

As Long as They're Happy:

How Job Opportunities for Children with Intellectual Disabilities Impact their Families

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Abstract

This exploratory study examines the employment of children with intellectual disabilities and the overall impact on the family. This study's main goal was to understand the differences in difficulties for families with employed intellectually disabled children and families with unemployed intellectually disabled children. Qualitative interviews took place with six families throughout a rural community in Central Pennsylvania. Studies in the past regarding employment and children with disabilities have focused on how the children impact parental health, parental quality of life, sibling quality of life, transitional programs into adulthood, and end-of-life care for adults. This study leads to a better understanding of the differences in life experiences for families with different employment statuses for their intellectually disabled children.

Introduction

Americans strive to reach the American dream—to be able to sustain their families with the best of care and have the opportunities to do whatever they want. These opportunities are taken for granted by those with accessibility to them. People are unaware that not everyone has the chance to be whoever they want to be. Families with disabled children deserve access to those opportunities, just as all families deserve them. Having opportunities available to them is very important, and one of these opportunities could be access to employment programs for their children.¹ Other opportunities include special education programs, basic skills training, and programs within the community to keep them busy with activities.

Families with non-disabled children send their children to school with high hopes and expectations that schools will prepare them for the future. Their children will most likely go to college, find a job, and move out of the home to enjoy their own lives of independence. What is the story like for families with children who have intellectual disabilities? These families will send their children to school, most likely special education programs, and hope they will obtain the skills that will allow them to participate in a structured employment program providing their children with consistency and time away from the home. What is less understood is how these experiences will impact these children and their families. How do their experiences growing up with family, receiving an education, and participating in services develop marginalized individuals in society? Are schools and outside services properly preparing these children for the transition into adulthood?

¹ Any time *child, person, individual, or adult* is written, it means a person with an intellectual disability. Any discussion of children without disabilities will be expressed as such.

This paper will focus on employment opportunities for children and their impact on families with employed children versus unemployed children. How will a child's transition to adulthood affect employment opportunities and impact the family's ability to plan for the future, in the opinion of the parents? This has not been focused on in the literature. Literature has looked at how children impact parental employment, but how are services impacting a child's employment as perceived by the parents?

This exploratory study will look primarily at four questions: 1) What are the experiences of families with employed intellectually disabled children? 2) How does this experience differ from that of families with unemployed intellectually disabled children? 3) How does the employment status of an intellectually disabled adult impact the employment of the parents? 4) How does the opportunity to participate in educational programs and transitional programs impact the intellectually disabled adult's ability and confidence in obtaining a job?

Literature Review

Research on families with intellectually disabled children has covered impacts on parental employment status, parental health, parental quality of life, sibling quality of life, transitional programs into adulthood, and end of life care for adults (Morningstar 1997; Chou, Pu, Kroger, and Fu 2010; Eisenman 2003; Gordon, Rosenman, and Cuskelly 2007; Heller and Arnold 2010; Winn and Hay 2009). This body of research has increased the knowledge available on families with children, but it is lacking a focus on opportunities for the children and their impact on families. Nowhere has research covered the impact on a family that has an employed child versus an unemployed child.

This is an important topic of study because research has not looked into employment of children and how different employment statuses impact families. Awareness of differences of

impact on families can help change the focus of opportunities available to families in different situations. If a program is impacting a family differently from another, the program is not necessarily benefiting all of its participants, which indicates that a change needs to occur. Another missing part of the research is the connection between available services and transition from childhood to adulthood and the impact on the status of employment for people. Studies have shown that all of the extra time and care needed to raise children places a burden on the overall family unit (Gordon, Rosenman, and Cuskelly 2007; Rogers and Hogan 2003; Chou, Pu, and Kröger 2010). This burden is emotional and financial; it is also time consuming and it occurs in order to provide their children with the best opportunities in life.

Services for Families

Services for families and their children are hard to come by in Pennsylvania. According to Act 198 of 2004 from the Pennsylvania Department of Public Welfare,

Pennsylvania does not have a dedicated program or funding to provide family support services. Family support services are currently available to some families in

Pennsylvania; however, the support is usually limited to respite care and dependent on the families' ability to meet various and specific eligibility criteria for the funding.

(Pennsylvania Department of Public Welfare 2008: 8)

This shows that support and funding is very limited and highly competitive for families with a child. This can become even more competitive when the eligibility changes to whatever specific disability is receiving funding at that specific time. This means that some programs will only have funding for children with specific challenges instead of opening up funding for everyone.

Act 198 of 2004 provided family support pilot projects put together by Pennsylvania's Department of Public Welfare as developed by Senator Pat Vance. The main goals of these

projects included maintaining family unity and keeping people with their loved ones, preventing placement of people outside of their homes, and reuniting people back with their families if they had already been placed somewhere else (Pennsylvania Department of Public Welfare 2008). Overall, the project was able to help only 127 families out of the 299 total with a one-time gift of \$1,500 each from the donations of the Barber, Keystone, and the Unified Certification Program (UCP) agencies located throughout Pennsylvania (See Table 1). This project was a start in the right direction because it was not limited to families with a specific disability. However, it is hard to justify that \$1,500 dollars is enough money to help pay for all of the extra family expenses that come with having disabled children. The overall goal of this pilot project was to make it a statement program. Projects like this are needed statewide to provide families with adults or children with disabilities an extra cushion to be able to live more comfortable lives. Services, aside from ones that just provide money, also need to provide some sort of developmental training in employment.

Table 1: Agencies Supporting the Family Support Pilot Projects

	Barber	Keystone	UCP	Total
Families Applying	71	55	173	299
Families Eligible	63	47	173	283
Families Completing Support Plan	44	47	36	127

(Pennsylvania Department of Public Welfare Act 198 of 2004, 2008)

Mary E. Morningstar (1997) found that the role of family in helping develop these career skills and preparing their children for employment was a major factor in the rate of the children being successful in obtaining employment. Children with mild intellectual disabilities or mental

illnesses who participated in vocational programs at their schools ended up developing more well-rounded skills in jobs dealing with office and clerical work (Morningstar 1997).

A study on the oppression of peoples in Britain was done in order to explain and provide information to prevent the exclusion of people in the labor force (Barnes and Mercer 2005). The research helped to clarify different social barriers that increased their oppression. One main social barrier was the lack of access to employment: the social exclusion of people from employment opportunities. A second social barrier was unequal wages for the company to adjust for their so-called “lost profit.” Lower wages for people is a social barrier because of a lack of access to a better quality of life in which one can buy food, live, and receive health services. This research shows that when there are unequal wages, there is an unequal access to opportunities as well as services in a community. Oliver (1983) discussed the functional limitations perspective from the individual model of disability, which viewed people with disabilities as a problem for society. Barnes and Mercer (2005) pointed out that this idea “ran parallel to the characterization of work in capitalist industrial societies in terms of paid wage labor and profit maximization” (p. 530), which allows legitimization of the exclusion of certain people in the workforce because their employment would prevent profit maximization. If society views disabled people as problems, then this makes it even more crucial for services to be available to them to maximize the circumstance of independent living and integration into society. The availability of services is crucial for the child’s transition from childhood to adulthood.

Transition to Adulthood

Career Development Theory (Szymanski et al. 1996) discusses that a person’s career developmental skills continue well into adulthood. Skills do not stop developing with an end in program participation and education because a person’s socialization further develops skills,

which can turn into a stable job. In the handbook, *Understanding the Office of Developmental Programs in Pennsylvania: Mental Retardation and Autism Services*, an outline of the process for the transition from childhood to adulthood for people with disabilities is provided (Stasko et al. 2010). Chapter 7 of this handbook describes the program of transition, which is most successful if begun at the age of 14 for the child. This allows for the most time for the child to develop a plan, set goals, and try reaching those life goals. This program is called the Individualized Education Program and must be coordinated with the student's school. It follows the idea of career development theory and the notion that an individual is developing skills constantly throughout life.

The main focuses of planning for adulthood include post-secondary education/ training, employment, and independent living (Stasko et al. 2010). The main question of this program is if families are utilizing an opportunity like this. If families are not using this program, then why not? The program summary is helpful and motivating in that it explains what the child needs to do to have the life he or she wants to have, but how exactly does a person get into the program and what if a person does not fit the requirements? The program requires the participants to create lists of wants for later in life, including what people the child wants to be surrounded by, whether or not the child wants to become involved in employment, and how far their educational goals extend. The program is consistent in the belief that the leaders of these personal transition programs are the children and they can choose what to do in their lives. It also believes choice is available for all of the participants. However, what are those who do not meet the requirements supposed to do? Their needs are just as important. A list of parent resource programs is provided, which includes Parent Education Program (PEN), Parent Education and Advocacy Leadership Center (PEAL), Mentor Parent Program, and Special Education Consult Line.

With handbooks like this, it is important to try and understand if they are actually helping families, and if these programs are being used, then is this increasing the chances of easing the transition from childhood to adulthood? Overall, the transition from childhood to adulthood impacts the level of skill and opportunity available to a child. Just as equal is the transition out of the home, whether that is to a family friend's home, a sibling's home, or a group home. The transition out of the home is a major step and process in families' lives because intellectually disabled adults may only know one home for most of their lives. This transition is also important because the skills these adults have acquired will hopefully help benefit them to be able to live more independently than if no skills training or services were utilized. Further studies looked into even earlier starts for families to begin preparing their children for the transition from childhood to adulthood, as well as the transition out of the home.

Berman and Kwan (2010) discussed the importance of early intervention where a child can be assessed from birth to around 3-to-5 years old to determine the strengths and needs of the child over his or her lifetime, which can help influence the overall transition into adulthood and the next transition out of the home. Some problems with the transition out of the home include this notion that the children have never had to make independent decisions, so once they are living somewhere else, it will be up to them to decide on issues like medical care and end-of-life care (Savage et al. 2010). However, with these decisions it is important to remember that a person's ability and capacity needs to be understood beyond their label (Johnson 2010).

Another option for the transition out of the home is with other family members, especially with siblings who have had the experience growing up with their brother or sister. As for the relationship between siblings, one having no disability and the other having an intellectual disability, it was found that siblings with disabled siblings are more likely to live in

the same state than siblings without a disabled brother or sister (Taylor et. al 2008). Taylor et al. (2008) also found that there was an obligatory relationship between the sibling and the disabled brother or sister. It was considered part of their responsibility to care for their siblings. This is consistent with Heller and Arnold's (2010) study, which found that siblings of brothers and sisters with disabilities usually became the primary caregiver when parents were gone. Positive relationships were usually found between a sibling without a disability and his or her brother or sister (Heller and Arnold 2010). Family closeness influences whether a child will go into a group home or move in with siblings or other relatives. Skills training, transitioning to adulthood, and developing a sense of independence all come into play when the job hunt begins for these children.

Employment Impact on Families

The crux of this study lies on employment of disabled children and its impact on families. The functional limitations perspective (Oliver 1983) argues that these children and adults are a burden for society. The opposite stance of this, the social model of disability, is that society imposes burdens on people (Oliver 1983). The functional limitations perspective has been a running theme found in the literature discussing a child's impact on parental employment status. The main discussion is the impact of having a child on a mother's health, quality of life, and employment status. Most of the research found that mothers were less likely to be employed or employed fulltime if they had a disabled child to care for (Lukemeyer et al. 2000; Chou et al. 2010; Witt et al. 2009; Breslau et al. 1982). Nowhere does the literature discuss how the employment status impacts families.

Overall, it was found that mothers without jobs and with disabled children wanted to work more than mothers who had no jobs and no children with disabilities (Gordon et al. 2007).

Other impacts on parents with limitations from children included poorer health and more missed days from work than parents without disabled children (Witt et al. 2009). Reischl (2000) reminds us that with such complex social systems in our world, it is important that we are given greater support systems to work through what is expected of us. This is important because some people with different life experiences and accessibilities need more support than others. Families with disabled children need more support than families with non-disabled children. The support systems are also crucial for families with only one parent.

Services and employment also impact families with disabled children differently if there is only one parent in the household. One study found that children with an intellectual disability as well as a developmental disability were less likely than children with other disabilities or with no disabilities to live in a household with both parents (Anderson et al. 2002). According to Sharon Hays (2003), American society tells single mothers to fulfill the traditional role and be the stay-at-home mom with the children, but also to be self-sufficient, which is absolutely impossible to do. This makes life even harder for single-parent homes with children. If it is impossible for families with non-disabled children, it is also impossible for families with disabled children. Another crucial point from Eisenman's (2003) study showed that females are less likely than males to be employed. Not only is having a disability a factor in preventing employment, but gender can add to this deterrence. Social class can also add to the differences in how children are raised, which influences employment status. Annette Lareau (2003) found that middle class families raise their children with the notion of concerted cultivation, which allows children to develop a sense of entitlement. Lower class families were found to raise their children with the accomplishment of natural growth, where children will learn how to get through life on their own. Accomplishment of natural growth includes the idea that change is

not necessary and children do not need to be placed in more activities because they are already happy with what they have. This is important in looking at families with disabled children to understand how the children's life experiences growing up in different social classes can influence later employment abilities and opportunities. This perspective is very different from the middle class ideal of concerted cultivation, where success can only be achieved with the participation in many activities to become a well-rounded citizen.

Overall, it needs to be understood what an opportunity like employment can do for families with disabled children. What are the differences in experiences of families with employed versus unemployed children? How do the opportunities and availability of services assist in the transition from childhood to adulthood, and how does this increase or decrease the development of self-sufficiency for the children in the families? It is important, at this time, to now look away from direct impacts on parental health and employment of parents with disabled children and focus on the impacts of the children's employment status and its effect on the family unit.

Methodology

In order to better understand the impacts of a child's employment on families, I felt that in-depth qualitative interviews would give me the best representation of real life issues for these families. The only requirement necessary for these families to be included in the sample was that they were raising a child with disabilities. Differences in employment status were also important but not necessary. Also, all families in the sample had their child participate currently or at one time with the program Opportunity 4 Us (Families interviewed can be found in Appendix B). Opportunity 4 Us is a common factor among all of the families. This program offers stable and consistent employment opportunities for its participants. It considers itself a

training facility where basic skills are acquired throughout the children's lives. The program takes children in at a young age and provides further educational classes aside from special education programs offered in the school. Gathering an appropriate sample was crucial for obtaining good data from the interviews. The location of the study was set in a rural community, City of Dreams, within Central Pennsylvania, with a population of about 35,000 people. According to the U.S. Census Bureau, the population of the community's civilians 5 years old and over with a disability makes up 23.7% of the entire population (See Table 2). This does not differentiate between different types of disabilities but is a general census of the disabled population.

Table 2: Selected Social Characteristics in the United States: 2005-2007: City of Dreams

DISABILITY STATUS OF THE CIVILIAN NONINSTITUTIONALIZED POPULATION	<u>Estimate</u>	<u>Percent</u>
Population 5 years and over	27,878	100%
With a disability	6,609	23.7%
Population 5 to 15 years	4,185	100%
With a disability	621	14.8%
Population 16 to 64 years	20,163	100%
With a disability	3,940	19.5%
Population 65 years and over	3,530	100%
With a disability	2,048	58.0%

*Data Set: 2005-2007 American Community Survey 3-Year Estimates U.S. Census Bureau
 Survey: American Community Survey
 Geographic Area: City of Dreams, Central Pennsylvania

Gathering the Sample

The methodology of this study consisted of qualitative interviews lasting around 30 to 45 minutes long. My sample was gathered with the snowball technique. I knew of two families

who were interested in being interviewed. I knew these two families through a special program at my college and contacted them by telephone. Each one of them provided me with the information of one more family, giving me a sample of 4. One family provided me with information of another family, which would have given me a sample of 5. I made contact with the family, but no response was ever given about their participation in an interview. The next family in my sample provided me with two more families whom they thought I would be interested in interviewing. Those two families agreed to interviews, giving me a total sample (N) of 6 families in my study. Interviews were conducted with the parents or parent of the child only. The child was unable to be interviewed due to his or her inability to fully volunteer for an interview. Most interviews were conducted with the mothers of the children, except one case where both the mother and father were present for the interview. More importantly, the sample consisted of families for whom equal accessibility to the main program, Opportunity for Us, was possible.

Location of the Interviews

Interviews were conducted in the homes of the families. After agreeing to meet with me, they provided me with addresses and directions to their homes. Meeting days and times were set up to appropriately fit their schedule—as well as mine—as best as possible. I felt that home interviews would be the most comfortable for the interviewees. Some families had difficulties with transportation due to car troubles or a lack of car ownership, so I did not want to make the interview more difficult. Consent forms were discussed and signed once I arrived at the family home. Permission to use a tape recorder for my own notes was also acquired. The tape recorder was on throughout the entire interview unless the interviewee wished to say something that was

not wanted as official data. Once interviews were concluded, gratitude and items of thanks, including grocery store gift cards, were given to the families as a token of appreciation.

Post Interview Methods

Once outside of the interview location, notes of the interview and experience, such as the surroundings and atmosphere of the interview, were taken immediately after the interviews were concluded and I had left the house. All notes, tapes, and consent forms were placed in discrete folders. A pseudonym sheet was kept separate from the data collected to honor promised anonymity and confidentiality. Transcribed data was kept in another separate folder with pseudonyms already in place in the transcriptions.

Types of Questions

Questions in my interviews were not meant to pry too far into the families' lives (See Appendix A for questions utilized in the interviews). I did not want to offend them in any way and wanted to make the experience comfortable. Interviews always started with the question of how the child's employment impacted the family. If the son or daughter was unemployed, I would ask, "How has your son's or daughter's unemployment impacted you and the family?" If the child was either employed or unemployed, I asked if the interviewee could explain their child's history with employment throughout their life. Once a history of the child's employment and unemployment experiences were discussed, I asked the interviewee about the child's attained educational level. I asked who helped the child develop the basic skills needed to be employed and be somewhat independent in the home with things including house chores and basic personal hygiene skills. After learning of the child's history with employment and their experience with skills training, I asked families about preparing their child for adulthood. This

usually was followed with a question about how well prepared they thought their child was for employment and adulthood in general.

Later questions in the interviews were geared toward looking at the financial stability of the families and the impact of their child's employment on this stability, if there was any. My final set of questions included parents' decisions about their child's transition out of the home. This was a tough subject and most families were not ready to even think about the idea of their child living somewhere else, let alone the question of whether or not their child would be prepared to live outside of the only home they had ever known.

Interview Concerns

Some issues I had throughout the interviews included a lack of clarity in some of the questions given to interviewees. It was hard for them to understand what I was asking in my questions, so I had to ask the question in a different way that would help them answer. For example, my first question was "How has your daughter's or son's employment experiences impacted you?" I would change this question around to ask, "Can you tell me about your son's or daughter's experiences with employment?" In some cases, the interviewee's answers were very short and to the point. I tried to make the interviews an easy conversation so when answers were given quickly, I would follow up with smaller questions to continue the discussion.

Another issue I had with my interviews was the presence of children in the room. In some cases grandchildren, nieces, and nephews without an intellectual disability were in the same room as the interview. In other cases the interviewee's child was in the room and tried to join in with the conversation. Anything the child said was not transcribed and not taken into account with the data due to his or her status among a special population and the inability to be able to fully volunteer for the interview.

Analysis

This analysis covers five themes that were found throughout the data and conveys family experiences with their children's employment experiences, family participation in helping the transition of their children to adulthood, future planning, and differences in difficulties experienced by families with employed compared to unemployed children.

Experiences with Children's Employment and Opinions of Services Available

Negative employment experiences need to be defined as experiences that caused families to be displeased with their child's opportunities, even to the point of terminating participation in employment. Negative experiences include a lack of diversity of jobs at Opportunity 4 Us, meaning that children are given very repetitive jobs to do. They also include lack of care for the participants in the program. All of the families interviewed still had or at one point had their child employed and active with Opportunity 4 Us, which is a program that gives children a place away from the home and a sense of independence with the ability to bring home a pay check because of their own work. In talking with Margaret Smith, she expressed strong critiques in the ability of caseworkers to relay important information regarding healthcare for children. Negative experiences with caseworkers can impact the ability of parents to even consider looking at different opportunities for their children, which is an added burden on parents to then be the providers of activities for their children. Margaret said,

Well yeah, sometimes she needed hearing aids, so we had to go through OVR, but a lot of parents don't know about these things. I think sometimes the caseworkers fail to let that be known to the parents you know to help us out, really.

This is only one example of negatives that can impact families even before children reach employment age and can deter parents from encouraging employment for their children.

Margaret's daughter, Alicia, was employed up until 2005, but both Margaret and Alicia were displeased with the programs to the point where happiness would be better achieved without the help of the program. Margaret said,

Yeah, she's happier now because, like I say, she got bored. She got bored with the repetitive stuff and the classes and like on days when they didn't have the work, which they really had a lot of difficulty getting work there. And, uh, they would do what they call "down time" where they'll get a little bit of pay, but it was like takin' a paper and stickin' it in an envelope, takin' a paper and takin' em out, you know. She's smart enough to know that it gets boring and they know they're not getting paid as much as they do if it's not down time. And that was a big thing back then. I don't know what it's like now, but they just couldn't keep work. That's why I say, I can't imagine they can't get something better. And like, for the classes, my friend was in the garden club. We did some projects with them. One time we took like pine cones and made little bird feeders out of them with peanut butter and the seeds. But then we did that a couple of times and then it was like they [the program] just lost interest in us coming.

Unhappiness with the program was furthered by the rejection of more ideas and projects implemented by parents; this made the parents feel as though changes could not be made with the current services provided.

A different aspect was given by Sarah Duffel, the mother of Amber. Amber is currently employed at Opportunity 4 Us, where she goes to work Monday through Friday from 8:30 AM to 3:30 PM and performs basic tasks. Duffel said,

With all of these experiences [they] have been good for her. She's had bad moments. She's had a lot of good moments. But she's learning responsibility. She's learning how to get along with other people, how to take constructive criticism, which she doesn't like. She wants to give it. So I guess it's been a good experience.

Unhappiness with work could be overlooked because the positives of the service provided with the program outweighed some of the negative experiences.

Kathy Brown and her daughter Ashley live together in a small apartment. Both Kathy and Ashley have experienced employment, but like Alicia, negative experiences were great enough to discontinue employment permanently for Ashley, where, as I'll discuss later on, circumstances made unemployment necessary for Kathy. She said,

She liked a lot of the parts of the job she did. Well then, towards the end, they put her with another job there that she called bean clamps. Now I don't know, but it was a dirty job. It required wearing gloves and she never had any. And it was hurting her hands. She didn't like it. She basically didn't like it. So there was a bunch of mornings where she was refusing to go to work, weren't you [looking towards Alicia]. So, one days we had a discussion and I said, "Do you want to stay home with mamma?" and she's been home with me ever since.

Neglect for these children in the work place is a major factor in ending employment participation. The mothers in all 6 families only wanted the best they could give for their children, which included making sure that their children's happiness came first, even if that meant ending participation in available services. Children's happiness was also important for the families who had good experiences with Opportunity 4 Us.

Parents did experience many positives with their children's employment opportunities. Positive experiences for families can be defined as experiences where independence and activities outside of the home were expressed by parents as great things for their children to be doing. Positive experiences expressed by parents included being able to have their child go somewhere to allow family separation periods. Although Margaret Smith felt that the program was not sufficiently benefiting Alicia, she did feel that overall it was a positive experience for her to have had:

Um, I think it was good for her to be out of the house, you know, and stay active. Some of the jobs she liked and others she didn't and, you know, it depended on what she was doing and what she was capable of doing. But then some of the classes, she would work part of the day and then go to

classes. The classes were kind of repetitive, so she got bored with those.

All of the mothers expressed the importance that their children need to stay busy, whether that is being part of an official program or smaller activities. Keeping the children busy was a major priority for parents to keep up their enthusiasm and prevent more difficulty for them later on.

Katie Henderson, her husband, Carl, and their son, Andrew, live together in one of the community's townhome developments where living expenses are much more affordable. Katie said,

Well, he seems very happy with what he's doing at the workshop, and when I ask him if he wants to go into the city and that I don't get any answer. So he knows that whatsoever as long as he is doing what he is doing I'm not going to push him to go anywhere else. He is very happy with what he is doing at the workshop and they insisted that he tried to go outside and find work somewhere else, but that didn't work out so. In fact he enjoys what he's doing and he's a good worker.

In this case, Katie's parenting style very much resembles Lareau's theoretical perspective of accomplishment of natural growth (Lareau 2003). This is expressed when Katie says she is "not going to push him to go anywhere else." Katie believes her son is happy, so there is no need to change anything. Katie was also pleased with Opportunity 4 Us because it has provided Andrew with medical benefits as well. She would trust them with any kind of emergency:

If they thought something was wrong and Andrew needed help, then they'd call me and I would right away get a hold of the doctor of whatever. He used to have seizures. You wouldn't want to see that because he was all over the place. You would have to hold him down and tell him to calm down. But they didn't last very long. He's on medication. I don't have to remind him to take the medication; he takes it himself. He knows what to do. He messes up mine [laughing].

She can even find a sense of humor in thinking about what Opportunity 4 Us has done for Andrew, which shows a lack of distress with her son's place in this program. The Opportunity 4

Us employment program plays positive roles in both Andrew's and Katie's lives because Katie is able to relax and take it easy with her reliance on these programs.

The Hanson family also believed Opportunity 4 Us was a great fit for their daughter. Amanda Hanson and her husband, Tom, both participated in an interview about their daughter, Julie, and her experiences with the employment programs offered. Julie has been employed ever since she graduated from high school:

We think it's great. She has a place to go. Somethin' to keep her occupied. Like I said, she earns 40 cents an hour or something like that. She gets probably between 10 and 12 dollars every other week.

Even with this meager pay, Amanda is happy because her daughter is happy. Amanda is proud that her daughter has something of her own and has something to work toward each week.

Monetary value is not considered important.

This also goes along with Lareau's (2003) accomplishment of natural growth because of Amanda's priority in making sure that Julie is happy. Katie's assumption that the programs and their services will keep Andrew in good hands and guide him where he needs to be also falls in accomplishment of natural growth. This assumption of the programs and services completely taking care of the children was apparent in all of the interviews. Positive experiences like Katie's and her son, Andrew's, allow Katie to believe that there are enough services and opportunities for her child. Negative experiences like Margaret's and her daughter, Alicia's, cause Margaret to believe there most definitely needs to be more out there for children to be involved in. These experiences had a tendency to influence continuation or discontinuation of participation at Opportunity 4 Us. When positive experiences were had with Opportunity 4 Us, families had a more positive outlook towards activities offered outside of Opportunity 4 Us. This

occurred for negative experiences as well, where a view that there was not much out there for the children prevailed.

Amanda's happiness over Julie's having something that is her own connects with her satisfaction with services available at Opportunity 4 Us. In asking Julie's parents about whether or not they were pleased with Julie's experiences, they immediately jumped in with a "Yes" and laughter, saying,

It's something to enjoy. They don't make much money, but it's hers. She won't trade it for a big pay check. It's hers.

Happiness for Julie, instead of a bigger pay check, has played a major role in her parents' positive opinion about services and employment.

It gets her out during the day. She's happy.

Keeping Julie busy and active is also important to the Hanson family, which is another reason for their happiness with Opportunity 4 Us.

Similarly to the Hanson's story, Alexis Lewis and her son Johnny are just as pleased with Opportunity 4 Us. He, too, has been employed there since he graduated from high school:

Well, I think he likes it. Like I said, he likes all of the people down there. As long as he's happy, I'm glad. And then I do meet a lot of people.

So, not only does Johnny enjoy what is offered with the employment program, but it gets him out of the house and interacting with his friends. Another plus for Alexis is the opportunity to meet many more people and keep her active in the community as well. For the Lewis family, Opportunity 4 Us has provided both Johnny and Alexis with a positive experience:

Well it don't really cost you a lot to do some of it. But bowling, you bowl. That costs 2-3 bucks for two games. The swimming and bocce. They donate those. The high school's been givin' it to them a long time. And the YMCA donates. And bowling costs you. Bocce and Roger [man in City of Dreams] donates his courts. He's got 4 of them. And the pizza place lets them

practice down in winter. They've got 2 down the stairs. You meet all kinds of people.

Alexis is fond of outside activities offered and even mentions how easy they are to become involved in because of the donations from outside businesses. To her, activities like Special Olympics are quite easy for her son to become involved in. Alexis even mentioned how she would not know what her son would do without his participation in Opportunity 4 Us:

Well, he wouldn't be able to see a lot of people. Yeah. He'd miss the socialization. He wouldn't survive very well. Until we pass away, I don't know what will happen to him. Cause I'm not livin' forever. I hope not. [laughing] That don't sound good.

These programs provide Johnny an outlet from the home and, more importantly, a core group of friends he can spend time with every day at work. Alexis is reliant on this consistency for him to have a place to be every day.

Consistent with more positive experiences with employment and this positive parallel with activities like Special Olympics offered outside of Opportunity 4 Us, Sarah Duffel felt that there are good services available in City of Dreams and that it was only a matter of searching and working together to become a part of these community activities. She said,

I'm very much involved with MH/MR. In fact, I'm expecting a phone call from her worker. We're in a waiver program where we have people take her and get her out and do things. She's involved in Special Olympics. Very involved in that. Your Best Buddies, Hand in Hand. As long as it gives her something to look forward to. She's in dance class with special needs. There's a lot for them to do if they're able to do it so there is a lot. Sometimes parents, we share our needs, and get more from other parents, but there are services where we do get a break.

Sarah's daughter's experience with Opportunity 4 Us has led Sarah to interpret the availability with other programs in the community as plentiful and a good experience. Positive experiences in the work place of the children seem to cause families to have positive experiences with

additional services. In asking about the overall experience for Amber's parents, Sarah responded:

Oh, it's been a wonderful experience for us to know that after she gets home from work she's got something to look forward to. She's gonna go do it and be happy about it and come back home and be happy with what she did because she's always looking forward to something else. Always.

This constant active participation is also crucial for parents to have time to themselves and have separation from their child. It is also vital for the child to be active to keep from being bored. Opportunity 4 Us and activities like Special Olympics provide families an escape from being the sole providers for their children and this actually can increase the happiness of their children's lives. Their children's happiness positively impacts parental happiness, which can potentially eliminate any additional stressors in the family.

The overall negative opinions of Margaret Smith regarding the services and employment available for her daughter Alicia were apparent when Margaret discussed her initial problems with general services when Alicia was just a baby:

No. No, I didn't. She was born in '71 and back then it was a whole lot different. Actually, she was born in Florida and um we moved around a lot so until we got back here then really they didn't discover that anything was really an issue with her until she was like 3 years old. Her speech was delayed and we got her into some therapy but other than that, no one ever guided us to the programs. Not back then.

These initial difficulties actually translated into unhappiness with employment later in life once Alicia graduated from high school. Negative experiences with services emphasized negative experiences with Opportunity 4 Us and an overall negative opinion of everything that was being done. Even now, services are not up to par with what Margaret believes her daughter and other families desperately need:

I think there should have been more services. Yea. And I think that its better today to a point, but there is a whole lot that needs to be done. And there's

been a lot of cutbacks with the federal funding, the state funding, and it just snowballs down the line.

The constant trend of negativity has been felt by Margaret and her daughter throughout Alicia's entire life. This has prevented Margaret's faith in employment programs like Opportunity 4 Us, unlike Katie, who would even trust Andrew's employer to take necessary steps in providing proper health care for him. These differences stem from varying experiences within the available programs. Families, such as the Duffels and Hendersons, who had positive experiences at Opportunity 4 Us led them to believe they had also done a good job in making known outside activities throughout the community, while families with negative experiences, like the Smiths, led them to believe that what is being offered is quite lacking.

Sarah Duffel's positive experience with employment and services spawned from Amber's positive experiences with skills training provided by her high school. The handbook of services and programs provided by the state recommends that skills training and developing a successful transition from childhood to adulthood must begin around the age of 14 (Stasko et al. 2010). Amber's high school, according to Sarah, gave Amber everything she needed to succeed later on in life:

Absolutely, she went to City of Dreams High School. They had a fabulous system for training. She was in school until she was 21 years old. Graduated from high school in 1994. They taught them the skills so that they could use, even though she's not able to read, they taught them things such as cooking with picture cook books. They taught them how to survive at the most minimal ability that they've got. Learning the survival words and learning how to go to public places and go to the bathroom. They taught them how to survive with what they've got.

Skills to survive, according to Sarah, are crucial for her daughter's happiness later in life. In other words, it would add additional difficulties for them if they had to completely develop Amber's skills without the help of school or the additional programs. Families, including the

Browns and the Smiths, where employment at Opportunity 4 Us did not work out felt that basic skills were better developed from family interactions.

Kathy Brown felt that her daughter's experiences were good for a certain period of time, but the program was not successful in keeping her daughter happy among all of the other children at Opportunity 4 Us. She felt there tended to be a lack of emphasis on the individual and an overall focus on the entire group:

Oh, I think it was nice. I think she enjoyed it and when she got something she didn't like then that was it. So I mean I think it was a good experience, I think she enjoyed. I also found out that she made a lot of friends, but there's also a lot of children that are on so much meds that their actions and behavioral problems. Some of them were nasty. She's a little love bug. I think you know that. And she don't handle it too good, so we had problems that way a little bit comin' home. Well she's still in it when she goes to Sunday school. We had a problem. I have to hear about it. They pinch her, poke her. Of course, she won't do anything back. I told her just to ignore it and walk away. We've had conversations about that. Well that's all I can tell you.

Overall, experiences in the workplace led Kathy to believe that it was a "good experience" but not a crucial one that her daughter should continue to participate in. Making friends was not enough for Kathy to be satisfied with her daughter's happiness. Being hurt by other children was especially a negative and major deciding factor in the discontinuation of Ashley's participation. This follows along the accomplishment of natural growth (Lareau 2003). Good experiences are great but not necessary if children can be happy doing something else. From this, it can be understood that Opportunity 4 Us can provide positive experiences in having a job for these children, but it cannot keep everyone happy. Whether or not the child was employed anymore at Opportunity 4 Us did impact parental employment.

Impact on Parental Employment

The employment status of the child did impact the employment status of the parents, especially the mothers, in most of the families. In the Duffel family, Hanson family, Lewis family, and Henderson family, the mothers had the option to stay home, while their husbands went to work consistently. For the Brown family and Smith family, due to the lack of a father in the household, it became a priority for the mother to go to work to provide for the children. Sharon Hays (2003) discusses that the two main goals in our society are to make mothers self-sufficient and to uphold the traditional family roles by staying home with the children. How can a woman go to work to feed herself and her children and also be expected to stay home with the children? If there is no partner in the home, this makes the goals even more impossible.

Alexis Lewis said there was no impact from Johnny's employment or unemployment because he could take care of himself if he did need to stay at home by himself all day. When Johnny was a child, Alexis and her husband, Rob, were both able to work because Johnny was at school during the day:

No, I've worked all the time within the last about 5 years.

Interviewer: And now you're doing Meals on Wheels?

You don't get paid for that though. [laughing] Like I say, we get lots of nice people. They tell me they love me all the time. They keep me going.

In asking Alexis if she thought her employment would be affected if Johnny was not also employed, she reminded me that Johnny could take care of himself for periods of time, especially now that he is much older:

No, he can take care of himself. He could live here. As far as cooking, he couldn't. While I do Meals on Wheels, his dad drives a van. He [Rob] goes in about 6:30 and he's home about 9:30. And he'll [Johnny] go for a walk and that. He's here until a little after 2, so he wouldn't be here alone by himself too long. I get off Meals on Wheels sometimes about 12 o'clock, sometimes 12:30. It depends on what kind of food you got.

Johnny can stay home by himself long enough so that his father can go to work and his mother can enjoy serving Meals on Wheels. In no way does his employment status impact his parents' employment statuses.

The Hanson family also felt that Julie's employment status did not impact their own employment ability. Amanda was very direct and firmly believed that Julie's employment status did not impact her and Tom's employment status:

No. I always worked the third shift when I worked.

This lack of impact might also be due to the fact that Julie has been employed with Opportunity 4 Us since she graduated from high school at the age of 21. Julie's activities outside of the home were conducive to her parents' employment statuses. This is the case for all of the families I interviewed whose children were employed by Opportunity 4 Us. They had never known any other way aside from having their child participate in the employment program and outside activities including Special Olympics.

Reflecting Hay's (2003) notion of this role dichotomy for women to perform, Kathy Brown was deserted by her husband and it became her sole responsibility to care for Ashley and her two other daughters. She said,

Oh, I heard about the program through my caseworker because her dad left when she was 3. And I gave up working. I was working up to that point before she was 5 and going to kindergarten. And then I made up my mind to stay home with the kids. It was too hard to find a babysitter and I didn't trust them and didn't like them in my home.

Undependable babysitting and an abandoning father led Kathy to completely stop working. Ashley's unemployment was not a reason for Kathy's decision to stop working, but it made it much easier for Ashley to stop participation in the work program because of her mother being home all of the time. Impact on parental status does not always have to be negative. With

Kathy's being home much longer, she was able to provide a stable home environment for her children, which allowed Ashley to end her unhappiness in the workplace and remain home without difficulty.

Margaret Smith's employment status was not impacted until Alicia ended her employment with the program in 2002. On top of this, Margaret's husband died a few years later. What once was very easy for Margaret to coordinate became very difficult for her to do on her own. She said,

No. Well, yeah I could work. But she can't be left alone so that's why I don't work now. It's very difficult because I mean for a couple of years, I didn't do anything. You know, when Peter passed away, it was just such a transformation that it was difficult.

Children's employment status seems to impact parental employment more negatively when there is only one parent in the household. When Peter was still alive, there was not much difficulty adjusting to Alicia's unemployment. Margaret was able to be there and take Alicia to outside activities. Now with Peter gone, there is greater difficulty finding activities for Alicia and being able to get Alicia to them.

Sarah Duffel's story with Amber's employment is unique to all 6 of their stories. Amber was and still is working with Opportunity 4 Us. One would assume there would not be much impact on parental, or at least a mother's, employment status. She said,

Actually, I did work from 1995 for five years. Once she got settled in to where she was, she did not like that I wasn't home even at her age now. She didn't like it. I was supposed to be here and that's that. I actually do take care of my grandson and actually do respite care and other activities with a mentally challenged lady.

Instead of Amber's employment positively impacting her mother's ability to be employed, Amber's need for her mother to always be home impacted Sarah's employment. Even when

Sarah was not home, Amber expected of her to be home. However, despite this difficulty, Sarah has been able to do other activities that keep her busy.

Throughout these stories there is a running theme of families managing to find a way to make life work out. They may not consider these issues as difficulties, but when families have to manage a way to get through each day, there is going to be an impact on the overall family unit.

Katie Henderson with her son, Andrew, feels that Andrew's employment has had no negative effect at all on Katie's and Carl's employment:

Hasn't affected us any. We've always managed to have somebody pick him up or he'd get a ride home through someone else. But otherwise, no problem. Especially when he was younger, I would make time to go pick him up. I used to work over at the college in the cafeteria. And, uh, time came to pick him up. I would tell them, "I'll be back in 15 or 20 minutes. I've got to go get Andrew." And they all knew what I was gonna do. Carl was usually home by then, but that's life. You do what you do for children that in that condition. So. And then, of course, his brother was home too, so Joe and Andrew on special days during the week. The two of them would just take off and do something together. Joe was very helpful with him too. [Pointing to the picture on the wall] Not the couple, the center picture, the one in the center there, is his brother. He's about 15 months apart.

They have "always managed to have somebody pick him up." These arrangements are an added strain on the family. Andrew's employed status does not necessarily directly impact his parents' employment because his work provides transportation to and from work, but there is a strain when Andrew needs to be at an activity and their car won't start. Katie stated later that if Andrew was unemployed while she was employed, it would definitely impact her job status:

Well, he goes and does it. I'd have to say no I won't be able to work. Now, I'm not working because I'm retired, but when I was working Carl would go to work and I'd go to work. I'd hate to see what the house would look like if he had to stay here by himself. He doesn't like the idea of having to stay by himself. So, I'm just glad that they have it [employment program]. As far as I know, they don't have any other places that supervise children like that.

So, instead of Andrew being unable to be home by himself, Katie expresses care for her son when she says he does not want to be home all alone. Andrew's comfort is very important to Katie and that would replace her job any day. Also, his hypothetical unemployment would directly impact Katie's employment because she would need to watch over her son all day instead of him being taken care of at his program.

Even though children's employment statuses do impact parental employment depending on the situation, it needs to be remembered that all families with disabled children or non-disabled children have to manage in getting them to and from different activities. The added concern about their children having to stay home alone is another difficulty, but these issues of children's impacting a parent's employment are universal to all families. Another theme found throughout the interviews was whether or not parents felt that Opportunity 4 Us provided their children with the skills needed for employment and if not, that skills were developed from the family.

Obtaining Skills from the Family or the Programs

The transition from childhood to adulthood is a major step in any child's life, with or without intellectual disabilities. It is extremely crucial in starting to prepare for adulthood with children because it takes longer for children to develop their basic skills. Socialization occurs primarily from the family and then education with peer interaction. There was an interesting comparison between skills being developed primarily from the family versus skills being primarily developed by special education programs and Opportunity 4 Us. Families who had positive experiences with their child's employment were more likely to feel that their child's skills were learned from their employment, which benefited their transition from childhood to adulthood. Families who had more negative experiences with their child's employment were

more likely to feel that their child's skills were developed well from family and friends and also that employment did not develop an increase in skills for the children.

Margaret Smith, overall, had negative experiences with her daughter's employment. This led her to believe that Alicia learned her basic skills primarily from family members:

I think it's a lot better now when they do a little bit of job training. They do cooking there. But other than that there wasn't a lot. I think most of that came from family. Yeah.

So, some skills were developed from the programs in her high school and Opportunity 4 Us, but life skills were developed from the family, enabling Alicia to transition to adulthood with her family by her side. Throughout Margaret's interview, it was apparent that family was her main priority and Margaret depended on them very heavily to help her through each day without her husband:

And she's just had a lot with the cancer treatment and all kinds of stuff. But my family has just been wonderful and our friends. And I think that a lot of people observe that.

Family has played the main role in Alicia's development including her basic skills to transition to adulthood more easily. This preparedness did not really affect her ability to get a job with Opportunity 4 Us because it did initiate some skills training.

Sarah Duffel had a similar story to Margaret's, but she had a mixed opinion on who helped to develop Amber's basic skills the most. Amber's inability to learn how to read was not able to be helped from the training classes provided at Opportunity 4 Us:

Actually, the training that she would get there, um, if she could read, if she could write, if she could handle money. They've tried her out in general public. They put her into a program for a while. They took her on job to job, but when you can't read to follow instructions you really can't succeed in that. Her thought is there. She wants to do that, but we all know she can't. She has to be satisfied with doing that repetitious every day same old same old and once in a while they get some new jobs and they're all happy.
[laughing]

So, despite the efforts of the programs, they were unable to further develop Amber's skills due to mental challenges. Outside of the programs, there is a huge effort on Sarah's part to make sure Amber is always developing her skills:

Well, actually Amber has been evaluated between a 5 and 7 year old. So basically, yes, she is an adult and in her mind she's 37 years old and in a lot of her thinking she's 37 years old, which makes it very difficult. She wants to be in control, but actually her evaluation has her otherwise. So, I have to look at her as a 37 year old young woman, but I have to guide her as though she were a 5 to 7 year old child. It's very difficult. She doesn't like it. She dislikes it very much. I don't like having to make every responsible choice for her because she has good choices. But in order to give her choices, what I have to do is give her 2 of them and let her pick one of those, making her think it's her thought.

The main concern for these families is getting their children prepared enough to take care of themselves with basic skills and then be able to get help with available programs, so it is difficult when Opportunity 4 Us and even families cannot further develop their children's abilities.

Kathy Brown also felt that her child was able to develop the best skills from help of the family. Kathy was quite unsure about my question of how Ashley was able to transition into adulthood:

I don't know how to get into that with you, honey. Just raise 'em. Talk to them and being out there with them. She knows right from wrong and basically she's not on her own out here. I don't let her go anywhere alone. So, that's about how that goes. She knows she's a young lady.

This approach seems similar to Lareau's (2003) concerted cultivation of parental responsibility to be there for their children and talk with them about everything so children gain a sense of entitlement to take charge in asking questions. Kathy was looking out for the welfare of her daughter, like any parent does.

Amanda Hanson was very similar to Kathy, except for the notion that she followed Lareau's (2003) lower class/working class method of accomplishment of natural growth:

Just growing up. I didn't foresee what was gonna happen later. We had three other kids after Julie so we just threw her in with all the rest.

Julie grew up with her three other siblings as though nothing was different between them. They all learned to grow up together with help from the parents when needed. There was not much thought on Julie's development towards adulthood. Her skills were obtained from Opportunity 4 Us, but of course interactions at home also helped develop Julie's skills.

Alexis Lewis and Katie Henderson both felt that basic skills came primarily from Opportunity 4 Us. Alexis felt that Johnny learned his skills from the different places the programs would take him:

Well when, what's her name, Harriet, no she wasn't the first one. Different people with the workshop would take more people down to the company and they'd be like a line supervisor and they'd tell him how to do it. So many different things and so many different people. Holly used to help him.

Johnny learned skills pertaining to the workplace in the workplace. Alexis did not attribute any skill development from the household. In fact, she did not really know how Johnny was able to successfully transition to adulthood:

Yeah, I don't know. 'Cause I don't know what made me survive all these years. I really don't know.

Interviewer: Take one day at a time.

Basically.

Alexis's humor was refreshing. She understood life to be something that one does every day and somehow people get to where they need to be. Katie, very similarly, depended on the employment training at Opportunity 4 Us to help Andrew transition into adulthood. Even if Opportunity 4 Us was no longer available to City of Dreams, she would go to great lengths to find something else for him:

We would probably try and find another program for him. It may not be in town, but we are just lucky that Barry Sullivan was the one that had started this program. And uh, that's how we got involved with them.

Katie did not take into account any family development that may have been going on to prepare Andrew to enter the program at Opportunity 4 Us.

Families, whether they realize it or not, tend to plan their children's lives with the hope of having a successful transition into adulthood. This was crucial for these families, whether they depended more heavily on family members or the employment programs to transition their children to adulthood or some aspect of independence to care for themselves at the minimal level. This planning is also crucial when looking down the road toward life changes, such as a change in home location and children moving out of the home.

Future Planning

Future planning for many families entails where their children will go to school, how they will pay for college, and eventually where they will live on their own. Future planning for these families is different in the idea that the children of all of these families can never live independently. They have the basic skills to live, but many need constant supervision and consistent assistance. When interviewing the families, future planning was not very apparent. Having their children live somewhere outside of the family home was something many of them had not thought about or did not want to think about.

The family with the fewest indications of any future planning was the Hanson family with Amanda, Tom, and their daughter Julie. They seemed the most unsure of where Julie would go if something were to happen to them:

[unsure and looks as though she hadn't thought about it] When we are gone, probably a group home. We don't want to saddle our kids with her. She's the oldest.

On top of being unsure of where Julie should go, Tom and Amanda did not want to place the responsibility on Julie's siblings. They did not want to "saddle" their kids with their oldest daughter, who needs the most help. This is an interesting response and the only one like this.

Alexis Lewis was also unsure of where exactly Johnny would go. She made no mention of his younger brother:

I haven't really thought about it. I don't want him in a big group home. He's a loner. So I wouldn't want him. I would want something private and stuff. Chance of that are mighty slim. He's big and everybody seems to be a little intimidated by him. He wouldn't hurt a fly.

Alexis seemed less worried of where Johnny would live and more worried about the other people living in a group home with him. Accessibility to a group home that would better suit Johnny was thought of as "mighty slim" for that to happen, meaning there is not enough options for families to choose from in sending their children to group homes. Similarities between Alexis and Amanda are their dependence on Opportunity 4 Us for their children, which is an indicating factor of why they would choose a group home for their children over siblings and other family. A dependence on the employment system leads to a further dependence on group home living. The system will take care of the future planning because they have always depended on the system. In other words, the system will take charge, which also follows Lareau's (2003) lower class notion of accomplishment of natural growth. According to Lareau (2003), parents took the backseat in their children's educations because they saw the educational system as the way of getting their children where they needed to be instead of arguing with the schools when satisfaction was not being met. Alexis and Amanda both assume that the system will carry out further help when the time comes for Julie and Johnny to be placed in group homes.

Katie Henderson has expressed very positive feelings towards Andrew's experience with employment. From looking at Amanda's and Alexis's dependence on the system, one would

think Katie would feel the same way about Andrew and group homes. She seemed very mixed about what to do:

And I'm not ready to let him go. But I'll look at 'em [group homes] and see what they're like. I don't think there is anything really scary about them. He has to take his furniture with him, but otherwise he doesn't have to worry too much about a group home. I think he wants to stay home. I think as he knows he can come home on the weekends, he'll be fine for the week.

Katie has not really thought about future planning for Andrew because she cannot imagine life without Andrew being home with her all of the time. It has always been Katie, Carl, and Andrew for Andrew's entire life, with the exception of when Joe lived with them as a child. In asking about having Joe take responsibility for his brother, Katie did not find this to be a good idea:

I don't think that his brother really wants to keep him. He has 3 children and twins. Noah is in the middle. They are Indians alright. Between the three of them, you never know what they are up to. I like to watch their eyes, and say, "Ok, who's the one that's gonna do the bad thing now?" All of them just laugh. They'll say, [imitating nondisabled child's voice] "I'm not gonna do anything." We have a cot and usually bunk them down here in the living room. They'll be real quiet and I'll hear one of them giggle and one will say, "Stop it, I'm trying to sleep." I love listening to them. Noah is 6. The twins are 4 and the twins are really a handful, but they are getting better. I haven't seen them for a year. They are bigger than I am. But he's [Joe] working and busy and with the kids and by the time they see us, hopefully they'll be down in the summer. They won't stop me from seeing my grandchildren. I just don't feel comfortable driving all the way up there. In that area, I get so lost. I couldn't find my mother-in-law's house. I finally did. I had to stop at 3 different gas stations to find out how to get where they live. When we both retired, I would have Andrew. I think that Andrew will be with us the rest of his life. So he can come with us. I wouldn't deny him that fact to come with us.

Aside from being concerned for Andrew's well-being, Katie is a concerned mom looking to keep both of her sons happy no matter what. She feels that it would be too much for Joe to step in with Andrew's care. Katie's lack of future planning is due to the fact that she believes Andrew will

be with them until the end, which means it is unnecessary to really look into group homes. In other words, if Andrew did want to, Katie would find a group home for him:

Yeah. Probably a little too close. I won't let him go. [laughing] Which I should do probably, but he's no problem to me. He helps with supper and does the dishes when nobody else will. You don't have to tell him to go do the dishes, he just does it. He'll do them once in a while and I'll try to do them myself. I'll do it tomorrow morning. We usually get paper plates, especially when it's warm outside. We do things outside on the grill.

Katie finds no real reason to place Andrew in a group home, which is a result of her lack of future planning, but also she is so close to Andrew she does not know how to live without him. This feeling is similar in any family where the parents do not want to let their kids leave. She measures his usefulness in the home in doing chores like the dishes. She feels he earns his keep to stay in the home, so there is no reason for him to leave.

Kathy Brown was very opposed to the idea of group homes. She was disappointed in Ashley's experience at Opportunity 4 Us, and thus it makes sense that she has depended more heavily on family support over system support:

Oh, I don't know what to say there, hon. After being with it for years and years. I'm out and about and I hear and know things. Sometimes I feel that there could have been more. Especially when getting into the adults. A group home is a good idea for those that need it. But it's not what I want for mine. Whether I'm here or not, I've got her sister to be her legal guardian. And she knows how my feelings are. I'm very much opposed to it for the simple reason that she's only been raised with family. Been around family. And I don't think she'd handle that too good. She makes friends, don't get me wrong, but I don't want it for her. No, I don't want it for her. No. Nope. As long as we've got a big family I don't feel she has to. No I don't.

Family dependence is what has kept Kathy and Ashley together. They've always depended on family through Ashley's transition to adulthood. Ashley's skills, in Kathy's opinion, came from family help. There is no reason, in other words, to depend on the system when they have been doing just fine with the support of family.

Sarah Duffel's story for Amber is a little different. Due to Amber's condition, she cannot be in any sort of general group homes and options for her are much fewer:

Well, Amber has Prater Willey and she cannot ever be out on her own. There are programs, but Amber cannot. She's got to have someone watch her food intake for the rest of her life, be responsible for her psychiatric issues, her behavior issues. There are homes for Prater Willey in Pittsburgh and in Scranton area. She cannot ever go into a general group home because there are none that lock off the refrigerator and lock up the food because that is their right. They can't take that right away from her so several years back in 2004 the Neuropsychiatrist that diagnosed her said at no time could she ever go into a general group home. There are possibilities out there. There are families that take kids and adults with issues, but that would have to be a very regimented program. It would have to be followed such as we have to do here. My oldest daughter will take Amber in any event of something happening to me and start a program. She knows how to get it started so that would be the plan for her.

Overall, Sarah has had mostly positive accounts of Amber's time at Opportunity 4 Us; however, she does not follow the trend of sticking with the system due to Amber's individual condition. In the end, Sarah feels that family will be the most reliable. It is hard to imagine what Sarah would be able to do for Amber if it was not already decided for her to go with her sister. Sarah seems to have the most future planning with her family. This is due to the strict regimen they must follow to keep Amber healthy.

Margaret Smith and Alicia's negative experiences have led the Smith family to depend more confidently on family and friends over the system. However, future planning has not really been on Margaret's mind:

Uh, I haven't really thought about it. [giggling] I'm sure my niece would either take her because she said she would so we have that already taken care of as far as you know the trust fund for her and she'll be taken care of that way too. And we worked with Foster Care, Peter and I, for 13 years. So there's one girl that lives in the state of Washington. She said she'd take her. If Alicia would want to do that, though. If she wouldn't want to then I wouldn't want that. She'll be taken care of. That's always a biggie on your mind, though. You know somebody might say they will because that happened to one of our foster girls. Her mother died when she uh, her

mother was only 48 and she was 16. And the aunt was supposed to take her and she really didn't want to take her so she came back with us. Yeah.

This worry of what will happen to the child after the parents are gone is always a worry for these families as it is a worry for any family. Family is only dependable to the point when they no longer keep their word. The system is worrisome for parents for the threat of their child being overlooked and not receiving proper care. There is another imminent problem with the continuous aging of the parents. All of the mothers interviewed were 60 years and older. There comes a point in time that they need to have a backup plan for their children. Group homes place children on waiting lists before they can enter, but without the parents' future planning, the children may not get in the home if something happened to their current caretakers. This is an ultimate difficulty for these families.

Difficulties for Families: Unemployed vs. Employed Children

From all of the interviews with the families, there were no major differences in difficulties for families with employed children versus unemployed children. The main difference was that families with unemployed children, like the Smith and Brown families, had a much more difficult time finding services and activities for their children to do. Families with employed children—the Lewis, Hanson, Henderson, and Duffel families—found it easier to stay active because their children had to be at work every day with consistent schedules.

Katie Henderson felt that Opportunity 4 Us was a huge help in increasing Andrew's quality of life. Not only did it give Andrew a place to go, but it gave them time apart from each other. In Katie's case, she felt that the money Andrew was able to bring home did help the family. The Henderson family was the only family who felt this way about income rates at Opportunity 4 Us. In asking Katie about other options for Andrew, she was unsure of many others out there:

There might be, but nobody's come to me about getting him enrolled or anything. There's no rumor going on that they [Opportunity 4 Us] might close. Andrew would have a terrible time if they would close. We would have to send him way out of town.

Not only would unemployment make Andrew unhappy, but it would put a strain on the family as well. If Opportunity 4 Us was not available, Katie felt it imperative that Andrew did something else:

Interviewer: So I guess, if he wasn't employed would it...

Oh, he'd drive me up a wall! [laughter all around]

Andrew's employment has given the Henderson family adequate time away from each other so they are able to have their own interests as well as time together as a family. This time apart from each other, as well as Andrew's extra pay checks, has been good for them:

And that's about it. If we have something to do outside, we'll go and see what we have to do. We go shopping Friday night sometimes to look out for Andrew. If money runs out, mommy's got his supply.

Interviewer: So, is that also a good plus with his employment? Bringing in extra money?

Yeah, Yeah.

Katie was the only mother I interviewed who said that money helped with extra necessities.

Another positive that comes with Andrew's employment is his health care coverage. Opportunity 4 Us has prevented the Henderson family from having to cover Andrew's medical bills, which puts much less strain on the family:

He's got, oh what kind of card is it, he gets almost everything done free. He has this card. It's this medical card that he gets for the doctor's bill and that. He never pays for physicals. The doctor says, "He's in better health than you are." And Andrew heard that and, "Mommy, I'm healthy." I says, "Oh, I'll get better."

If Andrew was not with Opportunity 4 Us, it would be very hard to say how Katie would get along. From Katie's perspective, she seems certain that Andrew's employment has only done positive things for her family. They are living an easier life than they would have if Andrew was unemployed. Katie is thankful for what her family has:

People have to be involved in these children to understand what they're going through because it isn't easy for them. They have their own minds and you can't change 'em. They have to experience what they have to do.

Katie believes the services in the community are good, but she reiterates what children need and that it is a lot for families to undertake, so the better the services, the better a family can live.

Margaret Smith did not feel that Opportunity 4 Us was the best experience for Alicia, but she did not feel that many difficulties became apparent until her husband passed away. The close support system was no longer there:

Karen has an IQ of like a 5 to 7 year old. But socially, she's totally different. And I think that was a biggie for her. She made friends into high school even and I mean she went to the prom. She was the first one in the special class to go to the prom. And uh, we just kept her active. And she always went with Peter and I no matter where we went, vacations, everything. She was an only child, so then when the foster kids came, she really liked that and that helped her a lot. But other than that, I mean, the thing is now with my husband gone, it's difficult 'cause it's all on me. So to get someone to take her and things like that it's difficult. But I have such a supportive family and friends, I'm lucky. I'm lucky.

Life is more difficult now because her husband is no longer there to give additional support.

Margaret was the only wife to speak so fondly of her husband as someone who helped out with the daily activities, which is indicative of the traditional gender roles in the other families.

Without employment, it is more difficult for Margaret to keep Alicia busy:

Yeah, we keep busy. Like she goes to the Community Arts theatre. She does Special Olympics. She would have taken dance classes, but then after when she got the cancer, then that kind of, she got out of that. But I mean she's busy all of the time. I think that's important, but it's usually family and

friends. We camp. We got to Florida for the winter. She loves to shop. She likes the yard sale. Whatever.

Keeping busy is a main priority for Margaret and Alicia. It is important for Alicia to have a lot of activities to do, especially with being unemployed and not having that consistency throughout the week:

Yeah, I think they need to be busy. So, right now she's ... they were walking over to the plaza and they were gonna take the bus back, but she needs to keep busy. You know, that was good [with employment]. And she needs time by herself and so did we. It was good.

Employment was good for them to have their time apart, but the negatives at Opportunity 4 Us outweighed the need to have their own space. Staying busy was a common theme among all of the families. Their children deserve to be just as involved in life as anyone else. Margaret also felt the money gained from Alicia's employment did not help out the family at all:

No, because they made very little. I mean sometimes it was literally pennies. The only thing instead of going through Opportunity 4 Us, she's gonna go through this new agency and that's through the federal government. But other than that, she gets her disability and that's it. Like one year working at the program was maybe \$144 dollars total.

Alicia's employment did not help the family increase its income in any way, so it was not difficult to step away from the program because of money issues:

Mm hm, which I had a big issue with that and I think other parents did too. They are capable of getting up in the morning, going to work, working all day, and you know they do their best, just like we would with a job. And I guess it's because it's a training center that's why they don't have to pay, but I don't like that at all. You know in Florida, they do like recycling and a big production where they can really, and it's a lot, and I don't understand why they can't get something like that here.

This lack of happiness with Opportunity 4 Us and how Margaret feels the employees are treated is another difficulty she must cope with.

Kathy Brown felt that there were no real difficulties throughout Ashley's employment and current unemployment. The only difficulty she saw was how Ashley was treated at Opportunity 4 Us with the different jobs employees were asked to do, but she only wants the best for Ashley and her other children:

Oh, well I made up my mind. No. No. Like I said, their dad walked out on us. And my oldest one was getting ready to go into kindergarten and I had her and I was having problems with babysitters and I made up my mind. I was staying home and raising my own babies. So that's how that all came about. We didn't have no problems. We all got along just fine, didn't we [looking to daughter]? No problems. No problems. That's what families are for. I have family that lives down the street.

Kathy felt she did not have any difficulties because of her reliable family and friends. They are what are most important to her so there was no difference whether Ashley was employed or not. She just wanted Ashley to be happy. She felt the best way to make Ashley happy was by staying home and fulfilling a more traditional motherly role as in Hay's (2003) discussion of the two goals about women in society: family and self-sufficiency. Kathy was able to support her family and be somewhat self-sufficient with her reliance on the family. Kathy did not need to depend on the system and programs offered because of her readily available family support system. Money from the employment programs was also not a factor in ending Ashley's involvement:

Her first paycheck, what did you bring home? [looking towards daughter] 96 cents. I didn't know whether I should go get it cashed or not. I think today, they are doing better for the kids, but they were making nothing. It was just a place for them to go and something to do. As far as me caring whether she wanted to work. I didn't care. It was up to her basically. It wasn't me, especially having her going to work, it makes no difference. It just gave her a little bit of extra spending money and two paychecks a month. We didn't go shopping that much. It was no big deal.

It was Ashley's choice to decide what she wanted to do and Kathy felt that her role should be one of support no matter what that was, employment or not. Kathy looked beyond the money because she felt they could make it work no matter what.

All of the families expressed the idea that they knew they would make life work by just taking one day at a time and getting through anything together. Sarah Duffel also commented on how important keeping Amber busy was to her and how employment has also helped with that aspect:

Under the circumstances, Amber has to be out there doing something. She's just got to be involved. And when she's here at the house, I tried it for 14 months to keep her home because she was having a lot of issues and had gotten out of the hospital. But it didn't work out because I can't provide enough for her. It's consistency. That's what Amber needs. She needs to have that daily routine of the same old same old—you get up, wait for your bus, go to work, you work an hour, you have a break, and then you go do something else. And she needs that because I need it and my husband needs it. We need to be away from one another and this work program she's in takes her out of here at 8:30 in the morning and brings her home at 3:30 in the afternoon. And that gives us all the time to do what we want to do, if we want to do anything.

Sarah and Amber need time away from each other in order to keep a happy family. Employment has provided Amber that space, which is another reason for Sarah's happiness with Opportunity 4 Us. This program has helped Amber have a life of her own while living dependently with her parents. Sarah does not express much difficulty, but life was more difficult for her when they tried having Amber home full time. Employment has provided each of them with personal time to themselves. It is not about the money. Amber's employment does not have an impact on their financial stability:

Not really because her training pay is very very minimal. In fact for two weeks, she makes \$10.00. To her though, that's gonna provide her everything she needs to do and everything she wants to do. But because she does get a disability factor and because my husband is disabled she gets social security benefits so that helps us to get her needs, provide her needs, as well as have our own. So whether she worked at the employment program or not it really wouldn't have an impact.

Money is not an issue for their family because they find a way to make it work with help from the state. Employment provides Amber her own independence with the little money she makes

and her employment gives her mom more free time as well. Overall, employment has impacted the Duffel family in a positive way.

Whether or not the children were employed at Opportunity 4 Us, there were few differences in difficulties experienced by their families. The families of Johnny, Andrew, Amber, and Julie were very pleased with employment because of the consistent activity throughout the week. The families of Alicia and Ashley found it more difficult in getting their children involved in activities outside of Opportunity 4 Us. The lack of participation in Opportunity 4 Us for Alicia and Ashley caused a lack of accessibility and awareness of other programs in the community. They depended more heavily on their caseworkers to let them know of available activities.

Discussion and Looking Toward Future Research

Looking at the first question in my study (What are the experiences of families with employed children?), I found that overall, positive employment experiences for families led to a more positive view of services and resources available in the community. Positive experiences included experiences in which the families were pleased with their child's participation in Opportunity 4 Us. Families were pleased with the option to have their child live like a regular adult: go to work every day and come back feeling accomplished instead of having nothing to do. Negative employment experiences led to more negative views of services and resources available. Negative experiences included experiences where a parent showed dislike for their child's employment and/or ended their child's participation in employment. Unhappy families, including the Browns and Smiths, disliked the amount of pay their children were receiving and the treatment of their child in the workplace, and they considered the kinds of jobs given to the children as monotonous. Even though the Lewis, Duffel, and Hanson families did not like the pay for their children, their children's ability to be employed outweighed the financial aspects.

They were more concerned with the welfare of their children and the happiness their children had in their employment. The Brown family and Smith family derived more happiness for their children in the activities done around the home with family. Family activities and other activities like Special Olympics outweighed employment experiences. The children from all of the families had been employed previously or are employed currently at Opportunity 4 Us, so it was helpful to ask families about the differences they noticed when their child was no longer employed. Differences in difficulties were also able to be understood from the families' experiences with both employment and unemployment.

In answering the second question of my study (What are the differences in difficulties for families with employed versus unemployed children?), I found that the main difference was awareness of other programs in the area. Families with unemployed children, especially the Smith family, felt there was very little for their children to do, and the difficulty was in finding available programs for their children to participate in. This was very apparent for Kathy Brown and her daughter, as well as Margaret Smith and her daughter. Consistent with these two families was a lack of a father in the home. Kathy's husband left them many years ago, while Margaret's husband died about two years ago. In looking back at the literature regarding mothers' employment differences and child status, one study found that mothers without jobs and with disabled children wanted to work more than mothers who had no jobs and no children with disabilities (Gordon, Rosenman, and Cuskelly 2007). This is important to realize also that if the resources are out there and services are provided, these women should have the right to choose to work and their children should also have the right to more opportunities despite their disabilities. However, in my study, both Margaret and Kathy did not want to work because they needed to be there with their children. They were the main caregivers, and not having a husband to help makes

having a job very difficult, as we can see in Sharon Hays' (2003) family plan versus work plan. Hays' main point is that it is impossible to be a self-sustained individual and be able to fulfill the traditional role of motherhood without giving up one of the roles to fulfill the other. Single-parent households make opportunities such as employment even more difficult to obtain, so it is important that services should be geared toward each individual family situation. The other four families in my study had greater support from each other because both parents were still in the home.

Happiness with a child's employment experience was also dependent on the available programs offered in Central Pennsylvania. The more programs offered, the more options for families to choose for their children, which could lead to a better experience in employment. Career Development Theory (Szymanski, Hershenson, Enright, and Ettinger 1996) discusses that a person's career developmental skills continue well into adulthood. This explains the necessity to provide families with the services that promote good career development so they are able to gain more independence further in life when parents may not be there to take care of everything. The children of the six families can never live independently, but career development theory explains that people continue to develop themselves and their skills. An opposite view of people constantly developing themselves and their career skills is the idea that people can be a burden for society.

Functional limitations perspective believes that people are a burden for society. (Oliver 1983). Oliver's (1983) social model of disability says that society places a burden on people. If people were given ample opportunity to become fully integrated into society, it would not be possible to even think that they are a burden to society. It is the lack of awareness in society that is preventing the proper approach to developing a successful transition from childhood to

adulthood which will further impact employment opportunity and finally impact the overall family unit. All six of the families learned of their children's disabilities between the time they were born and about 3 years old. Sarah Duffel's daughter, Amber, was not properly diagnosed until about 2002 and Amber is in her 30s now. These families should have been immediately informed of what was out there for their child because initial programs help the development and planning of the children's lives. For example, with the handbook, *Understanding the Office of Developmental Programs in Pennsylvania: Mental Retardation and Autism Services*, the planning program for children in special education is best to begin at the age of 14 (Stasko et al. 2010). The lack of awareness of these options makes society a burden for these families. And there is no reason for these children to be considered burdens to society if there were proper services available to care for each family. Differences in employment by gender also occurred.

Eisenman's (2003) study showed that females with a disability are less likely than males with a disability to be employed. Of the six families in the study, two of the families had males and both were employed at Opportunity 4 Us for over 20 years. Of the families with the females, two were consistently employed for the last 10 years and two were no longer employed with Opportunity 4 Us due to negative experiences.

In looking at how the children's employment status impacted parental employment status, mothers with unemployed children were less likely to work. This only included the Smith family. Sarah of the Duffel family did not work due to the need for her daughter, Amber to know that her mom was at home while she was at work. Kathy Brown decided to stop working when her husband left the family, so Ashley's unemployment status did not impact her employment status. Margaret Smith's employment was impacted when Alicia stopped working at Opportunity 4 Us because she could not be left home alone during the day. Interviews with

the mothers also reinforced the gender roles in our society. In every interview the father was absent, except in one case. The fathers were either working, in another room, or no longer with the family. In discussing employment of the parents, the father's employment was never impacted by the children's employment status. The mothers were the ones to quit their jobs in order to stay home with the children. Unemployment children impacted the mother's employment status.

Limitations of my study include the sample size. In no way can my sample size of 6 be considered statistically significant in the overall population of the area. If there were more than 3 months to do this study, a much larger sample could have been obtained, but this sample provided good information for the questions of my study.

More research is needed on how families are coming to the decision of whether or not their child should even come to be employed, but this is affected by the available services in the community for these families and parents' perceptions of their child's capability. In looking at the employment statuses of the children, other limitations include the lack of information on class differences between the families. Families' incomes and families' opinions of what social class they were in was not discussed in the interviews. If this study were much larger, I feel there would most definitely be differences among social classes, a child's employment status, and the impact on the family unit.

Morningstar's study (1997) found that the role of the family is crucial to the success of their child. The students in her study were better equipped for the vocational programs offered in school. If more schools were offering vocational programs as an extra focus for students, their employment rates and skills would increase. Some of the families said their children did not receive basic skill training in their schools. These sorts of programs would better ease the

transition from school or childhood to adulthood as well as the transition of living outside of the home. In a world full of unpredictability, these vocational programs might give children a better chance at improving their personal quality of life.

Reischl (2000) reminds us that with such complex social systems in our world, it is important that we are given greater support systems to work through what is expected of us. When so much of American society is based on achievements, how are people with intellectual disabilities supposed to be able to achieve with the amount of opportunity they are given? If the services are there, then the support system to follow through with the services also needs to be provided. In the case of this study, the opportunities and support systems were available, but for the Smith family especially, access to them seemed more difficult with the participation in Opportunity 4 Us.

Overall, families' difficulties whether their children were employed or not, were consistent with the difficulties of every family. Figuring out who will take one's child, disabled or non-disabled, to an activity because one has to work are common occurrences in every family. However, families with unemployed children did find that programs were less readily available to them than families with children involved in Opportunity 4 Us. The availability of services did not impact a child's ability in obtaining a job because the family was the main provider of teaching their child basic skills. Further skills were able to be developed from the family with the extra skill training through special education programs and Opportunity 4 Us. This study has provided information on how employment and unemployment can impact children and their families. To have the options and access to employment is most important whether parents feel their children need to have a job or not.

Appendices

Appendix A: Questions Asked During Interviews

What is your experience of having an employed intellectually disabled child? How has the opportunity of employment of your son/daughter impacted your family?

When your child was born, what kinds of opportunity did you know would be available to your child? Now that your child is older, what opportunity is currently available?

What is your family's daily routine? What is the daily routine of your child?

What is the education level of your child? What, if any, skill training was your son/daughter given?

What was your experience transitioning your child from adolescence to adulthood (18 and over)?

What does Williamsport offer as far as services and opportunity for you and your child?

Financially, how has having an intellectually disabled child impacted your family? How does his/her employment impact financial burdens?

How prepared do you think your child is for the workforce?

How has your child's employment impacted your ability to have a job?

Would it be more of a burden on the family economically speaking if you son/daughter did not have this job?

Has your child had an overall positive or negative experience being employed and what has his/her experience done for your family? Has your son/daughter's quality of life improved?

What kind of effect does his/her unemployment have on your family? Overall, what is your experience of having an unemployed intellectually disabled child?

Are you aware of the economic influx from Marcellus Shale gas drilling? If yes, do you know of any opportunities available from this to your child and family?

What are you planning for the transition out of the home and how prepared do you think he/she is to live outside of the home?

Appendix B: Families*Henderson Family*

Mother: Katie
Son: Andrew
Father: Carl

Brown Family

Mother: Kathy
Daughter: Ashley
Father: (absent)

Duffel Family

Mother: Sarah
Daughter: Amber
Husband: Jim

Smith Family

Mother: Margaret
Daughter: Alicia
Husband: Peter (deceased)

Hanson Family

Mother: Amanda
Daughter: Julie
Husband: Tom

Lewis Family

Mother: Alexis
Son: Johnny
Husband: Rob

References

- Anderson, L, S. Larson, C. Lakin, and N. Kwak. 2002. "Children with Disabilities: Social Roles and Family Impacts in the NHIS-D." *DD Data Brief* (University of Minnesota: Minneapolis, Institute on Community Integration) 4: 1-11.
- Barnes, Colin and Geof Mercer. 2005. "Disability, work and welfare: challenging the social exclusion of disabled people." *Work, Employment & Society* 19: 527-45.
- Berman, Lauren C. and So Yun Kwan. 2010. "Supports and Resources for Families of Children With Special Health Care Needs." Pp. 291-312 in *End-of-Life Care for Children and Adults With Intellectual and Developmental Disabilities*, edited by Sandra L. Friedman and David T. Helm. Washington, D.C.: American Association on Intellectual and Developmental Disabilities.
- Chou, Yueh-Ching, Cheng-Yun Pu, Teppo Kroger, and Li-yeh Fu. 2010. "Caring, Employment, and Quality of Life: Comparison of Employed and Nonemployed Mothers of Adults with Intellectual Disability." *American Journal on Intellectual and Developmental Disabilities* 115: 406-20.
- Eisenman, Laura T. 2003. "Theories in Practice: School-to-Work Transitions-for-Youth with Mild Disabilities." *Exceptionality* 11: 89-102.
- Dixon, Roselyn M. and Catherine A. Reddacliff. 2006. "Family Contribution to the Vocational Lives of Vocationally Competent Young Adults with Intellectual Disabilities." *International Journal of Disability* 48: 193-206.
- Gordon, Meg, Linda Rosenman, and Monica Cuskelly. 2007. "Constrained Labour: Maternal Employment When Children Have Disabilities." *Journal of Applied Research in Intellectual Disabilities* 20: 236-46.
- Hays, Sharon. 2003. *Flat Broke with Children: Women in the Age of Welfare Reform*. New York: Oxford University Press.
- Heller, Tamar and Catherine Keiling Arnold. 2010. "Siblings of Adults with Developmental Disabilities: Psychosocial Outcomes, Relationships, and Future Planning." *Journal of Police and Practice in Intellectual Disabilities* 7: 16-25.
- Hotchkiss, Julie L. 2004. "A Closer Look at the Employment Impact of the Americans with Disabilities Act." *The Journal of Human Resources* 39: 887-911.
- Johnson, Betsy B. 2010. "Practical Guide to Health Care Decision Making." Pp. 133-46 in *End-of-Life Care for Children and Adults With Intellectual and Developmental Disabilities*, edited by Sandra L. Friedman and David T. Helm. Washington, D.C.: American

Association on Intellectual and Developmental Disabilities.

Lareau, Annette. 2003. *Unequal Childhoods: Class, Race, and Family Life*. Berkeley: University of California Press.

Lukemeyer, Anna, Marcia K. Meyers, and Timothy Smeeding. 2000. "Expensive Children in Poor Families: Out-of-Pocket Expenditures for the Care of Disabled and Chronically Ill Children in Welfare Families." *Journal of Marriage and Family* 62: 399-415.

Morningstar, Mary E. 1997. "Critical Issues in Career Development and Employment Preparation for Adolescents with Disabilities." *Remedial and Special Education* 18: 307-29.

Oliver, Michael. 1983. *Social Work with Disabled People*. London: The Macmillan Press Ltd.

Pennsylvania Department of Public Welfare. November 2008. "ACT 198 of 2004: Family Support Pilot Projects Report of the General Assembly." Posted on DPW website. Retrieved on September 23, 2010 (http://www.dpw.state.pa.us/resources/documents/pdf/publications/act_198_of_2004.pdf)

Reischl, Thomas M. 2000. "Witnessing the Possible for People with Disabilities." Pp. 265-80 in *Part of the Community: Strategies for Including Everyone*, edited by Jan Nisbet and David Hagner. Baltimore: Paul H. Brookes Publishing Co.

Rogers, Michelle L., and Dennis P. Hogan. 2003. "Family Life with Children with Disabilities: The Key Role of Rehabilitation." *Journal of Marriage and Family* 65: 818-33.

Savage, Teresa A., Katherine Ast, Reva Bess, Marykay Castrogiovanni, and Patricia Conway. 2010. "Supports and Resources for Adults." Pp. 313-28 in *End-of-Life Care for Children and Adults With Intellectual and Developmental Disabilities*, edited by Sandra L. Friedman and David T. Helm. Washington, DC: American Association on Intellectual and Developmental Disabilities.

Sowers, Jo-Ann, Kim Milliken, Patty Cotton, Shawna Sousa, Leslie Dwyer, and Kris Kouwenhoven. 2000. "A Multielement Approach to Creating Change in a State Employment System." Pp. 203-36 in *Part of the Community: Strategies for Including Everyone*, edited by Jan Nisbet and David Hagner. Baltimore: Paul H. Brookes Publishing Co.

Stasko, Sheila, Lisa A. Tesler, and Maureen Devaney. 2010. "Understanding the Office of Developmental Programs in Pennsylvania: Mental Retardation and Autism Services." Vision for Equality, Inc. Retrieved September 26, 2010 (<http://www.temple.edu/thetrainingpartnership/resources/umrspa/goldbook201007.pdf>).

Szymanski, Edna Mora, Mary S. Enright, David B. Hershenson, and Judith M. Ettinger. 2003. "Career Development Theories, Constructs and Research: Implications for People with

Disabilities.” Pp. 91-153 in *Work and Disability: Issues and Strategies in Career Development and Job Placement*, by Edna Mora Szywnanski and Randall M. Parker. Austin: Pro-ed.

Taylor, Julie Lounds, Jan S. Greenberg, Marsha Mailick Seltzer, and Frank J. Floyd. 2008. “Siblings of Adults with Mild Intellectual Deficits or Mental Illness: Differential Life Course Outcomes.” *Journal of Family Psychology* 22: 905-14.

U.S. Census Bureau. 2005-2007. American Community Survey 3 – Year Estimates. (http://factfinder.census.gov/servlet/ADPTable?_bm=y&-geo_id=16000US4285312&-qr_name=ACS_2007_3YR_G00_DP3YR2&-gc_url=&-ds_name=ACS_2007_3YR_G00_&-_lang=en&-redoLog=false)

Winn, Stephen, and Ian Hay. 2009. “Transition from school for youths with a disability: issues and challenges.” *Disability & Society* 24: 103-15.

Witt, Whitney P., Carissa A. Gottlieb, John Hampton, and Kristin Litzelman. 2009. “The Impact of Childhood Activity Limitations on Parental Health, Mental Health, and Workdays Lost in the United States.” *Academic Pediatrics* 9: 263-9.