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Sheltered employment, sheltered lives: Family perspectives of conversion to community-based employment

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Abstract. This article examines selected aspects of one agency's conversion from a sheltered workshop facility to one providing community-based services for individuals with intellectual and developmental disabilities. Established in 1967 by parents as an alternative to institutionalization, this agency had remained entrenched in the sheltered workshop model for 35 years. A qualitative case study research design including semi-structured interviews, participant observation, and archival review was used to explore the families' perspectives and how they navigated the conversion process. Participants included a subgroup with a long history of sheltered work and a subgroup with no history of sheltered work. Conflicting issues emerged as families had different histories, culture, values, philosophies, and expectations of their children and their inclusion in community. While the initial transition was difficult, most families and participants were satisfied with the conversion process as long as they could maintain previous social networks and find acceptable employment in the community.

Keywords: Sheltered workshop conversion, community employment, vocational rehabilitation

Sheltered workshops increased in popularity throughout the United States in the 1950s and 60s when parents had few choices other than institutional placement or home care for their sons and daughters with developmental disabilities [18, 32]. Based on a philosophy of charity and a subminimum wage rate for subcontracted work, the segregation of adults with developmental disabilities became the norm for vocational services. Given the lack of choices, sheltered workshops became a sanctuary of sorts for many families as it provided a place where they felt their adult sons and daughters would be safe and occupied.

Community-based employment at a competitive wage was generally not an option for people with intellectual and developmental disabilities during the 1970 s and before. However, the advent of supported employment services in the 1980 s presented an

alternative to segregated employment. Supported employment enables people with significant disabilities to participate in community-based employment by presuming competence and providing needed supports. People who were once considered "unemployable" are now working and functioning as productive citizens in the workplace [18, 29, 36, 39].

Over the past 20 years, supported employment services have substantially increased the number of people with disabilities in the community workforce. Integrated employment of people with labels of intellectual and developmental disabilities increased from 33,382 in 1988 to 120,691 in 2008 [7]. Yet, despite these gains it is estimated that 75% of the people with intellectual and developmental disabilities remain in segregated, sheltered work or day programs [37] with the numbers in segregated employment actually on the rise [6, 9, 37]. This proliferation of segregated, sheltered employment

remains a monumental barrier to the community inclusion of people with disabilities [8, 17, 21].

The call to change sheltered workshops to community-based employment is growing. Several major disability advocacy organizations have issued formal position statements in favor of integrated, community employment for people with intellectual and developmental disabilities such as a joint statement of The Arc and the American Association on Intellectual and Developmental Disabilities [1], the United Nations Convention on the Rights of Persons with Disabilities [33], and TASH (formerly, The Association for Persons with Severe Handicaps) [31]. The Alliance for Full Participation (AFP), a partnership of fifteen developmental disability organizations, is campaigning to double the rate of community-based employment for people with developmental disabilities by 2015 [12]. AFP currently has 38 state teams working to improve community-based employment throughout the country. APSE, formerly known as the Association for Persons in Supported Employment [2], Self-Advocates Becoming Empowered [30], and the National Disability Rights Network [23] have gone a step further, not just supporting the expansion of integrated, communitybased employment, but explicitly calling for an end to segregated employment, sheltered workshops, and the subminimum wage for people with disabilities citing damaging isolation, financial exploitation, poverty, and an overall systematic failure of disability services to provide meaningful employment.

People with labels of intellectual and developmental disabilities are taking an increasingly strong stand against sheltered workshops as well. Self-Advocates Becoming Empowered (SABE) declares, "We have been prepared enough. Get us real jobs. Close sheltered workshops" [30]. Similarly, the Self-Advocate Leadership Network calls for an end to sheltered workshops and advocates for real jobs with competitive pay [26].

Several states are implementing "Employment First" initiatives to increase integrated employment by "expecting, encouraging, providing, creating, and rewarding integrated employment in the workforce as the first and preferred option of youth and adults with disabilities" [20]. APSE established a strategic objective to support and promote Employment First initiatives throughout the United States [24].

There have been a number of successful initiatives around the country associated with converting sheltered workshops to community-based supported employment [4, 10, 21, 27, 34, 38]. Research indicates that although the process is often difficult, successful

conversion results in people with disabilities being happier and receiving better services, agencies having better community and employer relations, increased staff satisfaction, and more cost efficient services [27]. Notable strategies for success include the need for; (a) a clear statement of philosophy and values, (b) strong leadership, (c) ongoing education and training of staff, (d) a flattened organizational structure, (e) teamwork, (f) the use of person-centered planning, (g) stakeholder involvement, (f) openness to risk-taking and (h) continuous improvement [5, 27].

Numerous barriers still exist. A national survey conducted by Rogan, Held and Rinne [27] on conversion from sheltered to community-based employment examined issues of organizational change among agencies that have been involved in the process. Major barriers to conversion included; (a) negative attitudes among stakeholders as the most significant, followed by (b) funding, (c) regulations, (d) lack of expertise, and (e) lack of leadership.

Families play an important role in this systems change, yet are often resistant to conversion efforts [15, 21, 40]. West, Revell and Wehman [40] found that among stakeholders of board members, consumers, funding agencies, and families; the families were the most resistant to change. A more recent study by Migliore, Mank, Grossi, and Rogan [19] indicated that people with intellectual disabilities and their families would prefer community-based employment if given the opportunity. They surveyed 210 adults with intellectual disabilities and their families from 19 sheltered workshops; the majority indicated a preference for community-based employment.

There is little research documenting the experiences and reactions of the participants and their families to the process of sheltered workshop conversion. The long-term effects of conversion have not been documented and the literature often treats the closure of the workshop as the final product [22, 28]. But simply closing a sheltered workshop does not equate to successful conversion if people continue to be segregated in day activity programs [3, 28].

Advancements in special education and vocational rehabilitation have created a new paradigm of services and expectations compared to the paradigm in which sheltered workshops were established. There are fundamental differences between a facility-based philosophy and a community-based philosophy. People with disabilities in the facility-based paradigm had been saddled with labels and expectations such as uneducable, untrainable and unable to be part of the community. This

Table 1 Paradigm shift in services

Facility-based paradigm	Community-based paradigm
Insular community	General community
Segregated	Included
Segregated sheltered workshop	Integrated community employment
Uneducable/un-trainable	Presumed competence
Childlike	Adults
Protected	Dignity of risk
Parent-determined	Self-determined
Potential untapped	Potential maximized
Entering education: segregated special education	Entering education: inclusive/special education
Older parents	Younger parents
Agency-based social activities	Community-based social activities
Community exclusion	Community inclusion

resulted in a lack of education and work opportunities and the perceived need to shelter and protect them from society. In a community-based model of service, individuals with disabilities are better educated with the expectation they would be part of the community and workforce, not segregated or excluded. Table 1 outlines aspects of the different paradigms.

The current study examined the experiences of the adults with intellectual and developmental disabilities and parents associated with one sheltered workshop's conversion to supported community-based employment. This workshop was started by a group of parents in 1967 as an alternative to institutionalization and presented the opportunity to explore those experiences in both the former (sheltered) and present (community-based) situations.

The questions that guided this research included:

- 1. How do the participants describe their experience in their former and present situations?
- 2. What are the hopes and fears of the families and participants related to the conversion process?
- 3. How do family members describe the experiences of their adult sons and daughters during and following the conversion process?
- 4. What are the challenges and benefits of conversion from sheltered to community-based employment?

This study fills gaps in the research by providing insight into the perspectives of the individuals and their families before, during, and after the conversion from sheltered work to community-based employment. It brings their voice to the issue and provides insights and guidance for others interested in pursuing conversion.

1. Methods

1.1. Design

This qualitative research case study design included semi-structured interviews, participant observation, and archival review to explore the meaning of conversion for its most affected stakeholders, namely individuals with developmental disabilities and their families. In order to understand the experience of the participants over time, a qualitative case study provides "depth, detail, and individual meaning" [25]. Discovering this meaning is important because it sheds light on how the participants navigate the conversion process. Data were collected one year before, and four years after the workshop closed.

1.2. Participants

The twelve participants for this study were drawn from a purposeful convenient sample of people who were involved in one agency as they changed from sheltered work to community-based employment. The twelve participants were sub-divided into groups based on their family history of disability vocational services. One group had experience with sheltered employment and the other group did not (see Table 2). This provided opportunities to inquire across the two subgroups of parents to ascertain potential similarities or differences in perspective. The subgroups are defined as follows.

The Sheltered Workshop (SW) group included parents and former workshop participants. Five mothers (n=5) whose adult children participated in the sheltered workshop were interviewed. Some of these parents had been involved with the agency since it was founded in 1967 and had a significant history with the sheltered

Vocational history	Parent/child (age)	Time in	Community
		workshop	employment
Sheltered workshop group	Doris**/Audrey* (53)	32 years	Daycare center
	Julia*/Ken (52)	31 years	Vending machines
	Lorna**/Peter* (44)	15 years	Airport
	Jan**/Jake* (42)	13 years	Food packaging
	Pamela*/Sam* (47)	4 years	Toy store
	Geraldine**/Jim (34)	0 years	Warehouse
Community employment group	Patty*/Dana (25)	0 years	Fast food
	Gwen*/Mary (24)	0 years	Fitness center

Table 2 Participants

workshop. Their adult children ranged in age from 42-53 at the time of the interviews. Among them, three men and one woman with labels of intellectual disability were also interviewed and observed regarding their sheltered workshop experience (n = 4). Each person had been placed in the sheltered workshop after leaving high school with his or her time in the workshop ranging from 4-32 years. All four participants were working in community-based jobs at the time of the interviews.

The Community Employment (CE) group included parents, all mothers (n=3) whose adult children never worked in the sheltered workshop, but received community employment services from the agency. Their adult children ranged in age from 24–34 at the time of the interviews. Although this group was not involved in the sheltered workshop, they are invested in the agency's employment services and its future.

Four of the parents in this study had also been interviewed one year before the sheltered workshop closed giving a pre and post perspective of the conversion process.

1.3. Setting

The sheltered workshop and subsequent communitybased employment options were located in greater Burlington, Vermont. As the last remaining sheltered workshop for people with intellectual and developmental disabilities in the state, its closure made Vermont the first state to close all its sheltered workshops in favor of community-based employment services; therefore its clientele did not have the option of transferring to a similar facility.

1.4. Data collection

Data collection included semi-structured interviews, participant observation, and archival review. A total of

16 interviews were conducted. Eight parents and four former sheltered workshops participants were interviewed. Four of the parents were interviewed twice (pre and post conversion). Eleven of the interviews occurred at the participants' home with three occurring at the parent's place of employment and two of the former sheltered workshop participants were interviewed at the agency. All of the interviews were conducted by the researcher and were one to two hours in length. Interviews were audio recorded and transcribed verbatim resulting in approximately 160 single-spaced pages of data. Transcribed interviews of the parents were returned to them for member checking to ensure their voices were correctly represented [11, 16]. Interviews of participants with intellectual disabilities were more difficult due to limitations in communication. One woman was primarily non-verbal and communicated by pointing to pictures in her scrapbook. Her support person helped with interpreting her speech and further explained the items in the scrapbook and their significance. Another participant was verbal but relied on prompts and reminders by his mother during the interview. He mostly gave one-word answers. The remaining two interviewees had higher verbal skills such that they were able to express themselves clearly. Due to their limited reading ability the transcripts were not returned to them for member checking. Of all four participants interviewed, their mothers were also interviewed as part of this study and supported their sons' and daughters'

Participant observations were conducted by the researcher over a period of three months of data collection and included observations within the agency as well as community-based activities. Observations included a self-advocacy class, parent support meetings, agency staff meetings, community-based job sites, home visits, agency picnics and parties, and board meetings. Memoranda were used in participant observation to record the

^{**}Pre and post interview, *Post interview.

researcher's personal reactions and thoughts on emerging themes, ethics, and methods [13, 16]. Archival review included newspaper articles, agency brochures, annual reports, strategic plans, videotapes, individuals' charts, and photographs covering the agency's 35-year history.

Descriptive field notes were taken during the interviews, participant observations, and archive review resulting in a "thick description" of what was perceived as happening [11, 13, 16, 25]. Thick description leads to theory building by examining the specific contexts and direct experiences of the participants and developing an understanding of those experiences.

1.5. Data analysis

Glesne [13] describes qualitative data analysis as organizing what has been seen, heard, and read to make sense of what is being learned. In this case study, the researcher sought to understand the 35-year history and culture of the organization, as well as the participants' reaction to sheltered workshop conversion and the following adjustment. Audiotapes and transcripts of the interviews were reviewed several times by the researcher to identify emerging themes. Themes were established based on the commonality and frequency of the responses. The data was initially categorized into broad themes of safety, community, potential and expectations, choice, and change. Each broad theme was sub-divided based on how participants' navigated the process in terms of accepting or resisting the change.

Archival data was reviewed and coded by title, date, and description of significance and examined for language, values, and philosophy of the time they were originally recorded. The archives were used to piece together a chronological history of the agency. The history and culture were an important aspect of this study given its 35-year history. Archival review, along with the parent interviews, allowed the researcher to "recreate" the life and culture of this agency over the years and gain a greater understanding of where they had been and the direction they were going [13]. Descriptive field notes from participant observations were analyzed and coded and concept maps were developed to help pull ideas together using a non-linear approach and assist in the identification of connections and relationships [16]. The data was sorted by emerging themes and categorized utilizing coding schemes, which assisted in comparing the data and discovering theoretical concepts [13, 16].

2. Findings

Findings from this study reveal how participants and families navigated the sheltered workshop conversion process. While the initial transition was difficult, most families and participants were satisfied with the conversion process as long as they could maintain previous social networks and find acceptable employment in the community. Getting to that point involved mixed feelings for many. Conflicting issues emerged as families had different histories, culture, values, philosophies, and expectations of their children and their inclusion in community. There were initial fears by some regarding safety and consistency, exploitation in the community, and loss of friendships, while others welcomed and expected inclusion in the community. The findings are categorized in the following sections.

2.1. Fear of the unknown

Review of the documents indicated that the decision to close the sheltered workshop was made by the executive director and the board of directors of the agency. The goal was to close it in one year's time. Parents with a long history of involvement with the sheltered workshop reported a strong attachment to it and reluctance to let it go. As one parent said, "We are scared to death". Another parent commented, "If it's not broke, don't fix it. Don't take away the safety". Another reflected on the workshop's history and purpose,

A lot of the families down there are my age and older that started the workshop because at that time there were no other services. And so I think from that point of view it's a little scary for some of them to let go... they really spent a lot of time and effort to get that started and having a place for their family members to go and be protected and feel good about themselves.

Parents expressed fear of a future without the sheltered workshop, "That's what I'm a little bit nervous over, after it's closed. If we don't have the workshop and we don't have training for them for a while what are we going to do?" Another stated, "I can't visualize it. I'm having a terrible time visualizing how this is going to happen".

The parents expressed concern about losing the social connection, community, and sense of place [35] developed over 35 years, "My biggest fear is that they'll separate these kids. If they get to attend occasional parties it will not be the same as being there everyday. They

like being together. Eliminating the workshop is eliminating the day-to-day interaction". Parents expressed hope to maintain that sense of connection, community, and place.

Whether it's a workshop where she really works or whether it's a place they can come and go. If they can just come back there and eat lunch so that they could see their own peers and belong, and feel that this is my place.

The sense of place seemed important to the parents as one mother described her daughter having a very full schedule of community-based activities (e.g. daycare job through supported employment, horseback riding, exercise at the local fitness center) with very little time in the workshop. Yet she still feared its closure.

A long history of professional services left some parents feeling angry and distrustful about the conversion and other systems failures,

Twenty-five years ago the 'experts' said that the state institution was the way to go. Then the experts said it had to close and people went to foster homes instead of the family, because experts said that would be best. [My son] was physically and emotionally abused at that foster home. He starved himself to get out. He had always been goodnatured, but became very unhappy and difficult. Talk about trials and tribulations. We weathered it all. They didn't live up to their word.

Another commented about the staff, "They have no idea what it's like to raise a disabled child!"

In contrast, parents with minimal or no history with the sheltered workshop had fewer concerns about conversion as their sons and daughters were more involved in community-based supported employment services. When asked about her son's involvement in the sheltered workshop, one parent replied, "No, he was never employed there. We never thought that would be a place for him". Yet, she expressed regret for those who valued it, "I hate to see it closed. It is valuable to those who are there. The sheltered workshop is good for those who cannot work independently. What is going to happen to them when the workshop closes?" Another parent whose son was in the sheltered workshop for a few years wasn't opposed to it closing, "No I don't mind them closing it and going out in the field, I think it's different. Like [my son], they had him soldering or doing something with wires and he'd come home and his fingers would be burned".

Despite families' apprehension or fears, the sheltered workshop was officially closed in June 2002 with a celebration of its history and its future. A letter from a Vermont U.S. Senator congratulated all on this momentous occasion stating, "As we close this chapter on work centers in Vermont, I hope that we encourage others to follow Vermont's lead to a place where all of us work side by side" [14].

2.2. After the closure

Four years after the sheltered workshop closed, the families were revisited and interviewed to get their current perspectives. The four previous families with a long history of sheltered employment, plus four additional families without that long history were interviewed. Differences and some similarities were noted between these two sets of families. Although the long time families had been resistant and fearful of the workshop closing down and reported regrets, they also reported positive outcomes. The newer set of families reported being pleased with the current services; these patterns are described in the subsequent subsections.

2.3. Consistency and safety

Based on interviews, observations and records, the sheltered workshop setting offered a fairly high degree of safety and security. Parents knew exactly where their adult child was for a certain number of hours per week and could rely on 20–30 hours per week their sons and daughters would be cared for in a professional environment, freeing them up for their own schedules. The change in this routine was difficult for some, "Well, I was nervous, like all of them, because [my son] is a routine type person and that June to January was rough on him, very rough". Another commented, "That was the hardest step for us as parents, letting our [children] figure what was happening, why they weren't there, getting them into a pattern, because as everyone knows, people like this follow a pattern".

In community-based services the consistency and hours could not be guaranteed and some people lost service hours. One parent reported her son used to come home at 3:00 but now comes home at 1:00, which disrupts her routine. She hired a person one day a week for respite, "That gives me a chance to go to lunch, or to do my shopping, and do other things, you know, to get out. I like a day once in awhile for just me".

The issue of safety was a theme across several interviews. Life outside the sheltered workshop seemed risky for some, "There are people out there who want to exploit them or use them and resent them". Another reported, "They're too vulnerable. They're too trusting. They really are". Families feared for their children's physical safety and well-being in community employment, such as a man with a seizure disorder and blindness, "What I would like ideally is for him to have a little space where he can sit and do his job and not have to wander around and not have to carry stuff in case he does have a seizure". Yet, many of the parents' fears didn't materialize. The community-based jobs were designed based on the individual's needs. For example, the man with a seizure disorder and blindness was placed in a packaging job where he could be seated with job coach support in a supportive workplace. As people spent more time in the community, the fears of abuse and ridicule did not materialize either, "He's out, yeah, and people are very kind to [my son] for some reason". Being out in the community enabled opportunity for socialization and meeting people, "You know, he went to this one restaurant, and they went there apparently a lot, and she said the guy came out with a piece of pumpkin pie for [my son]". Others reported being considered "regulars" at local diners and recognized in community. When asked about being in the community and making friends, a parent replied, "Absolutely. And he's out. He's meeting people all the time and I think that's one of the disadvantages of working in a sheltered workshop".

During participant observation it was noted that the lunch hour remained intact at the agency. This was based on wishes of several participants and families who wanted to maintain the sense of community and connection. Although people were out in their community jobs or social activities, they would return to the agency building for lunch. They would bring their lunches and socialize, catch up with each other, and go back to their jobs or other activities. The Executive Director supported this ritual realizing it was important for them during the transition.

2.4. Increased job satisfaction, skills and interests

Despite the longtime family fears, they reported that their daughters and sons were doing well in their new community-based lives. One parent who was resistant to the conversion said, "But as far as [my son] goes, he loves it. He likes his job very, very much". She reports that her son's life revolves around his new job and he gets upset if a holiday interferes with his work schedule. She didn't want to drive back one Sunday after a weekend trip and he said, "No, we've got to. I have to work Monday". In addition to his new job, her son gained additional interests, such as learning some Spanish. His mother reports,

It's simple words. He said he wanted to learn more Spanish and Mike [support worker] is working with him on that. Terms like "good morning, how are you?" the colors, the days of the week, the months, and the words, "bag" and "boxes," things that he uses down to work, "I need more bags, I need more boxes," and of course they [coworkers] think that is just great.

The mother reports he has also developed an interest in birds and birdcalls.

On their walks he takes them to places near parks where there are paved walks, and different places, and he'll say, "Listen, that's such-and-such a bird, or he'll come home and say, We heard a ... whatever bird it was, you know.

His mother stated, "I think he's happy, what more can I ask for than to have him contented and happy?"

Another mother commented on her 52 year-old daughter's increased skills since leaving the sheltered workshop,

[Her] integration into the community has been a remarkable move up the ladder for her in skills. She is so verbal you would not believe it. You cannot close her down sometimes. And you know, before she went into the workshop situation, she wasn't speaking at all.

One of the parents who was very opposed to the workshop conversion said her son is happy and she is pleased with the staff and current services,

Oh, yes, I feel they're excellent. I give them all kinds of credit. I don't even know how they do it sometimes, they're so great, they really are, and I'm so appreciative of it, because for [my son], because that makes him so happy.

2.5. Transition from sheltered work

The four former sheltered workshop participants who were interviewed had various tenures in the workshop ranging from 4 years to 32 years. Jake, who had been 13 years in the workshop was now working in a natural

foods store packaging dried fruit and nuts. When asked about any preference between the sheltered workshop and his new job, he simply stated, "OK with the new one". However, he said he missed the workshop too. Peter, who had been in the workshop for 15 years stated, "It was hard to let go of the workshop". When asked why he said, "I hated to see it go because I've seen parents get upset". Sam was in the workshop for just four years. He was one of the first to get a job through supported employment and has been working various jobs in the community since. When asked about the workshop closing he said, "Good change. People can get out and stuff like that". But he also seemed concerned about the parents and participants during the conversion stating, "Yeah, they made it just hard for people right now". However, he made it clear that he did not want to stay in the workshop, "Not for me. I wanted to do something to get out. Other jobs and stuff". Audrey had been in the workshop for 32 years and got a community job as a daycare worker. She was mostly non-verbal and shared her life through scrapbooks she kept. Her mother reported that she enjoys her daycare job as described,

She's the lunch lady there. She does the tables, cleans them all up, pours the milk, sweeps the floors, takes the garbage out, and she's been known to pat 20 children on the back and put them all to sleep there.

2.6. Expectations for inclusion

The newer parents saw their children benefit from a more inclusive education and leave high school with community-based employment. All three of the newer families interviewed stated that their sons and daughters graduated high school with a community-based job. Their children were never participants in the sheltered workshop. When asked about the sheltered workshop closing, they had no regrets. One of the parents saw the workshop tasks as "menial" and "redundant" and commented, "It's too reclusive... you're shut off from the rest of world and it sort of adds to the stigma, which is sad". Another parent commented on the social behavior of the long-term workshop participants,

I watch many of the people who were in the sheltered workshop and how they behave socially. I think maybe because they work in this closeted room or closeted box that they are in, that they don't have the opportunity to socialize and I think it comes out when you bring them to large groups of people. You see that.

Another parent made it very clear that her daughter would never be in a sheltered workshop, "she needs to be in the community with nondisabled adults". She went further to say, "putting people in a sheltered workshop is making them go away". She felt hiding her daughter and others with disabilities was a disservice to all,

I don't like the thought of putting people in an area where they're not seen. They need to be appreciated by the community. People need to know that there are people with disabilities out there, not hiding away somewhere working on projects.

The newer families do not seem to be seeking refuge or safety within the walls of the workshop. One parent described the therapeutic benefits of a community life,

What I like about [the agency] at this point is the use of the community-based program, going out in the community, working in the community. With my daughter, her disability has to do with socialization and communication so a lot of what she really needs is appropriate modeling of socialization. She does better when she is exposed to people without disabilities because she models what is in front of her. So that is why I like the aspect of not having a sheltered workshop.

In an observation of the self-advocacy class that combined high school students and former sheltered workshop participants, differences were noted as they worked on the assignment for the day. The topic was "goal-setting" and participants were to write down some goals they would like to achieve in the next six months, one year, and five years. The high school students were all able to read and write and complete the assignment with little assistance. They were dressed as typical high school students, some had cell phones, and expressed typical teen-age hopes and dreams such as getting a job in day-care, working with horses, taking a trip to New York City to see a Broadway show, getting a place of their own, getting their driver's license, buying a truck, having relationships, securing a new job at a specific location, or going camping at Niagara Falls. The students were hoping, and planning, for typical lives in the community. The former sheltered workshop participants were generally unable to read or write and needed close assistance from staff to complete the assignment. Their goals seemed less ambitious like going to the county fair, taking a long car ride, traveling to another state with their caregiver, and getting more work hours.

2.7. Looking back

Based on archival review, it seemed the goal and mission of the sheltered workshop had always been to include people in the community to the fullest extent possible. In reviewing the agency's archives there were dozens of 35 mm photo slides that depicted lessons on proper hygiene and self-care, money and banking skills, shopping, riding public transportation, various daily living skills, and learning vocational skills. Perhaps community inclusion was a dream goal that did not seem achievable at the time. Now that the mission had been obtained, there appeared to be some remorse and regrets of potential lost.

The longtime parents reported seeing the younger people today as benefiting from better education and services and recognizing that they never had that option. One mother commented, "I think people are capable and I notice the younger kids these days are being prepared and educated for that. They're gaining a lot more skills. You see, [my son] wasn't". One mother opposed to the conversion said, "We didn't prepare them for this. The younger kids have the potential, our kids don't. They have been too taken care of. It's not fair to them". Some seemed to express regret of missed opportunity as one parent spoke of the workshop conversion, "I realized what they were trying to do, you know, in their minds they were trying to help [my son] to get out in the community, but it was too late for [him]". Another reflected on it as a societal issue, "Like I always said, [my son] was ready for society, but society wasn't ready for [my son]". Or if they had received a better education and services, things might have been different, "If [my son] had been given the opportunity way back when, like the kids are given today, like we fought for the kids to have today, he could have gone to college. He could have, he's smart".

When asked about their current strengths and gifts, parents said their adult children were much more skilled and talented than people realized, "He knows more than you'll ever think he knows". Despite their reservations about the closure, they could now envision success in the community as one mother, who initially was opposed to the workshop closing, said, "I don't see why he couldn't [work], but it would have to be the right one, one that he really liked, and he would do it like clockwork!"

Given the values and attitudes of the paradigms they were accustomed to, some continued to view their sons and daughters as childlike and often refer to them as "kids" despite their adult age. Some parents viewed them as functioning in the range of a child and some viewed them as their duty stating, "God gave them to us to protect them from society". Not all were convinced that the conversion was warranted and wanted to maintain the workshop,

I'm very sorry about [the sheltered workshop] closing as far as what happened to it and I think that the state is going to regret it. I really do. Just letting them be normal in their normal sense, that's what [the sheltered workshop] was for. And yes, it's still needed. Places like that are still needed.

At a parent meeting after the workshop closed, another parent asked, "Isn't there any way we can bring the sheltered workshop back?"

3. Discussion

Findings from this study illustrate some families' reactions before and after the conversion of a sheltered workshop to community-based services. Differing perspectives of the conversion process became apparent based on the families' history and experience, values, philosophies, and expectations of their children and their inclusion in community. For some the workshop was seen as a sanctuary, for others it was seen as a barrier. In reviewing the findings the reader is encouraged to consider the study limitations. Data were collected from a relatively small number of participants from one sheltered workshop undergoing conversion to community-based services, therefore may not reflect the history and culture of other workshops. The families' adult children were all labeled with intellectual and developmental disabilities, but had differing levels of communication, social, and vocational skills. It cannot be assumed that all will have the same perceptions and reactions and the service systems may not be similar in other states or programs. Despite its limitations, the agency's origin of being founded and run by parents through the years is similar to many other agencies nationally. The voices, concerns, and experiences of family members may provide insight and guidance for other families and change agents interested in pursuing a conversion from sheltered workshops to community-based services.

Since families are often considered resistant stakeholders in the conversion of sheltered workshops [15, 21, 40], it is important to take their perspectives into account when attempting a systems change of converting a sheltered workshop, as it can be an emotional and sensitive issue. Some families had a long tradition of sheltered services and developed an insular community and became accustomed to the safety, security, and sanctuary provided by the workshop. Established as an alternative due to lack of services at the time, the sheltered workshop served an important role and provided a sense of place when community inclusion was not an option. The sense of place seemed to remain a primary concern of the longtime families. Walker [35] examined the concept of "sense of place" for individuals with intellectual and developmental disabilities and discovered that positive experiences came from a sense of safety, identification, familiarity, being known, feeling accepted, and a sense of accommodation. Negative aspects came from feelings of vulnerability, social isolation, disaffiliation and unfamiliarity, and rejection. For the longtime families, the sheltered workshop seemed to represent a positive sense of place, while the community was viewed as negative. Although, the newer families seemed to take an opposing view, whereas the community was their positive sense of place and the workshop appeared negative.

Now that community inclusion through supported employment and leisure/recreational activities is becoming the norm for this agency, people are discovering a sense of place outside the walls of the sheltered workshop. With the closure of the sheltered workshop, the parents who opposed the conversion have found their adult children to be increasing their skills and finding satisfaction in their community-based lives. The hours and location may not be as consistent as the workshop, but the fears of being ridiculed and unsafe in the community have not become reality. The families and participants with a long history of sheltered employment may miss the nostalgic sense of place and community they were accustomed to, but seem to be adjusting to the new realities of community-based services. Although the workshop is closed, in many ways they seem to have retained that sense of place by maintaining contacts and connections.

Reviewing the 35-year history of this particular sheltered workshop through family interviews, participant observations, and archival review, reveals the gradual progression of a sheltered workshop as an innovative alternative to institutionalization providing safety and sanctuary at a time when people with disabilities were not expected or welcomed in the community; to an outdated mode of vocational services which many now see as a barrier to community inclusion and community-based employment. At the time of establishment there were few choices for parents of children

with significant disabilities. Today, community-based services are available and society seems more ready and accepting of people with developmental and intellectual disabilities. The newer parents and their young adult children may not want sanctuary and shelter, preferring the risks and rewards of life in the community.

A fear of the unknown, an inability to visualize a future without sheltered employment, and the strong history and culture have been resistant factors in sheltered workshop conversion. The conversion of this particular workshop, and the subsequent adjustment, suggests that the process can be difficult, but can result in new and fulfilling experiences for participants. As more agencies successfully convert sheltered workshops to community-based employment, these examples may alleviate families' fears of sheltered workshop conversion and welcome a community-based life.

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