

# The Dilemma Between Easing Service Access Through a Clear Diagnosis of Disability and Unease in Assigning Labels to People with Disabilities: A Case Study

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Journal of Social Work Values and Ethics, Volume 5, Number 3 (2008)  
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## **Abstract**

This article examines how the dilemma regarding using disability labels to help people with disabilities access services versus promoting consumer self-determination that includes rejecting labels gets played out in a practice situation through looking at a case study of youth with disabilities receiving services from a foster care transition program.

*Key Words:* Youth with Disabilities, Strengths Perspective, Foster Care Transition, Self-Determination, Labeling

People with disabilities are often served by multiple service systems, including child welfare, education, health care, and social service and support systems specific to people with disabilities, such as vocational rehabilitation, developmental disabilities services or Centers for Independent Living. Each of the systems may take a different approach to how they work with clients or consumers, what their goals and outcomes are, and what methods they choose to employ to reach these goals. Often, a key difference among these systems is how they perceive and understand disability, and the importance they place on having the “label” of disability attached to the client. A lack of professional knowledge, training and comfort about disability services and disability rights may lead to lower quality and less appropriate services and supports for people with disabilities from service providers outside of the disability-specific realm. Whereas professionals in these other fields may be practicing to the highest standards of their discipline, their lack of disability knowledge and training may be detrimental to their clients with disabilities achieving the best possible outcomes.

## **The Dilemma**

In general, in order to access services designated specifically for people with disabilities, a person with the disability needs to have an acknowledged diagnosis of disability. The public sector has created multiple definitions of disability and degrees of disability (Rothman, 2003), but a person must meet the appropriate pre-determined criteria in order to access publicly funded services. Depending on the particular service, the diagnosis can come from a number of sources: medical professionals, education professionals, social workers, or the person with a disability himself or herself. However, for many individuals with disabilities, as well as for many social work professionals, there is a reluctance to self-identify or “label” someone as having a disability. Many social work professionals, strongly committed to a strengths-based approach to practice, are reluctant to label their clients as having a disability, viewing it as a negative attribute that limits opportunities and options, rather than as a key to access many of the community supports and services that are available. This article explores this ethical dilemma faced by social work practitioners through an introduction to social work and disability perspectives on this dilemma, and through a qualitative case study of both program staff members and program participants of a foster care transition program that provides services to many youth with disabilities.

## **Social Work Perspective on the Dilemma**

A commitment to strengths-based practice lies at the heart of social work practice. It is incorporated in the NASW *Code of Ethics*, into social work education, and into practice at all levels and settings. The strengths perspective of social work practice is based on the idea that all people have a wide range of talents, abilities, capacities, skills, resources, and aspirations. These strengths drive human growth, when they are identified, recognized, and developed (Saleebey, 2006; Weick, Rapp, Sullivan, & Kisthardt, 1989). Conversely, focusing on problems and deficits in people and communities inhibits growth. Therefore, social workers are encouraged to focus on strengths in order to enhance growth and bring about positive change with their clients (Saleebey, 2006; Weick et al, 1989). For many social workers, a disability diagnosis, rather than being neutral or a positive attribute, may be seen as negative or detrimental, and, therefore, something to avoid attaching to clients whenever possible.

Despite the good fit of the strengths model with social work values, some strengths theorists argue that it is a challenge for social workers to abandon a problem-solving model and focus on strengths because of the widespread acceptance of the problem-solving approach (Hill,

in press; Saleebey 2006; Weick et al, 1989). A central tension in social work practice is between this strengths-based approach and the need to assign diagnosis and classifications to clients to achieve appropriate diagnosis, referral, or services (Weick et al, 1989).

Compton and Galaway (1989) discuss the inherent tension between social work's responsibility to value the "...individual uniqueness and dignity..." (p.178) of clients while simultaneously performing necessary classification of individuals to diagnose, refer, and treat. Social workers, like all human beings, must use classification and labels to sort and make sense of the vast amount of information that is presented to them. However, at what point does a label become a negative, rather than a positive tool for organization? Compton and Galaway (1989) argue that "not only does labeling, or classification, lead to distortion of individual differences, but, as labeling theories and their supporting research have noted, when a person is labeled deviant, those doing the labeling and the surrounding audience frequently respond to the deviant based on the label rather than based on individual characteristics" (p.179). The classification, while providing an entrée to effective treatment, may also limit the self-determination opportunities available to the client, and remove opportunities for self-direction of services and supports for clients with disabilities (Compton & Galaway, 1989).

Despite its long-standing commitment to working with oppressed and disadvantaged populations, the social work profession has not been a leader in work with people with disabilities nor greatly involved in the disability rights movement (Mackelprang & Salsgiver, 1996; Saleebey, 2007). Most people entering the social work profession do not intend to work with people with disabilities, and there are few people with disabilities entering the social work field as practitioners (Mackelprang & Salsgiver, 1996).

Mackelprang & Salsgiver (1996, 1999) attribute the relatively small presence of social workers in organizations that work with people with disabilities to two primary obstacles. First, social work practice has historically drawn upon the medical model of intervention, which puts health care professionals, including social workers, in an expert role, directing patients' lives, treatments, and interventions (Mackelprang & Salsgiver, 1996). Although in some ways social work has moved away from this model in the recent past, incorporating a more strengths-based approach, many of the systems in which social workers practice still are structured according to the medical model. Further, social work's past adherence to the medical model has helped to foster

a difficult relationship between people with disabilities and many social work service systems and has created a reservoir of distrust for many people with disabilities.

A second reason Mackelprang and Salsgiver (1996) propose that social work is not consistently perceived as supportive of people with disabilities is the profession's traditional focus on individual problems and pathologies, rather than on individuals' abilities and community accessibility. The medical model typically views a disability in a pathological way, and professionals work to rehabilitate individuals so they will function within society. An alternative view of disabilities that is commonly employed by disability activists, the social model of disability, views disability more in terms of how society can be changed to accommodate people with disabilities (Oliver, 1983). However, the social model of disability is not routinely included in social work education, nor is this model used to structure social work interventions. The focus of the social work intervention with people with disabilities is often at the individual level, rather than systemic or community levels. Thus, a person's disability is often perceived as an individual problem or deficit, rather than a failure of a community to provide appropriate supports or accommodations. Social work interventions from the individual perspective tend to focus on alleviating an individual's "problem," which is often seen as paternalistic and intrusive by people with disabilities, rather than focusing on improving the interactions between the external environment and the individual (Gilson & Depoy, 2004; Mackelprang & Salsgiver, 1996; Saleeby, 2007).

Indeed, social work and people with disabilities have not always been an easy match, as "...the social work professional maintains the status quo by accepting, supporting, and enforcing diagnostically based legitimacy criteria and responses that maintain disabled individuals and groups in marginal positions" (Gilson & DePoy, 2004, p.135). Because of this, the disability community is often skeptical of social work and social workers. However, social workers often work with individuals with disabilities without adequate training and experience. They simply are unfamiliar with the social model of disability, unaware of the services and supports that are available, unclear on how to access services they are aware of, and/or uncertain how to best blend and braid disability services with the services and supports that are within their agency's specific purview. While there has been a growing emphasis on disability issues within the field of social work and a more strengths-based approach is taking root in providing services and supports to

people with disabilities, there are still reverberations of the historical perceptions and approaches that color present work.

### **Disability Perspective on the Dilemma**

Generally, the disability rights movement has fought for people with disabilities not to be pigeonholed by their impairments. Disability is often seen as neutral—neither good nor bad—and is as much a function of society's accommodation of the impairment as it is the impairment itself. Recently there has been a growing movement toward viewing disability as a cultural category, which has both positive and negative characteristics (Peters, 2000). This has been seen most notably among Deaf people, who have an entire Deaf culture and view themselves as a distinct cultural group (Padden & Humphries, 2005), but also amongst people with all types of disabilities. Some people with disabilities prefer to reject labels altogether (Mason, 2005), and particularly dislike being labeled by professionals. However, without a clear diagnosis or “label,” many services for people with disabilities are simply not available. An individual needs that diagnosis to access these services. This is clearly a systemic problem, not an individual one; however, it directly affects many individuals. One way that disability-rights proponents have addressed this disconnect is through an emphasis on self-determination and self-advocacy for people with disabilities.

In the United States, an independent living movement promoting self-determination for people with disabilities began in the 1970s and is still strong today (deJong, 1979). For disability advocates and service providers, the concept of self-determination is rooted within the client's or consumer's self-identity as a person with a disability. Gilson & DePoy (2004) describe self-determination within disability studies as an approach that places the locus of decision-making and control with the person with the disability. This decision-making can extend beyond selecting which services to receive, to choosing to abstain from any services at all. In the independent living movement, individuals with the disability are viewed as the foremost expert in any supports, services, or accommodations that they might need (Gilson & DePoy, 2004; Wehman 1993). Some publicly funded services have begun to respect the notion of consumer-controlled services, and there are now options under Medicaid that allow people with disabilities to have more control of their services, including in some instances the ability to hire and fire their own support givers (Benjamin, 2001). Consumer self-direction requires an individual with disability to have an in-depth knowledge of their support needs related to their disability. The concept of self-determination in disability practice does not call for people with disabilities to self-define solely

in terms of their condition; however, it does call for an ownership, as it were, of the diagnosis and its attendant constructs, when consumers are directing the services and supports that they need.

Closely linked with the concept of self-determination is a strong emphasis on avoiding “labeling.” Unfortunately, there is a common societal misperception that having a disability is equivalent to being “sick,” “deviant,” or “deficient” (Mackelprang & Salsgiver, 1999). Understandably, people with disabilities choose to self-identify in ways that are more positive. At the most basic level has been the push in the United States for using “person- first” language when referring to people with disabilities. The notion behind people-first language is that a person or group of people should not be identified first or solely by their disability (“a disabled man” or “the blind”), but rather a disability label, if used at all, should come after the (“a man with a disability,” “people who are blind”) (Lynch, Thuli, & Groombridge, 1994). However, there also are many who do not want a label attached to them at all. This becomes complicated when there is a need for a label for service provision, and there is a need for social work services and assessment to move toward a more contextual approach to assessment, rather than focusing on the presence or absence of pathology (Mackelprang & Salsgiver, 1996).

The dilemma between easing access to services through a clear diagnosis of disability and unease in assigning labels to people with disabilities is highlighted in work that is done at the boundaries of social service systems. Services that are provided to individuals who are eligible for services in multiple systems, or who are about to transition from one service system to another, often put additional stress on the need for clear definitions, labels, and prescriptions for services. Professionals from multiple service systems must “talk” with one another, share information and referrals, and attempt to streamline the rough edges between systems. In many cases, this magnifies the system’s desire for clear labels and diagnoses. At the same time, however, both the service recipients and providers may be resistant to labeling as they move into a new system of care. Social workers’ commitment to self-determination and empowerment for their clients may also affect their desire to shun labels and, instead, focus on their clients’ strengths. However, if they choose to do this, how does it affect access to services for clients? In addition, by choosing not to focus on disability, are “teachable moments” being lost in work with consumers who could benefit from practicing self-determination and self-advocacy?

## **How the dilemma affects practice: Findings from a case study**

This study examines how the dilemma regarding accessing services versus labeling people with disabilities gets played out in a practice situation through looking at a case study involving youth with disabilities in a foster care transition program, from both the perspective of the youths with disabilities and from the social workers working within the foster care provider agency. Although evidence is sparse, research has shown that a high percentage of youth in the child welfare system are youth with disabilities. The most rigorous studies of maltreatment of children and youth with disabilities estimate that the rate of maltreatment for children with disabilities ranges from 1.7 times (Westat, 1993) to 3.4 times (Sullivan & Knutson, 2000) greater than that of children without disabilities. A 2004 GAO report found that 30% to 40% of youth in foster care have chronic medical problems (GAO, 2004). Nearly half of the former foster youth in the Chapin Hall's 2005 Midwest Evaluation of Adult Functioning of Former Foster Youth had received special education services (Courtney et al, 2005). Thus, of the 20,000 youth who transition from foster care each year (GAO, 2004); a large proportion will also have some sort of physical, mental, developmental, or intellectual disability. While all youth transitioning from care face barriers, youth with disabilities face additional barriers. In general, these youth interact with many systems simultaneously, including the child welfare system, the adult disability system, the education system, the juvenile justice system, and potentially many others.

A young person's transition from youth serving systems to adult serving systems serves as an excellent case study of individuals with disabilities who are involved with multiple service streams. This transition generally takes place around the young person's 18th birthday, when many federally and state mandated youth services end. When a young person is enrolled in secondary school, the school identifies the young person as having a disability and provides an Individual Education Program (IEP) team that develops a yearly service plan for the young person. This plan identifies the young person's needs, contains the plan to meet those needs, and manages the services identified to meet them (Hart, Zimbrich, and Whelley, 2002; NCSET, 2004). Similarly, youth transitioning out of the child welfare system are mandated to have a plan that focuses on preparing them for adult life. In these youth-serving systems, the onus for identification and planning sits with the experts, rather than with the young person. However, when the young person turns 18, the responsibility for identifying service needs, providing the documentation necessary

to access those services (such as disability diagnosis), and making any requests for specific services, supports, and accommodations moves onto the young person's shoulders.

The purpose of examining how the dilemma regarding accessing services versus labeling people with disabilities is played out for youth with disabilities in a foster care transition program is to gain exploratory knowledge regarding how a strengths-based approach fits with the need for a diagnosis to access services. Further, this examination will help to develop strategies for social workers and service systems to provide effective services for people with disabilities. For this consumer group in particular, this study aims to give some guidance on whether or how social workers should help young people self-identify as having a disability, and how the social service system can better serve youth with disabilities in light of this dilemma.

### **Methods**

To explore how the dilemma regarding accessing services versus labeling people with disabilities gets played out in a practice situation, this article pulls from data gathered as part of a qualitative case study of a transition program for youth in treatment foster care. The program provides supports and services, independent skills training, and case management for youth ages 17 and older who are residing in foster homes managed by the treatment foster care agency. Semi-structured interviews were conducted with six program staff and three program participants. Program staff included both program managers and individuals who worked directly with the young people. Each interview lasted approximately 1-2 hours. Interviews were conducted over the course of several months.

The focus of the study was on the efficacy of the program and the perceptions of its success by both program participants and program staff. Program staff members were asked specifically about their knowledge of the disability diagnosis of youth in the transition program, what disability-specific supports they were accessing or might access, and how they felt having a disability affected the young person's transition. Program participants were asked if they had a disability diagnosis, about their knowledge and understanding of their disability, and if they accessed specific supports and services for their transition, including disability-specific programs and special education programs during high school.

Preliminary data analysis occurred during data collection, through an informal review of transcripts as they were completed. This preliminary analysis was used to hone interview questions with participants for better examining themes and addressing gaps in the information (Merriam,



1998). The interviews were tape recorded and then transcribed. Each of the two researchers independently reviewed the transcripts for themes and then compared and crosschecked their findings. The themes were refined, through comparison of the researchers' independent findings, to create finer categories and subcategories of data (Merriam, 1998). Refinement and discussion of the themes was continued until categories and subcategories of themes were developed that were exhaustive, mutually exclusive and conceptually congruent (Merriam, 1998).

This exploratory study does not intend to provide generalizable results for a wider population, and certainly, it is not possible to generalize from a case study of a single program. However, it is the researchers' hope that this case study will cast some light on the dilemma of services to people with disabilities and will lead to a wider discussion in the profession about the tension between labeling people with disabilities versus ensuring access to services.

## **Findings**

From this case study, several themes emerged related to the central dilemma about labeling versus self-determination. These themes included a general discomfort and lack of knowledge about disability labels by both program staff and program participants, a strong commitment to self-determination of program staff, and limited or poor experiences with the disability service system by both staff and participants. These themes are explored below.

### *Discomfort and lack of knowledge of disability labels*

Both the youth in the program and the program staff expressed discomfort and/or lack of knowledge about disability labels. This theme was the most predominant theme that emerged from the case study, and it was repeated in various ways throughout the interviews of both staff and youth. Youth were resistant to being labeled as having a disability, viewing it as negative. Program staff were uncomfortable with the label, not wanting to "put it on" the program participants. For both program staff and program participants, having a disability was viewed negatively, rather than neutrally.

On a programmatic level, the program's staff members are not required to have specific training on disabilities. The staff members have training in social work, psychology, education, or other related disciplines, but they do not receive disability-specific training as part of their work with the transition program. The program itself does not gather or report disability diagnosis information about its participants, even though likely a majority of its participants has a disability. This information may be available through other sources—for an example, the school system or a

medical provider—but is not part of the agency’s intake screening. When asked, the administration of the transition program estimated that approximately 50% of the youth who have participated in the transition program are youth with disabilities. When one of the front-line staff was asked how many of the youth on her caseload had a disability, she replied, “Some of them are on IEPs, not all of them. I would say 60% or 70% are on IEP.” Another staff respondent indicated that nearly all program participants had a disability, saying “I consider every one of our kids to have a disability. I mean, everyone is impaired or delayed in some way, shape, or form. And developmentally, definitely.”

Based on the interviews with program participants and staff, it would appear that program participants are not comfortable in naming a disability diagnosis, nor have they been specifically encouraged to do so by program staff. This is not to say that youth are unaware of their disability diagnosis; rather it was clear that they had not chosen to use it to access additional services and supports. Instead, they chose to ignore it or refuse the services that it might bring to them, preferring to be independent of the label and its attached services. For example, when asked if he had a disability, one program participant replied:

*No. I don't have a disability! I can do calculus in my head; I can do trig. I'm really good at math.... they had to get back at me. One of the teachers put EBD on me. So, I was kind of frustrated with that.*

Another respondent was more comfortable with his disability diagnosis but stated that he preferred to not access the disability-related services that he knew were available to him through his community college. He said:

*I can [access services], but sometimes I don't want to. Because I think I'm at about that age now, I should start trying to do things on my own. Because when I'm an adult, I'm not going to have a teacher there to help me out when I don't understand things. I'm trying to kind of start learning how to start drifting away from that, I'm kind of ....I know I have it, and I know I have the ability to go get help, but I just try to learn how to do it on my own.*

All of the program staff members who participated in interviews were asked if the youth participants were able to self-identify as having a disability. The responses to this question were mixed. Several of the respondents felt that the youth would not know, while others thought that some would know but be unwilling to self-identify. For example, one respondent described how it

depended on the individual program participants, saying “ ...It depends on the kids, yeah. Some kids have no problem, they’ll tell you, others ... you may have to prod them a little bit.”

Another staff member, when asked if the youth would be able to self-identify as having a disability said:

*No. You could say things like “what kind of things are you working on your treatment plan? Do you go to IEP meetings?”....But people with disabilities are in wheel chairs. People don’t say, “you are disabled,” they say, “you don’t learn as well as other kids.”*

It is notable that not only did the program staff not report a high level of knowledge or expertise in disability or disability rights; they also clearly felt that having a disability is a negative label. The program participants also reported this belief in the inherent negativity of a disability diagnosis--they saw it as a punishment, or at best, as a sign of weakness that they should leave behind as they become adults. Despite acknowledging that the majority of the youth in the program had a disability diagnosis, the program staff indicated that they did not work with the youth on self-determination or self-advocacy skills related to disability, nor did they feel that it was necessary for the program to reframe disability in a neutral context.

#### *A commitment to self-determination*

A second theme that was evident in this study was that the program staff had a strong commitment to a strengths-based approach to their work with youth. There was a universal desire to empower the youth in the program, and to work to provide them with opportunities for growth and self-actualization. For example, one staff respondent said, “Because we really believe in the self-determination. We don’t want to impose anything on them.” Another said,

*That’s one of the things I always tell them. I have no agenda. I have to do these things for funding, otherwise, as far as your future is concerned, I don’t have an agenda regarding what has to happen. That’s your job. If you tell me what you want to do, then we’ll go do it.*

However, the staff’s commitment to self-determination seemed to encompass a belief that a disability diagnosis or label was somehow negative and disempowering for the youth. The service providers indicated a reluctance to label program participants as having a disability. For example, when asked about the link between self-identification of a disability and accessing accommodations and supports, one respondent was quite negative about youth self-identifying as

having a disability. She said, “But at what cost? You have to self-label or self-degrade to get the help you need....” Similarly, another respondent said:

*It was another little tricky, “oh it’s ok, because they can write out the notes for you, it’s not about a disability” but, unfortunately, in school, they call it a disability office. I mean really big letters. Like you’re going to want to go with that? It’s kind of like a stamp on their forehead. I think they felt very stigmatized by that name.*

Finally, the emphasis on self-determination also meant that the youth were able to refuse to access disability-related services, even if the program staff had identified it as helpful and necessary. For example, when asked if she ever referred youth with disabilities to a disability-specific job-training program, one staff member responded:

*We tried to connect them with some of that stuff... We definitely expose them to it, but not all of them took advantage of it. It was more trying to get them to know that these things were out there, and they could do. And some took advantage of it, and some didn’t.*

Program staff clearly felt that the youth’s ability to refuse services was not always in their best interests and felt a tension in adhering to their strengths-based approach. For example, one respondent, describing a more extreme case, discussed some of the serious ramifications of self-determination. She shared the following story:

*Some of those kids refuse the help, which is normal, but they tend to not do very well. I had a lot of kids who had bipolar, a lot of my kids through care. I have three different cases, they all have the same offense, they have bipolar. One went to adult care and went to college and did great. One went home and was in jail in 20 days and pulled a gun on his dad. It’s just ridiculous. It just depends on what kind of support they are willing to take.*

The program staff members are very committed to providing strengths-based services to the youth in the program. They clearly want to help the young people succeed based on their own goals and desires. They worked closely with the youth to set goals and to help them achieve those goals. However, acknowledging a young person’s disability diagnosis was viewed as stigmatizing and negative, rather than neutral. Young people were made aware of disability-related services and supports, but were not specifically encouraged to access them, even in the extreme cases. It would appear that staff felt that the negativity of a disability diagnosis outweighed the positive of connections to specific services.

**Youth are over-serviced, and disability-specific services are excessive or unnecessary.**

A final overarching theme that emerged from this case study is that respondents reported that youth are over-serviced in general and that disability-specific services have been of limited or no utility to them. Youth were asked if they received any disability-specific services, with the researcher going through a list of possible services (for example, Centers for Independent Living, disability services in college, IEP/Special education services, vocational rehabilitation). With the exception of school-based services such as IEPs, none of the youth who participated in the study reported accessing any other disability-specific services. For those who had an IEP, their experiences with the IEP were mixed. One respondent very clearly felt that being on an IEP while in high school was insulting and unnecessary, saying:

*It was a pain in the neck! Cause you have to go to these meetings, and you get pulled out of your class when you have a big project you have to do! It's quite annoying. And then you fall back, and it's like, thanks. And it's like, it's not our fault, you have to work harder! Well, take me off the IEP then!*

Another young person had a different experience, reporting that the extra help he received as part of his IEP was, in fact, helpful. However, this respondent was very clear that he did not want to access similar services as an adult, preferring to work on his own in the future. He said:

*I'm just trying to make things on my own. I like to try to figure stuff out on my own. Because when I become a parent and have a family, I'm going to have to make it on my own anyways, besides the support of my wife or girlfriend. I'm kind of like an independent person, I'd rather be there for everybody else than for myself. I've kind of learned that, just being alone, being an adult.*

Program staff also reported mixed experiences with disability specific services. Several reported concerns with the appropriateness of disability services, wondering if the services were helpful for the youth they were working with. Another concern for program staff was that young people were simply over-serviced. They did not want to bring more services into a young person's life without certainty that it would bring something new and a tangible skill or outcome for that young person. One staff member said:

*...some of these kids got so many services that they started getting really over-serviced. They'd be like "don't tell me one more thing. Because my therapist tells me that, and my foster parents..." So, I really had to struggle with that with a lot of kids, they'd be like "why are you guys always telling me this? Why does everyone*

*keep harassing me about it?" And there were times where I'd have to be like, ok, let's think this through. ...Because it's too much! It's too much. And they don't like being told what to do. They don't need it from 500 people....*

One staff member felt that the services that one young person was referred to were not appropriate to his needs and, in the end, ended up hurting him.

*.... well, one time I had a young man who had been diagnosed with schizophrenia and needed to have a neuropsych done. So, his county worker got all that organized, and then she wanted a certain person to do it. Well, his report came back, and it was oppositional defiant disorder. And we were like, who is this kid? It was completely.... all the things on there were not this kid at all. It was the worst report I've ever seen. It was like, did you even talk to this kid? Because it's not accurate in any way. So, he didn't qualify for adult services. And we were like, what are we going to do?*

Staff also reported that, in some cases, youth did not qualify for adult disability services, despite being on an IEP. This caused some frustration for both the youth and for the staff. A program staff member shared the following observation about how difficult it was to get adult services for kids transitioning from foster care:

*A lot of them unfortunately did not make the cut. A couple of them did, but unfortunately, because it's voluntary, it was a struggle. So, I would say a small percentage, a very small percentage got some disability services. Some were offered and then refused, and the majority was not severe enough.*

Finally, staff reported difficulties in getting disability services and foster care services to work collaboratively. The rules and regulations for one set of services were often contradictory to what was available through another funding stream.

The findings from this case study indicate that some of the reluctance to access disability specific services comes from a belief that the services are not unique in what they provide, are difficult to access or qualify for, and may not be appropriate for the needs of the youth in the program. Additionally, the negative perception of disabilities also colors the young people's willingness to access these services, even when they have been helpful in the past. The program staff members were less likely to acknowledge that disability specific services had been helpful to the youth, often feeling that they were repetitive or ineffective or worked in opposition to the services that youth were already receiving. Why risk the negative implications of a disability label if it will not lead to the highest quality, most useful services?

## **Discussion**

The findings from this case study indicate that there is tension between the need for program participants who have a disability to carry a diagnosis or label of disability with them to access adult services, and participants' and program staff's discomfort with disability labels and diagnoses. However, without these labels, many publicly funded services may be unavailable to the youth program participants, not just as they transition out of this program, but as they move on into their adult lives. Indeed, in some instances, respondents indicated that forgoing services was preferable to having a disability label.

One of the most notable findings of this study is the universally negative perception of disability by all of the respondents in this case study. The program staff clearly felt that having a disability diagnosis or label was, at best, neutral, and more often, negative. These findings are not surprising, as many studies have shown that social workers who are not in the disability field are not comfortable working with people with disabilities (Manders, 1996), have little information about disabilities (Lightfoot & LaLiberte, 2006), and are in need of disability training (Lightfoot & LaLiberte, 2006; Orelove, Hollahan, & Myles, 2000). Whereas negative perceptions cannot be changed overnight, there is clearly a need for more efforts to promote a positive image of disability among social workers. Providing specific training to social workers and other service providers on alternate, non-medical model perceptions of disability could begin to bring about a positive change in the way disability is perceived and understood. In particular, there is a need for social workers to have training on how to integrate a positive perception of disability within a strengths perspective practice approach. This training should be integrated into both academic and post-academic training, such as professional in-services or licensure trainings, and should not be limited to those in the field of disability services.

The youth with disabilities in this study also had a generally negative perception of disability. While youth with disabilities in general lack positive role models (Burgstahler & Cronheim, 2001), youth in the child welfare system may have even less access to these role models. Many studies have shown that youth with disabilities need exposure to peer and mentor role models (Burgstahler & Cronheim, 2001; Lynch & Lynch, 1997; Rousso, 2001). Perhaps introducing foster youth to disability culture and providing opportunities for youth to relate with other youth with disabilities and young adults with disabilities could help them change their

negative perception of disability. However, social workers should have no illusions that this negative perception will change quickly, as it may be deeply ingrained.

The findings from this case study also point to the need for more universal services for youth that do not require specific labels for entry. If programs were designed to help any youth that needed assistance, such as independent living skills development, job hunting, or post-secondary training, youth would be able to receive such services without obtaining a disability label. However, as desirable as universal programs may be, they do have funding implications that often make them untenable. Further, programs that are universally designed might have more difficulty in providing appropriate services to the youth who need them most, and youth with disabilities might not get the tailored services that would best fit their needs. An alternative to developing universal programs is for programs that serve youth with disabilities to downplay the disability label in the marketing of its services to youth, so a youth who is apprehensive of his or her disability might not feel so uncomfortable in initially obtaining its services. However, programs must be careful not to play into the negative perceptions of disability and find ways to introduce a positive perception of disability within their programs.

The findings from this study point to the possibility that children with disabilities who have no parents or family members available to advocate for them may be less likely to have a disability label, or less likely to use the disability label to obtain services. The current system of special education services creates an important role for parents, in which the parents are involved in claiming the disability label for their child in order for their child to get services, and then the parent “carries” the disability label throughout the child’s development, until the young person is able to claim it for him or herself. Youth without parents or other close family members may have no one who will work with them on building a healthy self-identity, practicing self-determination, and learning to self-advocate for the services and supports that they need. Service systems, especially for youth and young adults, must stop assuming that there are parents or family members available to do this work for them, and there is clearly a need for youth with disabilities to be aided in understanding their own disabilities. In addition, disability advocates and professionals need to target people with disabilities who are not currently being reached, such as youth with disabilities in foster care.

Finally, existing disability services need to be of the very highest quality. While this is true of all types of social services, a number of respondents in this study did mention the futility of



labeling in the face of the poor services available. It will not help to assist youth in self-identifying and self-advocating so that they can access disability services only to have the services be inappropriate, low-quality, or unavailable as a result of budget, time, or service constraints.

While the findings from this study cannot be generalized to other professionals and participants involved in youth transition programs, it does provide some insights into how the tension between labels and self-determination play out in a social service setting. There is a need for further inquiry into how to best serve people with disabilities in non-disability specific settings. In particular, young people with disabilities who are vulnerable in some other way, such as those in foster care or in the justice system, may be in particular need for services and supports from a system that does not view their disability status as inherently negative.

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