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Parent and Youth Priorities during the Transition to Adulthood for Youth with Special Health Care Needs and Developmental Disability

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Abstract

Families undertake extensive planning during transition to adulthood so youth with concomitant special health care needs and developmental disabilities will have a long-term high quality of life. Findings from an interpretive field study involving 64 youth and their parents indicated that the meaning of adulthood was functioning as independently as possible with appropriate supports. Parental priorities included protecting health, assuring safety and security in multiple realms, finding meaningful activities after high school, and establishing supportive social relationships. These priorities demonstrated the need to broaden usual health care transition goals that focus on finding adult providers and optimizing self-management.

Adolescents with both chronic health conditions and developmental disabilities are likely to need continuing support for daily activities into adulthood. Therefore they, and their parents, face daunting challenges during the transition to adulthood. Health care research, policy, and support for the transition years have primarily focused on the need to move adolescents and young adults from child-focused to adult-oriented health care settings and providers. There has been less attention to priorities and goals of youth and their parents, particularly those with both health and developmental challenges. The term “youth” will be used to encompass the adolescents and young adults (age 14-26) who are the focus of this article. This term is recognized by the World Health Organization and widely used in transition literature.¹

This article will present findings about the meaning of adulthood and priorities for transition from a symbolic interaction-based field study in which we used ethnographic methods of interview and observation to study planning for the transition for 64 youth with special health care needs (YSHCN) and concomitant developmental disabilities. Aims for the study were to describe the meaning of adulthood for these youth and parents, discovering how

parents worked with school, community, and health care professionals and other resources in planning for the transition to adulthood, and to analyze the impact of care on family roles and responsibilities.

Background

In the U.S., more than 11 million children have special health care needs (CSHCN), and 1.3 million adolescents (age 12-17) were reported to have a chronic health condition as well as developmental, emotional, or behavioral needs for which they received special education services during the 2009-10 Survey of Children with Special Health Care Needs (CSHCN).² Children with both a physical health condition and a need for special education used significantly more health services (\$3,891/year) than those solely having a physical health condition (\$1,426/year), or those who were neither CSHCN nor enrolled in special education (\$644/year).³ Of YSHCN with developmental needs 29% were receiving the full spectrum of transition services recommended by The Maternal Child Health Bureau.²

Goals and priorities of health care professionals for the transition to adulthood of YSHCN are epitomized in joint documents created by the American Academy of Pediatrics, American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine.^{4,5} Working groups from these professional organizations have stated that planning for transition should be part of care within a medical home for all youth, include chronic care management as appropriate, begin in early adolescence, and continue into adulthood. The most recent joint report offers specific timelines and topics for clinical planning, and suggests actions by both pediatric and adult practitioners that are focused on assuring continuity of health care and assumption of increasing responsibility by youth as possible. Healthy People 2020 includes goals relevant for YSHCN and disabilities that include, but go beyond, health-related concerns. These include increasing transition planning in pediatric practices, decreasing barriers to participation in home, school, work, and community activities, and decreasing the numbers of people residing in large congregate settings.⁶

Youth with developmental disabilities are usually eligible for special education services codified by the Individuals with Disabilities Education Act (IDEA).⁷ Planning for the transition to adulthood is mandated within IDEA, and requires goals that facilitate movement of the youth from high school to post-school activities that can include college or vocational education, employment (either independent or supported), adult services, independent living, and community participation.⁸ Implementation and specific services offered varies widely by state and school district, however.⁹ Despite this emphasis on transition planning in health and education settings, outcomes for youth with health and developmental challenges remain worse than those for youth with typical health and development.¹⁰⁻¹² For example, data from the National Longitudinal Transition Study-2 (NLTS2), which followed youth for up to 8 years after high school documented that those with intellectual disabilities and/or multiple disabilities were significantly less likely to be employed or attending college, worked fewer hours and made less money, were less likely to live independently, were less likely to be married, and saw friends less frequently than individuals with other types of single disabilities, and those without disabilities.¹²

Existing research that includes goal setting or planning for the transition to adulthood from the perspectives of youth and parents indicates that hopes and needs of families are broader in scope than the dominant themes of the health and education literatures that focus on assuring smooth health care transitions and successful post-high school employment and/or education. Kirk¹³ points out that researchers rarely take a holistic view of transition to adulthood, usually focusing on one service or a single aspect of transition. She found that youth with complex healthcare needs described multiple transitions that occurred simultaneously as they moved to adult-oriented services, including the need to reestablish trust in providers, assume responsibility for self-management activities in multiple realms, and learn to navigate within an adult culture where expectations were uncertain and less parent-centered. Huyard^{14(pp540)} interviewed adults with Cystic Fibrosis and found that they had gradually experienced a “critical internalization”, in which they learned how to manage their illness, accepting or rejecting medical advice based on their responses, and concluding that having a genetic condition was not the same as being ill.

Schwartz and Drotar¹⁵ reviewed the role of goal-setting for children and youth with chronic health conditions and proposed an integrative framework that incorporates the impact of goals on subsequent behavior and factors related to disease, culture, and socioeconomics. The priority of maintaining normal aspects of life for both children and other family members in the face of care for chronic health and developmental needs was also reflected in research with families dealing with complex chronic conditions¹⁶ and HIV.¹⁷ In a survey examining goals and expectations of youth with disabilities and their parents, Powers et al.¹⁸ found that highest priority was given to completing high school, having health insurance, and having a good doctor. Lowest priority was given to having children and living in the same house as family; although, in a qualitative study with young women, the same research team found there was a strong theme of multiple goals, including marriage and parenthood, and young women often hoped they could combine career and family, “having it all”.^{19(pp 220)} Research around sexuality for youth with chronic conditions is scarce, but two studies have documented that youth had equal sexual interest compared to age appropriate reference groups, but low levels of sexual or romantic activities, high levels of worry, and limited discussions with health care providers about sexual issues.^{20,21} Culture has been identified as influencing goals and aspirations of youth with chronic conditions and disabilities.^{18,19} Rueda et al.²² studied Latina mothers of young adults with disabilities and found that rather than emphasizing independence, employment and productivity, participants conceived of transition as home and family-centered. Bures²³ documented that immigration, number of children, divorce and/or single parenthood, financial resources, mobility, and other demographic factors affect social supports available to children and parents, and impacted decisions around housing and household composition. She emphasized that a life course perspective is necessary to account for these influences that shape changes that occur within families over time. Families are also profoundly influenced by factors outside of the home, including available federal, state, and local resources, public policy, and relationships with providers and social networks.²⁴

In this study, we sought to enlarge professional perspectives about the transition to adulthood by taking a holistic and lifespan approach to exploring how parents and youth envisioned adulthood, and especially how they prioritized elements of planning for the

transition. By incorporating a long-term perspective and a comprehensive view of the needs of youth with physical and developmental chronic conditions, we aimed to clarify what matters to families as they tried to assure a high quality of life for their youth in adulthood.

Research Design and Methods

Theoretical Frameworks—This study was based on an interpretive/constructivist paradigm, in the symbolic interaction (SI) tradition.²⁵⁻²⁷ The current analysis is from an interpretive field study, often called ethnography in the sociological tradition, focused on planning for the transition to adulthood of youth, their parents, teachers, and health care providers. The purpose of scientific inquiry in this tradition is the understanding of everyday life experiences from the point of view of those who live it. Reality is assumed to be situated, relative, and changeable as understanding improves and conditions modify. Social and self-reflective processes result in personal and group meanings that lead to actions and decisions for individuals and families. Knowledge and the findings of research are considered to be transactional, i.e., jointly created by investigator and informant, and require the investigators to actively enter into the world of people being studied.^{25,27,28}

This research was informed by Transition Theory^{29,30} and Ecological Theory.³¹ Transition Theory is an emerging middle-range theory that recognizes that transitions profoundly affect health, and occur in multiple realms, often simultaneously. The health care provider's mission is described as facilitating transitions in order to enhance well-being during wellness or illness.²⁹ Ecological theory adds important insights about child development, the interactions of children, families, communities, and larger social influences such as state or national policy and funding priorities, that can inform and constrain planning.³² These theories provided a framework for initial interview guides and observations, and discussion points during analysis, though actual conclusions were induced from data.

Sample—Participants in this study included youth (n=64), their parents (n=77), their health care providers (n=27), and their special education teachers (n=46). Forty four per cent of youth were people of color, including African Americans (15%), Asians (20%), Latinos (7%), and more than one ethnic/racial identity (10%). Parents included African Americans (12%), Asians (16%), Latinos (5%), and more than one ethnic/racial identity (4%). Half of youth qualified for partial or complete government support for health care coverage.

All youth had both a chronic physical health condition, e.g., congenital heart disease, diabetes, genetic conditions, seizures; and, a developmental disability, most commonly intellectual and learning disabilities. All required ongoing monitoring for health concerns and many were receiving active treatment in the form of medications, assistive technology, and/or therapies, e.g., speech, physical, or occupational. Thirty one youth (48%) were verbal, and 24 participated in interviews. All youth participated in observations in the home and school setting. Youth were non-verbal or had limited speech because of cognitive or structural disabilities, though some communicated through assistive devices or augmentive techniques. All of the youth had intellectual disabilities or cognitive delays and all of the youth in the study required assistance with some aspects of managing day to day life. Because of these verbal limitations, the voices of youth included in this article were those

with higher levels of cognitive and physical ability. Parents of both verbal and non-verbal youth participants, who fell across the complete spectrum of physical and developmental ability, are quoted. This population was chosen because of the particular challenges that families face when youth need ongoing health care treatment or monitoring into adulthood, but are likely to be limited in their ability to independently manage their own lives and health. Youth were recruited from a variety of community and health care settings into one of three age groups: 14-17 years (N=23), 18-21 years (N=23), or 22-26 years (N=18). Youth in the 2 youngest groups lived at home with their families. Young adults in the oldest group participated in a variety of post-high school activities; 12 lived with family while 6 lived in community-based settings. All youth either were currently enrolled in special education, or had in the past received those services

Data collection—Ethnographic methods were used at an average of five data collection points for each youth. Single interviews and informal observations were conducted with youth who were verbal, teachers, and health care providers. Parents were interviewed twice and questions for second interviews were formulated after preliminary analysis. All interviews included open-ended questions and semi-structured probes on topics derived from Transition and Ecological theories, including current health and development status, expectations for the future, priorities and plans to achieve them in areas of housing, health, financial security, and the meaning of adulthood for the family, this youth, and perceptions of the impact of culture and community support on determining hopes and goals. Formal observations using investigator designed tools and field notes were conducted during home visits and at least one Individual Education Program (IEP) meeting (for youth attending school). The study was approved by the Investigational Review Board (IRB) at the investigators' university and representatives of youths' school districts. Informed consent, assent, or surrogate consent was given for youth, parents, and professionals, according to IRB specified procedures.

Data analysis—Data was analyzed in a multistep procedure that included construction of an overall family summary, line-by-line analysis that resulted in data-driven descriptive codes that were used to seek linkages between parts of the data. This coded material and the evident linkages were the building blocks for a list of major categories that were constructed by combining codes representing ideas, situations, actions, and decisions that were recurrent across families, and that identified the most important, recurrent, and supportable ideas in the data.³³

Each transcript was read by at least 2 members of the research team. Analytic memos were written to facilitate discussion and stimulate consideration of multiple points of view in the interpretive process. Overarching themes that united the categories and explained the potential for varying outcomes were identified.³⁴ Atlas Ti was used to manage and organize the data set. Preliminary findings were discussed with participants. During analysis, the PI, project director, and research associate met weekly, and were joined by co-investigators monthly, to review findings and reach consensus on important interpretations.

Findings

In this section we start by providing a brief overview of the meaning of adulthood for parents and verbal youth, because in symbolic interaction behaviors and decisions are driven by the meaning of the social situation in which actors are involved, in this case, planning for transition. Next, we will describe the four categories of priorities for planning for the transition to adulthood that were indicated by parents. Wherever possible we have included voices of youth, in addition to parents; however, because only 48% of youth were verbal, and levels of articulation of complex ideas were variable, we do not claim that we have completely captured priorities of this group of youth.

The Meaning of Adulthood

Participants defined adulthood as functioning as independently as possible, and transition was associated with growing independence and self-care of youth. Independence was recognized as likely partial and strongly contingent on establishment of individualized support systems. Parents universally expected to remain involved in the lives of youth during adulthood, though most hoped for less day to day responsibility that would allow more freedom for both youth and parents.

Ongoing needs for assistance in adulthood, varied from youth who would need assistance with basic care such as feeding, bathing, or diapering, to those who could manage their own lives with minimal supervision and support. One mother expressed a common perception among parents, "I don't think my job as being his mom will end. Never. It's always going to continue. He will always need some kind of support that maybe I can help him with." Definitions of independence had cultural overtones, with some families, most often African American and Asian participants, explicitly envisioning interdependence and ongoing cohabitation with youth as normative and desirable.

Many youth were able to achieve developmental milestones when appropriate accommodations were provided, but uncertainty about long term outcomes remained for many youth and parents. This mother expressed pride and hopes for her son, but reflected ongoing uncertainty and recognized that her son's current achievements did not guarantee a secure future:

My goal for [my son] is for him to reach the highest level that he can possibly reach to be functional in the society and culture that he lives in. So that being the case, I would love to see him achieve the high school diploma. At the same time I recognize that that's being done under tremendous modifications. So where will that lead [my son] as far as his true capacity to be integrated and to be completely self-supporting? I don't know.

Youth with verbal abilities could discuss their current interests and express an interest in particular fields or jobs, but were often hesitant to be concrete about their goals because they were unclear on steps needed to bring these hopes to fruition. For example, when asked about her hopes and plans for the future, a 20 year old young woman replied, "Oh that's a good question. I haven't even thought about it yet. I don't know." Then, she corrected herself:

I want to go to an advocate school, actually; but I don't know if that's possible or not; I don't know if there's any advocacy schools; but my mommy is going to try to get me a job with animals. And I'm going to put it on my application. My mom's going to try to get me a program where they train people, handicapped people just like me, in advocacy.

This young woman reflected the common experience of ongoing trust and reliance on parents to bring future hopes and plans to fruition. Another young woman, age 22 had recently moved to a supportive living community where she lived in her own apartment and received daily assistance with activities such as meal planning and preparation and taking medications. When asked the meaning of adulthood for her, she said, "Being on my own. Yes. Enjoying the freedom. Sometimes it's hard and sometimes it's not. Sometimes it's complicated, but I like being on my own. So I think that's what it means, you're on your own." Although she remained close to her parents, and her mother provided assistance with tasks such as making and keeping medical appointments, this young woman recognized that living in her own home, albeit with ongoing assistance, provided a level of independence and satisfaction that she had not achieved while living in her parents' home. She said, "I like it here. Sometimes I don't and sometimes I do. It just depends on which day you catch me at. I love my mom and I love my parents, but I love it here too." This young woman was able to recognize difficulties and variable day to day outcomes, but for her it was a positive transition to supported adult arrangements.

Priorities for the Transition to Adulthood

Specific needs of youth varied somewhat by age group, and specific plans were dependent on the individual abilities of youth, but parents shared overall priorities for the transition to adulthood that they felt would contribute to a long term high quality of life for their youth. These priorities included (a) protecting the youth's health, (b) assuring safety and security in adulthood, (c) enrollment of youth in safe, supportive, meaningful, and stimulating educational, employment, or activity programs after high school, and (d) finding safe, welcoming and appropriate social opportunities. The overarching theme of the priorities was to create a safe environment for youth in which they could enjoy a high quality of life as adults.

Protecting youths' health—Maintaining vigilance to prevent complications or deterioration in existing health conditions was a top priority for parents. A mom said, "First of all, I'd like to know that she's medically taken care of." Her daughter's health figured in considerations for future living arrangements. She said, "She is exactly in the place that she should be right now [living at home] but it has to continue -- somebody has to constantly be on top of what's going on with her." Another mother said, "I think health and safety are always the first things, though the medical is first, I think. And that's Maslow's hierarchy."

The interplay of a chronic health condition that needed ongoing treatment or monitoring and a developmental disability added complexity to planning for the future. Nearly all youth in this study had significant intellectual disabilities, and only a small number of parents expected their youth to achieve complete independence in managing their health conditions, though many continued to encourage youth to assume increasing responsibility as they

matured. This mother, like others, expressed her fear that medical complications would require her day to day supervision and support:

As long as his health is stable it's not too bad. But of course if he loses kidney function and we're back in that game, I know where I'll be. It's just with a medical issue it's so different. It dictates more, and affects his independence more, probably, in my opinion, than the disabilities. It is a disability to have a chronic medical condition, period.

Youth often struggled to master the skills needed to manage their health on a daily basis. A young man's story illustrates the developmental and medical issues that intersected to complicate his assumption of responsibility. When asked how he was doing with taking his medicine, he said:

Okay, I guess. I'm missing, not really forgetting to take them, I'm just forgetting to take them at the right time once in a while. I know how to fill my pillbox. Fill a pill box and then call for prescriptions myself. And then my mom goes, "That's your pills, you've got to go and get your prescription."

This story illustrates a growing, though still unreliable, skill set that included sometimes remembering to take medications, using a pill box, and calling to refill prescriptions, but necessitating ongoing reminders and monitoring from his mother. This young man did not drive, and would be driven to pick up prescriptions by family members; however, his teenage reluctance to interrupt other activities for necessary chores is revealed in his response to his mothers' reminder:

And I'm like, "I'm not going all the way to [a pharmacy] to go get them. I have to just stop what I'm doing and go get the pills." Sometimes I'm tired and I'm like, "I don't want to have to do that." But I'm like, no, I do it anyway. They're my pills.

A young woman, with congenital heart disease, living in a housing complex for people with disabilities, explained how she was assuming responsibility for her own health:

I eat lots of fruit and lots of vegetables, drink lots of water, juice. I'm not much of a junk food person. No chips, no soda, no whatever. My case manager helps me. We put a food plan together every week, and she's very healthy also, so she tells me what to eat, what not to eat, and all this different stuff, and she's really good about it... Three days a week, Tuesday, Thursday, Friday I go to [a gym] and I work out, and the rest of the week I do exercise here, and usually take walks or we do a video or stuff like that.

Five percent of youth were receiving primary health care in an adolescent clinic. Of the remaining youth, those who were receiving care in adult or family practice settings increased with each age group: 4% of 14-17 year olds, 26% of 18-21 year olds, and 94% of 22-26 year olds. Parents and health care providers (HCP) expected youth to delay primary care transitions until their mid-20s, due to perceived constraints in adult practice settings. The 2008 health care reform legislation, the Affordable Care Act, which allows youth to stay on family medical insurance plans to age 26, reinforced the expectation to remain with pediatricians into early adulthood.³⁵ Parents of younger youth expressed feeling little pressure to find adult-oriented primary care health providers because pediatricians told them

that they would continue to care for their youth as long as possible. One mother explained her conversation with her son's pediatrician, "When [my son] was 18, I was thinking, he may not want to see him. And he said, 'Normally I stop seeing kids when they're 18, 19, but he's one of my special kids so I'll keep him around.'" Parents were concerned that when their youth did transition that their adult provider be compassionate and caring. A mother said, "That's a big concern, when I think about who I want for his physician, somebody who will listen to him and spend some time with him and care for him. It's the same thing I want for myself."

Assuring safety and security in adulthood—Parents and youth considered multiple aspects of life that contributed to assuring safety and security in adulthood. These included housing, financial security, legal protections, personal safety and freedom from exploitation. Often safety concerns and financial constraints affected choices for housing and legal arrangements undertaken by families. Parents often dreamed of living arrangements that allowed optimal independence, including this mother:

I'm hoping that she'll be living maybe in an apartment or a house, just a handful of people, and where they have somebody who checks on them periodically, and doesn't necessarily live with them. Be sure their bills are getting paid and they're buying healthy food. That she has a job. And that she's going out with friends... She'll take my phone calls [laughter], that we spend time together, but she has more of an independent life and I have an independent life, and we stay in close touch.

Many parents agonized about finding appropriate long term solutions to housing and support for youth. A mother said, "I just thought about housing and stuff, I mean, I thought about it for years--should she live at home or should she not?" Of parents who had made a decision, the majority hoped to find appropriate supported housing in the coming years for their youth. However, other families, including many African American and Asian American participants, were firmly committed to keeping their youth in the family home on a long term basis. An African American mother explained her family's decision to keep their youth at home:

I think that's the one thing that minority families especially, that they like to take care of their own, their aging, and anyone that is disabled in some manner, to keep them at home. Because we look at we can give out better healthcare. I know we can, I don't know about anybody else. For us, I think me and [my husband] it's a child of ours so we love her. We want to show her that we love her so we want to keep her at home safe. Safety is a key, a big key. I don't want her to go to a group home and find out she's been molested or whatever bad thing that could happen to her...But that is, I want to say, a cultural thing. I think that's definitely it.

Nevertheless, some parents recognized that the aging of both youth and parents was a factor that could affect planning. A father explained his awareness that conditions could change:

I think he might possibly live with us for a long time. We've both talked about that, and that would be fine. That's kind of how my family does stuff anyway. I had an aunt that was schizophrenic. She lived with my parents. My grandfather did until he died, my dad's dad. My mother's mother did. So I don't see any problem with him

living here, and I think he would want to. The only thing I would worry about is later we would not want him to be too, too stuck on living with us because eventually we would be too old or whatever. So I would want something maybe that was gradual, but we would always be completely involved with everything.

Some youth expressed a desire to live in their own home, away from parents, while others preferred to stay in the family home indefinitely. One young woman said, "I'd continue to live here until mom tries to kick me out. Because she wants me to live on my own eventually." Youth who wanted to move recognized specific skills or emotional hurdles to overcome. An 18 year old youth said:

I still need stuff to do. I'm planning on living on my own. I don't know if it's going to happen, but I want to move out when I'm 26, 25. It depends on how good my skills are. I need to learn how to cook more. I know how to clean my room, I just don't want to.

This youth explained, "I have a fear of fire and spiders." He went on to explain his plan to overcome his fear:

When I get a house soon, I might get one of those new stoves where the stovetop turns red, those stoves? I'll get one of those instead of having that (points to mom's gas stove). I'm not scared of those. My friend has one of those. I just turn it on, and when the red light turns really red, it's hot. Don't touch it.

Many youth recognized the need for ongoing assistance, and some expected that specific family members would provide that. One youth envisioned eventually moving out of his parents' home with his brother, who was 15 years old at the time of the interview. He explained:

Because he already knows how to take care of me. He knows how to take me to the bathroom, take me to the shower, clothe, bathe me. See it would be hard for somebody who doesn't know and I admit I'm not a good person to explain something to someone."

A young woman who had made a successful transition to supported living explained how important it was to her, "I like it a lot better than living at home. I moved last October, just because I was just getting restless and eager. This is my own thing, and I'm proud of it."

In addition to housing, parents were concerned about issues of financial and legal security. Parents often chose to separate their own finances from the youth's in early adulthood in order to protect the long term security of other family members. Many youth were receiving SSI disability payments, and others would qualify as adults to receive this ongoing means of support. In addition, youth with significant developmental disabilities could qualify for government paid supportive services for housing, health care, and other services such as medical equipment or transportation. The complexity of considering multiple aspects of planning, along with ongoing uncertainty about her son's options, was reflected by this middle class mother:

So the social services really are something that I never in a million years, 20 years ago, would have believed that we would ever need for our family, but here they are,

SSI. As I'm staring at that, trying to figure out all the ramifications of if he gets a job and he doesn't get a job, what could Section 8 do for us, and could I get a voucher for him?

When youth were limited in their ability to make sound decisions in managing their daily lives, parents needed to investigate protective legal arrangements, such as conservatorship, that would allow them to continue supervision into adulthood. In making these arrangements, each youth's individual situation was considered by the courts before removing youth's autonomy in certain realms. A mother explained:

I make her decisions for school, for medical. You know, like for her money. That's pretty much it because they only give you so much limited [power]. If she were to have a husband, or have any kind of sex or anything like that, they don't give you those powers, just because they still have the rights. But as far as placement for her and stuff like that.

One barrier to making formal legal and financial arrangements for youth was the cost to set up conservatorship or trusts, which could be several thousand dollars. Parents with assets could formalize financial arrangements through a special needs trust, and/or formalized conservatorships. As a result of the expense, parents with fewer financial resources often delayed formalizing arrangements, and simply continued to care for youth at home after their 18th birthdays made them legal adults, making decisions informally.

Money management was often challenging for youth, and parents were concerned that youth could be exploited financially if they were too trusting or careless with money. The mother of a 16 year old said:

But I just see that he will never be able to handle money. I just don't, I mean I can't imagine it. Maybe he will. Who knows? But at this juncture he doesn't really get like it's \$300, it's \$2, it's \$3000. It's kind of like this emerging concept. If he goes to the store it's like "Give me twenty because I know that will cover it".

Meaningful post-high school activities—Enrollment in safe, supportive, meaningful, and stimulating educational, employment, or activity programs after high school was an important goal for youth, their parents, and teachers. Most desired programs that would help youth acquire skills to maximize their independence, as envisioned by this mother, "That he can live as independently with support as he can, and I know he is a great candidate for that."

School districts varied in specific services offered, and youth qualified for services at school and in the community based on their level of disability. Youth were entitled to educational services until age 22 if they qualified for special education. Most districts in California's Bay Area offered a certificate of completion and transition programs run by the school district or county, to youth who could not meet state requirements for a high school diploma. Six youth participants graduated from high school and had either enrolled or were preparing for college classes, some at institutions that offered supportive services. However, youth and parents often experienced frustrations in finding the types of classes, programs and supports

that they desired. Parents found that there was much less support available for youth at community colleges, compared to high schools. A mother explained:

I discovered [my son] didn't qualify for much because he wasn't impaired *enough* to meet a lot of their qualifications. I thought, no, he's bright enough to do college level work. I don't want him stuck in some vocational training program and not have a chance to move on if he can do this. Well, how do we work with the chronic health problems at the same time is the challenge. So what we decided, okay, he wants to go to college. He's going to have to take it at a slower pace than most kids. He can't do a full load. It's too much for him. Initially we went to [a community college] because they had the reputation for having a really good program for kids with learning disabilities. It was real clear to me quite quickly there wasn't enough support services up there, and I found out that 50% of the kids in their freshman year drop out.

Her son, like others who planned to attend college, tended to make plans with practical goals, but with unknown chances of achievement. He said:

I'd like to actually write science fiction, but realistically, to make money in writing you need to do some variety of journalism so I'm taking classes...the ideal setup for doing what I want and providing for myself would be to work mainly previewing and reviewing video games since I enjoy those. I figure, that's something that's you write an article and you get paid for it. I can live off that money on a consistent basis.

A young woman was aware of her special needs, "I guess it's just the different kinds of jobs I am looking at to see if they offer healthcare or not. See if they fit into what I want to do after college, working with books, maybe a public library."

Most youth who participated in the study will require supportive vocational or adult day programs after leaving school, and parents and teachers spent considerable effort searching for a program that was safe, facilitated acquisition of appropriate levels of vocational or life skills, provided social opportunities, and was enjoyable and meaningful to youth. A mother explained what she wanted for her son after high school, "That he's able to have meaningful work. You know, that he's able to engage in the world in a meaningful way, and be able to find joy and success and have support in doing that." A teacher explained her priorities:

So, what's really important in my position is to help the parents to see the picture for what it is. This is who you've got. This is who she is. The growth, if any, is gonna be minimal at best at this point. It doesn't mean we don't work with them... So, not changing their level of ability so much, but accepting their level of ability and figuring out how that child with that level of ability can be as independent as possible in the community.

A mother expressed her priorities for her daughter's activities, "I would like to find her a little corner, a little niche where she is comfortable and productive." Many parents worried that youth could lose skills if left in unstimulating or negligent environments. A mother said, "It's very important to me that she is gonna be stimulated-the thought of her just like sitting

on a couch all day will be so horrendous for me.” Another mother specified what she would like her youth to learn, and the difficulty of finding such a program:

I've been trying desperately to work within the school system to get him some kind of independent living skills training, cooking, transportation, going to the bank, dealing with money. I've hit nothing but walls. I mean everybody's doing this thing to me where they're pointing, go that way. So I'm more than frustrated because I've been trying to find a program to plug him into since he was 14.

Youth who were not planning to go to college were often aware of their need for further life skills training after high school. When asked what he was looking forward to as he enrolled in a county program to facilitate transition from special education to employment, a youth said, “Getting money and getting more pedestrian skills, safe, yeah.” A young woman was interested in gaining employment skills and proving that she could be a reliable employee. She said, “I wanted to maybe stand out because they like me. I want to show everybody yeah, I can do that work every day. And I'm showing slight improvement, but not there yet.”

The search for post high school activities was particularly troublesome for very disabled youth since existing employment programs would not accept them and finding the right activity program after high school was also challenging. A mother said, “We're looking, but you know she's a hard case in terms of what can she do, because so many things are oriented toward vocation, and that doesn't really make sense.” Another also struggled to figure out what kind of program would allow her daughter to feel productive and supported, “With [my daughter's] functioning level, I really don't know what she possibly could do. I'm sad...I really just don't have a good sense of it.”

Appropriate and satisfying social lives—Youth, parents, and teachers all recognized and prioritized social relationships and activities in planning for the transition to adulthood. In deciding his post-high school activities, a youth said, “I'd like to be here in this area because I had some friends here. I don't wanna end up with no friends around. 'Cause that sucks. I'd like to stay here, go to one of those schools around here.” A teacher equated ongoing peer relationships with quality of life for one of the study's participants, “It's quality of life over all, and being with her peers, around her peers a lot. That's important to her. I see the difference in her when she's around the peers.”

Although parents and youth explicitly hoped for satisfying social activities in adulthood, many acknowledged the ongoing social difficulties that youth had been experiencing throughout childhood and adolescence, especially in learning appropriate social skills that would help them to fit in with others, and make friends. Parents of some youth expressed frustration that their youth did not have friends and relied heavily on family for ongoing social interactions. A mother said, “Social is the worst for him. Just, he doesn't know boundaries, how regular people do things.” Another mother said of her son and some of his classmates, “They just don't read the nonverbal cues of social communication...He just doesn't understand when he's talking too loud or being a pest or whatever oddity he displays. It's usually a social faux pas of some kind.” One mother expressed her social goal for her son, “I'd like him to develop a circle of friends and people who know him and want to be with him and be able to extend his abilities as far as participating in a community. That's

what I want for him.” Another mother hoped that her son could expand his social circle beyond the family and attract friends with his personality:

He really does love to connect with people and I think that's going to be his strength. People like him. He's funny and he's friendly, and I would hope that he would be able to build on that and have his quirky place in life... Luckily he likes a lot of people and if they were the right ones I think he could have more experiences that aren't always to do with us.

Although parents knew that social relationships were critical to youth, safety was an important consideration in preparing youth for independence. A mother said:

I worry about friends; who's a friend, how can you tell if they're a real friend? There's a female with long hair, looking like an easy target. That, more than anything, is the biggest fear, sexual abuse. We started talking about that when she was very little, boundaries and my body.

Other parents were also concerned that their youth receive appropriate sex education at school, including their right to be sexual beings. A mother said, “Nobody at school is saying, you know, let's talk about pregnancy. Let's talk about sexually transmitted illness. You have every right to be a sexual person.” This mother noted, however, that ambivalence towards their children's sexuality was as common among parents as educators:

And I would say that the parents equally are also as rotten in that. They're equally as guilty in not wanting their kids to have that sexuality component as the school district. But as far as I'm concerned, that's an integral part of what I see as his independent living skills stuff. You know, how do you date? What's okay?

Parents often wanted their youth to have opportunities to socialize and interact with people with a range of abilities, which they thought would provide varied stimulation and appropriate social role models. However, professionals did not always plan activities to support those goals. A mother explained how she had to intercede at school to be sure her daughter had those opportunities:

All the teachers, cause she is in special ed, they will put her in the category, of where she needs to stay here with all the disabled kids. I didn't agree with that. I says “No, she doesn't have to sit here, she needs to sit where *she* wants to sit.” Everybody else had a choice to make.

Parents were also aware that people in the community, even health care and other professionals, sometimes did not engage directly with youth. A mother explained:

And one thing that's really important to me, and I see this all the time, is that people engage with [my son] and not engage with me. He's old enough where he can have the conversation and even I notice when we went to the bank to open up his savings account, I sat back but the guy never addressed [my son], only me. And I kept saying, “He's the one opening the savings account.” Same with doctors. I don't want them to talk to me. I want them to talk to him. And that's part of my philosophy.

Discussion and Clinical Implications

Transition planning for children with co-occurring health and developmental chronic conditions and their families exemplified the multi-faceted transitions described by Transition Theory^{29,30} and Ecological Theory^{31,32} as youth generally received multiple services within health and educational systems. Applications of Transition Theory have been most focused on adult populations, but features such as complexity, change over time, and growing awareness of needs and services were an excellent fit with the transition to adulthood. Parents recognized that youth would eventually age out of child-focused programs and would need to find services that supported meaningful involvement in adult life and optimal levels of independent or supported activities. Parents considered their youth to be a person with unique and important needs, and sought supports that would facilitate a high quality of life in adulthood, including meaningful involvement in important roles such as employment or activities that were interesting, a satisfying social life, and opportunities for continued growth and development.

Increasing self-management skills for health and other areas of life were emphasized by parents of youth in every age group. Regardless of abilities, parents and youth desired that youth be as independent as possible, with optimal levels of support and a high quality of life. These results echo common themes in the literature^{4-12,17,18}, but our findings also reinforce the importance of paying attention to cultural nuances.^{18,19,22,23} Exactly what constituted a high quality of life varied somewhat and specific plans for housing, financial support, legal protection, day to day care, and oversight varied by personal or cultural preferences. Parents universally planned to stay involved in their child's life in adulthood, though some parents hoped that youth would eventually live on their own or in a supervised environment, and others were determined to keep the youth in a family home. Like Rueda et al.,²² we found that cultural variations in the study were usually a matter of emphasis, rather than absolutes. All parents planned to stay involved with their youth into adulthood, but Asian and African American families were more likely to plan to continue to share housing. The diversity of the population, and the spectrum of abilities and ongoing needs of youth with co-existing health and developmental conditions, demands that goals for independence be individually tailored and supported.

Our results indicate that individual planning is complicated by the ongoing reliance of youth on parents, and the lingering uncertainty that parents and youth express about the youth's continuing progress towards self-management. Parents were uncertain about the abilities of their youth to undertake specific skills needed for life or employment planning; youth were uncertain about the processes that could lead them to their goals, or the goals themselves; and professionals did not, and perhaps could not, provide specific guidance to clarify what long term developmental outcomes or realistic expectations should be for particular youth.

Parents were aware of the goals for transition of the health professions.^{4,5} Most parents had been assured that youth could stay with their pediatrician into their 20s (84% of 22-26 year olds had transitioned to adult or family practice care), so were less focused on finding adult providers than in protecting the youth's health and safety. Parents in the younger age groups had seldom talked with their pediatrician about how or when this transition would happen.

Overall, finding an adult provider was not the focus of parents' worries. They were concerned about general well-being, increasing health care self-management for youth, safety, and prevention of complications related to chronic health conditions. Safety was a pervasive theme and youth were considered to be vulnerable to physical threats and emotional and sexual exploitation across the spectrum of physical and developmental abilities. Assuring safe environments crossed priorities, especially when parents considered future housing, employment, and social relationships.

The complex relationship between multiple layers of support and community involvement, evident in Ecological Theory,^{31,32} was reflected as parents and youth searched for appropriate post-high school employment or activity programs, often with the help of school personnel. Not any job or program would do, but parents emphasized the need to identify supportive, meaningful programs that would allow youth to develop social relationships, use their unique abilities, and satisfy their need to feel part of the community in post-school years.

While all of these priorities have been mentioned in the literature^{3-5,11,13,17-20}, they are rarely considered together when planning for transition. Pediatric and adult health care systems and public education systems are over-burdened and financially constrained, so holistic and life-course planning for the long-term and wide spectrum of needs of youth with both health and developmental challenges is rarely undertaken. Moreover, health and education systems do not routinely work together in management and planning for individual youth, so primary care providers and teachers rarely interact, share information about progress, or jointly plan.

Professional organizations for both pediatric and adult providers are attempting to address some of the range of needs identified in this study through joint identification of resources and the recent formation of *Got Transition: New National Health Care Transition Center*, which will serve as a resource to facilitate transition and is based on the organizations' recently issued joint clinical report⁽⁵⁾. Many other resources to assist with planning during transition are available through parent and community organizations, professional organizations, and organizations that support the rights of individuals with disabilities.³⁶⁻³⁸ Nurses serve as care providers, care coordinators, and consultants for youth with health and developmental chronic conditions, and they can greatly impact transition planning and outcomes of the transition to adulthood in health care and school settings.³⁹ Given their professional emphasis on holistic and life-course perspectives for health and development, nurses who work with youth and families are well-positioned to adopt recently developed tools and clinical guidelines,^{32,39,40} and to assist youth and families to set appropriate goals and anticipate possible further development.

While it was a strength that youth of all ability levels were included in interviews and/or observations for this study, it was a limitation that we could not completely capture the perspectives and experiences non-verbal youth. Another important limitation to this study was that all participants spoke English, and the experiences of families with no or limited English language skills may be different. Although the overall sample was ethnically diverse, numbers of individuals from particular cultural groups was small. Similarly, our

participants came from a wide range of educational and socio-economic strata, but were mostly well-educated and middle class. This type of heterogeneous study sample allowed us to describe commonalities between groups, but future research is needed with larger samples of ethnic and racial subpopulations and diverse language groups to be able to authoritatively describe cultural differences.

In conclusion, our findings of wide-ranging priorities of youth and parents and their emphasis on quality of life issues that stretch well beyond locating adult health care providers and after high school activities, demand that nurses recognize and act upon the imperative for comprehensive, holistic, and life-course planning during the transition to adulthood.

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