Transitional services for youth with disabilities is defined by the Individuals with Disabilities Education Improvement Act of 2004 as

a coordinated set of activities for a child with a disability . . . focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to postschool activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation. (sec. 602.34a)

The transition from school to postsecondary school can be challenging for youth generally, and more so for youth with intellectual disabilities. During the past several decades services for youth with disabilities have been developed to facilitate the process of transition

(e.g., Brolin, 1976; Brolin & Kokaska, 1979; Kolstoe & Frey, 1965). For example, between 1984 and 1989 there were more than 180 transition demonstration projects nationwide serving almost 19,000 persons with diverse disabilities (Jackson & Purvis, 1995).

The growth in community-based transition services can be seen perhaps as a natural extension of the continued human and civil rights movements for disenfranchised populations that have occurred since the 1950s and 1960s. Children and youth with intellectual disabilities who in the past might have been institutionalized, are now increasingly part of the educational, social, and vocational fabric of their communities. However, the findings from the second wave of the National Longitudinal Transition Study–2 (NLTS2; Wagner, Newman, Cameto, Levine, & Garza, 2006) indicate that despite some notable successes, there is a long way to go.

The study found that there remains a considerable gap in academic achievement and functional skills between youth with disabilities and their peers in the general population. Moreover, though youth with disabilities are involved with activities at home, personal friendships, organized extracurricular activities, and jobs. . . . With the exception of paid employment, rates of participation in these kinds of extracurricular activities fall somewhat short of those of the general student population. . . .
Furthermore, outcomes for youth with mental retardation or multiple disabilities were among the poorest. These individuals were the least likely to have completed high school, among the least likely to have graduated with a regular diploma, and among the least likely to be engaged in school, work, or preparation for work post–high school (Wagner, Newman, Cameto, Garza, & Levine, 2005).

Perhaps as a result, the focus of programs for postsecondary support services for youth with intellectual disabilities has become increasingly creative. One such example is that postsecondary programs for youth with mild or moderate to severe intellectual disabilities that focus on functional, life, vocational, and social skills are now being delivered in socially inclusive college settings (e.g., Dolyniuk et al., 2002; Eskow & Fisher, 2004; Jackson & Purvis, 1995).

Though the importance of such programs in providing typical community and transitional experiences for individuals with disabilities cannot be overstated, with a few notable exceptions (e.g., East Central University, Strive University, University of Maine, and Taft College in California), the current programs generally lack a true to life independent living component—that is a residential living experience.

A large private nonprofit organization that provides programs for individuals with developmental disabilities in western New York, in partnership with a small private college, designed and developed a dormitory living residence habilitation project, seen as the next logical step for participants in their day habilitation college-based program, Young Adult Life Transitions program or YALT. YALT started in July 2000 and was developed to offer young adults 18 to 22 with significant intellectual disabilities ages “an opportunity to develop goals for adulthood and learn social and life skills on a college campus in an age-appropriate setting.” Since its inception, the YALT program has expanded to four other locations in two counties serving approximately 40 to 50 young adults. Though housed on college campuses, the participants in YALT are not “students” of the particular college, but are utilizing the resources of the college as part of their day habilitation services from the agency.

In the summer of 2003, the dormitory living experience project was piloted with six participants from YALT (three boys and three girls), chosen to spend 10 weeks between June and August 2003 living in the dorms at a local private college. Participants were housed in two separate dorm rooms on the college campus, along with a male and female college student peer respectively.

The goals of the summer pilot were in part to provide an independent living opportunity in an age-appropriate setting for young adults who may never have spent an extended period of time away from parents or guardians, and to provide opportunity for participants to experience a transition from a “home” environment to an independent living environment. Though not explicitly stated, the goal of the program was to enhance the skills and abilities of the young adults to better enable a transition from living at home to a more independent living arrangement. Not entirely unique (see for example, the Transition to Independent Living Program at Taft College, California which began in 1995, see http://www.taft.cc.ca.us/til/), the summer pilot was developed in response to a need raised by two local parents, and was the first program of it’s kind in western New York. In part based on the generally favorable feedback from a focus group with the participants in the 2003 pilot, the dorm project was repeated in the summer of 2004, and a qualitative evaluation was integrated into the project.

Our research was guided by three questions:

1. How would the participants experience living away from their parents?
2. To what extent would the participants increase their independent living skills?
3. How successful was the project in enabling the participants to experience the transition to an independent living situation?

The importance of including the voices of young adults and their families in developing transitional services has been recognized in the literature (e.g., Davis & Clark, 2000). In accordance with that approach, we included both the young adults and their parents in the evaluation. Using a constructivist approach to the problem, an approach that recognizes there may be many truths and many ways of knowing (Lincoln & Guba, 1985), we sought to learn about and understand the experience as perceived by the participants, and to evaluate the program from their perspective.

**METHOD**

**Sample**

To be eligible for the dormitory summer program, a participant must have been receiving day services through the YALT program for a minimum of one year. All interested participants from that program were screened during team meetings between agency staff and a parent representative, and were invited into the
dorm project based on individual consumer need, ability to self-medicate, and interest. Participating in the dorm project were four girls and two boys (n = 6), males were 22 and 23 years old, whereas the females ranged in age from 20 to 22. All of the dorm participants lived at home at the time of the project, and at least one had a medical condition serious enough to require daily self-administration of medication through injection. In addition, all had at least one other sibling and on participant had six other siblings. Information obtained from the agency indicated that all of the dorm participants had mild mental retardation, and five of the six had parents who were their legal guardians.

All dorm participants and their parents or guardians agreed to be interviewed for this evaluation. For two of the participants, both the mother and the father were present during the interviews. Finally, two participants had siblings that had attended college. The total number of participants in the evaluation was 12.

Design and Procedures

Participants were living in the dorms during a 10-week period from mid June through mid August 2004. A pre-post design was used during the evaluation. Two semistructured interviews were scheduled with each participant; pre interviews were completed during late May and early June 2004, and post interviews were completed during late October through early November 2004.

A two-stage process was developed to allow for participant recruitment. During the first stage, a member of the research team attended the agency-college orientation session to present the evaluation to the dorm participants and their families. The proposed evaluation of the project was described in detail, including the time commitment, confidentiality, and the purpose of the evaluation. After allowing for questions, “initial consent” forms were distributed to the parent or guardian of each program participant. The purpose of this initial step was to obtain written consent for setting up the parent interviews and for a member of the team to approach the dorm participants for a separate interview.

At the time of the interview, the member of the research team provided each parent and dorm participant with a written explanation of the evaluation and verbally reviewed the evaluation in detail, including how data would be handled, the right for refusal or withdrawal at any time without penalty, the content and purpose of the interviews, the time commitment, and the voluntary nature of participation. In the case of the dorm participant, the written explanation and the verbal description was modified to insure it would be understandable. The purpose of this second stage was to obtain written consent or assent from each parent and dorm participant to proceed with the interview and the evaluation. This two-stage process for informed consent or assent was approved by the university’s Social and Behavioral Sciences Institutional Review Board. The participants received no compensation for their time in this evaluation.

Interviews were conducted by a member of the research team, a social worker with more than 30 years experience working with individuals with developmental disabilities. Each interview lasted approximately 30 to 45 minutes, with a couple of exceptions that went longer than 45 minutes. The interviewer wrote detailed field notes during the interviews, and the interviews were audio taped for later transcription. An MSW student transcribed the tapes verbatim. The transcripts were coded and deidentified by the transcriber, and after transcription, the audio tapes were erased.

Two dorm participants declined to be audio taped at the pre interview and one at post interview. The interviewer wrote detailed post interview narratives soon after completing each interview. Such a procedure sometimes referred to as process recording or significant process recording is not uncommon in social work practice, and can oftentimes lead to an almost verbatim transcript of an interview. Interviews were scheduled on the college campus for the dorm participant; parent or guardian interviews were scheduled in their homes.

Measurement

The interview was developed during a series of team meetings consisting of representatives from the agency, a parent representative, and the principal researcher, and was based in part on the results from a focus group held in October 2003 with the participants of the pilot. The interview consisted of open and closed ended items with possible probes related to the dorm program, and queries about transitional and independent living skills. A copy of the interview protocol may be obtained from the first author. In addition to collecting minimal demographic information such as gender, age, if the participant had a brothers or sisters living at home with him or her, if the participant shared his or her room at home, and whether the participant had past experience in the summer program, a series of skills-related items were also closed ended. For example, participants were asked to rate their skills at transportation, managing money, shopping for food and clothing, doing laundry and other chores, preparing meals, handling emergencies, and self-care. Based on the focus group, two problem-solving items were included in the interviews with the dorm participants (“Your roommate leaves old smelly food in the...
room and doesn’t throw it out. What would you do?” “The person living upstairs has the stereo on too loud. What would you do?”

Preintervention questions for the parent and the young adult also began with open-ended questions with regard to their expectations for the summer program, and how much contact they anticipated having with each other during the program. (e.g., What do you expect in the summer dormitory program?) Participants were asked to evaluate the ability of the dorm participant to live independently, and whether there were future plans for the young adult to move into a supported residence or apartment. The postintervention questions were reworded in part to maintain the substantive content but also to enable participants to reflect back on their experiences (e.g., In what ways do you think living in the dormitory this summer helped you to get ready to live on your own?) When evaluating the pre and post questions, researchers looked for any discrepancies between the preprogram expectations and the postprogram realities of the experience.

The interview was introduced with the statement, “The goal of our discussion today is to learn about your [your child’s] experiences in the upcoming summer dormitory living program,” a comment about the importance of providing both favorable and unfavorable information about the program (e.g., “Your opinions—what you think about the program—are very important to us and will help the agency plan other dorm programs. Sometimes people feel like they should only say nice things, or what they think we want to hear. But we really want to know what you think about the program—good and bad. There are no right or wrong answers.”), and assurances of confidentiality (e.g., “What you say to us about the program will be private and will not be repeated to anyone else in such a way that they will know who you are”). Content items were sequenced in a manner that would provide participants with the opportunity to think ahead (pre) or reflect back (retrospective and post) from when they first heard about the dorm living project (e.g., “What did you think the program is going to be like?”) to asking participants to comment about how the program may have helped them achieve specific independent living goals.

The size of the research team varied during the course of the study. On the final team, there were four persons, including a professor of social work with a young adult child who has a disability, two social work PhD students, one with practice experience in the field and one with a physical disability, and a professor of human services, a practicing social worker, with extensive practice and teaching experience in the field.

Although the sample size is considered substantial for a qualitative study (see Morse, 1994), to avoid overgeneralizing, three members of the research team were used as “controls” during data analysis. Once the transcribed textual interview data were entered into Atlas ti the first level of analysis was open coding, which involved line-by-line analysis (Creswell, 1998; Strauss & Corbin, 1998). Each transcript was reviewed separately by each of the three team members to identify common themes and those experiences that appeared common across interviews. The members then reviewed their results during team meetings to further differentiate that which might have been idiosyncratic, specific to a particular child or parent or guardian, from that which appeared across two or more interviews. When we were able to reliably identify themes and narrative relative to the themes (that is, issues that were found by more than one researcher and were not deemed to be idiosyncratic by any member of the team), we accepted the possibility that the particular theme might be generalizable.

Specific categories were formed when similar codes emerged that represented a critical event, concern, or issue (Glaser, 1978; Padgett, 1998; Strauss & Corbin, 1998). Stated somewhat differently, we identified examples both from our experience with the world of disabilities, and from the internal evidence, that seemed to “make sense.” When we compared parent or guardian interviews with dorm participant interviews, we could often identify converging descriptions of similar phenomena that gave us some confidence in their generalizability. Categories continued to be developed until saturation occurred (Creswell, 1998; Strauss & Corbin, 1998). This method of triangulation through the use of multiple researchers addresses in part the potential for bias during data analysis. The goal is to decrease bias through the use of multiple perspectives of the researchers with varied backgrounds with individuals with disabilities. In addition, the results of our analyses were submitted to agency personnel with first-hand knowledge of the dorm project for their review. No changes in the analysis resulted from this last step.

Overall, the process we pursued “assumes an organized social world with regularities, and assumes that, in the absence of evidence to the contrary, experiences in given settings are more likely to be typical than they are atypical” (Levine, Reppucci, & Weinstein, 1990, p. 346). This method of analysis, that is independent evaluation followed by a comparison of the result among several researchers, is considered an appropriate method to insure the reliability of qualitative data (Silverman, 1993). Silverman (1993) also asserts that the validity of a qualitative study is derived from the thoroughness of the analysis and not from the representativeness of the sample. We believe that our careful and considered approach was sufficiently comprehensive to enable us to stay true to the
The narrative examples presented here may have been edited somewhat to preserve confidentiality. However, we have tried to be faithful to the spirit of the comments and observations made by our study participants. For the sake of consistency and to enhance the anonymity of the participants, all will be referred to with feminine pronouns.

**RESULTS**

One dorm participant did not participate in the preinterview stage, and despite repeated attempts, the team was unable to connect with one of the parents during the postinterview stage. A total of 22 interviews were conducted, 5 pre and 6 post interviews for the dorm participants, and 6 pre and 5 post for the parents.

In general, some variability was seen across groups (participants, parents) and within groups at both pre- and posttest. For some participants, this was not their first experience in a dorm project, having participated in an earlier project by the same agency. For others, not only was this their first dorm experience, but also the data seemed to indicate that it might have been their first overnight experience away from their parents.

Thematically, the data are presented in three broad categories. The first category is normative life transitions. In general, the experience of living away from home was perceived as comparable to that of a typical college student. The second category is growing pains. Respondents recognized changes and improvement in life skills, an increased awareness of personal goals, enhanced vocational goals, and in some instances increased maturity or assertiveness. And the third category is what seemed like one step forward. Respondents were generally satisfied and indicated they would participate again.

By incorporating the participants and parents of the participants own words we are providing a unique opportunity to learn from the depth of their insights. The participants are providing a chance for us to learn how they view their lives in general.

**Normative Life Transitions**

**Student response.** The process of normative adolescent transitions, separation, individuation, and increasing independence from one’s parents, is a path that is not followed in the typical way by an individual with developmental disabilities. However, the opportunity to live somewhat independently in a college dorm, despite some uncertainty, was greeted with a level of excitement about “going to college,” as commented by Student 6 during the predorm interview:

> I had no idea what it will be like this year. No one really told me what it would be like. I was happy to get in the program and be able to go to college.

Others met the transition to the dorm with some nervousness, though the source of the nervousness was uncertain as evident by Student 4’s comment in the predorm interview, “I first got nervous, I was nervous, but now I’m ok with it.”

Family contact was another area that appeared to be illustrative of the normative college student experience. When asked about frequency of parental contact, Student 4 in the postdorm experience interviews stated the weekend visits were, “Just the right amount. In contrast, Student 3 replied, “Right.” when asked if she wished her parents saw her more while she was at the dorm.

As with many students away from home for the first time, being in the dorms did not separate the participants from their concerns about home. For example, Student 1 called her parents multiple times during the day to touch bases. During the postdorm interview, she reflected,

> Well my parents, my family was always yelling and screaming and I didn’t like it too much. . . . I didn’t want anyone to get divorced while I was at the dorm.

The participants were asked a series of questions in the pre and post interviews about how they felt about making new friends. The majority of participants expressed that making and having friends was something they clearly valued in life, and for some, making friends was a challenge. Student 5 in the pre interview indicated, “I’m pretty good at it [making new friends].” Student 3 commented,

> I’m not so good at this. I like guys and I have one friend at the daytime YALT program I go to. . . . I like guys, but I’m not ready to date them. I think I’m a little afraid.

[The dorm experience] might help me meet new people.

For some, the dorm was essentially a continuation of living at home, as this next comment by Student 5 illustrates.

> It was like home to me. . . . I had to do my own cooking, my own cleaning, my own laundry. . . . Sometimes it was a little scary.”

Student 6 in the post interview welcomed the experience, as it brought the opportunity for meeting new people, “I liked being on campus, meeting new people. I really liked hanging around with my friends and staff.
I didn’t really make new friends, but I got to know the friends I had before, better.” Student 4 commented in the post interview, “Um... The best part was living with [name] and all of my friends.”

Primary and secondary school children with intellectual disabilities are vulnerable to the negative comments and scapegoating of their peers. For some, these issues remained, albeit in an interesting way. Student 2, experiencing her second summer in the dorm, during her pre interview stated, “The worst thing would be that I will be with a bunch of people who are not as smart as me... The dorm program should be divided into two different kinds of groups, so that would be a group for people lower in ability and then a group for people like myself who are smarter.”

Parents’ responses. All the parents were excited for their children but also experienced some reservations about safety and, for some, being separated from them for the first time. As Parent 4 stated in the predorm interview,

I think as a parent when you have a child with a disability and especially when there is mental retardation there, I think you worry about their safety and I worry a little bit about her being out in the community alone maybe at some times. Although she has a very strong personality and I think handles herself pretty well and I think is pretty aware. But there is always a safety issue.

However, perhaps recognizing a common theme for her relationship with all her children, Parent 4 continued, “But I had that same issue with my other kids, so it’s not that different.”

Parent 1 indicated that her daughter saw going to the dorm as possible rejection. Like in any such situation, the parent sought to reassure her child. The parent explained,

And she said, “I really don’t want to leave the house... I want to stay with my family, why are you kicking me out?” and I said, “I’m not kicking you out, I will never kick you out, this is your home, you can always come, you are more than welcome to it, it’s just an opportunity for me and you, as much as it is to you, to me too and I want you to know that this is for your own good and I promise you that if you don’t like, or there is anything wrong, I will help you out.

Growing Pains

Student responses. Growing pains or stressful times are often a part of any transition or major life change such as living away from home for the first time, and that was evident in the comments of both the participant and the participants’ parents. The transition brings with it challenges for the participants in exerting newfound independence in the form of learning new skills and having an increase in the decisions one can make and for the parents in learning to let go and becoming more comfortable with the their child’s growing independence.

An important skill for all college-age individuals is money management. For individuals with intellectual disabilities, even simple money management skills can be problematic. When asked prior to the program about handling money and making change, Student 4 commented,

Money, I need help with. Because I don’t know how much money to have to bring with me, so I need help with money.

When asked about whether they learned or expanded on their skills of handling money at post interview, the responses varied, though Student 2 summed it up by stating, “[I] learned nothing.”

The ability to cook is an important life skill that consists of many additional skills, planning a meal, fire safety, following directions to prepare the meal, and keeping a watchful eye on time so nothing burns for example. The participants gave very specific examples of their prior cooking experiences before the dorm program. One participant explained that she had burned pancakes in the past and needed help with being around the stove. Another revealed that she had used the microwave and toaster but has not used the stove. Though participants generally wanted to learn more of these skills, Student 6 proudly commented during the post interview,

I can read simple directions for cooking, there were some problems but I learned how to measure and follow directions in order to cook simple meals without messing up.

Grilled cheese [sandwiches]. I learned how to cook them this summer. I couldn’t do that before the summer, now I can.

Participants in the pre interview were asked to evaluate their ability with regard to completing laundry, and Student 2 replied,

I’m good at it sometimes. Taking care of my uniforms from [work] and [internship], something like that... if I get something dirty [at work or internship] I just do that.

Her response implied that she recognized the importance of having clean clothes for work and knew that when it is dirty not to wear the item to work. The same participant seemed to show an awareness of a self-help strategy that she would need to be able to complete her laundry with complete independence:

I have to write it down to know how to do it.
Student 5 stated,

I don’t know how to do that. Like light to dark, I don’t know how to do that.

The dorm provided some opportunity for growth in this area, as illustrated by the following comment by Student 6 in the post interview:

I could do laundry before the dorm program, but not very well. I didn’t really sort the clothes and I didn’t fold or put them away very well. But this summer, I learned that.

The ability to negotiate a challenging social relationship is especially important as one matures. In the pre interviews, the participants were asked to respond to two hypothetical situations: what they might do in a situation where a roommate had left spoiled food in the dorm room and what they would do if loud music was being played and the young adult could not sleep. These hypothetical scenarios were used to evaluate the participant’s decision making skills, problem solving, and assertiveness in social relationships. The responses ranged from passive acceptance to assertive intervention.

Student 4 commented, “You just say, you can’t put dirty food, if you want to eat something, you have to eat it quick before it goes rotten.”

Student 5 commented, “I would tell the person please to throw the food out.”

Student 2 commented, “[I]... would just throw food away.”

Student 3 commented, “Open the windows up to cut down the smell.”

Another participant unassertively indicated she would say nothing to anyone, and throw the food away.

In contrast, the predorm responses with regard to dealing with loud music were generally consistent:

Student 4 commented, “I would say, can you turn it down, I’m trying to get some sleep.”

Student 6 commented, “I would ask them to quiet down, to please quiet down.”

Student 5 commented, “Um... ask them to turn it down; we are trying to get some sleep here, would you please turn it down?”

When asked what she would do if this strategy didn’t work, Student 5 stated simply, “I would get somebody else to help me tell them to turn it down.”

The participants were also asked how they coped with relationship issues that arose while at the dorm. They often gave a descriptive account of a specific incident where they experienced disagreements and/or “bossiness.” Responses varied from being assertive and addressing a problem directly with the person to asking staff to intervene when it reached a point where the participant felt a second party was needed. Student 2 commented during the post interview,

Basically if I had a problem I would just walk away and go somewhere.

Um... they well [name and name], they are loud. ... The staff would yell at them. They wouldn’t listen to me.

Yeah, but they would listen once in a while. If they did it twice then I would tell the staff.

In the post interview, Student 6 described a situation in which they directly addressed the problem:

Sometimes [name] would come into my room and bother me and interrupt what I was doing and try to boss me around. I learned how to ask her to please leave me alone when I didn’t want to hang out with her.

Parents’ responses. Two identified goals of the dorm program were to provide opportunity for the youth to gain independence and to provide an opportunity for the youth to learn about and practice skills for daily living. These two goals are described in the following by Parent 1 in the pre interviews:

I needed to test her, this was an opportunity for me to see how I am going to react without her being in my life for a while, and how she will deal with it. I think she is handling it much more than I am, honestly.

So when I found out that because it is an opportunity for her to learn and it is an opportunity for me too to get away from her, so for both of us. So we see how we are going to react, both of us.

However, it was not without some ambivalence on the part of the parent who indicated,

It is not easy in our custom and our tradition to let the children leave the house and go and live on their own and have their own apartment. ... Especially when it comes to handicapped people. We take care of them until they die. ... I think he is handling it much more than I am, honestly.

Parents discussed how the opportunity for their child to live with peers was beneficial in enhancing social skills and provided an opportunity to learn about independent problem solving when a conflict arose. During the post interview, Parent 2 commented,

Yes, she had a few fights with her roommate, and she told me not to get involved because she would take care of it and she did take care of it.

There were indications that perhaps the dorm experience may have facilitated some positive growth in independence and subsequent growth for the parent-child relationship. During the post interview, Parent 4 indicated,
She said to me yesterday, “Mom, life’s changed. . . . I’m going to work, I know that you will miss me and I’ll miss you too.” I said, “Do you want to come back?” She said, “No, I don’t want to come back, I’m having fun here.” So I’m seeing a really big positive from her.

In the post interview, Parent 3 explained that when their child came home she was more assertive and exercised a certain amount of autonomy. She recalled a conversation when her daughter stated, “This is my room and it’s not any of your business and I don’t have to do anything that I don’t want, because this is my room.” The parent concluded, “She did gain a certain autonomy, which you know is probably not a bad thing.”

One Step Forward

Both dorm participants and their parents indicated that the program had provided an opportunity for increased awareness of the steps involved for a person with developmental disabilities to transition into adulthood with the need for planning tailored to the individuals needs.

The participants, on completion of the dorm program, were asked what their plans were for the future. Responses ranged from some who indicated they had not really thought about the future, to another who decided she was going to continue to live with her parents. Student 3 responded when asked if she would like to live in her own house someday by stating, “Sometime, yeah. I would like that very much.” In contrast, Student 1 responded that it would be too expensive to live on her own and added, “No I can’t. I can’t be alone without my family.”

Parents’ responses. At post interview, a number of parents expressed disappointment about what they perceived as insufficient or nonexistent communication with staff during the program and evaluative feedback from the agency postdorm regarding their child’s experience. Regardless, all parents indicated they would have their child attend the program again, and the majority felt it was a good stepping stone for those who may move out of the house. For some, there appeared to be a new realization that their child had gained valuable life skills and the experience may have strengthened not only the participant’s confidence but also the parents. In the post interview, Parent 1 explained,

I started feeling that there is hope and it is a big hope for me. But going through it along with her and being in there checking on her and getting through the problems and the good ones, I found out at the end, that [she] really did a good job.

In the post interview, Parent 4 explained,

It’s made me more aware of the fact that she does have to make a lot of decisions on her own, or more aware of the fact that she does make decisions [italics added]. I guess that I wasn’t really conscious of the fact that she was making decisions, but she does. I’m more aware of that process.

Parents were mostly pleased at how their child managed on their own and in some ways it didn’t feel any different than when one of their children without a disability went off to college, as explained by Parent 3 during the post interview:

The best thing, I think was just my daughter being able to do this, being able to be there and be independent of us. Being able to go off to a dorm like her brother and sister.

Parent 4 discussed how it was not only freedom for her daughter, but it also gave her a sense of freedom as well:

And to me it was a big relief. . . . I had no restrictions on my going, coming, in and out. . . . gave me some freedom. I enjoyed it. Which is something that I never did, I used to worry. . . . Knowing that she is handling it on her own and that she is happy. . . . I was at peace.

Oftentimes, parents were thankful for the opportunity at independence that the dorm experience provided and the chance for the young adults to make decisions without consulting with them first, as was expressed by Parent 3, who indicated her young adult had limited opportunity to make decisions at home:

We have never put her in a situation to make decisions, . . . when she got lost, she made a decision, she knows that she had to find a way to phone me. This is the only time she made a decision [on her own]. . . . This was her decision.

Parents also had concerns about the ability of their child to make “good decisions,” as Parent 4 explained during the post interview:

I think that when kids are beginning any new experience, there is a trial and error type thing. And I think that she might make some decisions that aren’t the best, that will need correcting and I’m hoping that the program will do that, that there will be enough supervision that her bad choices will be made known to her and she can reconcile and make better choices.

A number of parents indicated that they felt the dorm experience would be a safe environment where the young adult can make his or her own decisions, make mistakes, and learn from them. This next quote from Parent 4 is illustrative:
Getting her to be more accustomed to being independent of us, not being around us for everything, not hovering over us to get our input into things. It really forces her to go out and make decisions and then understand the consequences of making that good decision or bad decision.

Finally, the dorm experience was generally viewed as an environment unlike home that had the potential to provide the participants with a growth experience, and a “trial run” for separation from parents. The following comment from the post interviews from Parent 2 is illustrative:

It’s one of those . . . you know, walk before run type questions to me. Send her out into; her next step will be some type of group setting without that transition. I think that transition did an excellent job of preparing her for leading a more successful [life].

DISCUSSION AND APPLICATIONS TO SOCIAL WORK

A major goal of the summer dormitory residential experience was to enhance the ability of participants to transition from living at home to a more independent group living arrangement when ready. For a person with developmental disabilities, many habilitative goals and the decision making process are determined by parents, teachers, or service providers, with little input from the person despite attempts at inclusion (e.g., Bannerman, Sheldon, Sherman, & Harchik, 1990). Oftentimes, young people with developmental disabilities watch as their sometimes younger siblings move out of the home, go away to college, live on their own, make their own decisions, and establish new relationships with peers, parents, and others while they remain under the roof and care of their parents or guardians relying on them for most if not all decisions. When given voice, young people with emotional or behavioral difficulties indicate that these same transitions are as important for them as for adolescents without special needs (e.g., Adams, Nolte, & Schalansky, 2000). Yet, for young people with intellectual disabilities, because the need for parent and/or significant adult support may be great, these same experiences leading to independence are not usually available. Faced with limitations in experiences, the tendencies to prolong childhood and to develop feelings of dependency toward parents are significant (Larose & Boivin, 1998). To what extent was the goal of transition from dependence to some independence accomplished?

A recurring observation throughout both participant and parental interviews was the parallels of experiences that were not unlike those experienced by a young adult going off to live at college for the first time. To the extent that college serves as a transition experience for individuals, the program seemed to accomplish a similar goal. When discussing plans for the future the attachment that many of the participants had to family, and perhaps their ambivalence about becoming independent or their awareness of the many challenges they will face in doing so, reflects responses that might be heard among young adults without disabilities.

When asked about opportunities for independence, some parents felt the dorm experience may be an opportunity to further develop independence and abilities in certain life skill areas; others felt the experience of being surrounded by peers would provide a unique opportunity to enhance social skills. Interestingly the participants had a keen sense of their ability levels with regards to life skills. They were able to recognize when supervision was needed with a certain task and more importantly were able to discern tactics (i.e., a written list of procedures, a reminder note) that would allow for independently completing a task. Given the depth of insight into strategies that may result in requiring less supervision, perhaps parents and dorm project coordinators would benefit from reflecting on whether the participants are provided with enough learning opportunities to enhance their skills and/or learn additional coping strategies.

Participant interpersonal skills were assessed through the use of the roommate scenarios. The responses to the roommate scenarios are reflective of the personality differences of the participants that may include being assertive or somewhat passive. It is interesting that although all the young adults did provide a response that shows a certain amount of problem solving ability, the variability of responses was marked and sometimes ended with calling for help. Assertiveness in this area might be improved on with additional practice and learning opportunities.

As was noted, for some parents, there may be ambivalence around their youth’s independence. Parents of individuals with developmental disabilities typically remain involved in all aspects of the child’s life for a greater amount of time than parents of nondisabled peers do. In addition, as we have seen, cultural values that place a premium on social responsibility and care giving may also cause a parent additional pain when it comes to the possibility for independence. Finally, there may be the additional burden of trying to fill the void not only in a social or culturally valued role, but in the sheer amount of time that was spent providing care. Placing a child with a disability into the hands of someone else who does not know their child has the potential to cause much fear and anxiety. In addition, despite the ambivalence, the planning involved in helping their youth to find independence...
through moving out of their home can be viewed as a daunting task that may require additional effort on the part of the parent to seek out services in the community (Brown & Percy, 2007). Perhaps a support group facilitated by social workers during and after a transitional living program might help the parents by providing information and an opportunity to normalize their feelings of loss, pain, or ambivalence. Providing additional support in the community for parents in helping to plan (e.g., find employment, place to live) for the transition to adulthood can decrease the stress of the situation. The timing and duration of this support is also crucial and should not begin when the youth is graduating from school but should be ongoing through the child’s education and should include parents, students, and professionals from the community (Brown & Percy, 2007).

The perception that communication between staff and parents was insufficient came across in the interviews. Given the time, energy, and resources that the agency and the college invest in the program, and the parent concern for the future well being of their child, this perception is an important one. Shields and his colleagues (Shields, Saladino, Proctor-Szilagyi, & Doueck, in press) have proposed an integrated and interactive model of communication among all parties in such programs, parents, participants, agency, and sponsoring college. Because even the best of programs can be perceived as inadequate, the importance of in-depth and continuous communication between all parties cannot be overstated.

Finally, interviewees were sometimes uncertain about whether they were referring to the Y ALT experience or the summer dorm experience, and seemed to think of them as one and the same. The agency compartmentalizes these programs as residential habilitation versus day habilitation, though both were administered simultaneously at the same college. This separation, although it may reflect categorical funding streams and would be similar in most agencies servicing persons with disabilities, might need to be revisited. The participants were the same in both programs, and their individual service plans (ISP) were the same regardless of program.

Social workers can play a key role in facilitating joint meetings between the day and residential program staff, representatives from the college, parents, and participants relative to ISP that would go a long way to enhance participant learning and benefit the program. In addition, though the overall goal of independent living is important, creating narrower more specific goals for each participant can further assist staff in enhancing skill building. Furthermore, timely follow up evaluations for the participants, the parents, and day habilitation program providers with individualized comments with regard to each participant’s performance could enhance follow up and generalization across settings.

Stated somewhat differently, despite the common challenges of specified funding streams, particularistic service goals, and unique program staff, integration, and continuity between day and residential transition efforts are essential to maximize the benefit to the individual. The same way that residential habilitation funds can be used in unique and creative ways as this program attests to, so too must the funds for a program like Y ALT (day habilitation on a college campus) be flexible and used in creative ways. Perhaps having staff in common across both programs, or at the very least, frequent cross program staff meetings might go a long way in integrating the two cultures and toward shared common outcomes.

This evaluation is not without limitations. At times, it was a challenge for the interviewer to elicit a detailed response from the dorm participants. As a result, some of the richness and nuance of thought about the program may not have been adequately captured during an interview. Future evaluations might explore interview techniques that are friendlier for individuals with developmental disabilities. In addition, dormitory staff and agency professionals were not interviewed for this evaluation, two groups that would have enriched the narrative by providing an added interpretation to the dormitory experience. At times it was unclear if the interviewees were referring to the Y ALT program or the summer dorm program. Moreover, we do not know whether the two individuals who opted not to participate—one at pre and one at post—did so for reasons that would be important to the conclusions that can be drawn. In addition, despite the care with which we analyzed the data, and the fact that we submitted the results to agency supervisors and administrators familiar with the program for their review, we did not have an actual member check, that is, a parent or dorm participant review. Though care was taken, bias might have occurred during the analysis that absent a member check went undetected. And finally even the best memory and professional practice is not as good as if we had been able to tape record all interviews, thus making the replication of methods difficult.

Future studies would benefit from more clearly defining outcome measures to enhance the evaluation of program effectiveness (Brown & Percy, 2007). As suggested by Davis and Clark (2000) future longitudinal research is needed to monitor whether skills acquired are maintained over time and if goals of the young adults are accomplished. In addition comparisons between the findings of this program with others that have a similar design would also be helpful in distinguishing
programs strengths and weaknesses. Although this study only included individuals with mild developmental disabilities, it is imperative that future studies include evaluation of supports that exist for participants who have severe developmental disabilities. Last, future studies should also look to include a sample with more diverse ethnicities (Brown & Percy, 2007).

The results from the evaluation present a picture albeit a somewhat limited picture, of subjective experiences of life in the dorms for individuals with developmental disabilities. Did the agency achieve the goal of enabling individuals to transition toward a less restrictive group living situation? The answer from this evaluation would seem to be “It depends.”

Did we achieve our goals? In an earlier edition of this journal, Shek, Tang, and Han (2005) identified several steps for enhancing the quality of published reports detailing qualitative studies. For example, they suggest that the authors identify the philosophical base for the study, provide a clear description of the sample recruitment, pay special attention to the possibility for bias, provide a clear description of data analytic procedures, use techniques such as triangulation, peer checking, and member checking to enhance the “truth value” of the findings, and consider alternative explanations and negative cases. This article was written in that spirit. If the perceptions and lived experience of participants and their parents have contributed in some small way to a better understanding of the hopes, dreams, and the realities of young adults with disabilities as they transition from life with their parents to a life separate from their parents, then we are satisfied.

REFERENCES


