**The Role of Families of Students with Disabilities in Postsecondary Education**

**Introduction**

In 1987, Everson and Moon wrote “professionals and parents are struggling with the roles and responsibilities they need to assume to ensure meaningful adult outcomes for young adults with disabilities” in regards to transition services. Kohler & Chapman (1999) posed the following question as one to answer in respect to the implementation of the National Transition Alliance Transition Practices Framework: “In what roles do family members participate in providing transition-related education and services?” (p. 18). These statements apply to the current situation of students with disabilities, parents and disability support personnel in postsecondary educational settings as well. The purpose of this paper is to report on a study using focus groups of postsecondary education students with disabilities, families of students with disabilities and disability support personnel. The results of the study reveal an array of useful roles for families of students in postsecondary education that parallel family, ecological and cultural theory.

**Statement of the Problem**

**Legal Changes.** Legally, parents have mandates under IDEA 1997 to direct curriculum, placement and supports until students with disabilities are 18 years old or exit public education. Upon entrance into postsecondary education, students have rights and responsibilities under Section 504 of the Rehabilitation Act and the American with Disabilities Act 1990 to identify and negotiate their own accommodations and supports. Family members are not allowed access to records or support personnel in postsecondary education without the expressed permission of the student. This is a rapid departure from the role of legal advocate that parents played in secondary education. Parents and family members need to adapt to laws and regulations governing postsecondary education. If family actions, however well intended, are not well prepared for and executed, their activities can be detrimental (Everson & Moon, 1987; Morningstar, Turnbull & Turnbull, 1996; NCSPES, 2000).

**Family Roles.** Historically, the roles of families of students and adults with disabilities have evolved over time.
Some roles, i.e. problem source, have been negatively assigned by professionals. Other roles, i.e. source of assistance in planning, imply that parents and family members have an empowering role with the person with disability and act towards self determination. It is important to remember that all of the roles discussed below may still exist and overlap (Hanley-Maxwell, Pogoloff and Whitney-Thomas, 1998). Several roles for families of students and persons with disabilities have been identified by Turnbull & Turnbull, 1990 and Alper, 1994. They are families as:

- Problem Source
- Political Advocate
- Service Developer
- Decision Recipient
- Learner & Teacher
- Decision Maker
- Family Member

Adolescents themselves have reported on the roles that their families have played in their lives as they make decisions of:

- Career – selection guide & role model
- Source of social support
- Source of assistance in planning of the future (Morningstar, Turnbull & Turnbull, 1996).

Family roles are one perspective of the family as adolescents enter adult life.

Family Changes. As students enter postsecondary education many changes are occurring in their family. All families go through a developmental sequence called a life cycle; couple just married, family with young children, family with school-aged children, family with adolescents and then couple alone (Carter & McGoldrick, 1999). In a family with adolescents, the family is moving from one life cycle stage to another; that of a family with a adolescent to a couple alone. This is called the launching process. As families with adolescents are successful, they have coped with the changing demands of their members, increasing flexibility and boundaries to accommodate the adolescent’s independence and moves in and out of the family (Carter & McGoldrick, 1999; Kreppner & Lerner, 1989; Schutze, 1989). The primary goal of the family in the adolescent years is to transform and launch its member, yet it’s the adolescent’s goal to maintain a relationship with the parents (Schutze, 1989). The fluctuation and balance among these relationships are called the "modulation of dependency". It is the tension between the need for family and the desire to break away (Collins & Russell, 1991). As families accomplish this launching task, families can develop to the next stage, but if adolescents are not launched, family development is arrested which may cause stress build up and mal-adaptive coping strategies (Alsdous, 1978; McCubbin & Patterson, 1983).

The launching process is especially difficult for modern, multi-cultural families with teens with disabilities. Culture interacts with life cycle development at every stage. Even the members of a family are culturally defined from Anglos identifying members as intact families to Chinese including all ancestors and descendents (Moore Hine, Garica Preto, McGoldrick, Almedia &
Specific to the stage of families with adolescents and the launching process, life cycle varies in importance by ethnic group: Anglo families consider moving out of the family home as indicative of launching, (Moore, et al, 1999). While Latino families consider courtship/marriage as launching, it is not the autonomy of decision-making, and the ability to support oneself emotionally and financially. And for Jewish boys the tradition of the bar mitzvah is launching (Falicon, 1999). In regards to disability, it is a fundamental dilemma of parents of adolescents with disabilities that they need to wean the adolescent from the protections and restrictions of parental control, yet the parents are faced with the increased need of advocacy in the face of decreased services (Nisbet, Covert, & Schuh, 1992). But all launching tasks require a significant alignment of family roles as the adolescent considers his personality, cultural values and interpersonal environment (Schutze, 1989).

Autonomy Development as the Foundation of Self Determination. The individual’s growth during adolescence is a product of contextual change and the intertwining of the individual and the family development (Kreppner & Lerner, 1989). A major task of adolescence is the development of ego identity or autonomy as evident by role taking, self-direction and self-determination (Schutze, 1989). These skills are developed in the context of emotional relationships (Carter & McGoldrick, 1999) the family being pivotal. Further more, these skills are gender tied as males are considered to have primary values of separation and autonomy while the context is primarily for females (Carter & McGoldrick, 1999).

Students with disabilities in postsecondary education have reported feeling overprotected by their families (NCSPES, 2000). Yet antidotal evidence suggests that students perform better when parents advocate for them (S. Burgstahler, personal communication).

**Research Questions**

What are the experiences and perceptions of students with disabilities, family members of students with disabilities and Disability Support Coordinators regarding the role of family members in providing supports to students with disabilities in postsecondary education?

What are the discrepancies among the experiences and perceptions among these groups?

What role don’t parents/family members play?

In what functions do students with disabilities need assistance?

Who provides each type of assistance and support?

How should supports and assistance be coordinated?

**Methods**

Focus groups are designed to reveal multiple perspectives and are best suited to address questions that inform or assess policy and practice (Brotherson & Goldstein, 1992). The information produced in a group discussion format will be richer, more complete and more revealing than that
which can be obtained in individual interviews, surveys, or questionnaires (Bertrand, Brown & Ward, 1992). Focus group research is a qualitative method used to gain a more complete understanding of such issues as motivation, behavior, feelings, or decision-making strategies (Krueger, 1988; Morgan, 1988). Focus groups are designed to reveal multiple perspectives, are well suited to assess policy and practice, and their format often yields richer, more complete, and more revealing information than that obtained through surveys, questionnaires, or individual interviews (Brotherson & Goldstein, 1992; Brodigan, 1992). Also, focus group participants can express their ideas in ways that are not as structured by the researcher’s prejudices and expectations (Bertrand, Brown & Ward, 1992), and they often feel more secure discussing sensitive topics, helping to encourage more candid expression of their opinions and perceptions (Byers & Wilcox, 1988). Focus groups have been used to assess and improve the quality of college programs, to identify critical support services and programs for postsecondary students with learning disabilities, and to determine compliance with the Americans with Disabilities Act (Brodigan, 1992; Bers & Smith, 1987; Armstrong, 1996; Finn, 1997).

The Committee on Human Studies at the University of Hawaii at Manoa and University of Washington reviewed this study. The Participant Action Research team also reviewed this study proposal, gave substantial feedback which was incorporated into the design of the study. Students with disabilities, family members and disability support coordinators (DSCs) for the focus groups were recruited through Disability Support Centers on campuses and community agencies were asked for informant nominations.

Sampling Three groups of informants were chosen; one group, the students themselves; one group, the family members of students from postsecondary institutions and the third group, Disability Support Coordinators from postsecondary institutions. There were two groups of student informants, two groups of parent informants and one group of Disability Support Coordinators. Informants were identified in three ways. First, the Participant Advisory Team for Hawaii was asked to nominate informants. Second, referrals to community agencies were also accepted. And finally, informant nominations for Disability Support Coordinators were solicited from the AHEAD (Association on Higher Education and Disability) conference in July 2001. This strategy is not intended to be representative or typical in contrast to quantitative sampling methods but broad, to reveal multiple perspectives. A group of 7 to 12 informants was selected from the nominations and focus group meetings were scheduled.

Data Collection Permission for research on human subjects was obtained from The Human Subject Research Committee at the University of Hawaii at Manoa. Consent for the study was obtained from the informants. Disability Support Coordinators were recruited through the Association on Higher Education and Disability (AHEAD). All focus
group meetings took place in comfortable rooms and refreshments were provided. Experienced facilitators and recorders were chosen from the NCSPES network. The facilitators at each site increased the reliability of the study by using the same list of probe questions. Repeating the same questions with each group-family, student or disability support coordinator increased the internal validity of the study. The Focus Groups were audio taped and notes were taken as well, contributing to credibility.

Data Analysis The data from the focus groups were brought to the University of Hawaii at Manoa. A content analysis of the data was completed using a constant comparative method yielding themes (Glaser & Strauss, 1967), analytical induction (Taylor and Bogdan, 1984) and domain analysis (Spradley, 1979). A second researcher analyzed the data. Comparisons of findings were generated in an inner rater reliability process as each researcher presented her findings and compared them to the other’s thereby increasing triangulation and contributing to the validity of the findings. To organize the main issues across the groups, the UH team grouped symbolic categories into domains so that all members of that domain share at least one feature of meaning (Spradley, 1979). A chart was constructed for the focus groups, with the issues placed into the appropriate domain.

The University of Washington: Do-It Project has an established network of parents who are connected by the Internet. In keeping with the spirit of participant action research (PAR), the report of findings from Part I will be posted on-line and parents will be asked to validate the findings by reporting their reactions on-line. These reactions will be sent electronically to the University of Hawaii at Manoa where they will be entered into the computer analytical program, analyzed for themes using a constant comparative method by a researcher. This process will also contribute to the credibility of the study as Participant Verification. All of the data will be analyzed together, with member checks and searching for grounded theory, salient themes and potential variables (Miles & Hubberman, 1994).

Findings

Encouragement. Families can be the "rah rah" section for students with disabilities in postsecondary education. Families may give guidance to the student and instill a vision for the future. Encouragement from families to students is appreciated by all stakeholders. But some students feel like they need to prove themselves before receiving needed support; and some families show a delay of encouragement.

"What I have tried to do with my son is to constantly remind him that he has more choices than are presented to him. That he doesn't have to take those choices that people just automatically offer. You know he doesn't have to stick with one set. Some of the choices that were presented to him in high school were like janitorial work, McDonalds, military. They were very mundane choices and it's not gonna excite him
about his future. I've always tried to tell him what is your dream? What do you want to do with your life? Where do you want to be working? He just got no guidance on those things."

"Parents encouraging and teaching and helping their child advocate for themselves is one of the things that parents could do to make a difference for their child. Either they need to teach them or change their advocacy skills and then the parent need to be there encourage and support them, push them come on – you can talk to them. You know who to talk to – call them, email them."

➢ Towards Self Determination. Typical parents and families advocate for their members, give choices, teach members to advocate for themselves, teach skills and foster self determination. Families offer balance to students with disabilities in postsecondary education; a balance of reality and a balance of protection and self determination and empowerment. And families continue to provide supports such as negotiating the bureaucracy, funding and scholarships. In this study family members and disability support coordinators talked about self determination and students did not. Parents and disability support coordinators find it difficult to balance between advocacy (for students) and self determination.

"And advocate for themselves. I have had student in the office who have never said a work the entire time they were in the office with their parents. Mom and dad did all the talking and the son didn't say one work in the hour they were there. And I have a student who the student is - I can't get him to come into the office. Help them to be self advocating and make choices and let them accept the consequences."

➢ Transition. The change in the law governing education from secondary to postsecondary has direct implication on family involvement in the student with disability's education. No one can have access to student information or records without the express permission of the student. Disability Support Coordinators felt at times this is to the students benefit and at times it is not. Other issues of student preparation were found to be sub-themes. Students with disabilities are not allowed to fail until they are in postsecondary. And in secondary school, the focus is on the immediate environment, not on the outside world.

"So the id gets the message even if I show up every day and by one work then that's enough 'cause I'm gonna pass cause I can't fail anyway. So there's no …incentive for the child."

"Yeah, but part of the problem is that when the kids in secondary school are taught, my standards are this high – I can't fail so why try. And then all of a sudden they want to go to college and they come and they take this placement test and they say 'well I punched in three keys, what do you mean I didn't pass?""

"They do not have the challenge; they do not have the knowledge that they got to work harder. It's not that it's given to them they got to work harder."
Instrumental Supports Families continue to provide for the basic necessities for their family member as they are students in postsecondary education. Some as basic as food, clothing and shelter and transportation. Some instrumental support is reading/studying with students. People said just an occasional check helps and that families provide a safety net- a home to go to.

"I have used DVR. They advanced the money for tuition and for books. They pay for tuition and books, but Brian (the student) has to apply for the Pell Grant and then I (Mom) pay the money back to DVR."

"We need food, you know, somewhere to live."

Inner Family Support. Families have habitual helping relationships. They are the source of unconditional love, parental understanding/acceptance, with no one else to play the family role. But not all of the people we talked to had this experience. Family stress was increased in some situations by the disability. Some found a need to decrease discrimination with in the family with a lack of understanding/knowledge of disability. There are important non traditional families as well as "chosen" families.

"Being there throughout all the ups and downs and the triumphs and tribulations. Unconditional love. That's always important for both ways. I don't know I can't put anything into words. The main thing is loving each other."

"When the parents do play the role responsibly, it is the best. They know they can count on us (disability support coordinators). I know I can count on them, and more importantly the student knows they can count on both of us."

Implication & Recommendations

This study has revealed the tensions and confusion among students with disabilities, their families and disability support personnel. More information needs to be given to practitioners regarding the important role that families play for students and adults with disabilities. Parents need to be honored during the transition time and included in supporting their young adult, as the student begins to exercise self determination in postsecondary settings. Policies regarding transition planning in secondary school and disclosure in postsecondary education need to be implemented in ways that include family support. And finally, research on the role of families in a youth and adult life need to continue to identify critical questions as to effective support roles for the families and methods to elicit those roles for practitioners.

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