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The Transition Experience of Developmentally Impaired Young Adults Living in a Structured Apartment Setting

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The purpose of this qualitative descriptive study was to identify the lived experience of young adults with a history of pervasive developmental disorder and associated difficulties with aggressive behavior transitioning into independent living through a transitional apartment program. Nine men and 1 woman, aged 18 to 24 years, were interviewed. Nine were interviewed in their apartment, and 1 was interviewed in an adjacent staff office. Individuals were dealing with normative transition issues of adolescence compounded by significant developmental and psychiatric impairments that tended to delay their developmental trajectories. Themes of poor physical health and loss were identified. The research emphasized the need for individually tailored transition services based on needs and level of disability.
Key words: *autistic spectrum disorder*, *pervasive developmental disorder*, *qualitative research*, *transition to adulthood*, *young adults*

FOR MANY ADOLESCENTS with developmental or psychiatric impairments, their 18th birthday marks a discreet end of involvement in a child-centered mental health system. Involvement with the adult mental health system may involve changes in mental health provider, level and type of support provided by an oversight agency, and eligibility for educational services.

Understanding their difficulties, concerns, and perceptions of the transition can guide development of community interventions that consider their psychosocial needs. The purpose of this qualitative descriptive research was to describe how individuals in late adolescence or young adulthood, with a childhood diagnosis of pervasive developmental disorder (PDD), perceived their life in a transitional apartment setting. Nine individuals were interviewed in their apartments; 1 was interviewed in a staff office adjacent to the apartment.

Interviews occurred in 3 stages. The first involved obtaining consent for participation, followed by questions aimed at ascertaining personal history, current health status, social relationships, and information about the apartment. The third part involved a question about the growing-up experience and perception of the transitional experience to independent living. The analysis of the growing-up experience described by the participants showed predominant themes around poor physical health and issues of loss. Understanding the life experiences and struggles experienced by young adults with a history of PDD

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and other psychiatric disorders has implications for program planning and intervention. This study gives voice to the concerns directly expressed by individuals at risk for silence during the planning and provision of their care.

AIMS OF THE STUDY

The purpose of this descriptive study was to ascertain the specific experiences of adolescents and young adults with a childhood diagnosis of PDD who were receiving state-funded transitional clinical and living services and had transitioned into a supervised apartment setting associated with an adult mental health care services provider. The research was aimed at nurses involved in policy making, care planning, and treatment implementation for individuals with these issues. In this study, adulthood was arbitrarily defined as age 18 years. While this is arguable from a developmental standpoint, in the state in which the research was conducted, clients enter adult care at age 18 years and become ineligible for state-funded child/adolescent services.

Individuals with a diagnosis of PDD during childhood are likely to struggle with the transition into independent adult living. In addition to the normative stresses of living independently, these individuals must cope with the developmental and psychiatric difficulties imposed by their diagnosis. The concept of transitions was used as a theoretical framework for this study. While not confirmed through review of clinical records, this population likely had other comorbid diagnoses in addition to the PDD.

The questions that guided this research were as follows: How is it to transition into independent living if an individual is developmentally impaired, with behavior problems that necessitate psychiatric care? What is the lived experience of adolescents with PDD who have transitioned into a supervised apartment setting with an associated adult services model of care? How do they perceive their current functioning and the process of their transition into independent living?

REVIEW OF THE LITERATURE

The transition to an independent living situation, for all young adults, represents a normalizing task of late adolescence and early adulthood. For many individuals, this transition involves going to college, joining the armed forces, or choosing to live with friends. For adolescents with PDD in this study, the experience of transitioning to independent living occurred against a backdrop of impaired social relatedness, lengthy past out-of-home placements, limited family support, and limited financial resources.

Autistic spectrum disorders and pervasive developmental disorder

Pervasive developmental disorder is part of a broader spectrum of autism spectrum disorders (ASDs) that result in a neurodevelopmental disability with a range of impairments in communication, social reciprocity, and social relatedness. More specifically, ASDs can result in problems interpreting social cues, dysfunctional peer relationships, and problems with executive function.[1] These impairments inhibit the mastery of developmental skills throughout childhood and adolescence. Children and adolescents with PDD often struggle with modulation of anxiety, atypical social relatedness, and peculiarities in thinking and language, and this persists into adulthood.[2]

Individuals who experience early, severe, and persistent disturbances that disrupt the processes of socialization and the emergence of personal autonomy have been described for several decades.[3-5] Individuals with developmental disorders struggle with the transition to independent living from adolescence into adulthood. Long recognized and treated as a psychiatric disorder, ASDs, including PDD, are a complex mix of developmental difficulties and psychiatrically related symptoms.[6] Howlin,[7] in follow-up studies with adults with ASD, noted that high IQ and good language abilities influence outcome. Educational preparation, transitional programs, employment opportunities,

supportive families, and supportive community systems were identified as key to achieving independence and success.

Transitions of emotionally disturbed youth into adulthood

Most researchers agree that adolescence as a life stage presents significant challenges to individuals without developmental or psychiatric problems.[8] For developmentally or psychiatrically impaired adolescent youth, the transition is often complicated by poor mastery of developmental tasks characteristic of the latency stage of development. Browning and colleagues[9] noted that many of the developmental tasks of transition characteristic of adolescence require the very abilities that are impaired in youngsters with severe emotional disturbance. This impairment compounds their attempts to transition from adolescence into young adulthood.

Quantitative research on young adults with ASD or specifically, PDD, focused on adult outcome,[10] psychiatric and psychosocial problems,[11] employment,[12(p570)] and quality of life.[13,14] Only one study used qualitative methodology to interview adolescents with ASDs, looking at perceived stress and coping as they left school.[9(p36)] Participants with ASD perceived themselves as dealing with poorly with stress, but they could not give reasons for their poor coping. They believed they would fail and were concerned about interpersonal relationships.

SAMPLE

Participants were recruited by their case managers from a state-funded program providing supervised transitional living services for young people with a history of PDD in childhood. The mission of the service was to provide apartment living and associated case management aimed at increasing life skills and community independence. All individuals accepted into the program exhibited other high-risk behaviors and/or diagnoses, such as aggression or a history of significant sexually inappropriate or sexual offending behavior, along with a childhood diagnosis of PDD. At the time of the research, daily case management activities of the program were administrated through a team of staff and coordinated by a case manager. The program offered a variety of educational, vocational, and structured social activities in addition to apartment living. Specifically, staff worked with participants around job coaching, management of the apartment, grocery shopping, cooking, and social involvements with peers. All received community mental health services. While many participants had involved families, all of the individuals in the program were residing in structured apartment settings rather than family homes. Experiences in a family home were not systematically assessed before conducting the researcher. The researcher had no access to any participant clinical records before conducting the study and could not confirm or deny the presence of any other diagnoses.

Referrals to the program came from residential treatment settings, community caseworkers, and welfare department staff. Each accepted individual received a monetary stipend for his or her apartment and living expenses. The goal was increasing independence and less need for fiscal support as the individual obtained a job or more vocational skills. The exact arrangements of this were unknown to the researcher. Case managers shared that approximately 36 individuals lived in 3 structured apartment programs at 3 different geographical locations in the state.

DATA COLLECTION METHODS

Approval from university and agency local institutional review boards was obtained. The researcher initially attended a staff meeting with regional leaders of the program, answering questions, and distributing consents to contact. Three case managers expressed willingness to recruit participants from their caseloads of individuals involved with the transitional living program. Several phone

contacts were made with each case manager, and the study design and purpose was re-explained. Case managers then reviewed their caseloads for eligible individuals and invited them to participate in the study. Once eligible participants agreed to participate in the study, the case manager obtained the initial written consent, which allowed the researcher to contact the participant by phone.

Twelve males and 3 females were identified by case managers as eligible for the study and represented about one-third of total individuals involved in the living program. In case of 3 referred participants who initially consented to the study with their case manager, the researcher recognized their names from past clinical encounters and did not contact them. The case manager returned to the participants and indicated that the researcher could not do the interview because of the past clinical knowledge. It was reported by case managers that they accepted this with no questions. For 2 other participants, consent was obtained by the case manager; one dropped out of the transitional living program, and the second, in the presence of a program staff person, stated, "I am the soldier of death, getting ready to fight World War III." The interview was stopped immediately and the case manager was contacted; she then arranged psychiatric intervention. No other contact occurred with this individual.

Sample size was determined by the numbers of individuals willing to participate in the interview. All eligible participants needed to have verbal communication skills. Literacy was not required, as all consent forms could be read to the participant by the case manager or researcher. Any prior clinical involvement with the researcher, where the researcher or participant was specifically known to each other from a previous clinician-patient relationship, disqualified the participant from the study. No participants participating in the interview were known to the researcher; 2 participants thought they remembered the researcher from a previous clinical setting but could not remember exact circumstances; they chose to continue the interview.

Case managers verbally indicated that they reviewed their caseloads for eligible individuals, but the researcher had no knowledge of exact numbers of individuals who might have been eligible or who were approached and declined involvement. Clinical or demographic characteristics of others involved in the transitional living program were not specifically identified to the researcher. While program eligibility requirements were strict, the researcher could not make the assumption that others in the program, who did not participate in the research, were similar to the population that was interviewed. Representativeness of participants could not be clarified.

It took 4 months from the initial staff meeting with program staff to obtain the first consent to contact participants. It took 6.5 months to conduct interviews. At the conclusion of the last interview, all 3 case managers indicated that there were no other eligible or interested individuals in their program. Sample size, 9 men and 1 woman, was determined by the numbers of individuals willing to be interviewed referred by case managers.

Prior to each interview, a phone contact was made with all participants to schedule an interview and do a brief explanation of the research. All first face-to-face contacts with participants were planned and expected. All participant interviews occurred willingly, with case manager knowledge and backup, if needed. No adverse reactions to the interviews were identified by participants or case managers after the conclusion of the interview.

Typicality of the informants and their responses was established through description of the participant sample. Program staff members indicated, based on their extensive knowledge of individuals in their program, that the 10 individuals who agreed to participate in the research were representative of individuals in the project, their life situations, and concerns. The researcher was unable to confirm this and had to rely on case manager perceptions and the general eligibility requirements for involvement in the program: a

history of PDD, a problem with aggressive or violent behavior, and readiness for community living. Participants represented a range of ages, all within the criteria for late adolescence or young adulthood (ages 18-24 years).

This study followed the guidelines of Beck[15] to evaluate credibility, fittingness, and auditability of qualitative research. Credibility was assessed through constant checking of field notes, clarifying ideas with a research advisor, and consideration of researcher presence on the process of the interviews with participants. At the conclusion of each interview, field notes were documented, and a follow-up phone call to the caseworker was made, at program and institutional review board request, identifying whether there were any problems noted with the participant. All participants knew that this phone call would occur after the interview. A written summary of findings was sent to each caseworker, who agreed to distribute this to participants, if requested. The researcher was not allowed further contact with participants after concluding the interview. A presentation of research findings was made to 2 different groups of caseworkers at staff meetings.

While member checking may be the ideal way of assessing auditability, it was not possible in this study. Ideally, the researcher would have done a follow-up interview with participants to conduct member checking of the interview; this was not allowed by the internal review board of the state agency that funded the program. Staff concerns centered on participants getting too attached to the researcher. As a result, multiple methods of data collection could not be used to determine congruence of the results among participants. Janesick[16] noted that a valid variation from this could involve having an outsider read field notes and transcriptions. In this study, the research advisor reviewed all data collected throughout the study. All research activities were carefully documented and composed of an audit trail that could be followed by others.

DATA ANALYSIS METHODS

The researcher brought nearly 25 years of clinical involvement with psychiatrically disturbed children and adolescents to this research study. Familiar with transitional living programs, psychiatric hospitalization, and residential care settings, this knowledge was constantly evaluated and checked for bias as data were analyzed for themes. The researcher had clinically treated many adolescents with a childhood diagnosis of PDD and was familiar with the particular challenges presented to this population as they mature into adulthood.

The research interview process was divided into 3 parts. The first involved obtaining written consent from the participant. The second involved a semistructured interview schedule that was developed to better understand participant transition into adulthood (Appendix). The 11 questions posed prior to the predominant research directive involved inviting participants to talk about themselves. These questions were organized around themes of living environment, presentation of self, personal history, and relationships with others. The questions were developed to allow participants to become comfortable with the researcher and to provide a background of their life experiences. The researcher used probing questions to elaborate each of the 11 questions if participant descriptions were not clear or required elaboration. Probing stopped when the participant had nothing else to say about the question.

The third part of the interview involved the predominant research directive: "Tell me something that has happened in the last few months that helped you understand that you were growing up and becoming more independent in your living." This directive was developed in consultation with professional colleagues and other researchers. It was designed specifically to identify a part of the transition experience between adolescence and adulthood.

The 7 questions after this directive were designed as probes to assist participants in elaborating about their experiences. Each participant was asked these questions in the same order.

The interviews lasted between 35 and 60 minutes; 9 occurred in the participant's kitchen or living room, and 1 occurred in an adjacent staff office with the door closed. Two tape recorders were used to capture the narrative. No notes were taken by the researcher during the interview. Several participants smoked during the interview and drank soda or coffee. All who agreed to the interviews were gracious, polite, and expressed no hostility toward the researcher. All were curious about the research and accepted that an abstract of the study would be sent to their case manager for distribution to them. Interviews directly followed the semistructured questions noted in the Appendix.

Descriptive qualitative research, defined by Sandelowski,[17] was chosen as the qualitative methodology for this study. After an exhaustive literature review, no studies were found that specifically asked adolescents with PDD what it was like to grow into adulthood. There was no description of the growing-up event from the perspective of the individual. Most research was quantitative in nature and addressed psychiatric diagnostic issues or specific issues of functioning, such as language, occupational status, or intelligence. No research was found that interviewed this population in their home environment. Participants, by nature of having PDD, could be limited in their ability to interpret their life situation or their transition into adulthood. Qualitative descriptive research offers "a comprehensive summary of an event in the everyday terms of those events."[17(p336)] Before conducting the research, the researcher was uncertain how participants would respond to the interview questions and how they might answer the potentially affect-laden questions. Despite these concerns, their verbal responses, cryptic at times, allowed a picture of their transition into adulthood to emerge. These responses, combined with researcher observations of the environment, of the participants' affects, and of the participants' appearance, make this research a descriptive snapshot of feelings and thoughts of the moment, of the participants' view of the transition into independent living, and of participants' view of growing up at the time of the interview.

The interviews recorded on audiotape were transcribed verbatim and analyzed by the researcher and a research colleague. Line-by-line coding occurred after ascertaining predominant themes. All personal information that could compromise anonymity was removed from the transcript. At the conclusion of the research, all interviews, tapes, and transcriptions were destroyed.

FINDINGS

All participants had a documented past diagnosis of PDD and a history of difficulties managing aggression. All but one participant had experienced psychiatric hospitalization(s) and/or residential placement(s) as children, adolescents, or young adults. Four participants had ongoing extended family involvement and support. Six participants reported limited or no family support and relied exclusively on project staff to meet their kinship needs. One participant indicated current involvement with the adult probation system due to a past assault. Socioeconomic status of family or origin was not assessed.

All participants were white and English speaking, with 9 men and 1 woman participating in the study. Ages of participants ranged from 18 to 24 years, with a median age of 20 years. Six participants were living alone, and 4 were sharing an apartment with 1 or more roommates. All had lived in the structured apartment setting for at least 4 months at the time of the interview. Six participants were involved in attending high school, vocational training, or community college. Of the others, 1 individual attended a full-time therapeutic day program, 1 individual volunteered, 1 worked part-time, and 1 participant did not work or attend school but was looking for a

job. One interview occurred in early evening, and all others occurred during daytime hours.

Analysis of semistructured interview themes

Themes from the semistructured questions (Appendix) were organized around living environment, presentation of self, personal history, and relationships with others. Living environment was defined as the space where participants made their home. Nine of the 10 interviews occurred in participant apartments; the 10th interview occurred in a staff office adjacent to the participant's apartment. All apartments appeared run-down and physically dirty. One participant lived on the top floor of a multifamily house. Like the other apartments, his living environment was accessed by a long climb up a narrow, poorly lit staircase. His apartment was cluttered but neat, and he was the only participant who made direct, detailed comments about his living environment. He stated:

> It's a lot bigger up here than it is downstairs. It's a lot more space, a lot more room, and the only thing I miss that I had downstairs was the cabinet space. The counter space . . . my coffee pot and my strainer take up the whole counter . . . the living room is bigger.

He seemed emotionally connected to his apartment in ways that were different from the other participants who tended to be emotionally detached from the environment.

The 9 apartments where interviews occurred were sparsely furnished, with various degrees of cleanliness, devoid of personal belongings such as pictures or books. Two apartments that were staffed many hours of the day appeared cleaner.

Most participants appeared unkempt and messy; two were oddly dressed for the context of the interview. Although a cold winter day, the female participant wore a short-sleeved summer weight dress with no stockings, tights, or socks, and low-heeled pumps. She did not comment about the cold environment of the office where the interview occurred. Another participant's apartment was extremely warm, yet, he remained dressed in a heavy winter coat, cap, and gloves throughout the interview. He seemed unaware of his dress and did not appear warm.

All participants presented with varying degrees of guardedness in the beginning of the interview. For 3, this persisted, and for the other 7 participants, it seemed to dissipate as the interview progressed. One participant had significant difficulty organizing his thoughts and verbally expressing them. He was easily disorganized and clearly distressed by some interview questions. He was short of breath throughout the interview, and when asked, he reported that he had asthma. His movements and responses were, at times, slow and delayed.

Interviews with 8 participants seemed characterized by feelings of depression and sadness. Most seemed unsatisfied with their living situation, but when questioned further, they were unable to define ways that this could improve. All participant descriptions of feelings associated with answers to questions seemed limited; it was unclear whether this was a reflection of their inability to easily define affect, of trust in the researcher, or was part of deep and painful feelings about their life situations.

Personal history was defined as participants' view of life events and relationships from the past and present and the way they related this to their future. Nine of the participants in the research shared that they had been psychiatrically hospitalized or residentially placed in childhood or adolescence prior to the interview. Seven participants related that they had spent several years in residential treatment settings.

Participants had mixed opinions about residential treatment programs. One stated:

> B. (residential program) kicked me out. Because I mean I hated it. You lived in this room with like sex offenders and just kids with real problems. And I was sitting there and man, I was so pissed off. I would just jump out the window and just go out and spend the day outside in the fresh air. And they

call it running away. . . . You know I just needed some space.

The female participant spoke positively about the residential program she was in for 4 years and talked about missing her therapist stating, "She was like the grandmother type." When asked about his most recent residential placement, 1 participant noted:

I liked it and I went through a lot there . . . had some bad times . . . at first when I got there I kind of hated it, you know because of the rules and stuff and all the things with staff. I wasn't really used to the place but now that I'm gone actually I love the place and I miss it big time. And all the people there.

Another participant expressed insight into his past residential placement, lasting 6 or 7 years. He stated:

You learn a lot when you go (to residential setting). You learn a real lot, a whole much . . . just that you learn how to be independent, you learn how to make your own decisions. I mean it is hard and it is not easy. You learn how to live on your own. But you don't get to practice that because you are very secluded from everything. You don't learn very much when you are secluded. But you learn how to do it. They don't show you how to do it.

He went on to relate that he was presently trying to practice independent living skills such as shopping and paying bills in his current apartment situation. He had a full-time staff member assisting him.

At the time of the interview, 1 participant was volunteering at a firehouse, cleaning ambulances (with staff supervision). Six participants were attending a formal school program. One participant was involved in an adult therapeutic day program. One participant was working in a family restaurant, and 1 participant was unemployed and not in school but searching for a job. Only 1 shared that he enjoyed his present activities working in a children's restaurant. He related that he had found the job "on my own" and that the boss had recently praised him for his good work. No other participant spoke as enthusiastically or positively about work or school activities.

Relationships with others were defined as all relationships identified by participants, including roommates, family, friendships, romantic interests, pets, and relationships with staff. For 1 participant, the most discussed relationship involved his pet cat. Four participants lived in an apartment with a roommate, and all complained about the roommates. One participant was very negative about his roommates and saw them as "disturbed." Only 1 participant expressed a positive connection to one of his roommates, whom he called "my best friend."

Six participants described painful feelings when questioned about their families. They cited nonexistent or difficult relationships. Five participants seemed avoidant of any in-depth discussion of their families, even with researcher probing. The exception to this was one of participant, who was vitriolic about his mother and her treatment of him. His voice rose in fury as he spoke of her rejection and his pain at her behavior.

The other 4 participants spoke of their families in positive terms. One participant described separating from his mother during an argument and then renegotiating a healthier relationship several months later with staff assistance. As he described this, his bland affect and simple resolution to an emotionally charged relationship seemed incongruent. When this was pointed out to him, he did not seem to understand the probe.

Others described a positive relationship with grandparents, of missing a mother who was placed in elderly housing, and of attachment to a supportive father. Only 1 participant volunteered that he was loved and wanted by his extended family.

Four participants spoke of making friends within the program and viewed this as positive. Several participants spoke of friendships with individuals outside of the program, including church friends, or past childhood friends. One participant also refused to discuss friends, and it seemed a painful topic. Another noted, nearly in tears, "I had relationships I shouldn't have." He refused to elaborate more about this.

Only 2 participants identified having an ongoing romantic interest. While 1 participant's romantic interest was psychiatrically hospitalized at the time of the interview, the participant noted that they planned to marry. When asked what this would be like, the participant answered, "I'll probably just revert back to type where my . . . I'll be expecting him to do everything for me and I can't. I've got to start learning for myself to do everything on my own." Plans for this relationship seemed unrealistic and idealized. While several participants related they wished for a romantic relationship, no others had begun dating or having social involvement with peers.

Relationships with transitional living staff seemed a blend of positive and negative. The 2 participants who were most dependent upon staff supervision complained the least about the constant involvement of someone else in their lives. One participant complained about the lack of availability of program staff; 4 participants cited that the assistance with money management and budgeting was very helpful. One longed for freedom from staff. While he raged at their intrusion, it seemed part of his anger was with himself for reluctantly relying on the support they provided.

Another participant seemed bitter about staff and talked of wanting to move out of the program. He said that "staff are too nosy" and "they do all this stuff but the last couple of weeks I've been having trouble with them, they switched my case manager because I was talking inappropriately but they gave me one I don't like. And this is tough." He complained about staff not providing a timely ride, about the staff office being too physically close to the apartment, and about the lock on the door being deficient. His apartment was very dirty, and he complained that staff expected him to keep the apartment clean. He presented as generally unhappy with these demands.

Only one participant had a pet. The dark messiness of his apartment was eclipsed by the presence of a beautiful, well-fed calico cat. Carefully groomed, she was sprawled on the back of the living room sofa through most of the interview. As we spoke, she seemed to peer from face to face, as if listening to us talk.

Analysis of growing-up event

In the third part of the interview, all participants were asked to describe the transitional event that signaled, to them, that they were growing up and becoming adults. The specific question, posed to each participant, was "Tell me about something that has happened in the last few months that helped you understand that you were growing up and becoming more independent in your living." This was then followed by probe questions to assist them in elaboration of the answer.

One participant's response was odd that could not be clustered with others. He stated, "It would be beginning to feel more energetic." He stated that this increase in energy had happened "awhile ago." He noted that he was "fat" and had lost about 16 lb. He did not or could not elaborate on this issue. His answer was in direct contrast to his laborious, slow mannerisms, his difficulty moving from one location to another, and his shortness of breath (which he said was from asthma). He did not present as energetic and seemed to be trying to convince the researcher that he was doing well.

The remaining 9 participants clearly identified events that indicated, to them, that they were growing up. The 10th participant was less specific about the event but spoke about other issues that related to growing up and becoming more independent. Events were clustered around increasing independence, including the physical move into the apartment and specific tasks related to adult behavior. Clarification of relationship with mother and accountability for behavior were also noted as symbols of growing up.

Five participants related growing-up events that involved increasing independence in conducting daily tasks. These included getting into an independent apartment, opening a bank account, shopping alone in the grocery, and living in the world without assistance.

One participant recalled a specific day when he began realizing he was growing up. For him, this involved noontime on a Saturday when he was in his apartment, playing games on his PlayStation. He recalled that his windows were open and it was warm. He stated, "I felt like I was born again. I felt like people actually respected me . . . I was a citizen of this country . . . it felt good." He talked about loving the freedom of his apartment.

Similarly, another participant cited that getting his apartment was the event that marked his growing up. He related this identification with the boy character in "Home Alone" and said that he related most to the part where he took care of himself, going to the grocery, and cooking his food. Other themes included, grocery shopping and opening a bank account: "No body touches it except me so I like that."

Another participant responded to the question by stating:

> Actually, I have the answer already. Because I am thinking about when I was in [another program site] and I was always relying on staff there to give me rides and stuff. You know, to help me out with stuff and whatever. But now, you know because I don't rely on them so much anymore. Sometimes I do but when I moved to [a new town] I'll need them less and stuff. I'll need to be on my own and I basically ask, why should I have staff do stuff? When I can do it on my own?

In contrast to these specific answers was the response from the participant who expressed the most dissatisfaction with the transitional living program and did not directly answer the question. He stated:

> Pretty much I've lived independent you know and that's why when I see staff come in and you know I've been on my own for awhile and come and go as I please, I'm used to, you know freedom, actual freedom.

The edge of suspiciousness and paranoia that characterized the entire interview and his need to describe his negative feelings about his mother and family seemed to prevent him from considering a specific growing-up event. When questioned further about his "independence," he admitted that he had been "living on the streets."

Two participants spoke movingly about their mothers and how the move to increasing independence had affected these relationships. One participant stated:

> Like, um, when I'm upset and I know my mother isn't there to hold me and to tell me "there, there, everything is going to be OK" and like she used to when I was little. You know . . . you're alone, you can't rely on your mother anymore. You can't call her Mommy and go "mommy, mommy, I need you, I need you," you know. You've got to live on your own for once and do you know, grow up. You can't be a big baby anymore. You've got to clean your own apartment, you've got to take care of yourself, you've got to do everything on your own . . . learn how to pay bills eventually . . . learn how to pay the rent. You can't spend all your money at once . . . it's just the whole nine yards.

Another participant went into great detail about his realization that he was becoming an adult. When asked the research question, he quickly stated that it was "when I stopped speaking to my mother. When we were fighting I realized that I had stood up for myself and that I had told her how I feel. I'm sorry, but I don't want to have her disrespect me in my home." Expression of his anger toward his mother and setting limits on her behavior seemed to symbolize his transition into adulthood. He said, "I'm really, really trying to grow and realizing that it is time for me to stand up and fight for my own rights and independence." He noted that he has changed, "I think I have become a lot more independent, a lot more stronger, like in my beliefs." He acknowledged the negative parts of growing up, stating, "Because you miss your family, you miss people you love and you have a hard time dealing with things that you go through when you are growing up." This participant ended the interview by noting that the positives of growing up far outweighed the negatives.

While each participant hinted at some accountability around being in an independent apartment, only one used this theme in describing his growing-up experience. The first

participant interviewed for the study, talked at length about his probation, given for 3 years for breach of peace because he had "kicked someone and hit someone." In both situations, he was arrested, psychiatrically hospitalized, and given 3 years of probation. He said, "I had a year of jail sentence hanging over my head," noting said that the courtroom was "awful." He became tearful at this point and took a break from the interview.

Later, he noted that he was "surprised at the fact that if I violated my probation I might go to jail." He stated that he had "a different perspective on life ... now I can look forward to my future ... not doing the wrong thing." This participant concluded the interview by noting that he was "growing up in pieces." He did not elaborate on this.

It is notable that many of the participants in this study had nonexistent or unrealistic plans for the future. Three participants could not elaborate on future plans. In contrast, 1 participant was able to articulate clear future plans and stated, "My eventual goal is to move out of this program and be on my own, to live in this apartment, to support myself and pay my own bills." He worked part-time in a small retail store and had a goal of independence from the program within 1 year. It was unclear whether or not his current employment could support financial independence, even if the job became full-time. Similarly, another participant noted that he wanted to become independent from the program, with a patent for a sneaker design. He admitted that he had sent several designs to a sneaker designer, but they were not interested. This seemed unrealistic for a young man who was struggling with finding a menial job.

One participant was working on her high school diploma, and once this was finished, she wanted to go to community college to take a course in early childhood development. Her goal was to open her own daycare center. She stated, "I love little kids ... any age from newborns up to second grade." She had never worked in a daycare situation and was not employed at the time of the interview. I had difficulties imagining this disheveled, disorganized young woman running a daycare center.

Two participants worked part-time in restaurants and talked vaguely about getting full-time jobs, going to college, or designing video games. It seemed nearly impossible for these young men to become fully independent, given their perceptions of their future.

One participant, dissatisfied with the program, was attending a local high school for individuals with special needs. He wanted "something better," yet, he described being unable to participate fully in the work-study program in the high school, designed to give participants spending money. He gave no explanation for this other than saying, "I'm stressed with the program and with bills, bills." He was unhappy with the decreasing amount of public aid he would receive as he became older. He did not speak of earning his own money or being self-supporting. He spoke vaguely but vehemently about leaving the program stating:

> Cause it's not real life. In real life you wouldn't have someone making sure that your bills are paid ... I want someone to help me but I want more freedom. This is "their" apartment; it's not my apartment. This table is not mine, it's theirs, that's theirs, all except the fish and the clothing ... is mine.

DISCUSSION

It is normative for adolescents to complete specific developmental tasks in order to move into young adulthood and assume associated independence and reliance upon self. Cognitively, they move to more abstract representations, more multidimensional thinking, more relativism, and increasing self-reflection and self-awareness.[18] Social development is characterized by increasing importance of peer relations, expanding social networks, and modifying relationships with family.

Similarly, for youth with disabilities, a predominant task for young adulthood becomes ascertaining job and vocational interests, receiving training, and then getting a job that is self-supporting and provides independence.

Howlin et al[19] cited the importance of family in providing assistance during the transition, whether or not the individual was in an independent living situation or still residing at home. Participants in this study were experiencing a transitional experience into adulthood that encompassed more life issues than their structured living apartment. These issues included vocational choices, social relationships, and negotiating tasks such as caring for themselves physically.

The initial questions that guided this research were as follows: How is it to transition into independent living if an individual is developmentally impaired, with behavior problems that necessitate psychiatric care? What is the lived experience of adolescents with PDD who have transitioned into a supervised apartment setting with an associated adult services model of care? How do they perceive their current functioning and the process of their transition into independent living?

The transition experience was likely influenced by the individual's history of placement, diagnosis, ability to manage increasingly independent living, and length of time in the transitional living program. None of these issues were systematically evaluated before conducting the interviews with participants. During the interviews, it was ascertained by the researcher that participants tended to live in poorly tended apartments devoid of personal belongings, they struggled with family relationships, and they had mixed interpersonal relationships with others. All participants received state financial support, but none expressed concrete plans for becoming self-supportive. It was unclear whether this was related to their mental status, their emotional fragility, their inability to actualize independence, or to their diagnosis. It seemed as if staff were providing high levels of encouragement and training around increasing independence of participants. Was this a disconnect between participants' specific ability to be independent and expectations of the program? It was simply unclear how much they could make use of this assistance.

Two predominant themes emerged from the gestalt of the 10 interviews. At the time of the interview, the growing-up experience of participants seemed colored by a theme of loss. This involved loss of positive family relationships, loss of normative adolescent and young adult living, and loss of independence. At some point in each participant's interview, the researcher perceived some sadness about life situation or relationships. The researcher was also left with a sense of personal sadness at the conclusion of each interview. Upon analysis, this personal sadness seemed related to the lack of supportive intimate relationships many participants experienced.

Yet, caution must be exercised is assuming the presence of loss and associated feelings in these participants since questions involving sadness and loss were not directly posed to them. Several participants seemed sad and, at times, tearful over simple interview questions about their families or functioning. Eight of the interviews had themes of sadness and pain. The researcher also experienced personal sadness at the conclusion of each interview.

The second theme identified by the research was participant description and researcher description of poor physical health. All participants were younger than 24 years and should have appeared in optimal health for their age. Instead, nearly all appeared chronologically older. Eight participants appeared significantly overweight. Nine participants shared that they were taking 2 or more psychotropic medication to treat psychiatric disorders. They identified medication that could be used to treat a variety of symptoms including impulse control disorders, psychosis, depression, obsessive compulsive behavior, insomnia, and anxiety. Associated side effects, ranging from slowed movement and mannerisms, to obesity, to dulled affect, and to difficulty concentrating, were likely adversely affecting their physical health. It is probably these same medications that were enabling these individuals to function in the community, outside of a more restrictive psychiatric hospital or residential center.

Only 2 participants complained that medication "didn't help."

The only participants who noted a variety of foods in their diets were the 2 participants who had 24-hour staff assistance and supervision. Other participants talked of eating a limited type of food, such as hamburgers or burritos. One participant only used the microwave to make meals, after he accidentally caused a fire on a friend's stove. Of the 9 kitchens observed, only 3 appeared organized and clean, free of clutter, and dirty dishes. Healthy eating did not seem a high priority for any participant.

While all participants identified leisure activities that they enjoyed, including basketball, volleyball, and swimming, all cited rare opportunities to participate in these activities. Reasons for this were unclear. When asked why they did not regularly participate in these activities, most stated they did not know. One participant noted that "it had not been arranged," suggesting a reliance on others for setting up leisure activities involving exercise. The predominant leisure activity for each participant seemed to be watching television and playing video games. In one of the programs involving participants, there was a "TV room" where meetings and games occurred. Three participants identified this as a social outlet outside of their apartment.

When questioned, participants were vague about physical health issues. Hypothyroidism, hypertension, and asthma were identified by 3 participants as health problems necessitating medication. Participants appeared to be experiencing symptoms of metabolic syndrome, but none identified concerns about obesity or diabetes. No participants appeared physically healthy or could identify physical health as a priority, and most appeared sedentary and obese without a conscious sense of physical health needs.

There were several significant limitations to this study. The most significant involved the researcher's limited access to participants. While participants might have seemed representative of individuals involved with the transitional living program, they did represent only those participants who responded positively to the invitation to be interviewed. It is unclear whether the participants in this study were representative of all adolescents/young adults with PDD living in the program. While the researcher suspects that they were representative of a more dysfunctional group with PDD, there is no way of confirming this information. Most adolescents and young adults with psychiatric or developmental disorders are cared for within their families and have active involvement in their transition to more independent living. Six of the 10 participants had little or no family support, and the remaining 4 participants were unclear about their ability or willingness to rely on family.

Another limitation involved the lack of researcher query into participants' sexuality, a normative part of adolescent development. While 2 participants spoke indirectly of intimate relationships, this was not directly assessed and poses another study limitation.

It is important to note that 9 participants had experienced an out-of-home placement, suggesting that their behavior and symptoms as children and young adults were unmanageable in a less restrictive setting. This posed a limitation of the study around generalizing results to all individuals with PDD.

Another limitation of the study involved the researcher's role as an experienced clinician. There was a continual process of balancing, probing the participant for more information and respecting the nature of the disorder and what appeared to be emotional fragility. The researcher's experience could also be seen as a strength. The inability to conduct member checking after the completion of the interviews hindered the depth of the research. Also, the research was ethnically limited in that all participants were white.

This research could not answer whether or not participants in this study understood exactly what they had lost in terms of normative adolescent functioning. No participant noted a direct wish to be functioning in a different way, at least specifically. While interview questions were fundamental

and not designed to be emotionally probing, 4 participants became tearful at the point of asking about a growing-up event. Four participants expressed affect during the interview that suggested sadness and emotional pain. This involved memories from residential treatment, shame at a job, distress about a past arrest, and believing that "no one cared." Only 2 participants presented as upbeat and positive, expressing future plans and some satisfaction with their lives. For 8 of the participants, the researcher ended each interview with the sense that the individual was aware of missing social normalcy, which could be defined as a clean, home-like environment with caring family. These participants seemed to lack this normalcy, missed it, and did not appear to have the life skills necessary to change this.

Were participants aware of their limitations and did they experience emotional pain regarding this? One interview is not sufficient to explore this, and the question would require further interviews and research with a broader group of this population. The researcher's experience of subjective emotional pain felt during the majority of interviews would warrant further examination of this concept applied to adolescents with PDD. No literature was found that evaluated these issues. Meleis and colleagues[20] noted that completion of a healthy transition involves "mastery of the skills and behaviors needed to manage their new situations or environments."(p23) Each participant was experiencing a complex, multidimensional, interrelated transition that impacted living environment and encompassed health, nutrition, economic stability, separation from caregivers, and increased independence. At the time of this research, they seemed to be developing the skills necessary for ongoing mastery of the transition into adult living. Was this really happening or were participants simply "going through the motions" required by the living program? The unknown or unexamined factor in this transition involved their capacity or ability to master the transition to independent living. What type of transition could they accomplish, given their interpersonal, developmental, and psychiatric limitations?

While participants were not directly interviewed with these factors in mind, it seemed that there was some evidence of participant involvement in the beginning stages of a health transition. All participants had a least one personal connection to another person and indicated some type of interaction with staff or peers. While many apartments appeared transitory, participants were living in urban/suburban communities, on bus routes, near shopping areas, and restaurants. Their confidence and coping skills, at least around the limitations of their disability, were not assessed. It was not clear whether or not they understood the complexity of their limitations. All were attempting to develop new skills with staff support. All participants appeared involved in the transition, although the move to adulthood had not been completed. Meleis and colleagues[20] noted the need for individuals to reformulate their identity as they move through various transitions.(p24) For these participants, this meant integrating an apartment environment, possibly a roommate, and a new job or school milieu; most seemed in the midst of this role reformulation. What was lacking was a sense of self-reformulation or internalization of the independent expectations set out by the program.

All participants were experiencing multiple transitions, most aimed at increasing independence. The questions raised by this research include the following: Are participants capable of being independent? Are the interventions sufficient to help them become autonomous adults? How normative are these transitions when compared with peers who are not impaired with developmental or psychiatric issues? Despite numerous physical, social, and psychiatric vulnerabilities and despite the peripheral nature of their living environments, they were, as 1 participant described, "growing up in pieces."

CONCLUSIONS

This study, while limited in scope and generalizability of findings, gives consumer voice to service planning and delivery for similar young adult populations transitioning to structured community living. In retrospect, the research should have begun with questions such as Do you believe you are growing up? or "What does growing up mean to you? The researcher made the assumption that all were going through this transition based on their living environment and involvement with transitional living. In reality, this should have been clarified with each participant.

Each person in this study presented with emotional and/or developmental disabilities that made him or her vulnerable while transitioning to independent adulthood. This research illustrated the need for ongoing planning and support around concepts of wellness, such as psychiatric medication management, nutrition, exercise, and emotional well-being. The notion of graduated steps toward independence was not articulated by this particular transitional living program and was not cited by participants as they were questioned about plans for the future. It is not clear whether this existed.

This study presented a beginning query into the obstacles faced by individuals without intensive family supports, with chronic psychiatric and developmental difficulties, moving toward increasing adult independence. A broader knowledge base of each participant, including family background, clinical status, long-term plan of care, and level of functioning would have been a helpful backdrop to the study.

Additional questions raised by the research include the following: What nursing intervention holistically meets individual needs and results in a more productive and healthier level of functioning? Could these participants become self-supporting? Could they achieve increased independence within the limitations of their present functioning? Are there successive steps toward an integration of an autonomous model of independent living? How is their functioning influenced by perceived loss? These are all questions for future nursing research.

This group reflected the trend toward community-based models of care, and this transitional living program might have been a more adaptive alternative to more restrictive living environments. These participants were living and functioning in established urban/suburban communities with identified case managers, budget planning meetings, therapy groups, and job coaching. They could articulate their involvement in these activities and seemed to, for the most part, accept them as part of the transitional living program. The question remains: Did this model best meet the individual's needs for transition to independent living? Is there a better way to assist in the transition to adulthood?

One of the greatest concerns identified by this study was participant lack of acknowledgment of physical health issues, involving obesity, smoking, and lack of exercise. There are complex links between obesity and chronic mental illness and developmental disorders. How could nurses intervene with this life-threatening comorbidity?[21] Further research and interventions are needed to ascertain ways to improve physical health status, identify quality-of-life issues, and facilitate progression to increasing independence. Participants, while they complained about staff and certainly seemed to feel pain about their experiences in treatment systems, were functioning in their community apartments. While unclear how they were going to negotiate further transitional processes into independent living, at the time of the interviews, their descriptions of their growing-up event illustrated that these participants were experiencing the developmental transition into adulthood and trying to grow up.

Finally, this study, while limited in scope and generalizability of findings, emphasizes the need for consumer voice in planning care. Nurses must ask how they can adapt their practice to better meet the emotional and physical health needs of this population while assisting them in the transition to more

independent living. There should be a comprehensive needs identification, followed by a seamless transfer of information between policy makers, treatment planners and providers, and consumers.[22] Ongoing clarification of individual needs and abilities should occur in a feedback loop that adjusts services as required and tailors interventions. It is essential that attention be paid to the physical health status of these individuals. This has serious implications for long-term well-being and the high economic and personal costs of utilizing health care services for chronic physical conditions. Despite their limitations, these participants were undergoing a transitional experience to more adult levels of functioning.

REFERENCES

1. Tani P, Newton N, Kaur A. Clinical neurological abnormalities in young adults with Asperger syndrome. *Psychiatry Clin Neurosci*. 2006;60:253-255.
2. Billstedt E, Gillberg IC, Gillberg C. Aspects of quality of life in adults diagnosed with autism in childhood: a population-based study. *Autism.* 2011;15:7-20.
3. Kanner L. Autistic disturbances of affective contact. *Nervous Child*. 1943;2:217-250.
4. Putnam MG, Rank G, Pavenstedt E, Anderson IN, Rawson I. Round table 1947: case study of an atypical two-and-a-half year old. *Am J Orthopsychiatry.* 1948;18:1-30.
5. Rank B, MacNaughton D. A clinical contribution to early ego development. *Psychoanal Study Child*. 1950;5:53-65.
6. Freitrag C, Kleser C, Schneider M, von Gontard A. Quantitative assessment of neuromotor function in adolescents with high functioning autism and Asperger syndrome. *J Autism Dev Disord*. 2007;37:948-959.
7. Howlin P. The outcome in adult life for people with ASD. In:Volkmar FR, ed. *Autism and Pervasive Developmental Disorder*. 2nd ed. Cambridge, England: Cambridge University Press; 2007:269-306.
8. Cuffe SP. Assessing adolescents. In:Dulcan MK ed. *Dulcan's Textbook of Child and Adolescent Psychiatry*. Washington, DC: American Psychiatric Publishing; 2010:47-57.
9. Browning J, Osborne LA, Reed P. A qualitative comparison of perceived stress and coping in adolescents with and without autistic spectrum disorders as they approach leaving school. *Br J Spec Ed*. 2009;36:36-43.
10. Eaves LC, Ho HH. Young adult outcome of autism spectrum disorders. *J Autism Dev Disorder*. 2008;38:739-747.
11. Hofvander G, Delorme R, Chaste P, et al. Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC Psychiatry*. 2009;9:35. http://www.biomedcentral.com. Published June 10, 2009. Accessed January 18, 2012.
12. Taylor JH, Seltzer MM. Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *J Autism Dev Disorder*. 2011;41:566-574.
13. Billstedt E, Gillberg IC, Gillberg C. Autism after adolescence: population-based 13-to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. *J Autism Dev Disord*. 2005;35:351-360.
14. Lee LC, Harrington RA, Louid BB, Newschaffer CJ. Children with autism: quality of life and parental concerns. *J Autism Dev Disord*. 2008;38:1147-1160.
15. Beck CT. Qualitative research: the evaluation of its credibility, fittingness, and auditability. *West J Nurs Res*. 1993;15:263-266.
16. Janesick VJ. The choreography of qualitative research design. In:Denzin NK, Lincoln YS, eds. *Handbook of Qualitative Research*. 2nd ed. Thousand Oaks, CA: Sage; 2000:379-399.
17. Sandelowski M. Whatever happened to qualitative description? *Res Nurs Health*. 2000;23:334-340.
18. Keating D. Adolescent thinking. In:Feldman SS, Elliot GR, eds. *At the Threshold: The Developing Adolescent.* Cambridge, MA: Harvard University Press; 1990:54-89.
19. Howlin P, Goode S, Hutton J, Rutter M. Adult outcome for children with autism. *J Child Psychol Psychiatry*. 2004;45:212-229.
20. Meleis AI, Sawyer LM, Im EO, Hilfinger M, DeAnne K, Schumacher K. Experiencing transitions: an emerging middle-range theory. *ANS Adv Nurs Sci*. 2000;23:12-28.
21. Taylor VH, McIntyre RS, Remington G, Levitan RD, Stonehocker B, Sharma Am. Beyond pharmacotherapy: understanding the links between obesity and chronic mental illness. *Can J Psychiatry*. 2012;57:5-12.
22. Lawrence DH, Alleckson DA, Bjorklund P. Beyond the roadblocks: transitioning to adulthood with Asperger's disorder. *Arch Psychiatr Nurs*. 2010;24:227-238.

APPENDIX

Growing Up in Pieces

Appendix. Interview Structure and Questions

Each interview will begin with an explanation of the research through reading the informed consent, clarifying questions about the research or the consent, and obtaining subject signature. Before beginning the interview, each subject will be told the following:

It is the researcher's view that moving into adulthood is a process that takes a long time and involves many things. Turning 18 or even 21 does not mean that a person is automatically an adult. Moving into an apartment is one step in making the transition to adulthood. I hope you can help me understand what it is like for you to be in the process of becoming a grown-up.

Qualitative questions for subject: Individual description of life situation

1. *Tell me about yourself*
   - Where were you born?
   - Who is in your family?
   - Where did you go to school?
   - Have you ever been in the hospital?
   - Do you take medications?
   - Do you work or go to school?
   - What do you like to do for fun?
   - Do you have friends?
   - If so, who are they?
   - When did you move into this apartment?
   - How is it to live here?
2. *Tell me about something that has happened in the last few months that helped you understand that you were growing up and becoming more independent in your living?*
   - When did this occur?
   - How old were you?
   - Where were you?
   - Describe the place.
   - What were you doing?
   - Were you with other people?
   - What were you feeling?