

**PHASE II (MS#081d(1)-H01)  
PRODUCT OF STUDY #13**

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A Rehabilitation Research & Training Center  
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THE ROLE OF FAMILIES OF STUDENTS WITH DISABILITIES  
IN POSTSECONDARY EDUCATION

This work is supported in part with funding under grant #H133B980043 from the National Institute on Disability and Rehabilitation Research (NIDRR) within the United States Department of Education. The opinions and positions stated within this paper are those of the authors and do not represent an official position of the funding agency.

# **THE ROLE OF FAMILIES OF STUDENTS WITH DISABILITIES IN POSTSECONDARY EDUCATION**

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## **Abstract**

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 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?” (pg.18). These statements apply to the current situation of students with disabilities as well as parents and disability support personnel in postsecondary educational settings. 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 the 1997 Amendments to the Individuals with Disabilities in Education Act (the primary legislation concerning students with disabilities) 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 of 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**

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 effect upon the person with disability and can promote 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 characterized 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 regarding:

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

Redefining family roles is one challenge to 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 an adolescent to a couple alone. This is called the launching process. Successful families 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 is the adolescent's goal to maintain a relationship with the parents (Schutze, 1989). The fluctuation and balance among these relationships is 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, they can develop to the next stage, but if adolescents are not launched, family development is arrested, which may cause stress buildup and maladaptive coping strategies (Alsdous, 1978; McCubbin & Patterson, 1983).

The launching process is especially difficult for modern, multicultural 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 parents and children to Chinese including all ancestors and descendents (Moore, Hine, Garica Preto, McGoldrick, Almedia & Weltman, 1999). In addition to family composition, the stages of the launching process vary according to culture. Anglo families consider moving out of the family home as indicative of launching, (Moore, et

al, 1999 )and, while Latino families consider courtship/marriage as launching their children into adulthood, this launching does not give the autonomy of decision-making, and the ability to support oneself emotionally and financially. Jewish boys are traditionally launched by the bar mitzvah (Falcon, 1999). A fundamental dilemma of parents of adolescents with disabilities is that they need to wean the adolescent from the protections and restrictions of parental control, and yet are simultaneously faced with the increased need for advocacy in the face decreased services (Nisbet, Covert, & Schuh, 1992). While launching may take different forms, 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 evidenced by role taking, self-direction and self-determination (Schutze, 1989). These skills are developed in the context of emotional relationships (Carter & McGoldrick, 1999) with the family being pivotal. Furthermore, these skills are gender influenced as males are considered to hold primary values of separation and autonomy while the context of relationships is primary for females (Carter & McGoldrick, 1999).

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

### Research Questions

1. What are the experiences and perceptions of students with disabilities, family members of students with disabilities and Disability Support Coordinators (DSCs) regarding the role of family members in providing supports to students with disabilities in postsecondary education?
2. What are the discrepancies among the experiences and perceptions of these groups?
3. What role do parents/family members not play?
4. In what functions do students with disabilities need assistance?
5. Who provides each type of assistance and support?
6. 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 researchers' prejudices and expectations (Bertrand, Brown & Ward, 1992), allowing them to feel more secure discussing sensitive topics and 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, Lewis, & Neult, 1996; Finn, 1997).

The Committee on Human Studies at the University of Hawaii at Manoa reviewed this study. The Participant Action Research team, an advisory board that participates in research by contributing to the design, implementation and evaluation of studies, also reviewed this study proposal and 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. In addition, community agencies were asked for informant nominations.

### Sampling

Three groups of informants were chosen; one group, the students themselves; another 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 the Center on Disability Studies-Research, Rehabilitation and Training Center in 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

Consent for the study was obtained from the informants. All focus group meetings took place in comfortable rooms and refreshments were provided. Experienced facilitators and recorders were chosen from the National Center for the Study of Postsecondary Educational Supports (NCSPEs) network. The facilitators at each site increased the

reliability of the study by using the same list of probe questions with each group- family, student or disability support coordinator.. 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 using 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 shared at least one feature of meaning (Spradley, 1979). A chart was constructed for the focus groups, with the issues placed into the appropriate domain.


## Findings

### ➤ Encouragement.

Families can be the "rah rah " section for students with disabilities in postsecondary education. Disability Support Coordinators spoke about it being important that families support students with disabilities in postsecondary education. Families may give guidance to the student as they attend postsecondary education and instill a vision for the future. Encouragement from families to students is appreciated by not only the Disability Support Coordinators, but the faculty and some most students as well. An ideal situation is one that involves a triangle of support among the DSC, the student, and the parents.

“If that triangle works well, they trust us and allow us to do the job and allow the student to fail. If the student is trying we won't let them fail.”

However, some students feel like they need to prove themselves before receiving needed support, in effect refusing or delaying support from family and paid professional supporters. Some families were reported to show a delay of encouragement until they were sure that the student would be successful.

"What I have tried to do with my son is to constantly nd 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, teaching, and helping their child advocate for him or her self 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 or then the parent needs to be there to 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 with empowerment and a balance of protection with self determination. Families continue to provide supports such as negotiating the bureaucracy of 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 cultivate in the students a balance of both self-advocacy and self-determination.

"I have had students in the office who have never said a word 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 word in the hour they were there, And, I have a student - 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 access student information or records without the express permission of the student. Disability Support Coordinators felt that 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. Conversely, in secondary school, the focus is on the immediate environment, not on the outside world.

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

"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 are as basic as food, clothing and shelter and transportation. Another example of instrumental support is reading/studying with students. People said just an occasional check helps and that families provide a safety net against failure.

"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.

Most families have habitual helping relationships. They are typically the source of unconditional love and understanding/acceptance. However, family stress was increased in some situations by the disability. Some DSCs found a need to decrease discrimination within the family first, to fight a lack of understanding and knowledge regarding the disability. There are important nontraditional 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. 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 with disabilities, as they transition into postsecondary education. Parents need to be involved 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 addressed 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 as well as methods to elicit those roles for practitioners.

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