

Parent, Advocate, and Educator Perspectives on the Inclusion of Young People with
Disabilities in Positive Youth Development Programs

by
Sarah J. LeComte

A THESIS

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(Honors Associate)

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More than six million American students have a diagnosed disability (NCES, 2015). Research suggests that 62% of them may never participate in clubs, sports, or other organized activities in their communities (Coster et al., 2012). Parents, advocates, and educators of individuals who experience disability were interviewed to gather their perspectives on facilitating inclusion in positive youth development programs. Perceptions on the benefits, barriers, and facilitators of inclusion in structured recreational settings were collected. Analysis of interview data led to the discovery of four themes related to benefits: potential for developmental gains, social connection, vocational development, and positive self-concept. Analysis of barriers and facilitators illuminated five potential areas of influence in promoting inclusion: organizational policy and practices, community partnerships, universal design, outreach, and fostering comfort with disability. Findings suggest that those who care for and work with youth who experience disability value inclusive programs and can offer beneficial guidance to youth organizations striving to welcome all youth.

Key Words: Disability, Inclusion, Youth, Development, Qualitative

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I understand that my project will become part of the permanent collection of Oregon State University, University Honors College. My signature below authorizes release of my project to any reader upon request.

Sarah J. LeComte, Author

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“At times our own light goes out and is rekindled by a spark from another person. Each of us has cause to think with deep gratitude of those who have lighted the flame within us.”

— Albert Schweitzer

This thesis is dedicated to my parents, Jacques & Kay LeComte

my rock, Kenneth Dryden

and my children, Vaughn & Violette

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Parent, Advocate, and Educator Perspectives on the Inclusion of Young People with Disabilities in Positive Youth Development Programs

Introduction

More than six million American students have a diagnosed disability (NCES, 2015) Research suggests that as many as 62% of them may never participate in clubs, sports, or other organized activities in their communities, compared to 30% of their nondisabled peers (Coster et al., 2012). Programs invested in serving all youth can benefit from learning about the barriers and facilitators that impact the participation of individuals who experience disability. The purpose of this thesis is to explore the perspectives of parents of youth with disabilities, special education teachers, and disability advocates, on factors that influence inclusion.

This project was completed in cooperation with Oregon 4-H, in service to the organization's efforts to expand participation among underserved youth, including those who experience disability. As the largest Positive Youth Development (PYD) organization in America, 4-H serves some six million young people nationally, including one in twelve students in Oregon (Annual Report, 2016). Given the reach of 4-H programs, the organization has broad potential to improve and increase participation among youth with disabilities.

Positive Youth Development programs like 4-H help children and young people learn by doing. By connecting participants with each other, caring adult mentors, and learning opportunities, PYD organizations enrich lives and communities. PYD is grounded in ecological systems theory (Bronfenbrenner, 2005) that understands human development to be plastic and responsive to a web of influences at the individual, familial, and broader community level. PYD research emphasizes the assets and

protective factors of youth, as opposed to viewing young people through a pathological lens (Zurakski, 2015). This positive view stands in contrast to earlier perspectives of adolescence as a problematic time of storm and stress.

There are a host of potential benefits to participation in structured development activities. A meta-analysis of youth programs found that those who employ evidence-based approaches resulted in positive outcomes in seven areas: improvements in self-concept, prosocial behavior, attitude towards school, and academics, and reductions in problematic behavior (e.g., aggression), risky health behaviors (e.g., drug use), and conduct issues (Durlack et al., 2007). Involvement in 4-H has been shown to promote civic engagement, participation in science, and health behavior (Lerner, 2013).

For the purposes of this writing, disability is defined broadly as conditions or impairments that impact multiple life areas, resulting from an interaction between the condition itself and environmental factors ranging from physical to cultural (WHO, 2016). The term encompasses developmental, intellectual, and physical disabilities including vision and hearing impairments.

Publicly operated youth organizations are mandated by the Americans with Disabilities Act (ADA) to reasonably accommodate participants with disabilities. The ADA is a comprehensive piece of civil rights legislation that ensures people with disabilities have access to the same opportunities and spaces that other Americans enjoy, and prohibits discrimination against them (ADA, 1990). “Reasonable” means that the accommodation must be logistically feasible, not pose undue financial burden, and be effective in promoting the access of the individual with a disability. While ADA guarantees a minimal level of accommodation to people with disabilities, it is incumbent upon organizations to foster truly welcoming and inclusive environments.

Youth with disabilities experience barriers that may limit their participation in community activities (Law et al., 2015). Factors that restrict participation are often environmental, and therefore modifiable, such as attitudes and physical environments (Anaby et al., 2013). Individuals with disabilities cannot share in the benefits afforded by PYD programs if their participation is discouraged, whether intentional or due to implicit bias. If PYD organizations can better understand the factors that influence inclusion, actions can be taken to overcome these barriers.

Opportunities to be involved in youth development programs may have unique impacts for individuals who are disabled. Positive outcomes associated with participation in PYD programs relate to some of the disparities experienced by people with disabilities. Limited social support (Carter et al., 2013), higher rates of obesity (Froehlich-Grobe and Lollar, 2011), and high unemployment (Sipperstein et al., 2013) are some of the disparities experienced by people with disabilities.

Research on the benefits of participation in PYD programs specific to youth with disabilities is limited. One study has suggested a predictive relationship between participation in structured recreation and higher levels of self-determination among young adults with intellectual disabilities (McGuire and McDonnell, 2008). Participation in PYD settings may assist young people with and without disabilities in learning valuable life skills, connecting with peers and mentors, and transitioning to the workforce. It is possible that increased access to beneficial development opportunities may impact some of the disparities faced by youth who experience disability.

Parents have historically played a significant role in advocating for increased inclusion and opportunity for individuals with disabilities (Mead and Page, 2008). As key facilitators in their children's participation (Anaby et al., 2013), parent perspectives are foundational to successful inclusion. Parents are likely to have valuable insight into how to overcome some of the barriers to inclusion. They also have knowledge of disability specific resources in their communities.

Special education teachers and coordinators may also inform the efforts of PYD organizations. The Individuals with Disabilities Education Act (IDEA) is a piece of legislation that establishes rights for parents and students (IDEA, 2004). IDEA mandates that students with disabilities receive Individualized Education Programs, known as IEPs. Education teams are supposed to consider participation in activities outside school when developing IEPs, however one review demonstrated that just 11.3% of student IEPs contained any mention of extracurricular activities (Vinoski et al., 2016). Educators might serve as an important link between PYD opportunities and their students.

Advocates work in a variety of contexts that offer unique views of the landscape navigated by individuals with disabilities and their families. Advocates who specialize in serving youth with disabilities may have expertise in how to best help them transition from school to work, or how to provide accommodations. Oftentimes advocates are also parents of individuals with disabilities or experience disability themselves.

This thesis will explore the perspectives of parents, advocates, and educators in order to illuminate what is needed, and what is missing, in facilitating meaningful inclusion in positive youth development settings.

Methods

IRB designated this project an extension of a previously exempted program evaluation. A purposive sample of participants was obtained through networking within the disability advocacy community of a midsize Oregon county. Nineteen special educators, advocacy group directors, and parents were extended invitations to interview and a total of ten respondents resulted from the invitations (52% response rate).

The common quality of all respondents was multiple years of experience caring for, advocating for, or directly working with the target population. Eight of the ten respondents had more than ten years of experience in the disability community.

Respondents had awareness of PYD organizations, with some being heavily involved in 4-H or other programs. Three were leaders in facilitating community groups for other families. Five of the respondents had significant cross-disability experience, whereas the other half had more expertise around a particular diagnosis. More specific descriptions of respondent experience with disability is outlined in Appendix B.

All respondents identified as women, six out of ten were parents to youth with disabilities, and four of the ten were current or former special education teachers. All respondents were involved in some type of advocacy, either for their own child, or as a function of their employment. There was a near even split between those who lived in rural portions of the county and those who lived within city limits. Further description of respondent characteristics can be found in Appendix C.

An interview protocol and questionnaire were developed to guide discussion with respondents. Questions focused on respondent experience with youth who experience disability, the status of inclusion in PYD programs, barriers to participation, possible

facilitators, and perceptions about the benefits of inclusion (Appendix A). Interviews were semi-structured and ranged in duration from thirty to ninety minutes.

Four interviews were conducted in person and six were done by phone. All interviews were recorded with the knowledge and consent of the participant. Confidentiality is maintained to enable respondents to speak freely. All respondents were notified of the confidentiality of their involvement. Organizations that operate across the country or State of Oregon are named when doing so holds no risk of identifying respondents.

Interviews were transcribed and coded for themes related to the three preset categories: benefits, barriers, and facilitators. Emergent themes relating to each of the preset categories were identified using the Taylor-Powell Renner method of qualitative analysis (Taylor-Powell and Renner, 2003). Analysis focused on topics mentioned most frequently across the respondent group. As subthemes of benefits, barriers, and facilitators were discovered, they were organized into primary categories. Themes relating to barriers and facilitators were ultimately collapsed into five categories, which will be referred to as areas of influence. Data was coded using NVIVO 11 Pro software.

Results: Benefits for Kids and Community

Respondents recognized meaningful inclusion as providing a range of benefits for youth with and without disabilities. Participation in inclusive programs was believed to be a key context in which all youth build important skills and friendships. For youth who experience disability, subthemes related to the benefits of inclusion were identified (in order of reference frequency) as: potential for learning, social connection, vocational development, and positive self-concept. Further benefits to inclusion were described for the parents of youth with disabilities and peers.



Potential for Learning

The importance of opportunities to engage with and learn from diverse peers of similar age were frequently mentioned across participants. Some parents felt that these experiences may be supportive of development. Of significant concern to several participants was the fact that many children with disabilities experience segregation in public education, which limits their opportunities to model diverse peers and denies their peers the benefits of knowing them. While disability specific groups and settings provide important support and information, respondents felt that opportunities for meaningful inclusion in youth development programs carried distinct benefits.

The following quotes from parents are representative of a common thread in many of the interviews, a belief that opportunities to watch, engage with, and learn from diverse peers is beneficial for youth who experience disability:

Respondent E: *“One of the reasons we worked so hard to find inclusive events is, it raises the standards. For my daughter who is nonverbal, being around peers that are verbal and communicate in different ways is a great model for her, and allows her to try things that she maybe never would have.”*

Respondent F: *“They can model from other people and children around them. All too often people with disabilities are put into settings where they are only around others with disabilities, some who may have behavioral challenges, and they model that. To be able to be around mainstream kids...gives them a bigger variety of ways to learn things. When they are learning alongside, from, and with their peers, it raises the bar. I believe this strongly, put in situations like that, these kids will do more than they do at home. I’ve seen it again and again where a parent says, “I cannot believe my child just did that.” [laughs] Then maybe they get to raise the bar a little bit too.”*

Social Connection

Respondents also spoke of the benefits of social connection for youth who experience disability. All respondents felt that PYD settings offer an additional avenue for youth to connect with peers. Spaces outside of school that provide opportunities to foster friendships may be especially important for young people who are at times not fully included in educational settings. Some respondents also felt that there is increased safety for vulnerable populations when they are known by friends and neighbors. Social isolation was repeatedly cited as having a negative impact on the mental and physical health of youth with disabilities and their parents. Increased opportunity for organically occurring social support was generally believed to be supportive of better emotional and physical health outcomes. Meaningful connection with others was also frequently mentioned in relation to future employment and self-sufficiency.

This parent and cross-disability advocate believed that school environments were limited in their ability to nurture friendships between youth with disabilities and their typical peers. She concluded that PYD settings may offer a richer opportunity to build friendships:

Respondent A: *“Ultimately they get a chance to make friends. When I hear about families who invite the peers of their children with disabilities to their birthday parties, most of the attendees are from clubs or church groups that they are a part of, and very few are from school. I think that that says a lot right there, these opportunities are so important in creating meaningful friendships.”*

An advocate with cross-disability experience echoed the sentiments of other respondents when she emphasized the importance of naturally occurring social support:

Respondent C: *“If you look at adults who experience disability, the ratio of relationships in their lives, on average they have more than twenty paid human services professionals in their lives and just two friends. The more we can emphasize the power of natural social support, the better life outcomes are going to be for people.”*

Vocational Development

Engagement in PYD settings was thought to be supportive of future employment in a number of ways. Knowing one's community, and being known by others in the community, provides not only personal support but opportunities for employment related development. This factor was closely related to fostering comfort with disability in the community. When youth with disabilities are visible and engaged within the community, stigma may be reduced. Participation creates opportunities for youth to be known for

their strengths, and to network with prospective employers. The skill-building that occurs in structured development activities was also seen as supportive of future employment.

Parents and advocates alike expressed that inclusive participation is supportive of future employment:

Respondent I: *“People need jobs and experiences out in society. Vocational rehabilitation, you could talk all day about that. Accessibility is super important for events and activities that support future employment.”*

Respondent C: *“Kids who have peers who experience disability are more likely to be adults who befriend people with disability, employ people with disability, stand up for people with disability, and I have to also say it the other way around, kids who experience disability who have non-disabled peers are more likely to befriend them, and hire them, support them, and stand up for them.”*

Positive Self-Concept

The development of positive self-concept was important to respondents. Opportunities to experience success and mastery of skills were viewed as confidence building. Exposure to the full range of human diversity was seen as advantageous for youth with and without disabilities, leading to increased acceptance of self and others. Respondents shared several personal anecdotes from observing youth with disabilities experiencing success in PYD settings, and in 4-H specifically. For some respondents, these experiences allowed for the recognition of strengths that often go undeveloped and unacknowledged in formal educational settings.

Respondent F: *“I can tell you, from my own daughter, [participation in PYD programs is] an amazing confidence builder. It gives her something she can talk about with her typical peers.”*

Respondent C: *“One benefit I see is, they start to understand that disability is a natural kind of human diversity and that it doesn’t define who they are. I think when kids are segregated, they start to believe that the reason they are being segregated is because of who they are, when they are not segregated, I think they start to see their differences as just differences.”*

Respondent B: *“A sense of pride in what they do.”*

Peer Benefits

In addition to the four themes relating to benefits for youth with disabilities, respondents frequently touched on potential benefits for youth without disabilities. These tended to fall within three categories: gaining familiarity with and knowledge of disability, positive character development, and skills related to future employment. There were several overlapping benefits that were thought to be derived by youth with and without a diagnosed disability.

Respondent C: *“There is a natural benefit for children, as young in age as possible, being exposed to all kinds of diversity, it helps us be more understanding, more sensitive, more patient, more compassionate, more empathetic, not only with other people, but with ourselves.”*

Respondent B: *“They will develop skills to be able to communicate to a different population. So that skill can be transferred to anywhere they go, whether someone goes by in a wheelchair and they say, “Hello”, or they work with somebody with a disability. [They are] developing transferable skills.”*

Respondent A: *“The ability to be accepting and honoring of people who are different than you is so critical. It’s critical in relationships, it’s critical in marriage, it’s critical at work, because everyone is unique...in those instances where peers are helping each other, it can build their confidence and build their desire to help others. It makes them more caring and more considerate human beings.”*

Respondent J: *“It can be a great career-type of exposure.”*

Parent Benefits

Parents also frequently noted that their child’s participation in PYD activities was rewarding and beneficial to them personally. Opportunities to see youth grow, accomplish goals, and be included often arose as significant for families. Reducing the isolation some parents experience was also mentioned as a primary benefit, one that also impacts their children. Parents and advocates felt that some degree of participation in PYD settings helped families forge connections that support health and wellness.

This parent touched on the importance of seeing children accepted and valued as individuals, experience success, and acquire skills. She also saw value in having diverse friendships:

Respondent A: *“It’s an opportunity to see their child fully accepted for who they are and valued for who they are...it’s in those times when the disability kind of fades to the background, which isn’t always easy to do. Where the child can just be a child and not the child with a disability. For parents to be able to see that and the child to be able to experience that. They get to see their child succeed and develop skills that they enjoy. The opportunity to see them flourish I think is really valuable, and then to not solely live in the disability world of only making friendships with parents whose children experience disabilities.”*

Most of the parents interviewed shared similar sentiments around observing their child’s success and connecting with other families. This mother, whose children are active in 4-H, shared a response representative of those themes:

Respondent H: *“Parents who do not have a youth participating in an inclusive program can experience a lot of grief and loneliness. Parents who participate get*

to watch their child experience some of the same things as their typically developing children. And, it gives them an opportunity to interact with other parents, that's a huge thing."

Another parent was overjoyed reflecting on what successful participation in PYD programs means to other parents of youth with disabilities:

Respondent E: *"Oh, [laughs] they get to see their kiddo shine!"*

The benefits discussed in these interviews highlight the potential for PYD experiences to positively impact youth, families, and their broader communities. These perspectives provide support for the "why" of inclusion. These benefits can provide motivation for stakeholders to work actively towards inclusion in PYD programs. Equally important are perceptions around the "how" of inclusion, what promotes equal participation and what prevents it.

Results: Five Areas of Influence

Moving towards more inclusive and welcoming PYD programs means first asking what audiences are not present, and then listening to the perspectives of those who have historically experienced exclusion. Respondents shared a wealth of ideas on how their children and students can experience meaningful inclusion. They also spoke of the hardships they sometimes face in seeking PYD experiences for their children and students.

To focus the discussion of results on actionable facilitators, themes were grouped into key areas of potential influence. Coupling the barriers and related facilitators discussed by respondents resulted in five potential areas of influence, organizational policy and practices, partnerships, universal design, fostering comfort and connection, and targeted outreach.



Organizational Policy and Practices

The importance of organizational policy and practices around inclusion was a primary area of discussion. Respondents felt that building an organizational culture of inclusion begins with setting clear expectations for staff and volunteers, providing supporting resources, securing additional staff or volunteers, and offering training on how to successfully include all youth.

For some parents, simply not being turned away or charged more to participate would represent an improvement over past experiences. The following parent discussed the importance of PYD organizations being open and willing to engage youth with disabilities:

Respondent E: *“It can be really hard as a parent in this area, finding places that will actually accept people with disabilities. A lot of people are very hesitant to even let them in their program. Even being open is a huge thing. If we can get ourselves in the door, we find a lot of times that organizations are really positively surprised by what they learn and take away from experiences working with people with disabilities. Those have been the most successful organizations for us, those that were willing to welcome us in the first place, hear our concerns, and actually look for opportunities to include.”*

This advocate echoed the sentiments of several other respondents who wished that more PYD organizations had a consistent belief that all youth can be included, even when making that inclusion happen may take some additional learning or effort:

Respondent C: *“[Organizations should] start from a place of high expectations, “Of course we can figure out a way for this to work for you, we just have to think creatively”, and go from there.”*

Clear expectations and guidelines for staff and volunteers were thought to be important in developing inclusive environments. This theme tended to arise in regard to rules and competitive contexts. Staff and volunteers may struggle to identify the best approach to accommodation if they don't have guidance on acceptable rule changes. Avoiding situations where inclusion becomes a haphazard afterthought due to rigid rules or competition was mentioned frequently.

The following parent, 4-H leader, and special education coordinator underscored the importance of clarity in organizational rules and policies:

Respondent J: *“Willingness to make accommodations is important. It helps if the organization has parameters around inclusion and accommodations. Staff need to know if there are adaptations and what is acceptable in that activity...so everyone knows, and staff don't have to worry, “Oh my gosh, I can't do this because we'll forfeit the game,” but know exactly what is it that they are allowed or not allowed to do.”*

In maintaining an expectation of inclusion, staff and volunteers need to be supported by necessary resources, such as specific guidelines, manuals, or a point person. It may be necessary to establish open lines of communication with disability organizations or set aside funding for interpreters and other accommodations.

These respondents both recognized that needs around adaptive equipment and other accommodations may necessitate some additional funding:

Respondent C: *“Sometimes it means equipment, modifications, or adaptations. Some organizations don't have funding or aren't well networked and connected in their communities to benefit from donations or support from other organizations.”*

Respondent J: *“I think being able to have training and support from the organization, also it might mean some possible funding or accommodating type of equipment.”*

The need to support staff in feeling confident accommodating youth who experience disability was again highlighted by this parent and educator:

Respondent J: *“I think if the larger organization has some sort of manual for staff, “Students with disabilities are welcome in our organization, we’re here to help you”, so that [staff] know when a child comes in the doors, they may not be perfectly prepared, but they know where to go, or a list of resources and materials, sometimes those get so outdated, but maybe resources within the community where they can go for more information”*

The existence of resources and funding alone is insufficient to support inclusion if staff and volunteers don’t know how to access and utilize them. Providing staff and volunteers training in accommodation and inclusion helps prepare them to serve all youth. All ten respondents discussed the importance of making some type of training available for staff and volunteers. This selection of quotes highlights the significance of this subtheme:

Respondent G: *“Volunteer training, and maybe adding a little bit of that training into other things that are already going on.”*

Respondent C: *“Some basic training, there are lots of organizations all over the state that can do what we call Disability is Natural training, that introduces the idea that disability is just one of many kinds of diversity, and maybe some training in strengths and gifts identification so staff feel they have the skills to recognize what every kid might want to contribute.”*

Respondent A: *“[Training on] how to deal with sometimes uncomfortable and delicate situations. How do you support a child who is incontinent but they are*

eight years old? That kind of thing. Maybe having some kind of empathy training and situational guides, scenarios.”

Respondent F: *“Improving training and having lots of access to training opportunities is always a benefit, because there are such a wide variety of people with special needs. Learning how to communicate and listen is sometimes tricky. Those are the kinds of things that I think all organizations need.”*

Staffing and volunteer ratios were another area of interest for most participants.

Depending upon the support needs of the youth in the program, additional sets of eyes or hands may be necessary. While some youth have parents or support personnel, an organization that is prepared to secure additional volunteers or staff was generally viewed as fostering a welcoming environment.

Respondent A: *“[Organizations] might experience challenges with proper coverage and staffing...some families will want to be really active in supporting their child in those environments and others might have what’s called a personal support worker who is available to support the child in the club activity, but there are some families who want to be able to drop off their child for activities, just like everyone else. I think that would create a situation where ensuring that you have staff and volunteers who are ready, prepared, and available would be the biggest challenge.”*

Respondent D: *“Maybe even some more support staff. Maybe just some extra staff or volunteers or having programs where if family members or parents want to volunteer, that they have something for them.”*

The importance of organizational policy and practices around inclusion arose throughout and across interviews. Setting clear expectations, allocating resources, providing training, and securing additional staff and volunteers when needed were the key themes that emerged in relation to organizational policies and practices.

Partnerships

Interviews suggested that inclusion in PYD programs would be supported by cooperative partnerships with parents, advocates, and organizations that have disability specific experience. A consensus quickly emerged around the importance of partnering with key stakeholders in the disability community. It was frequently noted that no better partners exist than adults who experience disability and those with significant direct experience working with and caring for young people with disabilities. Participants felt that PYD organizations should seek consultation from local parent networks, special education teachers, individuals with disabilities, and programs that serve youth with disabilities.

Respondent C: *“One of the places you have to start is asking, ‘who do we know that is already engaged with that population?’ ...sometimes it’s easier if you say, ‘We want to learn to be more welcoming, can we come to you?’”*

Respondent F: *“One of the suggestions I would start with is trying to contact either the [education service district] or teachers in special education, and ask them for resources, ask them for someone to do training for staff and leaders. Colleges that have special education programs, I would see about partnering with them, maybe having their students as a resource. If you have parents who are already expressing interest, hold a panel with them so that they can share ideas. Parents are an awesome untapped resource. Have them give suggestions about their children, have a conversation, you know, ‘What helps make people in this population be successful?’”*

Some respondents with personal experience in 4-H club settings gave specific examples of organizations that could be reached out to when accommodating youth. This therapeutic riding program director and former 4-H leader felt that organizations like hers could help inform horse 4-H clubs seeking to accommodate youth with disabilities:

Respondent G: *“If a club had someone [with a disability] who wanted to do horse 4-H, and the leader had no idea how they were going to go about it, they should reach out to a therapeutic riding program in their area and see how that works.”*

It was further noted that these community-based assets might help fulfill some of the needs around acquiring volunteers. This educational director was confident that alumni from her school would be willing to volunteer in inclusive settings:

Respondent I: *“I’m thinking of the alumni association here. If you put out a flier through their website requesting volunteers, you would get takers.”*

Partnerships were viewed as a fundamental support for successfully inclusive programs. Respondents made frequent reference to community based assets in discussing barriers and how best to address them. Respondents underscored the fact that there are many non-profit organizations whose mission is to contribute to more inclusive community environments for individuals with disabilities. Respondents affiliated with some of these organizations expressed interest in partnering with 4-H and other PYD organizations.

Parents of youth participants with disabilities were also mentioned as a critical resource. However, it was noted that some parents of youth participants in PYD programs may be more willing to be consulted than others. Organizations should be mindful of approaching parents respectfully, without an expectation that parents should or must consult them. Organizations can offer opportunities for families’ individual needs to be heard without creating a situation where they alone are responsible for educating program staff, volunteers, and participants about a particular disability or accommodation.

Universal Design

Universal design is a concept used to describe environments and services that are constructed or delivered with the intent of including all who wish to enjoy them. This approach to design strives to consider the plasticity and diversity of human ability, age, culture, and communication style. The principles of universal design can be applied to the built environment, approaches to teaching, and communication accessibility.

Themes related to universal design emerged frequently in data analysis. Respondents spoke to the importance of youth with disabilities having physical access to PYD spaces and activities, and the importance of appropriate assistance with communication through the use of devices or interpreters.

Willingness to teach and explain activities in a variety of ways was of particular interest to parents of youth with intellectual disabilities. Respondents offered guidance on how to plan activities for diverse learners and skill levels. Several respondents recommended that program leaders learn about the individual needs and strengths of their participants through Person-Centered Planning instruments. They also encouraged communication between program leadership and the parents of participants who experience disability so that an appropriately individualized approach can be taken.

Respondents felt that mindfulness about meeting spaces and activity instruction was central to crafting welcoming environments. Parents and advocates alike considered this awareness critical:

Respondent D: *“Definitely make sure that anywhere a meeting is held or the group is gathering, make sure that it is ADA accessible.”*

Respondent C: *“It might really come down to restroom accessibility that makes something not feasible.”*

Specific accommodations and supports for children with sensory needs, anxiety, and physical impairments were all discussed. This cross-disability advocate provided a helpful series of questions staff and volunteers can ask themselves when planning events:

Respondent C: *“A quiet place to go that is designated, and offers sensory supports. Is there a weighted blanket available in that quiet space? Is there a variety of music to listen to in that space? Is there a bean bag chair to sit in? Are there a few different lights you can choose from? I also think of ramps, basic accessibility for the terrain that you are on. Being aware, are kids sitting? Standing? What is the environment like where kids are going to be spending their time? How can we make that an even playing field? Are there chairs with empty spaces for wheelchairs right next to them? If we are going to be sitting on the floor, does that work for everyone? Are pillows available? Are there some kids in chairs and some kids elevated? If you're going to be standing for a long period of time, do we also have some chairs available? If we are going to be on something that moves, do we have a variety of seat styles and harnesses or buckles available if you have a hard time holding yourself up? Switches are a basic tool people can have on hand so, if we are going to be driving something or maneuvering something, we have an option for someone to use a switch and still engage.”*

Communication needs were a frequent area of interest. Three respondents with extensive experience with deaf and hard of hearing students explained that having access to certified interpreters, not family members or people who only know how to finger spell, was central to the inclusion of this population. A director of a school for deaf and

hard of hearing individuals had this to say about accessing community programming for her students:

Respondent I: *“We’ve tried different programming in the community, but if there is no accessibility communication wise, we can’t participate. If there is no ASL, there is no access.”*

Staff and volunteers will need information about how to successfully communicate with nonverbal youth as well. Several parents discussed the relationship between meaningful inclusion and the willingness of program staff, volunteers, and participants to communicate in a variety of ways:

Respondent A: *“If you have a child who doesn’t use verbal communication, maybe there could just be a discussion about, you know, “How can we support Susie in participating?” that could be using a communication device, it could be, “Do you want to know the activities in advance so you can program her device?”*

Respondent B: *“What if you are communicating with someone who is nonverbal? Communication is big.”*

Teaching and providing materials to diverse learners was a recurrent theme that many respondents believed would be supportive of youth with disabilities and their typical peers. Planning activities that are inclusive of a variety of ability levels was also seen as good universal design. A parent advocate gave the following analogy:

Respondent A: *“I think about it like a fitness video. You know how they will have the advanced, moderate, and beginner levels of demonstrators? Being intentional about having activities that can be accessed at a variety of skill levels.”*

Several respondents believed that some youth may benefit from having advance information about events or meetings, such as the order of activities. Breaking down and clearly explaining processes was also seen as beneficial for some youth who do not experience disability. The use of social stories to help guide youth in navigating peer and staff interactions was another tool that was recommended:

Respondent C: *“Having social stories available. Some kids who experience autism, it’s not a universal, but some kids, and honestly some kids who just experience anxiety, benefit from knowing what to expect in a sequence. So, a picture sequence, here’s what today is going to look like, or here is what this class looks like. We call those social stories. That’s something that can be given out ahead of time. Then there are visual schedules, for when they are there and participating and look up and say, “I understand where we are right now and what we are doing next.” Social stories can be given out in advance and visual schedules are for the day of an activity.”*

Respondent H: *“Communication in terms of, listening to her needs, communicating at her level, education, teaching at her level. If the expectations can be modified to meet various learning abilities that would be so cool.”*

The importance of recognizing individual needs and strengths was a common thread throughout interviews in this study. Respondents stressed that there is significant variation in the strengths and support needs of individuals, including those with the same diagnosis. It was repeatedly suggested that staff and volunteers take care not to make assumptions about what is, and is not, possible for participants who experience disability and instead seek the input of parents and youth themselves.

Respondent A: *“Every child has their own accommodation needs. Like, if you have a child who doesn’t use verbal communication then maybe there could be a discussion about that...I think asking the family without being intrusive, which can be delicate. Just framing it in a way, you know, “We’d love to receive the*

information if you want to share it.” There is no expectation. Some families want their child to go in and be treated just like everyone else. Other people appreciate specific accommodations. Being individualized and being respectfully inquisitive is really the best thing.”

Person-Centered Planning instruments were suggested by several respondents. These documents offer an opportunity for youth to share their strengths, goals, and needs with program personnel. Such instruments were thought to be beneficial for youth with and without diagnosed disabilities, as all young people have unique interests and obstacles. Respondents saw a benefit in employing approaches that encourage people to get to know the whole person, rather than solely focusing on accommodation needs.

Respondent A: *“Person-Centered Planning is basically a process where you identify a person’s strengths, interests, and skills, hopes, and dreams...also what works well for that person and what doesn’t work well. So, indoors or outdoors, time of day or certain weather, some types of clothing may not work well. Then you compile that information into a one page profile. It’s a great document, and it’s a cool activity that clubs could do together. It’s nice for anybody to have.”*

Respondent C: *“I wouldn’t say every organization needs to understand Person-Centered Planning...but there are a few components to having a meaningful conversation about support needs...asking, ‘What works for you?’ and, ‘What doesn’t work for you?’ ...wouldn’t it be great if an organization asked that of every family and child, whether they have a diagnosis that is shared with them or not? The other pieces are, ‘What do you love?’ and, ‘What are you really good at?’”*

Person-Centered Planning might also help alleviate one of the primary barriers discussed by respondents, the discomfort and uncertainty of those who do not have experience with disabilities. Meaningful inclusion is facilitated by opportunities that allow staff, youth, and families to know and value each other.

Fostering Comfort and Connection

Lack of exposure to and discomfort with disability were presented as major barriers to meaningful inclusion in PYD programs and communities broadly.

Respondents made frequent reference to the anxiety, fear, and uncertainty of those who do not have experience with disability. One respondent described this common trepidation in the following way:

Respondent H: *“In general, people who do not have a fairly close association with somebody who experiences disability have a fear of how to work with that person, how to best support them. I don’t know how to say, ‘Learn how not to be afraid,’ you know? [laughs] ‘Talk to those people, just embrace them as people.’”*

Three approaches emerged from respondent suggestions on countering this stigma: making space for questions, building interpersonal connections, and engaging adults with disabilities as staff and volunteers. Creating opportunities for youth who experience disability to be known by their peers, as well as program staff, was believed to combat negative preconceptions:

Respondent E: *“I think having personal experience is one of the greatest ways that we eliminate prejudice in our lives.... Our parents may have taught us [prejudice], our grandparents may believe it, then suddenly you are confronted with this person who you become deeply connected to, and it goes against everything you thought you believed. I think that’s one of the most powerful ways to change perceptions.”*

Respondents reported that anxiety is sometimes alleviated when people are given permission to ask difficult questions in a safe environment. They cautioned against placing youth with disabilities into situations where they or their parents would be educating others about their diagnosis without first privately asking for their consent.

Given that note of caution, there was substantial agreement across interviews that answering people's questions was useful in promoting meaningful inclusion:

Respondent A: *“One of the needs might be a safe and open opportunity to ask questions...every situation is going to be different and unique, but I think that kids have questions, they want to know, you know, ‘Why are you in a wheelchair?’ ‘why do you have a cane?’ ‘why do you have a guide dog?’ Even older youth might benefit from the opportunity to ask questions without feeling guilty or feeling like a bad person for wondering. I think that’s a big need.”*

Respondent C: *“I think the same kinds of supports that I talked about for the kids are good for staff and volunteers, an opportunity to have space to ask questions, even questions they might think they are not supposed to have.”*

Another suggestion to build comfort with disability and foster inclusion was to seek out staff and volunteers with disabilities. This suggestion arose in a number of contexts. Respondents believed it would be beneficial for participants with disabilities to have models involved in the program. Additionally, respondents saw value in all participants and staff building relationships with adults who experience disability.

Respondent B: *“I would definitely set it up so that they see adults that reflect them. So, if you have kids who are wheelchair bound, find an adult volunteer who is also. [Promoting inclusion] by modeling and example is probably the best approach.”*

Respondent I: *“If you have a particular event with deaf and hard of hearing students, I would make every effort to involve deaf adults in leadership, planning, or conducting of the event.”*

Respondent J: *“I think any staff and volunteers can talk with an adult with that particular disability to gain insight, that is always helpful.”*

Maintaining a focus on building connections between participants with disabilities, peers, and staff was recommended by several respondents. Some proposed that one way of accomplishing this might be to facilitate peer supports, so that youth are encouraged to engage with one another. This provides a learning experience for both partners and opportunities to get to know more about each other:

Respondent E: *“Using our peers is probably one the most beneficial ways I have found to be more inclusive, finding ways to buddy up or have that peer relationship.... I think oftentimes we overlook some of our greatest assets that are right there, especially within youth organizations. Kids are very welcoming, and they have some of the best ideas for how to do things, because they aren’t so blocked up with ideas about the way things should be. I think really using the youth of an organization to come up with ideas, and to reach out to others, and to buddy up.”*

Respondent A: *“Maybe facilitating those peer supports early on.”*

Proactively encouraging peer interactions may help reduce feelings of isolation and tokenism. Most respondents expressed that meaningful inclusion involves more than merely being in attendance. Youth should be engaged and contributing to activities in accordance with their abilities, strengths, and interests:

Respondent B: *“I think a lot of times people think that inclusion is the same thing as just having them present, which is not what we would consider being included in something.”*

Respondent A: *“When a child or a student is kind of a visitor in a particular activity or on the sidelines it doesn’t seem to be as rich of an experience. So truly feeling like they are contributing, I think that has to be intentional too, that everyone is contributing to the outcome of the activity, I think is important.”*

The approaches shared by parents, advocates, and educators may help to reduce discomfort with disability, contributing to more inclusive PYD programs. Creating these spaces in which young people can learn from one another is central to the role that PYD organizations play in society.

Targeted Outreach

Parents of youth with disabilities often face difficult realities accessing PYD opportunities. Repeatedly being turned away and having to push organizations to secure accommodations leads some parents to opt out of pursuing activities outside the disability community. For this reason, respondents felt it important that organizations should engage in intentional outreach once they are adequately prepared to receive more youth who experience disability.

This parent described some of the challenges of navigating PYD opportunities for youth with disabilities:

Respondent E: *“It’s really hard because you are faced with people who basically tell you no, and you don’t really find a lot of support. It’s very defeating after a few times of hearing that...you don’t even want to seek out those opportunities, a lot of parents just quit, they’ll only go to [disability specific organizations]”*

An organization’s marketing materials can signal whether they are inclusive or not. If materials are not explicit in their invitation to all youth, some parents may assume they are not welcoming of youth with disabilities:

Respondent D: *“I didn’t feel comfortable asking for them to [accommodate], because there was nothing mentioned about any special training or that they are inclusive, I like to see that.”*

Including photos of diverse youth and statements regarding any special training or inclusive design the organization has implemented are some suggestions that arose. Being intentional in outreach efforts was underscored by most respondents:

Respondent B: *“Put out marketing that uses inclusive imagery. Use a statement that says the organization is inclusive. I’m envisioning a flyer saying that the organization is open to accommodating all children.”*

Respondent A: *“Outreach really needs to be intentional. A campaign of sorts, ‘Welcoming to all families.’”*

One potential avenue for outreach was related to relationships with entities that serve individuals with disabilities. As previously stated, these relationships were suggested by respondents to support inclusion in a variety of ways, including outreach. Reaching out to educators, family networks, occupational therapists, and advocacy groups was thought to raise awareness about the availability of programs that welcome youth with disabilities.

Respondent D: *“I would approach family support networks, because those are your groups that would help word of mouth. Not to necessarily to actively recruit, but say, hey, “we know that this is important and we want to make this more inclusive and more welcoming, this is our mission, and we want you to know that these are the opportunities that are out there.”*

Respondent F: *“If you don’t advertise it and let it be known, it’s not going to be known, so I think a little recruiting has to be done. Teachers would love to have access to the same kind of information, so that they can share it with parents.”*

Respondent D: *“Having your child with a disability asked if they would participate? I think that would be amazing. Our children rarely get asked to participate in things - truly asked to join. We’ve dealt with our kids getting left out of birthday parties and even classroom activities by their own teachers, so, yeah, I*

think that would be amazing if it was really said, 'Hey, we want everybody to come have fun with us, not just because you have a disability, but everybody, and that includes you!''

The five areas of influence outlined provide a map of what parents, advocates, and educators believe is needed to facilitate meaningful inclusion: organizational policy and practices, partnerships with the target audience, universal design for learning and the built environment, fostering comfort and connection, and targeted outreach.

The perceptions and recommendations collected in these interviews can inform PYD programs in addressing the needs of youth participants who experience disability.

Organizational policy and practices set the expectation of inclusion and provide the necessary resources to see that expectation become reality. Partnerships with the disability community can provide specialized knowledge, support, and human capital. Universal design in instruction, communication, and physical environments provides the necessary foundation to welcome and serve all youth. Fostering comfort with disability and connection with individuals who experience it helps to establish a culture of meaningful social inclusion. Intentional outreach to the disabled community lets them know PYD organizations are for all youth, and that includes them.

Discussion

This thesis aimed to explore the perceptions of individuals invested in the success of youth with disabilities. Respondents were asked for their thoughts on potential benefits to participation in PYD programs for young people with disabilities. Findings indicate that respondents value inclusive PYD experiences and believe them to hold an array of benefits. Four themes were identified: potential for learning, social connection, vocational development, and positive self-concept.

It was believed that parents, advocates, and educators close to this population would have a valuable vantage point from which to base recommendations on how PYD organizations can welcome and serve those who experience disability. Interview data coalesced around five spheres of influence perceived as facilitative of successful inclusion.

Benefits

Potential for Learning

Participant perspectives on the benefits of engaging alongside diverse peers and mentors were consistent with previous research in educational settings. In a 2015 study, Ledford and Wolery found that children with intellectual and developmental disabilities displayed increases in unprompted prosocial behavior (e.g. sharing, saying please and thank you without being asked) when instructed alongside typical peers. Additional studies have documented the influence of peers, particularly among children diagnosed with autism (Jones and Schwartz, 2016). The positive impact of adult mentors is also established in PYD literature. Further research is needed to understand specific learning benefits for youth with disabilities resulting from participation in PYD programs.

Social Connection

Positive peer interactions have been shown to be beneficial to youth with and without disabilities. Some studies have shown that fostering connections between youth with disabilities and their peers in school results in increased social support, school satisfaction, and overall well-being (Carter, 2013). Community-based activities are considered an important alternative context for social connection outside of school (Carter et al., 2013). This research shows that parents, advocates, and educators see PYD programs as providing additional space for youth to build meaningful friendships.

Vocational Development

This collection of interviews highlights an interest in programs supportive of future employment for youth with disabilities. In 2013 the employment rate for individuals with disabilities was just 30% (Siperstein et al., 2013). While discrimination and implicit bias play a role in this disparity (Draper et al., 2011) researchers have also provided evidence of the importance of early employment related skill building, and raising community awareness about the potential contributions of youth with disabilities (Lindsay et al., 2011) More research is needed to understand potential relationships between involvement in inclusive PYD programs and employment outcomes.

Positive Self-Concept

Aiding the formation of positive self-concept is a central objective of PYD programs, and naturally, central to the interests of those who care for youth with disabilities. Interview data shows that opportunities to experience success and meaningful connection in PYD settings are believed to be supportive of young people's self-esteem.

Evidence documenting impacts of involvement in youth development programs on psychological adjustment specifically regarding disabled participants is limited. Research does suggest a relationship between participation and healthy psychology among youth in general (Vinosky et al., 2016).

Areas of Influence

Policies and Practices

Participants in this study indicated that organizations with clear policies and practices around inclusion may be best prepared to serve youth with disabilities. Studies in youth sports clubs have shown that the nature of volunteer guidance and support can shape the quality of inclusion (Jeanes et al., 2017). Volunteers supporting youth with autism in structured leisure settings reported higher levels of satisfaction when they received ongoing support in facilitating inclusion (Nieto et al., 2015). Perspectives collected in this research were aligned with recommendations of advocacy organizations.

Partnerships

It is meaningful that parents, advocates, and educators interviewed expressed the importance of establishing partnerships between PYD organizations and the local disability community. Notably, forming partnerships with the disability community has the potential to impact nearly all the other areas of influence identified in this research. Partnerships between schools, community entities, and parents have been shown to produce positive outcomes for students and increases in volunteers (Gross et al., 2015).

Universal Design

This study demonstrates support for the principles of universal design in both learning and built environments used by PYD programs. In an analysis of twelve academic papers on universal design in learning, eleven found positive outcomes related to implementing diverse approaches in teaching and communicating (Al-Azawei et al., 2016). By rethinking the ways activities are presented and taught PYD organizations may better serve youth with and without known disabilities. While ADA offers some guidelines for physical access and interpreters, respondents felt that all too often they encounter a lack of mindfulness in these areas. A study investigating the perspectives of adults with disabilities found that physical access and communication resources were central to feeling welcomed in community activities (Devine, 2015).

Fostering Connection and Comfort

A significant barrier was described by participants as uncertainty or anxiety about disability, making accommodations, or saying the right things. Research on ableism shows that as education and exposure increase, negative perceptions about people with disability tend to decrease (Morin et al., 2013). Creating space to ask questions and encouraging program activities that raise ability awareness are suggested both by this data as well as existing literature (Storey, 2007).

Targeted Outreach

Finally, this research demonstrates support for targeted outreach and the use of inclusive marketing materials. Families who have repeatedly been denied access in their communities need to know they are welcome in PYD programs. This finding is aligned with best practices in reaching underserved audiences.

Limitations

A significant limitation of this research lies in the nature of its design, as qualitative research is not generalizable to a larger population and no statistical inferences can be made from the data. While the small sample size is useful for investigating perspectives, no two parents or youth who experience disability have the same barriers or needs. Disability, like all identities, is intersectional in nature. Socioeconomic status, type of disability, gender, sexuality, race, ethnicity, and a host of other factors can contribute to significantly different perceptions about the benefits, barriers, and facilitators of inclusion. Data was collected across a mid-size county in Oregon, perspectives may vary in other areas.

The cross-disability approach to this research is limiting as specific diagnoses may require vastly differential support needs. While efforts were made to include a range of perspectives, the parents of children with autism were most heavily represented in this sample (Appendix C).

While the perspectives of parents, advocates, and educators are valuable in facilitating inclusion, it is imperative that the perspectives of individuals who experience disability inform efforts to include them. Also of value, but missing from this research, are the perspectives of program staff and leadership who deliver PYD programs. Organizational policy and culture around inclusion are central to creating programs that truly welcome all youth.

While it is not uncommon for disability advocates and educators to be majority female, it should be noted that all respondents in this research identified as women. The perspectives of fathers, male advocates, and male educators is also valuable in informing inclusive program design.

The respondents interviewed were not selected at random, and all were very active and confident advocates. Several respondents had decades of experience and accumulated knowledge. While there is significant value in their views for this reason, the perspectives of parents with less experience and knowledge about self-advocacy would be extremely valuable, as most parents approaching PYD programs for the first time will not have similar levels of experience.

The researcher was a long-time participant in 4-H. While efforts were made to be mindful of any potential biases, it should be noted that the researcher values positive youth development programs.

Conclusion

This project sought to inform the inclusion efforts of positive youth development organizations by amplifying the voices of key stakeholders and potential partners. Advocates, educators, and parents saw value in community programs that welcome and serve all youth. Key areas of influence identified by respondents offer support for established recommendations and specific, actionable ideas for organizations to consider. These perspectives from key stakeholders provide an understanding of what families face when seeking PYD opportunities for youth with disabilities. As key facilitators and potential partners in promoting inclusion, the perspectives of these stakeholders enrich the understanding of organizations striving to include all youth.

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Appendix A

Interview Protocol

Welcome and thank you for participating in this interview. My name is Sarah LeComte, I am a member of the 4-H Inclusion Team at Oregon State University. The purpose of the interview is for us to gain information related to your perspective about the inclusion of youth with disabilities.

With the information we gain from these interviews, 4-H will be better able to understand how to serve youth with disabilities. We are talking with you today because of your role/experience as _____ and the important perspective that you bring to the table. Before we begin, I'd like to review a couple things with you:

- First, your participation in this is voluntary, and you can stop at any time you would like or skip any question you like.
- With your permission, I would like to tape our conversation so that we don't miss any of your important comments. To maintain confidentiality, these tape recordings will be shared only with myself and OSU/4-H faculty involved in this program evaluation. Are you OK with our recording and taking notes on our conversation?
- It is important to remember that there are no wrong answers. We are interested in your experience and opinions, so there cannot be wrong answers.
- For confidentiality, once we capture the content of the recordings of this interview into written text, we will not use your name, or associate your name with a particular comment or question.

Lastly, we are going to talk broadly about disability. We are interested in every type of disability, vision impairment, hearing impairment, speech, learning, physical, cognitive, and mental health challenges. That said, if you have information or experience with a particular disability or disabilities, I encourage you to speak from your experience. It is entirely acceptable for you not to be familiar with every category listed.

Do you have any questions before we begin?

I would like to thank you for your time today and for sharing your insight. If you have any questions after the interview I am happy to address them immediately, or you can e-mail me at any time.

We'll start off with a few questions about your knowledge of/experience with disability.

- 1) What is your experience with youth with disabilities?
- 2) Is there a disability, or disabilities, with which you have special knowledge or experience?

Next we'll discuss youth organizations you are familiar with.

- 3) Do you have any personal experience with youth organizations, clubs, or programs?

As a volunteer, a participant, a parent of a participant, or in any other capacity?

- 4) Are you familiar with 4-H? If so, what is your knowledge of or experience with 4-H?

Now I am going to ask about the inclusion efforts of organizations you are familiar with, or have experience with in [location redacted].

- 5) Did you consider your experience with the organizations you mentioned previously to be inclusive of youth with disabilities?
- 6) If yes, what made that organization inclusive? Were there particular factors, accommodations, or an atmosphere you felt made it so?
- 7) If not, what factors made it seem unsupportive or not inclusive?

Next we have a few questions about the status and utilization of youth programs in [location redacted] in relation to youth with disabilities.

- 8) Overall, how well do you perceive youth organizations in [location redacted] to be serving youth with disabilities?
- 9) Do you think that many youths with disabilities and their parents are participating in youth programming in [location redacted]? Why or why not?
- 10) Do you think that many youths with disabilities and their parents are seeking opportunities to be involved with youth programming in [location redacted]? Why or why not?

Now I am going to ask about your opinions and perspectives on inclusion.

- 11) What would inclusive programming look like and mean to you?
- 12) What do you think it looks like and means to [your child/the youth you serve]?
- 13) What kinds of accommodations would you like to see be made available more readily among youth organizations?
- 14) Are there any kinds of activities, clubs, or organizations you would especially like to see for youth with disabilities?

Next we have a few questions about the benefits of inclusion from multiple perspectives, such as participants, parents, and the community.

15) What benefits do you see for youth with disabilities participating in programs or clubs?

16) What benefits do you see for the parents of a youth with a disability in participation?

17) What benefits do you see for youth in the program who do not have personal experience with a disability?

18) What benefits do you see for the community as a whole?

Now that we have highlighted the many benefits of inclusion, let's discuss some of the needs and challenges.

19) What challenges and needs might arise in an organization's inclusivity efforts?

20) What challenges and needs might you anticipate for the youth with disabilities?

21) What challenges and needs might their families experience?

22) What challenges and needs do you think the youth without disabilities might have?

23) What challenges might you anticipate for staff and volunteers?

Now I will ask about some ways to address those needs and challenges, and any resources you may be familiar with.

24) Can you suggest ways that a youth organization might anticipate or prepare for these needs and challenges?

25) Can you offer any guidance on how staff and volunteers who may lack experience can best prepare to serve youth with disabilities?

26) Are there any specific resources, trainings, or materials you would recommend for organizations that might help their inclusivity efforts?

Nearly done, I will now ask a few questions about recruiting youth with disabilities.

27) What are your thoughts on youth organizations actively recruiting youth members who have disabilities?

28) Could you suggest avenues for organizations to proactively recruit youth with disabilities?

29) What kinds of partnerships do you think might support youth organization's efforts to recruit youth with disabilities?

Final question.

30) Is there anything you would like to add, or anything you'd like to ask me?

Thank you very much for your participation. We greatly appreciate your perspective and the time you took to share it. Again, if any questions come to you at a later date or there is anything you'd like to add, you are welcome to e-mail me.

Appendix B

Respondent Descriptions

Respondent A	Parent to a young adult on the autism spectrum, executive director of a cross-disability family network, over twenty years of experience as a leader in cross-disability disability advocacy
Respondent B	Transitional employment services specialist, cross-disability experience, Summer youth employment program coordinator
Respondent C	Engagement Coordinator of statewide family network, works closely with Marion County family network, cross-disability advocate
Respondent D	Long-time disability advocate, founder of a rural disability group, parent to two teenage boys on the autism spectrum
Respondent E	Former K-12 educator, therapeutic and adaptive horseback riding specialist, parent to child with a rare genetic disorder, board member of a cross-disability family network
Respondent F	Parent to young adult with autism, certified sign language interpreter, former special education teacher, Special Olympics coordinator
Respondent G	Adaptive and therapeutic horseback riding specialist, former 4-H leader, sister to program co-founder who experiences Muscular Dystrophy, extensive cross-disability experience
Respondent H	Executive director of Down Syndrome parent advocacy group, parent to a young adult with Down Syndrome, extensive cross-disability experience
Respondent I	Former special education teacher, certified sign language interpreter, director of a school for the deaf and hearing impaired, cross-disability experience
Respondent J	Special Education Coordinator, experiences hearing impairment, former 4-H leader, parent of a child with fine motor impairment and learning disabilities, cross-disability experience

Appendix C**Sample Characteristics**

10/10	Identified as women
4/10	Current or former special educators
6/10	Parents to one or more children with disabilities
-	(3 autism, 1 Down Syndrome, 1 Angelman Syndrome, 1 learning/fine motor)
1/10	Identified as having a disability (hearing impaired)
4/10	Live in rural areas
5/10	Live within city limits
1/10	Live outside target area but had extensive, ongoing work experience there

