

Restoring Youth Leadership and Advocacy in Disability Communities

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Abstract

Transition-aged youth are those between the ages of fourteen to twenty-four, a period when one moves from school to employment and/or independent living. Transition-aged youth with disabilities and advocacy groups are essential to the survival of disability rights and those disability rights were passed as a matter of federal law in 1990, in the Americans with Disabilities Act. But, those rights are still being challenged. Disability Partners, a local non-profit organization, is affiliated with the nationally recognized Center for Independent Living. This local organization is concerned about who will replace those retiring as disability advocates and leaders. They wish to empower the youth who have a disability with independent living and leadership skills and want to foster the youth's connection with their community and strengthen their voice. Academic research was reviewed and recorded interviews from parents of children with disabilities were conducted to understand the barriers and expectations for a youth leadership group. Currently, there are no youth disability leadership or outreach programs in Western North Carolina that are affiliated with the Center for Independent Living. In order to evaluate the needs of youth with disabilities in the terms of leadership development and outreach, parents in Buncombe County were given eight interview questions and their responses were recorded for analysis. This information will be used by Disability Partners to implement a plan of action to attract youth with disabilities, into their leadership program.

Keywords: Advocacy, Disability, Communities, Leadership, Transition-Aged Youth

Origins of the Project

This paper is in regards to working with local non-profit communities in the Western North Carolina (WNC) area. Disability Partners is my chosen organization, which serves a wide range of persons with disabilities, in Buncombe County. They provide a wide array of services to the community at no or low cost, including: information and referral, independent living skills, peer support and advocacy. They host numerous disability community events such as, planning a meal on a budget, computer skill training, emergency preparation and assistance, social gatherings, recreation and sports. Their mission statement is to “partner with individuals and the community to enhance, advocate for and support personal choices, independent living and community inclusion (Disability Partners).”

The director and coordinators at Asheville Disability Partners want me to investigate the barriers and expectations for a youth leadership program and create a plan of action as to how to attract local youth with disabilities. They have attempted to make contact with local schools and their counselors and special education teachers and have not been able to attract any participants for this program. Disability Partners has also presented in classrooms and handed out flyers to the students about their program in local schools, to no avail. Because of privacy issues regarding children and parents’ names in the disability community, direct contact is almost impossible.

Methods and Work Undertaken

Disability Partners has asked me to collect audio/video interviews from parents with children who have a disability, who are between the ages fourteen and twenty-four years old, about their expectations and barriers to their children attending their youth leadership program. Additionally, they want me to research successful youth leadership programs and how to bridge communication with those who work with children with disabilities and reach their parents. I am also developing a marketing plan designed to attract youth to their program. Here are the eight interview questions asked of parents whose child has a disability:

What extracurricular activities does your child participate in?

Has he/she shown any interest in a leadership program?

What might be some barriers that have kept her/him from attending such a program?

What may attract you/your child to a leadership program?

Where might you seek information on a program like this?

Do you think disability advocacy is important for your daughter/son?

Do you expect your daughter/son to live independently and if so at what age?

Do you have any plans about how your child will live independently, and if so do you think a leadership program would assist in that plan?

Consent forms and questions, as well as the purpose of this study were submitted to the University North Carolina of Asheville Institutional Review Board (IRB). This project was determined exempt from further review due to the risk/benefit ratio of the project and a project design that minimizes risks. I believe this decision may have been reached because of my attention to IRB rules and regulations for my protocol application, due to me studying and passing the Collaborative Institutional Training Initiative (CITI), IRB online training. My design keeps the names of the parents and children confidential, while ensuring recordings are in a secure location, and finally passes the final product, recordings and data, to Disability Partners, after editing out any personal information. Parents' names were obtained through networking like-minded organizations and personal referrals.

Ties to Academia

Some of the most influential federal legislation that impacts the rights of youth with a disability, is the Americans with Disabilities Act (ADA), and the Individuals with Disabilities Education Act (IDEA), both passed in 1990 (Wehmeyer & Gragoudas, 2004). The ADA was passed to protect those with a disability from discrimination, much like the civil rights movement of the 1950's and 1960's (William & Shoultz, 1982). ADA has endured much litigation over the vagueness of its statutes, although these challenges have added new amendments, bringing clarity and small gains for the disability rights movement (O'Brien, 2004).

The Individuals with Disabilities Education Act (IDEA) allows each state responsible for implementing the law, as to whether they want to accept the governmental funding, for transition-aged youth between the ages of fourteen to twenty-one (Wehmeyer & Gragoudas, 2004). This law was passed with the intention that schools provide transition services for students in regard to future employment, college and independent living (Sheldon & Golden, 2005). IDEA requires that those states that accept funding incorporate transition services in an Individualized Education Program (IEP), for all students with a disability by the age of sixteen (Wehmeyer & Gragoudas, 2004). Although, federal laws govern basic transition services for youth with disabilities in high schools, most fail to comply (Greene & Kohler, 2004; Test, Fowler, Wood, Brewer, & Eddy, 2005). To date, all the states have accepted funding, and yet not only do a majority fail at supplying basic transitional resources, they also lack instilling essential skills such as self-advocacy, self-determination, leadership, and independent living skills, as well as leisure activities that develop inclusion with the community, which research indicates essential for successful transition into adult life (Badia, Orgaz, Verdugo, Ullan, & Martinez, 2011; Caldwell, 2010; Carter, Swedeen, Walter, Moss & Hsin, 2010; Test et al., 2005; Wehmeyer & Gragoudas, 2004). Further research indicates a lack of understanding youth with disabilities, knowledge of available resources and connection between organizations, agencies and institutions inhibiting youth from attaining transitional services and support (Badia et al., 2011; Caldwell, 2010; Carter et al., 2010; Test et al., 2005; Wehmeyer & Gragoudas, 2004).

Leadership

The development of youth leadership skills has been associated with successful transition into adulthood for all students (Carter et al., 2010). Yet youth with disabilities are less likely to participate in leadership building activities that would positively influence their lives, as well as the lives of others. Carter et al., (2010) questioned thirty-four young adults with different disabilities, about what factors foster leadership development for them.

Results show that the attitude and skills associated with leadership were effective communication and perseverance. Effective communication consisted of public speaking, networking, conveying ideas and being a good listener, while perseverance related to self-determination. The ability to influence others was another key indicator of leadership (Carter, et al., 2010). Carter et al., (2010) found advocacy and self-advocacy, speaking up for one's rights and being aware of one's personal limitations, as important factors in leadership development, followed by helping others, becoming a mentor or role-model for others.

Experiences that fostered leadership are disability specific leadership training, service clubs and extracurricular activities, in school and community clubs, in which they are involved with youth without a disability (Carter et al., 2010). The most influential relationships in developing leadership skills were with parents and family members, followed by teachers and other school staff, such as counselors (Carter et al., 2010).

The greatest barriers for developing leadership skills were due to limited opportunities for participation in leadership activities, which were either not available, accessible or well publicized (Carter et al., 2010). Another barrier Carter et al., (2010) found were the low expectations of teachers, counselors and parents, the very group from which youth with disabilities needed support, encouragement, advice and to be taught self advocacy. Youth were either discouraged and/or given limited confidence of success (Carter et al., 2010). Another barrier perceived as hindering their opportunities is overcoming stereotyping from school staff and peers (Carter et al., 2010).

Carter et al., (2010) concluded that leadership opportunities are critical for successful transition to adulthood, but most participants reported not having access to these opportunities. Youth with disabilities need to be encouraged, supported and taught self-determination and advocacy skills (Carter et al., 2010). Becoming a role model or mentor for others with disabilities is extremely beneficial in allowing them to take the role as caretaker (Carter et al., 2010). Carter et al., (2010) found these opportunities can be found not only in disability-specific programs but also by being included in other activities, such as volunteering, involvement in student government and other non-academic clubs.

Importance of self advocacy

Test et al., (2005) developed a conceptual framework of self-advocacy for students with disabilities based on intervention studies. They found self advocacy and self determination skills are crucial for the success of youth with disabilities in terms of employment and financial independence. Test et al., (2005) labeled four components that are the foundation for self-advocacy; knowledge of self, knowledge of rights, communication and leadership.

The Test et al., (2005) study found that knowledge of self and one's rights is the first component that needs to be developed in order to understand oneself before being able to understand others. These two components involve knowing one's strengths, weaknesses, needs and legal rights: such as the ADA, and IDEA (Test et al., 2005). Communication was found to be important in all studies reviewed, and includes how to negotiate, problem solve and be assertive without being aggressive (Test et al., 2005). Understanding body language, developing listening skills and being able to express oneself in group settings need to be developed for good communication (Test et. al., 2005).

The last component, leadership, is clarified by Test et al., (2005) and its implication for youth with disabilities. They found that leadership did not necessarily mean leading a group, but understanding the roles and dynamics of groups and how to become an effective team member as a person with a disability. Test et al., (2005) names National Youth Leadership Forum as an exemplary model of leadership, emphasizing group communication skills, advocacy and political lobbying.

Importance of transition-aged youth programs and early intervention

Test et al., (2005) further concludes that self-advocacy skills are lacking as part of a student's IEP, and that these skills should be taught at an earlier age than recommended by the IDEA. They believe that teachers comprehend the importance of developing these skills, but lack knowledge about how to incorporate them into the lives of students with disabilities. Test et al., (2005) confirm that all students benefit from opportunities to practice self-advocacy in environments that foster those skills, and that it is important that students with disabilities have experiences and interactions with other students to develop those skills. The earlier these skills are developed the more "meaningful and seamless transition" they have into adulthood (Test et al., 2005: p. 52).

Empowerment and self determination

Wehmeyer & Gragoudas (2004) experimental study involved the creation of an empowerment group for transition-aged students that orchestrated a transition coordinator, and a teacher from a local school, with the local Center of Independent Living (CIL). Through collaborative effort, the empowerment group was a success. Youth members were given ownership, by having them select a name for their group, establishing rules for each session, and then planning a final leisure activity. Material was used to promote self-determination through the understanding of issues, rights and responsibilities. A district school bus was made available through the school. Youth met once a week for eight weeks for about an hour. Students were encouraged to contemplate their future goals and how to accomplish them, and then present to the group in their preferred format, such as a poem, collage or skit. Individual counseling from teachers, facilitators and other adults with disabilities was available during this process.

Their final project was to plan an outing anywhere they wanted, but they needed to consider transportation issues, present various options, come up with solutions and finally vote as a group on the final decision (Wehmeyer & Gragoudas, 2004). The event, bowling and pizza, was a success and members were very satisfied with their ability to develop such an event. Wehmeyer and Gragoudas (2004) believes this is a simple and inexpensive approach that connects the CIL with students in transition and their community, ensuring successful transition after graduation for youth with a disability.

Importance of service learning

O'Connor (2009) suggests that service learning projects are an important interactive tool that increases academic achievement, career awareness and personal and social development. Youth with disabilities, as well as those without a disability, benefit from learning in various settings (O'Connor, 2009). Teachers found IEP objectives were obtained through service learning projects by increasing self-determination, autonomy, decision making skills, occupational awareness and career goal development (O'Connor, 2009). All of which are important knowledge regarding transitional goals for youth with a disability (O'Connor, 2009).

O'Connor (2009) suggests four common types of service learning projects; environmental projects, cultural and regional history projects, projects addressing social issues, and advocacy and civic engagement. These projects incorporate real world knowledge with academic studies, giving students a deeper understanding of course work. Service learning also increases interpersonal relationships with real world occupations, as well as student-teacher relationships (O'Connor, 2009). Specifically, students with disabilities learn personal responsibility, work ethic and their rights and responsibilities as citizens through service learning projects (O'Connor, 2009). It also empowers them to feel that they can make a difference in the world and the lives of those around them (O'Connor, 2009). Students with disabilities are often given negative messages, a sense of failing and develop learned helplessness; therefore service learning is not only helpful but very important to quality of life (O'Connor, 2009).

Gender, race, ethnicity, and class considerations

Groce (2004) brings forth what makes a successful program that serves youth with disabilities. She discusses four categories in which this population is underserved, based on gender, ethnicity and minorities. Groce (2004) found that most programs for transitional youth were found in urban areas with more affluent youth. These programs, therefore, do not represent the general population of transitional youth with disabilities (Groce, 2004).

Programs for transitional-aged youth need to be more gender sensitive (Groce, 2004). Groce (2004) found that most programs for this population were male-dominated and that young women were more likely to leave a program if their specific needs were not addressed. She found similar trends within ethnic and minority groups, especially those from rural areas and/or lower socioeconomic status (SES).

Groce (2004) notes that “broader leadership and policy roles” are needed for these groups, involving all members in designing, overseeing and evaluating their program (pg. 23). Attention to historical factors, as well as ideologies and cultural differences need to be discussed and embodied in group activities (Groce, 2004). Lastly, Groce (2004) agrees that a program for youth with disabilities will be more successful with adult mentors with a disability. I suggest that attention should be given to recruiting mentors with diverse backgrounds and to balancing gender participation, if possible.

Barriers to participation in leisure activities

Badia et al., (2011) found similar factors and barriers, among youth with developmental disabilities, in the participation of leisure activities, and emphasize the importance of inclusiveness in their local community. The more involved people with a developmental disability are in leisure activities, the more positive effect it has on the quality of their life (Badia et al., 2011). Badia et al., (2011) experimental study found several factors that affected participation for youth; type of schooling, gender, perceived barriers such as not having enough time, being too tired, fear of being mocked and depending on others to participate or not feeling good enough or capable of participating.

Badia et al., (2011) found that youth with disabilities who were educated with those without disabilities, versus those in special education, were more likely to participate in leisure activities. They also found that females of this population were less likely to participate in physical activities or sports, and therefore males participated in more types of activities. The type or severity of one’s disability was not a factor. Badia et al., (2011) found that those with a developmental disability participated in leisure activities more during youth than in adulthood and that the more they participated in leisure activities in their youth, the more likely they will be to participate in adulthood. This reaffirms the importance of participation in these types of activities during the transition years.

Badia et al., (2011) reviewed numerous other studies to confirm that independent living and employment opportunities enhance participation in leisure activities. Those still living at home or in institutionalized settings are less likely to become involved with the community (Wehmeyer, 1995). Emotional support from family, friends, teachers and employers increases one’s likelihood of participation (Heller, Miller, & Hsieh, 2002; Renblad, 2002). Low SES negatively affects participation (Kraemer, McIntyre & Blacher, 2003). Self-determination is linked with one’s level of education, work and residential environment, not one’s disability (Chambers, Wehmeyer, Saito, Lida, Lee & Singh, 2007). One can conclude that empowering youth with opportunities and support to increase employment, freedom, and opportunities for leisure activities are cornerstones to a better quality of life in adulthood. These are the basic principles of a CIL and therefore can make a strong impact on transition-age youths lives.

CIL obstacles

As mentioned before, the greatest obstacle is CILs connecting with children with disabilities and their parents, due to privacy laws. Partnership with local schools and like-minded organization is the best avenue for results. Wehmeyer and Gragoudas (2004) believe this may be because schools and CILs have different philosophies when it comes to transitional youth plans. Public school systems use a medical model to address transitional needs, whereas CILs believe in empowerment and self-determination. Collaboration between schools and CILs would greatly benefit this particular population and federal legislation mandates it, according to the IDEA (Wehmeyer & Gragoudas, 2004). However, only half of the nation's CILs have youth programs and/or youth participation (Wehmeyer & Gragoudas, 2004).

Western North Carolina's CIL's for Buncombe, Henderson, Transylvania, Madison, McDowell, Rutherford and Polk Counties, to date, have no youth transition services (RSA-704, 2011). This is not due to a lack of interest, but to a lack of recruiting expertise. Overall, youth membership is much lower than adult membership at CILs (RSA-704, 2011). Buncombe County has more CIL members than any other county in WNC (RSA-704, 2011). Even though, it is natural for urban areas to initiate developing a plan to promote a youth transition program, special attention should be given to developing a program that would serve rural areas of WNC.

Challenges

Challenges I experienced connecting with parents of children with a disability were similar to those of Disability Partners. While like minded businesses and organizations were very interested in referring parents, direct contact information could not be obtained due to privacy laws. The only approach I found that worked was to use a "snowball method" which built on one parent referring me to another. A referrer would offer appointment times that I had available for the parent, and then have that parent agree to a time and location. Once the interview was completed parents were very willing to refer another parent of a child with a disability, establishing another appointment time, in a similar manner. This "snowball" or "word of mouth" approach was limiting in term of getting people outside of a relatively small group of parents and unpredictable in terms of scheduling therefore reducing the number of participants interviewed. Another form of contact with these parents including mailings, membership lists, and contact through local agencies and institutions like schools and nonprofit organizations would most likely have increased to the number of potential subjects interviewed for this project.

Another challenge was navigating the IRB application process. My faculty advisor, Dr. Kenneth Betsalel, and I were already CITI trained, certified and experienced in the application process before applying for the Community Engaged Scholar Award, this helped a great deal. Even with following procedures, through no fault of the IRB, the process is one that takes time and there may be unforeseen delays in the process before getting final approval. In particular minor errors in the application and additional time for confirmation for exemption from IRB resulted in less time for the actual field work portion of the project which resulted in a smaller number of participants interviewed. I suggest that those applying for the Community Engaged Scholar Award complete this process the semester before their study.

Dr. Betsalel wants to continue collecting interviews for Disability Partners. Necessary steps for IRB protocol are now established for this project in order for it to continue with less expense of

time for the next researcher. I have offered to train the next researcher, to ensure that this project has the speed necessary to make a more substantial impact for this community.

Results

Collected interviews indicate several themes in regard to expectations and barriers, for youth participating in a youth leadership program. One issue I found in my experimental research was that of being labeled disabled. Another problem was parents thinking their child were either too disabled or not disabled enough to attend such programs. Disability Partners does not discriminate based on severity of disability, as long as it affects at least two areas of their life. In fact, variance of disabilities has positive consequences for either party in mentor/mentee interpersonal relationships.

Another issue found was that fact that parents were unfamiliar about transitional programs and the federal regulations mandating it. Most parents were surprised that a local organization such as Disability Partners offered such services with minimal or no cost. One more common theme was that parents were uncertain about when or how to plan for transition into independent living, steps toward a college education and leadership within their own community. Even though most parents hoped for their teens to live independently, they thought that it would not happen until their mid twenties. Other issues included: either their child being too involved in other extracurricular activities, or their child not being interested in any social interactive organizations.

Final barriers included concerns from parents about whether staff at group meetings would be able to properly address their child's issues, for their specific disability. Disability Partners director Kathy Hollingsworth explained that while it is difficult for staff to be knowledgeable about all disabilities, personal attendants would be allowed at the youth leadership program. Most parents thought that helping others was a natural part of their children's ideology and that doing so would provide them with leadership skills and employment possibilities. Parents especially thought that community service was on important in their life, particularly those projects which involved youth with disabilities engaging with the community at large.

Sustainability

My service learning project is expected to be implemented after my recommendations. Disability Partners is actively trying to recruit youth with disabilities. I hope that my academic research and interviews will assist in this process. Interviews with parents have already created interest and awareness of transitional programs. A handbook on how to increase youth leadership participation, including academic research contained in this paper, will be forwarded to Disability Partners, as well as audio and video recordings of parents who have children with disabilities in the local area. Furthermore, I will extend my contact with Disability Partners even after graduation and hope to work with this organization during my graduate studies. I am

currently a board member at Disability Partners and am passionate about assisting them in their future endeavors.

Conclusion

Based on academic research, transition-aged youth with disabilities become more successful in adulthood when youth leadership skills are encouraged, such as advocacy, self-determination, and empowerment. Research also supports the importance of access to leisure activities and education through service learning projects. Both CILs and school systems are important contributors to affecting youth with disabilities in developing the resources necessary for earlier and successful transition into adulthood. Without the emergence of these two contributors, youth with disabilities are at a great loss.

Sheldon and Golden (2005) suggest several possibilities for connecting with children with disabilities and their parents. One idea is to provide mailings in envelopes with stamps already on them to schools, which have a mailing list of parents who have an adolescent with a disability. In this situation, parents and children's names are kept confidential, and schools are less burdened with postage and the burden of distributing the material, making it easier to comply with federal regulations (Sheldon & Golden, 2005).

Another idea Sheldon and Golden (2005) propose is to offer a potluck dinner to like-minded organizations that are involved with youth with disabilities. Partnerships could be made with vocational rehabilitation agencies, the Social Security administration, United Way and other non-profit organizations. In return, CILs could attend youth/parent service providers meetings and offer to do a presentation or set up an information table at their events (Sheldon & Golden, 2005). It would also increase contacts with the community by using media which parents and children would be likely to read (Sheldon & Golden, 2005). A good example is newsletters from other programs that specifically work with youth with disabilities (Sheldon & Golden, 2005).

Special attention needs to be paid to identifying and recruiting youth from all backgrounds ranging in: type of disability, severity of disability, gender, ethnicity, residential area and race, so that all youth can participate in the program. Attitudes of teachers, family, peers and other faculty are extremely influential on youth and their transitional goals, and an investment needs to be made in the youth, by encouraging and supporting them in their ventures. Feelings of not fitting in and/or being incapable of attending such programs was high on youth's list as a barrier, and parents and teachers need to be educated on how to empower youth with a disability (Badia et al., 2011).

And finally, youth with a disability need to know their rights and become self-aware of their limitations and strengths in order to advocate for themselves and others. Ironically, this paper begins with information about the lack of enforcement of transition training that specifically applies to youth with disabilities. Yet, if these youth are not educated and empowered, who will make sure the next generation gets the services they so desperately need? Without organizations like Disability Partners, persons with a disability from this local area would be at a great disadvantage. My hope is that this project will assist them in reaching this underserved population and sustaining this program into the future, for all those living with a disability.

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