license as a topic that youth
aged 14–18 are highly interested in. This topic was
suitable to be explored in sessions teaching problem
solving, goal-setting, self-advocacy, or independent
living.

The sites that were successful in drawing consistent
attendance saw positive results from group interac-
tion among teens. Youth became engaged when they
had opportunity to interact with other teens. A case
manager reported: “We have a group of about five
boys that always come, and they’ve gotten to know
each other. They look forward to pizza and seeing
each other.”

Multi-media materials. Curricula in all sites
employed multi-media materials including slides and
use of video clips. Trainers commented that use of
short video clips were effective in getting attention,
but that longer videos containing complex messages
would lose participants’ attention. Video content
needed to be directly on-point of the topic being cov-
ered and relevant for the age range of the participants.
Trainers reported that when possible, videos that
One case manager described the situation of a youth in a self-contained classroom who wanted to join the school choir. The case manager suggested the youth and parents bring that request to the IEP meeting. At the next case management meeting the youth said she is now in choir. Also, the parents and youth discovered they could ask for things in an IEP meeting.

A different case manager described an example of a youth in foster care who spoke with her mother by phone once a week. The youth experienced frustrations on these calls because her mother seemed to only talk about herself. The case manager helped the youth role-play conversations with her mother using language that was more assertive. The youth reported positive feelings after asserting herself with her mother.

A third case manager explained that he saw his role as a coach. For example, a youth with a 504 plan was struggling in school. The case manager reviewed the 504 plan in the monthly meeting with the youth and his mother. The youth’s mother and case manager coached the youth on how to advocate for changes in the plan to receive different kinds of support. The youth reported changes in his plan and improved grades. These examples illustrate how case managers seamlessly incorporated goal-setting, problem-solving and self-advocacy practices into case management meetings, thus reinforcing self-determination teachings.

Case managers were positive role models for parents about expectations for their youth. The case manager’s beliefs about youths’ potential influenced parental expectations about their youth’s capabilities. One case manager reported, “I’ve seen parents open up more, and expect more from their kids, now that I’m expecting more from their kids.” As a result, parents who initially expressed a view that their youth would never drive a car, live on their own, or work for pay changed their expectations. Parents opened up to new possibilities for their youth, thus permitting the youth more responsibility and independence.

In addition, case managers provided feedback to the trainers about impact of the trainings. Case managers routinely asked youth for their reactions to the recent self-determination class they attended in their monthly meetings. Case managers then informed the trainers which activities were effective, and which did not work. For example, a case manager reported:

I always ask youth when I meet them monthly what they think about the last class. I’m able
to get feedback, then I go back to the instructor and say, ‘Could you talk more on their level?’ or, ‘Could you play a game so it’s a little more exciting because they’re getting bored.’

Case managers would request trainers to address specific, real-life concerns that youth were facing. Case managers used topics discussed in case management meetings to suggest activities for the training, such as, obtaining a volunteer position or making friendships. These topics changed as the youth aged and matured. The case managers helped trainers customize the training to content that was relevant and timely for specific youth. Thus, case managers’ feedback to the trainers served as a formative evaluation function for improving the training.

3.4. Impact of intervention on youth (Research Question 4)

This study gave researchers the opportunity to obtain qualitative responses about the impact of ASPIRE interventions on youth’s behavior. Case managers and trainers described their perceptions of ASPIRE youth over time as the youth progressed through the interventions. Their responses point out two salient components of self-determination: self-awareness and disclosure of disability.

Self-awareness. Self-determination is intended to enhance youth’s awareness about their own identity as a person with disability. Trainers were asked whether they were comfortable facilitating discussion about participants’ disability. Two trainers who were interviewed admitted they were not comfortable discussing the youth’s disability because, “we’re not sure how much the kids know about their own disability.” One trainer admitted she had a background as a youth trainer but had no prior experience training youth with disabilities.

Other trainers described changes they observed in youth between early sessions, when youth were age 14–16, and later sessions at the time of these interviews (i.e., three to four years later). In regard to early sessions, one case manager put it this way:

Most of the youth I work with were not really open to talking about their disability. When I talked about their IEPs or 504s they were not quite sure of the connection. They just know they have a meeting and they know that they get some assistance through a resource center or a teacher, but not the link as to why it’s occurring.

Another case manager described it this way:

I don’t think I had any kid that could say their disability. I had youth that could say, ‘I go to the resource room because I have problems in school,’ but they could never say, ‘Oh, I have a reading disability and I have an IEP.’

A trainer described a progression that would occur after students had attended several self-determination sessions. This trainer described a typical student experience:

On the very first worksheet, she wrote, ‘there’s something wrong with my legs.’ So after the first class I gave them all a goal. Our goal is to figure out what your disability is. Ask your parents, your special education teacher, your case manager. Ask somebody what your disability is so you know a name. And we got to a few classes later and she was able to write down. ‘I have cerebral palsy’ and then she listed a few other things that she found out was also a disability.

Once the participants had words or language to describe their condition, they were encouraged to express how it affected their functioning. The same trainer stated: “Youth have gotten better over the years in being able to explain disability. Maybe they can’t say the right words, but they can describe how it affects their lives.” These activities built the youth’s ability and confidence to describe their differences, needs and strengths, and gave encouragement to parents as well.

Trainers and case managers reported that prior to ASPIRE, parents often did not have conversations with youth about their disability: “With parents I saw they didn’t talk to their kids about their disability at all. It was something that I guess everyone just knew was there, but no one ever talked about it, or said it by name.” Then by addressing disability through the training, “it made them think, ‘this is an OK thing to talk about.’” Coaching the youth to describe their disability as well as their strengths was a consistent theme woven throughout the lessons of self-determination. “I can see a lot of progress being made since our initial self-determination meetings when we would ask, ‘what is your disability?’ And nobody would say a word. Now I can say we’ve come a long way in the last four years.”

Disability disclosure. Self-awareness of one’s strengths and limitations is a necessary prerequisite for explaining one’s disability and requesting accom-
modations. Youth who are in a Special Education setting are not accustomed to explaining their disability in order to receive services. A case manager described the issue this way: “In high school [youth with disability] got help even if they didn’t ask for it, now in college they’re having to go and say, ‘Hey, I’m struggling.’” Not all ASPIRE youth are eligible for Special Education or 504, but all ASPIRE youth should understand the rights and protections of the ADA. One case manager expressed: “We need to help youth who are starting to leave high school realize that there is a ‘special education component’ at the higher education level they may not have been aware of.” Case managers observed that some individuals have concerns about asking for accommodations for fear of being different or standing out. One case manager stated: “They don’t want to use something in class (such as a tape recorder) and draw attention to themselves.”

The choice to disclose a disability or not, to whom to disclose, and in what manner, is a very personal and situation-specific decision. Trainers and case managers reported covering the topic in multiple sessions. One trainer queried:

How to ask for an accommodation? It’s something we have to continually talk about. At the training, during your meeting, when you’re talking with parents. Kids or parents sometimes just don’t realize they have that right to ask for those accommodations – especially with many youths working now.

Trainers explained the protections provided by the Americans with Disabilities Act (ADA) in college or job settings if an individual with disability is willing to disclose. The ASPIRE sessions provided a safe place to talk about the pros and cons of disclosure. Astute trainers helped participants explore the consequences of a decision to disclose or not to disclose. A case manager reported her surprise that youths were comfortable and willing to disclose a disability when applying for jobs: “A couple of youth that have applied for jobs just went ahead and disclosed their disability with the potential employer when they put it on their application.”

Discussing disability disclosure in the self-determination trainings was valuable because youth learned disclosure was an important part of self-advocacy. A case manager reported that one youth felt like she was the only student on campus with a disability. But through experience in self-determination training she learned, “There’s kids on my campus that have disabilities and struggle with school, and I feel like I’m not alone now. It’s OK that I struggle sometimes and it’s OK that I need extra help.”

Examples of behavior change. Study informants provided the following four examples in which youth demonstrated changes in self-determined behavior:

One youth was involved for three years as a volunteer for an annual statewide leadership conference for youth with disability. He helped with giving out handouts and serving as a “peer mentor” at the conference. Now, as a senior in high school, he is taking a leadership role in setting up the conference.

Two brothers attending the ASPIRE self-determination trainings were both very quiet in the beginning, but gradually became more outgoing and talkative. When the case manager commented on this change in behavior, one said that he is more talkative now because the instructor, “gave me time to think.” The way in which the instructor responded to this youth allowed the youth to process his thoughts and become more comfortable expressing himself. The case manager said she has seen huge improvements in the communication skills of both brothers.

One teen entered college as a nursing major due to the strong persuasion of his mother. He spent a year at college and did general requirements and those required for nursing. After his first year at college he told his mom he was going to change his major to become a teacher because teaching has always been what he wanted to do. His mom was able to step back and tell him she respects his decision.

A youth would not come out of his bedroom to meet with the case manager at the first meeting with a family at their home. This teen eventually attended self-determination training but would always sit in a back corner. Recently, the youth has “come out of his shell” and become more interactive with other participants. The youth was willing to accept a ride with the case manager one time when his mother could not take him to the training. The case manager said, “it was a huge step for this youth to get into my car and come to the training with me, when four years ago he would hardly look at me.”

3.5. Limitations

In regard to Research Question 1, the study was limited by researchers’ lack of access to all curricular materials. The researchers were not able to obtain commercial curricula that required purchase; rather researchers relied on trainers’ descriptions
of these materials in addition to Internet descriptions. In regard to Research Questions 2 and 3, the study was limited by the small number of trainers (five) who were interviewed out of a possible 20 trainers who were directly involved in delivering self-determination training. These individuals may not have represented the full range of training experiences. Site coordinators reported turnover among trainers in three sites. Concerning Research Question 4, case manager focus groups were limited to 13 participants that may not have represented the full range of opinions. The one-hour time limit of each focus groups permitted only brief comments and anecdotes from case managers.

4. Discussion

As one of the PROMISE projects, ASPIRE sought to enhance education and employment outcomes to reduce long-term reliance on SSI. Project designers selected self-determination training as an evidence-based intervention that is associated with employment and post-secondary outcomes. Early quantitative findings from ASPIRE suggest that self-determination was a key factor in predicting employment for the target population (Ipsen et al., 2019). The qualitative data presented in this paper provide a more in-depth inquiry into the process of implementing self-determination training and provide lessons learned to inform future programs.

4.1. Lessons learned

This study has several lessons about teaching self-determination to teens with disabilities. A first set of lessons relate to curriculum and delivery, including content selection, trainer qualifications, adapting content, improving attendance, and supporting families. Another lesson is to focus the training toward education and employment outcomes. A final lesson that arises from the data are two components of training that appear to be fundamental building blocks to prepare youth with disabilities for life after high school.

Content. The curriculum should be interactive and focus on skill development. To enhance skills, trainers should emphasize practicing desired behaviors both in class and at home, and case managers should reinforce these at monthly case management meetings. Skills that youth could practice are, advocating for oneself in an IEP or 504 meeting, exploring volunteer opportunities, or interviewing for a job. Trainers could use multi-media materials that are directly relevant to the topic and avoid didactic/lecture-based sessions, text-heavy slides, and long videos.

Delivery. Trainers and case managers can use a variety of strategies to increase attendance and engagement. Case managers who have clear knowledge about the training content and purpose can be more effective at recruiting youth to attend. Case managers who attend the training will observe first-hand, and be able to explain what happens in self-determination training, to reassure skeptical youth. Training schedules and locations should respond to the needs of families. Using a school setting might reduce transportation barriers. Involving parents in identifying times and places and co-locating parent and youth trainings are strategies shown to improve overall attendance. Trainings have broader appeal and appear to motivate families to attend when held in conjunction with activities or entertainment for the entire family. Examples are swimming or bowling. In addition, an important strategy to increase attendance is for trainers to contact individual families prior to the sessions to confirm their attendance, answer questions, and send a message that they are expected.

Trainers should have experience working with teens, and understand their perspectives, language, and issues that are important to them. Familiarity and ease of working with teens enable trainers to pitch messages that are relevant and resonate with the youth. Trainers should respectfully interact with individuals with disabilities and be comfortable talking about disability.

Financial support for families to attend the training is necessary for this low-income population. Families with limited resources need financial support for transportation and in some situations for overnight lodging and meals. The program should have mechanisms for advance payment or prompt reimbursement of expenses.

Focus on outcomes. Trainers facilitate a gradual awakening and acceptance of what makes each person unique. Self-awareness is a foundation for self-advocacy, and self-advocacy is a precursor for self-determination. These skills are critical building blocks for youth with disability to be successful in pursuing post-secondary education and employment.

Self-understanding and acceptance leads to youths’ identification of their support needs. Prac-
ticing disclosure in a safe setting provides youth with a repertoire of responses if they should choose to disclose. Evaluating choices to disclose one’s disability is relevant and timely when youth are deciding to enter post-high education programs and employment. Self-determination training should prepare youths to embrace the post high school and employment challenges they are likely to face.

4.2. Implications for practitioners

This study has implications for practitioners seeking to instruct youth in self-determination. Activities that promote interaction among youth are likely to be more engaging. Goal-setting and problem-solving practice sessions are more effective when using issues and concerns generated by the youth. Parent and case manager expectations for youth can influence the outcomes. This study can inform trainers how to design and deliver lessons that can positively impact youths’ careers after high school.

The study has implications for vocational rehabilitation programs that provide high school age youth with Pre-Employment Transition Services (Pre-ETS). One of five Pre-ETS that is required by the Workforce Innovation and Opportunity Act of 2014 (WIOA) is instruction in self-advocacy. This study provides insight into critical components of self-advocacy instruction: self-awareness of disability and decisions around disclosure. Self-awareness about one’s abilities and limitations is an essential building block for making decisions about one’s future. In addition to self-awareness, youth need information and feedback about a decision to disclose disability. Whether to disclose or not, when and in what circumstances to disclose, are choices that could have serious implications for individuals after high school. These two components of self-determination training are a foundation for self-advocacy instruction leading to post-high school education and employment.

4.3. Implications for research

Practitioners would benefit from an inventory of self-determination training materials, including videos and interactive activities. The inventory should identify existing curricula, catalog what is available and describe the intended audience and the focus of each curriculum. This would help trainers make appropriate selections of curricula. Experimental or quasi-experimental studies that compare outcomes of different approaches to training, and study the impact of training on individuals with different types of disability would contribute to the knowledge base.

Additional qualitative research among students with disabilities on their perceptions of the risks and benefits of disability disclosure would be useful. Focus groups would be useful to explore reasons individuals may be reluctant to disclose in a college or a job setting to receive accommodations, and to identify types of supports or environments that would reduce barriers for individuals to disclose.

5. Conclusion

Results of these analyses reveal the challenges and successes in implementing ASPIRE self-determination training. Trainers confronted issues such as sporadic attendance, difficulty in motivating youth to attend, and challenges in training a group with a range of disabilities. ASPIRE staff and trainers used various strategies to overcome these challenges. Their approaches included case managers attending the self-determination training so they could better engage participants, scheduling other events in conjunction with the self-determination workshops, and trainers adapting curriculum to be more interactive and relevant to the interests of attendees. Case managers and trainers perceived that increased self-awareness of one’s disability, and decisions and practice around disability disclosure are foundational elements of training with a goal toward education and employment outcomes. Despite the challenges experienced by ASPIRE staff and trainers considering the wide variety of training content and delivery formats used in ASPIRE sites, self-determination training was able to affect observable behavior changes in ASPIRE youth. Implications for vocational rehabilitation are that building self-awareness and evaluating decisions around disability disclosure are important transition skills for youth with disabilities. More research is needed to document curricula for self-determination training and outcomes of training on diverse populations. In addition, research is needed on the supports and environments to reduce barriers for students to disclose disability in post-secondary education.

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Conflict of interest

None to report.

References


Workforce Innovation and Opportunities Act of 2014. Public Law 113-128.