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Transition Satisfaction and Family Well Being Among Parents of Young Adults With Severe Intellectual Disability

Cameron L. Neece, Bonnie R. Kraemer, and Jan Blacher

Abstract

The transition from high school to adulthood is a critical life stage that entails many changes, especially for youth with severe intellectual disability. The transition period may be especially stressful for the families of these young adults, who often experience a sudden change, or decrease, in services. However, little research has examined what constitutes a successful transition for the families of these individuals. The present study examined parent perspectives of transition for 128 young adults with severe intellectual disability, specifically, parent satisfaction with transition. Results suggested that transition satisfaction is related to young adult, family, and environmental characteristics, with environmental characteristics being the strongest predictors of transition satisfaction. Furthermore, transition satisfaction is related to multiple measures of family well being, indicating the tremendous need for considering the broader family system when planning for a young adult's transition. Implications and directions for future research are discussed.

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The transition from adolescence to young adulthood is a critical life stage for all individuals. The time period brings about many changes, which can drastically affect the daily lives of young people and their families. As a result, this transition period may be an especially stressful time. In typically developing individuals, young adults usually go off to college or enter the workforce. However, for young adults with severe intellectual disability, postschool options are often much more limited. In the United States, after an individual with intellectual disability exits the school system, which can occur as late as age 22, services change from a system of entitlement to a system of eligibility. Parents must find appropriate programs and services for their young adult and this can be very difficult. Indeed, research has shown this transition period to be especially stressful and difficult for young adults with intellectual disability and their families (Gallivan-Fenlon, 1994; Thorin & Irvin, 1992; Thorin, Yavanoff, & Irvin, 1996). Thorin et al. conducted focus groups with parents of transition-age young adults with intellectual disability and found families face many common dilemmas, such as, “wanting to create a

separate social life for the young adult and wanting to have less involvement in his or her life” (p. 19). Because families experience increased stress and are faced with these dilemmas during the transition period, it is important to consider what factors make a transition successful or unsuccessful to minimize this potential stress.

Previous research on transition has focused on young adult outcomes such as vocational placements (Johnson, McGrew, Bloomberg, Bruininks, & Lin, 1997; Luftig & Muthert, 2005; Mank, Cioffi, & Yavanoff, 1997a, 1997b, 1998), social networks (Johnson et al., 1997), residential placements (Johnson et al., 1997; Luftig & Muthert, 2005) and quality of life (Halpern, 1994; Kraemer, McIntyre, & Blacher, 2003; McIntyre, Kraemer, Blacher, & Simmerman, 2004). Currently, researchers with the National Longitudinal Transition Study-2, (NLTS2; see Wagner, Newman, Cameto, Garza, & Levine, 2005) are attempting to measure factors that are associated with positive outcomes for youth transitioning out of high school. This sample of over 11,000 transition-age youth with disabilities is very heterogeneous, containing participants from each of

the 12 federal special education eligibility categories. NLTS2 outcome variables include, among other things, academic achievements, postsecondary education participation, student involvement in transition planning, employment after high school, leisure activities, and social involvement (Katsiyannis, Zhang, Woodruff, & Dixon, 2005; Wagner et al., 2005; Wehmeyer, Garner, Yeager, Lawrence, & Davis, 2006).

Although findings from the NLTS2 will contribute significantly to our understanding of the transition period for youth with disabilities, the specific outcome variables examined to measure transition success may not be as relevant for young adults with more severe intellectual disabilities. Traditional indexes of transition success (e.g., paid employment, number of hours worked, wages, extent of independent living in the community, and extent of social networks), although certainly important, may not be as appropriate an index of successful transition for individuals with severe adaptive and cognitive impairments. Thus, in this current study, we proposed other indexes of transition success for these individuals.

Because of cognitive and communication limitations of young adults with severe intellectual disability, much of our understanding of their transition experiences depends on parent perspectives and contributions. Moreover, much of the transition literature examining parents' perspectives includes parental aspirations and expectations for their young adults after they exit the school system (e.g., Chambers, Hughes, & Carter, 2004; Hill, Wehman, Kregel, & Banks, 1987; Kraemer & Blacher, 2001; McNair & Rusch, 1991; Wehman, Kregel, & Banks, 1987; Whitney-Thomas & Hanley-Maxwell, 1996). Many of these studies examining parent perspectives on the transition to adulthood found that most parents expected their young adult with severe intellectual disability to work in a segregated environment and to continue living at home after high school. These expectations can have implications for how the transition process will affect families.

To date, however, little research has been conducted examining how the transition process affects families, beyond expectations, even though researchers have found that families, not just the individual with an intellectual disability, are affected by transition (Morningstar, Turnbull, & Turnbull, 1996; Szymanski, Hershenson, & Power, 1988). Indeed, it has been suggested that the success of the

young adults' transition may have direct implications for the well being of the family. Blacher (2001) proposed a conceptual model in which various domains (young adult characteristics, environment, culture, and school programming) contribute to transition success, which in turn may influence family well being. Previous research has examined how this transition process affects the young adult's quality of life (e.g., McIntyre et al., 2004), but to date little research has examined how transition will affect family well being.

The purpose of the current study was twofold. First, we wanted to explore a measure of transition success for individuals with severe intellectual disability because many of the traditional indexes of successful transition may not be applicable. Because of the level of cognitive, behavioral, and sometimes physical limitations of many individuals with severe intellectual disability, along with the idiosyncratic nature of what each family considers a successful transition, we deemed it critical to assess family perspectives. Specifically, we used parent satisfaction with their young adult's transition from high school to adult life as an index of "transition success."

Second, we wanted to examine the relationship between transition satisfaction and family well being. Blacher (2001) suggested that, "Satisfaction with transition experiences and placements will likely bear a strong relationship to family well being during this developmental period" (p. 179). However, the extent to which well being of the family is influenced by a successful transition of the child with intellectual disability is unknown. Consequently, three research questions guided this investigation: (a) Are there differences in young adult, family, and environmental characteristics between families who experience a satisfactory versus dissatisfactory transition? (b) Which of these characteristics are the best predictors of transition satisfaction? and (c) Are there differences in family well being, determined qualitatively as well as quantitatively, among transition satisfaction groups?

Method

Participants

Participants were parents (primarily mothers) of 128 young adults with severe intellectual disability, all of whom were part of an ongoing longitudinal study. The young adults were between the ages of 19 and 28 years ($M = 23.0$, $SD = 2.6$) and all had exited the public school system.

Table 1 provides parental and family demographics. Respondents were primarily biological mothers and ranged in age from 34 to 73 years. The majority of the respondents were either White or Latino and most were employed. Over half of the participants had at least some college and an annual family income of \$40,000 or more.

Table 1 provides young adult demographics. Just over half of the sample was male, and the average age of the young adult was 23 years. The young adults in this sample had a variety of diagnoses in addition to intellectual disability, such as cerebral palsy (25.4%), Down syndrome (24.6%), and autism (11.5%). The diagnostic labels were reported by parents but were determined by service agencies in California that specialize in identifying and providing services for people with intellectual

disabilities. Overall, the sample had a mean Vineland Adaptive Behavior (Sparrow, Balla, & Cicchetti, 1984) standard score that was nearly five standard deviations below the mean of the normative sample, indicating that these young adults had severe cognitive and adaptive impairment.

Procedure

Families were recruited 6 to 8 years earlier though the Southern California Regional Center system in California, a statewide network in which the majority of persons identified with intellectual disability are registered. At that time, Regional Center staff mailed letters of invitation to families with adolescents with reported levels of moderate to severe intellectual disability. Regional Centers continued to send letters until the response crite-

Table 1 Caregiver and Young Adult Characteristics

Characteristic	<i>M</i>
Caregiver/family characteristics (<i>n</i> = 128)	
Age (<i>M</i> years)	52.9 (<i>SD</i> = 6.7)
Education (% some college)	62.5%
Health (% good/excellent)	73.8%
Employment (% employed)	76.2%
Marital status (% married)	66.4%
Family income (% ≥\$40,000)	55.7%
Ethnicity (%)	
White	52.5%
Black	4.9%
Latino/Hispanic	36.9%
Asian American	3.3%
Other	2.5%
Young adult characteristics (<i>n</i> = 128)	
Age (<i>M</i> years)	23.0 (<i>SD</i> = 2.6)
Gender (% male)	54.1%
Ambulation (% ambulatory)	82.0%
Diagnoses (%)	
Undifferentiated intellectual disability	22.1%
Cerebral palsy ^a	25.4%
Down syndrome	24.6%
Autism	11.5%
Other etiologies	16.4%
Residential status (% out-of-home)	12.3%
Adaptive behavior mean standard score	25.4 (<i>SD</i> = 10.5)
Mental health (% at risk, Reiss screen)	32.0%

^aIn addition to intellectual disability.

tion was met, so we cannot compute the percentage of responses returned. However, given the size of the sample and the relative homogeneity of the young adult functioning, we regard the sample as representative of young adults with moderate to severe intellectual disability.

Prior to scheduling the interview used in this study, caregivers received information about the study by telephone. Families were asked to complete mailed questionnaires and participate in an in-home interview. If they were interested in participating, informed consent forms and questionnaire packets were mailed to the family. Project staff then conducted in-home interviews with the families, in either English or Spanish, according to parental preference. Most interviewers (and all interviewers for the Latino families) were bilingual and Latino. Interviewers received extensive training in the administration and scoring of measures and questionnaires, general interview techniques, and protocol. A clinical psychologist who was a consultant to the study provided training in culturally sensitive interview techniques and in the reporting procedures (e.g., for child abuse, severe depression) in the event they should be necessary. Home visits were conducted in teams of two for reliability purposes and for safety, as nearly all interviewers were women and the interviews were at all times of the day or evening. Typically it took between 2 and 3 hr to complete the in person interview. During the home visit, interviewers (a) explained and obtained signed informed consent; (b) answered questions regarding the study; (c) collected the completed, previously mailed questionnaires; and (d) administered additional measures verbally. Each family received an honorarium for their participation in the study.

Immediately following the home visits, interviewers wrote narrative, descriptive notes to capture their perceptions and observations during the interview. Interviewers also received group training for writing these field notes by a consultant trained in ethnographic research. The field notes were written immediately after the interview, not during the interviews themselves. Interviewers followed a pre-established template with specific focus areas outlined. These areas included information about the home and physical environment, as well as the interviewers' perceptions of family characteristics, parent-child attachment, amount and types of support the family received, and parents' expressed views about how well the school prepared their son/

daughter to transition to life after high school, to community living, and to the future.

Measures: Questionnaires

Questionnaires used in this study pertained to demographics, transition experiences, parental involvement in transition, parental depression, family impact, young adult adaptive behavior, young adult mental health, and young adult quality of life.

Family data sheet. This was an assessment of family demographics and young adult characteristics, which are listed in Table 1.

Transition Experiences Survey (TES; Kraemer & Blacher, 2001). This is a 38-item interview protocol that assesses the transition process and transition outcomes for the young adult and his or her family. It contains questions about their young adult's participation in school programming related to transitioning from the school system to adult life. It also contains questions pertaining to parent expectations of postschool outcomes, as well as items about the current living situation and work outcomes of the young adult. The measure includes both open-ended and close-ended questions related to employment (e.g., young adult's current work arrangement [competitive employment, supported employment, sheltered workshop, not working, young adult's paid work experience while in high school]), community living (e.g., parent views of young adult moving out of the family home, current setting where young adult lives), and socialization (e.g., how often young adult participates in social activities out of the home, size and make-up of social network).

Parent Involvement in Transition Planning (Kraemer & Blacher, 2001). This is a 17-item measure consisting of dichotomous and Likert-scale items. Parent knowledge of transition services/supports, their level and type of involvement in the transition-planning process, and their satisfaction with involvement were assessed using this questionnaire.

Center for Epidemiologic Studies—Depression Scale (CES-D; Radloff, 1977). Parental depression was assessed using this 20-item, Likert-type questionnaire. A total score of 16 or greater designates the clinical range for depressive symptomology. This measure has been used frequently in cross-cultural research (Blacher, Lopez, Shapiro, & Fusco, 1997; Blacher, Shapiro, Lopez, & Diaz, 1997; Magaña, 1997). Cronbach alpha for the present sample was .93.

Family Impact Questionnaire (FIQ; Donenberg & Baker, 1993). The FIQ is a 50-item questionnaire

that asks about the “child’s impact on the family compared to the impact other children his/her age have on their families” (e.g., Item 1: “My child is more stressful”). Parents endorse items on a 4-point scale, from 0 (*not at all*) to 3 (*very much*). Although the FIQ has six subscales, the present study used two subscales: the Negative Impact composite subscale, which is a sum score of negative impact on feelings about parenting (9 items) and negative impact on social relationships (11 items), and the Positive Impact subscale (7 items). Alphas in the present sample was .90 for maternal reports of child’s negative impact and .86 for reports of positive impact.

Vineland Adaptive Behavior Scales (VABS; Sparrow, Balla, & Cicchetti, 1984). This measure was used to assess the young adult’s adaptive behavior. This measure was administered as a semistructured interview with caregivers. The overall adaptive composite score was used to characterize the young adult’s functioning. The VABS comprises communication, daily-living skills, and socialization domains; it has a mean of 100 and a standard deviation of 15.

Reiss Screen for Maladaptive Behavior (Reiss, 1986). This is a 38-item screening tool developed to facilitate the identification of dual diagnosis (joint presence of intellectual disability and mental illness). We used it to assess young adult mental health. Table 1 indicates the percentage of young adults whose Reiss scores placed them at risk of mental health disorder. As suggested by the Reiss manual (1994), a cut-off score of 9 or above was used to classify participants who were “at risk.” The total score, a composite score of 26 items, was used in the analyses for this study ($\alpha = .85$).

Quality of Life Questionnaire (QOL-Q; Schalock & Keith, 1993). The QOL questionnaire was used to examine the young adults’ quality of life. This measure, completed by caregivers, has 40 items that assess quality of life in four domains: satisfaction, competence–productivity, empowerment–independence, and social belonging–community integration. The total score was examined for this study ($\alpha = .87$).

Measures: Outcome Measures Derived From Field Notes

In addition to the more traditional quantitative questionnaires discussed above, two outcome indexes were created to examine the research questions of interest. These indexes were created by coding

the narrative information contained in the field notes. Here, we describe the development of the indices.

Transition Satisfaction Index. A coding system was devised to measure parents’ satisfaction with their young adult’s transition out of high school into adulthood. Themes drawn from the narrative field notes created the criteria for three satisfaction groups: *transition satisfaction*, *transition dissatisfaction*, and *cannot classify due to lack of information*. This coding system used a nominal scale; the criteria for each category are discussed below. If the descriptions in the field notes met only one criterion for a code, the family was assigned to that category. If a set of field notes contained criteria for multiple codes, the family was assigned to the category that best fit, as determined by coders. One coder read all the field notes and classified them into the appropriate category. As a measure of interrater agreement, 20% of the field notes were also read and classified by a second coder. There was 96% agreement among the two coders using this system.

Transition satisfaction was indicated by (a) the presence of diversified and stimulating services or activities for the young adult, (b) a well-executed transition plan, (c) competent and sensitive service providers, and (d) parents’ explicitly stating their satisfaction with transition. As an example, 1 mother in this group was pleased with her son’s transition and said, “It felt wonderful that [young adult’s name] was moving out of the school system.”

The main indicators of a *dissatisfactory transition* were (a) a lack of transition preparation and/or plan, (b) poor quality of services, (c) an inability of the young adult to maintain his/her placement in a job or day program, and (d) explicitly stated dissatisfaction with transition by the parent. The following quote from a mother taken from a set of field notes is an example of a family who was classified as dissatisfied with transition: “Two years ago I had hope that she would leave school and get a job. Now, there’s no future outside her leaving school.”

Cannot classify was used when field notes did not contain enough information to classify the young adult’s transition as satisfactory or dissatisfactory. Sometimes the young adult had lived outside the home for many years, and in a few cases the parents were unaware of what occurred during the young adult’s transition from high school. In addition, this category was used when the field notes did not contain any information related to this topic.

Family Well-Being Index. A second coding system was developed to assess family well being from the detailed description in the field notes. The more traditional measures of family well being (i.e., Center for Epidemiologic Studies-Depression Scale [CES-D; Radloff, 1977] and FIQ [Donenberg & Baker, 1993]) that were administered as part of the family interview were somewhat one dimensional, consisting of subscale and total scores in one particular area. Thus, a broader, more encompassing measure of family well being was created by analyzing the field notes.

Family well-being codes were created using a nominal scale, similar to the transition satisfaction coding system previously described. There were three groups: a *high family well-being group*, a *low family well-being group*, and a *cannot classify* group. The main indicators of high family well-being were low or no family stress, family harmony, and satisfaction with services. The main indicators of low family well-being were family stress, family conflict, and dissatisfaction with services. Similar to the transition satisfaction coding system, if the descriptions in the field notes met one criterion for a code, then the participant was assigned to that category. If a set of field notes contained criteria for multiple codes, the participant was assigned to the category that best fit, as determined by the coders. As with the Transition Satisfaction Index, one coder read and classified all the field notes and another coder read and classified 20% of the field notes to serve as a measure of reliability. There was a 97% agreement between coders for this coding system.

Results

The distribution of the sample for the Transition Satisfaction Index was 52.3% ($n = 67$) in the transition satisfaction group, 43.0% ($n = 55$) in the transition dissatisfaction group, and 4.7% ($n = 6$) in the cannot classify group. Six of the 128 sets of family field notes could not be reliably classified. There were no significant differences between the demographics of these six families and the rest of the sample except for mother's education, where the "cannot classify" mothers had significantly less education than the mothers in the transition satisfaction and dissatisfaction groups, $t(126) = -2.19, p \leq .05$.

For the Family Well-Being Index, there were 42 participants (33%) in the low family well-being group and 70 participants (55%) in the high family

well-being group. In 16 cases (12%), a family well-being code could not be determined because an equal number of low family and high family well-being criteria were described in the field notes. These 16 participants composed the "cannot classify" group and were not included in analyses. There were no significant differences among the demographics of these 16 participants and the rest of the sample.

For the purpose of data analysis, independent variables were identified that previous research has shown to be important to transition and/or family well being. These independent variables were grouped into three domains: young adult characteristics (variables pertaining to the young adult, such as age and adaptive behavior), family characteristics (variables pertaining to family demographics or the family environment, such as family income and positive impact on family), and environmental characteristics (variables related broadly to school programming and service quality, such as young adult work experience while in school and development of a transition plan; see Table 2). Independent sample t tests and chi-square analyses were run to determine which of these independent variables differed significantly among the Transition Satisfaction Index.

Are There Differences in Young Adult, Family, and Environmental Characteristics Among Families That Experience Satisfactory and Dissatisfactory Transitions?

As indicated in Table 2, two young adult variables differed between the transition satisfaction groups, ratings of mental health, $t(120) = 2.02, p \leq .05$, and quality of life, $t(120) = 4.38, p \leq .001$. In the transition satisfaction group, the young adults exhibited fewer mental health problems. Parents in the transition satisfaction group also rated their young adults as having higher quality of life.

Three family characteristics significantly differentiated transition satisfaction groups: negative impact on the family, $t(114) = 1.98, p \leq .05$, maternal depression, $t(116) = 2.56, p \leq .05$, and the effect of worrying on the family, $t(120) = 2.14, p \leq .05$. Mothers in the transition satisfaction group reported less negative impact on the family, lower rates of depression, and less worrying about transition on the family.

In addition, three environmental characteristics significantly differentiated transition satisfac-

Table 2 Group Differences

Variable	Transition satisfaction	Transition dissatisfaction	<i>t</i> or χ^2
	<i>M</i> or % (<i>n</i> = 67)	<i>M</i> or % (<i>n</i> = 55)	
Young adult characteristics			
Age (in years)	24.25	24.36	<i>ns</i>
Gender (% male)	52.2%	56.4%	<i>ns</i>
Ethnicity (% White)	49.1%	63.3%	<i>ns</i>
Vineland standard score	24.97	25.89	<i>ns</i>
Reiss total score	5.97	8.18	<i>t</i> = 2.02*
Quality-of-life total	81.54	73.15	<i>t</i> = 4.38***
Family characteristics			
Family income	7.93	7.45	<i>ns</i>
Mother education	4.90	4.56	<i>ns</i>
Marital status (% married)	70.1%	61.8%	<i>ns</i>
FIQ Negative Impact score	17.16	21.58	<i>t</i> = 1.98*
FIQ Positive Impact score	14.06	13.08	<i>ns</i>
CES-D total score	10.14	15.74	<i>t</i> = 2.56*
Effect of worrying on family	4.52	5.47	<i>t</i> = 2.14*
Environmental characteristics			
Service quality			
Parent aware of services (% aware)	83.6%	69.1%	<i>ns</i>
Level of involvement parent has in transition	3.68	3.75	<i>ns</i>
Parent satisfaction with their involvement in transition planning (PIT)	4.28	3.58	<i>t</i> = 3.58***
Was there a plan before the YA exited school? (% with plan)	64.2%	47.3%	<i>ns</i>
Social domain			
How often YA participates in activities outside home (TES)	4.21	3.65	<i>ns</i>
How many friends the young adult has	1.66	1.29	<i>ns</i>
Residential domain			
Parent's expectations for YA moving out of home	2.25	2.27	<i>ns</i>
YA's current living arrangements (% out of home)	10.4%	14.5%	<i>ns</i>
Vocational domain			
Young adult has had paid work (% with paid work)	46.3%	23.6%	χ^2 = 5.76*
YA's current work arrangements	2.42	1.89	<i>t</i> = 3.35**

Note. FIQ = Family Impact Questionnaire (Donenberg & Baker, 1993); CES-D = Center for Epidemiologic Studies Depression Scale (Radloff, 1977); PIT = Parent Involvement in Transition Planning (Kraemer & Blacher, 2001); TES = Transition Experiences Survey (Kraemer & Blacher, 2001); YA = young adult.

* $p \leq .05$. ** $p \leq .01$. *** $p \leq .001$.

tion groups: parent satisfaction with their level of involvement in transition planning, $t(120) = 3.58$, $p \leq .001$; whether young adults had any paid work experience, $\chi^2(N = 122) = 5.76$, $p \leq .05$; and the

young adults' current work arrangements, $t(120) = 3.35$, $p \leq .01$. Parents in the transition satisfaction group were more satisfied with their involvement in transition planning, had young adults with paid

work experience, and had young adults with more normative work arrangements (i.e., holding a job in the community or working in a sheltered workshop vs. being in a day treatment program with no vocational emphasis or at home not working).

Which of These Characteristics Were the Best Predictors of Transition Satisfaction?

To address the second research question regarding which of these variables were the best predictors of transition satisfaction, a series of logistic regressions were run. First, logistic regressions were run for each domain (young adult characteristics, family characteristics, and environmental characteristics). The *t* tests and chi-square analyses performed to analyze Question 1 were used to determine which variables to enter into the logistic regressions. All variables that differed significantly ($p \leq .05$) among transition satisfaction groups in Question 1 were entered into one of three logistic regressions (e.g., child, family, or environmental characteristics). In addition, a final logistic regression was run to examine which of the characteristics across the three domains were the strongest overall predictors of transition satisfaction. In this regression, all of the variables that were significant at the .10 level in the first three regressions were entered into the final model.

The first regression examined young adult characteristics as predictors of transition satisfaction. Two variables were entered into the model: young adult Reiss score and young adult quality of life. As shown in Table 3, the first logistic regression revealed that the young adult's quality of life was a unique predictor of transition satisfaction ($p \leq .01$). The second regression examined family characteristics as predictors of transition satisfaction. In this analysis, three variables were entered into the model: negative impact on the family, maternal depression, and the effect of worrying on the family. This regression indicated that there was a trend suggesting that both maternal depression ($p \leq .10$) and the impact of worrying on the family ($p \leq .10$) were unique predictors of transition satisfaction. The third regression examined environmental characteristics, and three variables were entered into the model: parent involvement in transition, whether the young adult had paid work during school, and the young adult's current work arrangements. This analysis showed that parent involvement in transition ($p \leq .001$) and the young adult's work arrange-

ments ($p \leq .01$) were both unique predictors of transition satisfaction.

The final regression examined which characteristics were the strongest predictors of transition satisfaction. In this analysis, all five variables that were significant predictors (at $p \leq .10$) in the three domain regression models were entered into the model. As shown in Table 4, the environmental characteristics were the strongest unique predictors of transition satisfaction: parent involvement in transition ($p \leq .01$) and the young adult's work arrangements ($p \leq .05$) were the strongest overall predictors of transition satisfaction.

Were There Differences in Family Well Being Among Transition Satisfaction Groups?

One purpose of this study was to examine the impact of the young adult's transition on parental (mainly mother) well being. Well being was conceptualized as having negative components (e.g., depression, worry, negative impact on parenting) as well as positive components (e.g., positive impact on parenting). The Family Well-Being Index was used to establish evidence of well being derived from interviewer narratives.

Independent sample *t* tests and a chi-square analysis were used to examine if there were differences in family well being among transition satisfaction groups. Differences in the traditionally used quantitative measures of well being were examined, as well as the researcher-derived index of well being.

Codes of well being from field notes correlated with more traditionally used quantitative measures of mother well being. The Family Well-Being Index was significantly related to the FIQ Negative Impact scale ($r = -.52, p < .001$), FIQ Positive Impact scale ($r = .39, p < .001$), and CES-D total score ($r = -.28, p < .01$).

A chi-square analysis revealed that there were significant differences in the Family Well-Being Index between the transition satisfaction and the transition dissatisfaction groups, $\chi^2(1, N = 122) = 6.70, p = .01$. The majority of the families in the transition satisfaction group (64.1%) were classified as having high family well being. As an example, 1 parent in the transition satisfaction group described her young adult child as follows, "She is the most joyful thing in this world. Nothing in life measures up to her pure love . . . you cannot live with an

Table 3 Logistic Regression for Young Adult Characteristics, Family Characteristics, and Environmental Characteristics

Variable	β	SE	Wald	<i>p</i>	OR	95% CI
Young adult characteristics regression						
Reiss total score	−0.02	0.03	0.39	.53	0.98	0.92–1.05
YA quality of life	0.07	0.02	12.11	.00***	1.08	1.03–1.12
Family characteristics regression						
FIQ Negative Impact Scale	−0.01	0.02	0.16	.69	0.99	0.96–1.03
CES-D total score	−0.04	0.02	3.44	.06*	0.97	0.93–1.00
Effect of worrying on family	−0.16	0.09	2.98	.09*	0.86	0.72–1.02
Environmental characteristics regression						
Parent involvement in transition	0.82	0.23	13.17	.00****	2.28	1.46–3.56
YA has paid work	0.30	0.53	0.31	.58	1.34	0.48–3.79
YA current work arrangements	0.90	0.32	7.68	.01***	2.46	1.30–4.64

Note. OR = odds ratio; CI = confidence interval; YA = young adult; FIQ = Family Impact Questionnaire (Donenberg & Baker, 1993); CES-D = Center for Epidemiologic Studies Depression Scale (Radloff, 1977).

* $p \leq .10$. *** $p \leq .01$. **** $p \leq .001$.

angel and not be touched.” A set of field notes for another satisfied family read “Overall, she is not a stressor . . . [and] the family is happy with what she is doing right now.”

Conversely, the majority of the families in the transition dissatisfaction group (63.8%) were classified as having low family well being. One of the parents in the transition dissatisfaction group explained that her young adult’s siblings “refrain from bringing their friends to the house for fear of any embarrassment that their brother might cause them,” whereas another parent reported that she “has had trouble staying in a long term romantic relationship because her son needs to always be where she is.”

Discussion

The purpose of the present investigation was to develop an appropriate measure of transition success for young adults with severe intellectual disability. Traditional measures of transition success, such as competitive employment, may not be appropriate for this population. In addition, we suggest that a successful transition is based, in part, on how well the family is doing and how parents perceive the transition. Previous research has shown the transition period to affect both the young adult and his or her family (Morningstar, Turnbull, & Turnbull, 1996; Szymanski, Hershenson, & Power, 1988). Therefore, this article focused on parent perspec-

tives of transition in a sample of young adults with severe intellectual disability who were unable to provide their own responses. Our index of transition success was parents’ satisfaction with the young adult’s transition. In addition, we were interested in how transition satisfaction related to family well being.

In the current study, transition satisfaction related to a variety of young adult, environmental, and family characteristics, with variables in each domain remaining in our final regression models. Specifically, when we examined young adult characteristics, transition satisfaction was related to young adult mental health and young adult quality of life. Interestingly, it was not related to adaptive behavior. There was no significant difference in adaptive behavior of the young adults in our transition satisfaction group and our transition dissatisfaction group. Thus, adaptive behavior of the young adult was not as critical a variable in this study as it has been in other studies (e.g., Mank et al., 1997a, 1997b, 1998). In addition, given the severe impairment of the young adults in this sample, there was less variance in our measure of adaptive behavior compared with other studies, thereby limiting our ability to find a significant effect.

Young adult mental health was related to transition satisfaction. This was likely due to our measure of mental health being heavily influenced by the presence of maladaptive behavior. Indeed, by adolescence, estimates of mental health or psychi-

Table 4 Logistic Regression for Overall Model

Variable	β	SE	Wald	<i>p</i>	OR	95% CI
YA quality of life	0.03	0.03	1.20	.27	1.03	0.98–1.09
Parent depression	−0.02	0.02	0.70	.40	0.98	0.95–1.02
Effect of worrying on family	−0.09	0.10	0.89	.35	0.91	0.76–1.10
Parent involvement in transition	0.72	0.24	9.23	.00	2.06**	1.29–3.29
YA current work arrangements	0.89	0.35	6.45	.01	2.43*	1.22–4.81

Note. OR = odds ratio; CI = confidence interval; YA = young adult.

p* ≤ .05. *p* ≤ .01. ****p* ≤ .001.

atric disorder in intellectual disabilities has consistently found from a third to half of these individuals meet criteria for one or more mental disorders (Emerson, 2003; Gillberg, Persson, Grufman, & Themer, 1986; Kaptein, Jansen, Vogels, & Reijneveld, 2008). It is often difficult to find quality adult services for individuals with intellectual disability who have concomitant behavior problems (Maes, Broekman, Došen, & Nauts, 2003; McIntyre, Blacher, & Baker, 2002). Parents may be less satisfied because they have experienced difficulty obtaining services or disappointment that the current services do not address the young adult's individual needs. Thus, they may view their son or daughter's transition as less successful than parents who do not have these complications.

When we examined environmental characteristics, or characteristics related to school programming, parent satisfaction with their involvement in transition planning was a key variable related to overall transition satisfaction. This finding is not unique. Several authors have demonstrated the critical relationship between involving parents in their son's or daughter's school–transition programming and more successful outcomes (e.g., Kim & Turnbull, 2004; Kraemer et al., 2003; Kraemer & Blacher, 2001; Salembier & Furney, 1997). Evidence has shown that the majority of families want to be involved in planning for their sons' or daughters' transition from school to adult life and that they feel more empowered and more positive about their sons' or daughters' experience if they are.

It is important to note, however, that we do not know the direction of this relationship. It may be that parents prefer to be involved with young adults who have more interesting and satisfying work arrangements or that parents' high involvement may lead their young adults to more satisfying work arrangements. Nevertheless, these results are encouraging because they suggest that there is a re-

lationship between what service providers do and how satisfied parents feel.

An obvious implication of these findings is the need for school personnel to create more opportunities for parents to get involved in the transition planning process. Such involvement opportunities abound during the earlier school years, but many school systems do not have well-defined roles for parents of high school students. Perhaps if parents were encouraged to have an active role in planning, their satisfaction with transition outcomes might increase. One way to do this may be to begin transition planning earlier, even before the mandated age of 16, providing parents more time to prepare for the transition and more opportunities to get involved in the process. Implementing person-centered planning is another way to increase parent involvement in the transition planning process and has been shown to be beneficial for high school-age students with intellectual and developmental disabilities (Brown, Galambos, Poston, & Turnbull, 2007; Hagner, Helm, & Butterworth, 1996; Miner & Bates, 1997).

A unique aspect of this study was the examination of family characteristics and transition outcomes–transition success. Three family variables—negative family impact, maternal depression, and the effects of worrying on the family—were related to transition satisfaction. Here, we begin to see how family variables, including aspects of family well being, are potentially affected by the success or non-success of the young adult's transition out of the school system. The young adult's program is a critical piece of the broader family environment; when the program fails or perhaps does not live up to parents' expectations, the family system is affected. This could manifest as maternal depression or stress in the overall family. Of course, the bi-directionality of this relationship must be acknowledged. It may be that parents who are depressed or are more neg-

actively affected by their young adults disability are more likely to view the world negatively, to be less involved in their young adult's transition, and, thus, experience a dissatisfactory transition. The use of cross-sectional data does preclude making causal inferences.

To put these findings into context, there is a strong literature attesting to the long-term care often provided by mothers of young adults with intellectual disability (Heller & Factor, 1994; Krauss & Seltzer, 1999; Seltzer, Krauss, Hong, & Orsmond, 2001). As caregivers themselves age, it is important to have well-articulated plans for schooling, residence, social life, and work for the young adults with intellectual disability. Our findings suggest that future plans affect the well being of families as early as the exit from high school.

Last, using a broader index of family well being created for this study, we were able to further demonstrate the relationship between family well being and transition satisfaction. As a whole, parents who were more satisfied with their son's or daughter's transition had higher well being than parents who were dissatisfied with their son's or daughter's transition. This underscores the important role that successful transition plays in the overall ecology of the family (Bonfenbrenner, 1979). Conversely, unsuccessful transitions that are stressful may have collateral effects on broader family functioning (Blacher, 2001).

This study contributes to the existing literature by exploring a unique indicator of transition success, examining predictors of a successful transition, and investigating the relationship between transition success and family well being. Given the limited empirical research on families during the transition period, future work must continue to examine the implications of young adult transition outcomes for family well being. In particular, it will be important to examine the longitudinal relationship between transition satisfaction and family well being, focusing on how transition experiences influence family well being across the lifespan of the young adult. Longitudinal data would allow investigators to examine the immediate, as well as the distal, impacts of transition on the families of these young adults. Although this was a diverse sample that encompassed many regions and school districts in southern California, the outcomes of the study may be influenced by the policies of individual school districts (e.g., some districts—programs may prioritize transition and life planning more than others). There-

fore, it is important to investigate the variables of interest in samples in other areas of California or in other states, in part to determine the generalizability of these findings. Last, future work should continue to examine additional ways of measuring transition success for young adults with severe intellectual disability. This would expand opportunities for researchers and practitioners to evaluate whether postschool outcomes for the young adult and his or her family are optimal.

References

- Blacher, J. (2001). Transition to adulthood: Mental retardation, families, and culture. *American Journal on Mental Retardation*, 106, 173–188.
- Blacher, J., Lopez, S., Shapiro, J., & Fusco, J. (1997). Contributions to depression in Latina mothers with and without children with retardation: Implications for caregiving. *Family Relations: Interdisciplinary Journal of Applied Family Studies [Special Issue: Family Caregiving for Persons With Disabilities]*, 46, 325–334.
- Blacher, J., Shapiro, J., Lopez, S., & Diaz, L. (1997). Depression in Latina mothers of children with mental retardation: A neglected concern. *American Journal on Mental Retardation*, 101, 483–496.
- Bonfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press.
- Brown, I., Galambos, D., Poston, D. J., & Turnbull, A. P. (2007). Person-centered and family-centered support. In I. Brown & M. Percy (Eds.), *A comprehensive guide to intellectual and developmental disabilities* (pp. 351–361). Baltimore: Brookes.
- Chambers, C. R., Hughes, C., & Carter, E. W. (2004). Parent and sibling perspectives on the transition to adulthood. *Education and Training in Developmental Disabilities*, 39, 79–94.
- Donenberg, G., & Baker, B. L. (1993). The impact of young children with externalizing behaviors on their families. *Journal of Abnormal Child Psychology*, 21, 179–198.
- Emerson, E. (2003). Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *Journal of Intellectual Disability Research*, 47, 51–58.
- Gallivan-Fenlon, A. (1994). "Their senior year:" Family and service provider perspectives on the transition from school to adult life for young

- adults with disabilities. *Journal of the Association for Persons With Severe Handicaps*, 19, 11–23.
- Gillberg, C., Persson, E., Grufman, M., & Themner, U. (1986). Psychiatric disorders in mildly and severely mentally retarded urban children and adolescents: Epidemiological aspects. *British Journal of Psychiatry*, 149, 68–74.
- Hagner, D., Helm, D. T., & Butterworth, J. (1996). “This is your meeting:” A qualitative study of person-centered planning. *Mental Retardation*, 34, 159–171.
- Halpern, A. S. (1994). Quality of life for students with disabilities in transition from school to adulthood. *Social Indicators Research*, 33, 193–236.
- Heller, T., & Factor, A. (1994). Facilitating future planning and the transitions out of the home. In M. M. Seltzer, M. W. Krauss, & M. P. Janicki (Eds.), *Life course perspectives on adulthood and old age* (pp. 39–52). Washington, DC: American Association on Mental Retardation.
- Hill, M. L., Wehman, P. H., Kregel, J., & Banks, P. D. (1987). Employment outcomes for people with moderate and severe disabilities: An eight-year longitudinal analysis of supported competitive employment. *Journal of the Association for Persons With Severe Handicaps*, 12, 182–189.
- Johnson, D. R., McGrew, K. S., Bloomberg, L., Bruininks, R. H., & Lin, H. (1997). Results of a national follow-up study of young adults with severe disabilities. *Journal of Vocational Rehabilitation*, 8, 119–133.
- Kaptein, S., Jansen, D. E. M. C., Vogels, A. G. C., & Reijneveld, S. A. (2008). Mental health problems in children with intellectual disability: Use of the strengths and difficulties questionnaire. *Journal of Intellectual Disability Research*, 52, 125–131.
- Katsiyannis, A., Zhang, D., Woodruff, N., & Dixon, A. (2005). Transition supports to students with mental retardation: An examination of data from the national longitudinal transition study 2. *Education and Training in Developmental Disabilities*, 40, 109–116.
- Kim, K., & Turnbull, A. (2004). Transition to adulthood for students with severe intellectual disabilities: Shifting toward person-family interdependent planning. *Research and Practice for Persons With Severe Disabilities*, 29, 53–57.
- Kraemer, B. R., & Blacher, J. (2001). Transition for young adults with severe mental retardation: School, preparation, parent expectations, and family involvement. *Mental Retardation*, 39, 423–435.
- Kraemer, B. R., McIntyre, L. L., & Blacher, J. (2003). Quality of life for young adults with mental retardation during transition. *Mental Retardation*, 41, 250–262.
- Krauss, M. W., & Seltzer, M. M. (1999). An unanticipated life: The impact of lifelong caregiving. In H. Bersani, Jr. (Ed.), *Responding to the challenge: Current trends and international issue in developmental disabilities* (pp. 173–187). Cambridge, MA: Brookline Books.
- Luftig, R. L., & Muthert, D. (2005). Patterns of employment and independent living of adult graduates with learning disabilities and mental retardation of an inclusionary high school vocational program. *Research in Developmental Disabilities*, 26, 317–325.
- Maes, B., Broekman, T. G., Došen, A., & Nauts, J. (2003). Caregiving burden of families looking after persons with intellectual disability and behavioural or psychiatric problems. *Journal of Intellectual Disability Research*, 47, 447–455.
- Magaña, S. M. (1999). Puerto Rican families caring for an adult with mental retardation: Role of familism. *American Journal on Mental Retardation*, 104, 466–482.
- Mank, D., Cioffi, A., & Yovanoff, P. (1997a). Analysis of the typicalness of supported employment jobs, natural supports, and wage and integration outcomes. *Mental Retardation*, 35, 185–197.
- Mank, D., Cioffi, A., & Yovanoff, P. (1997b). Patterns of support for employees with severe disabilities. *Mental Retardation*, 35, 433–447.
- Mank, D., Cioffi, A., & Yovanoff, P. (1998). Employment outcomes for people with severe disabilities: Opportunities for improvement. *Mental Retardation*, 36, 205–216.
- McIntyre, L. L., Blacher, J., & Baker, B. L. (2002). Behaviour/mental health problems in young adults with intellectual disability: The impact on families. *Journal of Intellectual Disability Research [Special Issue: Mental Health and Intellectual Disability]*, 6, 239–249.
- McIntyre, L. L., Kraemer, B. R., Blacher, J., & Simmerman, S. (2004). Quality of life for young adults with severe intellectual disability: Mothers’ thoughts and reflections. *Journal of Intellectual & Developmental Disability*, 29, 131–146.
- McNair, J., & Rusch, F. R. (1991). Parent involve-

- ment in transition programs. *Mental Retardation*, 29, 93–101.
- Miner, C. A., & Bates, P. E. (1997). The effect of person centered planning activities on the IEP/transition planning process. *Education & Training in Mental Retardation & Developmental Disabilities*, 32, 105–112.
- Morningstar, M. E., Turnbull, A. P., & Turnbull, H. R. (1996). What do students with disabilities tell us about the importance of family involvement in the transition from school to adult life? *Exceptional Children [Special Issue: Families of Children and Adolescents With Special Needs]*, 62, 249–260.
- Radloff, L. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Assessment*, 1, 385–401.
- Reiss, S. (1986). *Manual for the Reiss Screen for Maladaptive Behavior: Version 1.1*. New York: International Diagnostic Systems.
- Reiss S. (1994). *Reiss Screen for Maladaptive Behavior: Test manual* (2nd ed.). Columbus, OH: International Diagnostic Systems.
- Salembier, G., & Furney, K. S. (1997). Facilitating participation: Parents' perceptions of their involvement in the IEP/transition planning process. *Career Development for Exceptional Individuals*, 20, 29–42.
- Schalock, R. L., & Keith, K. D. (1993). *Quality of Life Questionnaire manual*. Columbus, OH: International Diagnostic Systems.
- Seltzer, M. M., Krauss, M. W., Hong, J., & Orsmond, G. I. (2001). Continuity or discontinuity of family involvement following residential transitions of adults who have mental retardation. *Mental Retardation*, 39, 181–194.
- Sparrow, S. S., Balla, D. A., & Cicchetti, D. V. (1984). *Vineland Adaptive Behavior Scales*. Circle Pine, MN: American Guidance Service.
- Szymanski, E. M., Hershenson, D. B., & Power, P. W. (1988). Enabling the family in supporting transition from school to work. In P. W. Power, A. E. Dell Orto, & M. B. Gibbons (Eds.), *Family interventions throughout chronic illness and disability* (pp. 216–233). New York: Springer.
- Thorin, E. J., & Irvin, L. K. (1992). Family stress associated with transition to adulthood of young people with severe disabilities. *Journal of the Association for Persons With Severe Handicaps*, 17, 31–39.
- Thorin, E., Yovanoff, P., & Irvin, L. (1996). Dilemmas faced by families during their young adults' transitions to adulthood: A brief report. *Mental Retardation*, 34, 117–120.
- Wagner, M., Newman, L., Cameto, R., Garza, N., & Levine, P. (2005). *After high school: A first look at the postschool experiences of youth with disabilities. A report from the National Longitudinal Transition Study-2 (NLTS2)*. Menlo Park, CA: SRI International.
- Wehmeyer, M. L., Garner, N., Yeager, D., Lawrence, M., & Davis, A. K. (2006). Infusing self-determination into 18–21 services for students with intellectual or developmental disabilities: A multi-stage, multiple component model. *Education and Training in Developmental Disabilities*, 41, 3–13.
- Whitney-Thomas, J., & Hanley-Maxwell, C. (1996). Packing the parachute: Parents' experiences as their children prepare to leave high school. *Exceptional Children*, 63, 75–87.

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