PHASE II
PROPOSAL BRIEF #13
(MS#028a(1)-H01)

University of Hawai`i at Manoa Center on Disability Studies
National Center for the Study of Postsecondary Educational Supports
A Rehabilitation Research & Training Center
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The Role of Families of Students with Disabilities in Postsecondary Education

Statement of the Problem

Youth with disabilities have been educated in increasingly inclusive settings for the past 25 years. And during the past 15 years there has been an array of many school-to-work programs funded by the federal government. Concurrently, transition to work is a priority of Rehabilitative Services as stated in the 1992 Rehabilitative Amendment (PL 102-569).

Yet youth with disabilities complete public education and enter uncertain futures. A survey commissioned by the National Organization on Disability (1998) concludes that only 29% of persons with disabilities of working age are employed full or part-time as compared with 79% of those who don’t have disabilities. Of people with disabilities who are not working, 72% report that they would prefer to have a job. One avenue to secure better skills and higher wages is higher education and the enrollment rates for students with disabilities are increasing (Stodden, 1998).

But students with disabilities are often not prepared in many ways to enter college. In one way, students with disabilities have not had the opportunity or the skills to advocate for themselves during secondary school. Legally, parents have mandates under IDEA to direct curriculum, placement and supports until Students with disabilities are 18 years old or exit public school. Students are confronted with many different expectations as they enter postsecondary educational institutions. They are expected to make choices of colleges and courses, and need to negotiate their own supports. Students with disabilities who participated in the National Focus Groups (NCSPES, 2000) found the array of supports conflicting and wanted the system of supports to be more coordinated.

So, where are these postsecondary aged students with disabilities? Too often at home, dependent upon their families. The time when children become youth is called the launching period. It is a time when typical families have decreasing parental responsibilities as youth grow in social and financial independence. But families with youth with disabilities often encounter an increase in their responsibilities during the launching period. Students with disabilities, who have lower employment rates and lower attendance rates in postsecondary institutions, are too often
at home and isolated. This situation, a mismatch with the typical family, often leads to family stress (Dunst, Trovette & Deal, 1994; McCubbin & Patterson, 1983). There are other conflicts during the launching period. Anecdotal evidence suggests that students perform better when parents advocate for them during secondary school (S. Burgstahler, personal communication, September 21, 2000). Yet students with disabilities in postsecondary institutions sometimes feel over protected by their parents. Although as with all consenting adults past the age of 18, parents cannot obtain information from postsecondary disabled support services or other organizations. And the final conflict is that students with disabilities want assistance in the use of the confusing system of supports found at the postsecondary level (NCSPES, 2000).

Research Questions

1. What role should parents/family members play with students with disabilities in post-secondary education?

2. What role shouldn’t parents/family play?

3. In which functions do students with disabilities need assistance?

4. Who should provide this type of assistance?

5. How should supports and assistance be coordinated?

Study Method

It is clear that the role of families during the launching period is conflicting and confusing. To better understand the role(s) of families during postsecondary education, an exploratory design using focus groups is proposed.

Part I. 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). Initially, this study will be reviewed by the Committee on Human Studies at the University of Hawaii at Manoa. Three groups of informants will be chosen: one group, the students themselves; second group, the family members of Students with disabilities from postsecondary institutions; and the third group Disability Support Coordinators from postsecondary institutions. Two leading associations representing postsecondary education will nominate the informants. One association Higher Education and the Handicapped (HEATH) is a parent and consumer group and another; AHEAD is an association of Disability Support Coordinators. With the assistance of the National Center of the Study of Postsecondary Educational Supports (NCSPES) personnel, these two associations will be asked to select a group of 5 to 15 informants and to schedule a meeting. Permission for research on human subjects will be obtained from The Committee on Human Subjects at the University of Hawaii at Manoa and from the University of Washington. These informants being “elites” of their group will increase the trustworthiness of the study. Consent for the study will be
obtained from the informants. The focus group will occur just before or after an Advisory Board or Board meeting. An experienced facilitator and recorder will be chosen from the NCSPES network. The same list of probe questions will be used by facilitators at each site to increase reliability of the study. The Focus Groups will be audio taped and transcribed.

Data Analysis

The data from the focus groups will be sent to the University of Hawaii at Manoa and entered into a qualitative analysis computer program (i.e., Qualog or Ethnograph.) A content analysis of the data will be completed using a constant comparative method yielding themes (Glaser & Strauss, 1967). A second researcher will analyze the data to increase reliability and comparisons of findings will be generated. The computer program, enhancing replicability, will record an audit trail of the findings, and themes in this analysis. A report of the findings will be generated.

Part II. The University of Washington’s DO-IT Project has an established network of parents who are connected by the Internet. Some of these are parents of students with disabilities in postsecondary institutions. DO-IT staff will choose informants from this group who have children in postsecondary education or who are graduates. In keeping with the spirit of participant action research (PAR), the report of findings from Part I will be posted online and parents will be asked to validate the findings by reporting their reactions online. 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 and then a repetition of this process. All of the data will be analyzed together, with member checks and searching for grounded theory, salient themes and potential variables (Miles & Hubberman, 1994).

Products

It is anticipated that several products will result. A poster presentation, and a presentation at a national conference will distribute the findings to a select audience. A research brief and journal article will further the distribution. The findings will assist disability support coordinators, parents of Students with disabilities, the students themselves, high school teachers and administrators in understanding and guiding the parent’s in appropriate directions of support of the Students with disabilities.

Reference List


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### Work Plan

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<tr>
<td>October 1, 2000</td>
<td>Research Brief Submitted.</td>
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<tr>
<td>November 1, 2000</td>
<td>Obtain Human Subject Research Approval</td>
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<tr>
<td></td>
<td>Schedule Focus Groups</td>
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<td>Identify Focus Group Facilitators</td>
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<tr>
<td>December 15, 2000</td>
<td>coordinate the collection of data through Focus Groups Meetings</td>
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<tr>
<td>December 30, 2000</td>
<td>Focus Group findings due at the University of Hawaii at Manoa</td>
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<tr>
<td>January 31, 2001</td>
<td>Content Analysis completed</td>
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<td>Findings Report to UW</td>
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<tr>
<td>February 28, 2001</td>
<td>Findings validated by UW DO-IT parents</td>
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<tr>
<td>Date</td>
<td>Event Description</td>
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<tr>
<td>March 30, 2001</td>
<td>Poster presentation of preliminary findings</td>
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<td>Findings brief</td>
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