

September 29, 2003

Jo Anne B. Barnhart, Commissioner
Social Security Administration
PO Box 17703
Baltimore, MD 21235-7703

RE: Notice of Proposed Rulemaking - Revising Regulations About Benefit Continuation While Participating in Appropriate Vocational Rehabilitation Services [Federal Register - August 1, 2003]

Dear Commissioner Barnhart:

We submit these comments on the Notice of Proposed Rulemaking (NPRM) on behalf of the Association of University Centers on Disabilities (AUCD).

AUCD promotes and supports a national network of university centers on disabilities that includes the University Centers for Excellence in Developmental Disabilities Education, Research and Service (UCEDD); the Maternal and Child Health Leadership Education in Neurodevelopmental and Related Disabilities programs (LEND); and the Developmental Disabilities Research Centers (DDRC). Currently the network has 61 UCEDDs [every state and territory of the country has at least one] and 35 LENDs. Each is affiliated with a major research university.

The UCEDD/LEND programs are interdisciplinary centers that provide pre-service and continuing education and technical support to professionals working in the field of developmental disabilities and to individuals who have developmental disabilities and their families. The centers provide training and technical assistance, conduct research, perform diagnostic and assessment services, and link individuals and families to community services and supports. The UCEDDs were created in 1963 as part of the initial legislation developed to implement recommendations from President Kennedy's Panel on Mental Retardation.

Our Work with SSA and State Disability Determination Services (DDS)

In 1998, the Office of Disability at the Social Security Administration (SSA) requested assistance from AUCD and its network because of our substantive expertise. Our initial work involved six centers performing interdisciplinary assessments for children applying for Supplemental Security Income (SSI) benefits. The Children's SSI Project, now in its fifth year, has grown to almost 40 participating centers and a broader scope of work. Through it, SSA has gained valuable knowledge about childhood assessments and our members have learned a great deal about how state Disability Determination Service (DDS) agencies operate.

A major component of the Children's SSI Project is to help SSA learn more about specific assessment instruments or tests that may improve case adjudication and ways to enhance adjudicator training. Since 1998, 28 centers have evaluated over 500 children and young adults at different stages of eligibility. We have assessed children applying for benefits for the first time; those having a "continuing disability review" to determine their on-going eligibility; and current beneficiaries at age 18 having an eligibility review. Our comments today incorporate our experience assessing the age-18 individuals.

In the project's third year, our centers assessed certain individuals with cognitive, neurological or psychiatric/emotional impairments for their age-18 redeterminations. We share the following observations from these assessments:

- * Case files were often missing vital information that indicates the current level of impairment(s) for this age group. Among the most common missing types of evidence were employer reports, school records, psychosocial information and functional/academic testing.
- * Case files generally had little or no longitudinal history for this age group.
- * Case file evidence often focused on the ability to perform simple, repetitive tasks. While we understand that this reflects the policy of adult adjudication, we believe that it precludes a "full picture" of young adults who are generally only beginning to have relevant vocational experiences.
- * Adjudicators need more specific guidance about information to request from consultative examiners for this age group (e.g. How do they respond to supervision? Are they able to work a full week?)
- * Our centers found that collateral source evidence was immensely helpful to gain a full understanding of the young adult's impairments in all settings - at home, in school and in the community.
- * Our centers found that specific components of their interdisciplinary assessments were especially useful for this age group: neurodevelopmental; speech and language; adaptive and functional measures; and psychosocial/mental health.

In short, our experience performing these assessments revealed serious concerns about adjudicators' level of understanding about how to evaluate on-going impairments for this age group.

Our Comments for NPRM

AUCD commends this effort to expand eligibility for continued benefit payments to certain individuals. In particular, we support the agency's decision to consider a student's completion of or continuation in an individualized education program (IEP) to be analogous to other approved programs of vocational rehabilitation services. Under the new rule, students who receive services under an IEP when their disabilities cease, as result of continuing disability reviews or age-18 redeterminations would continue to receive disability benefits through age 21. We applaud this effort to encourage young people with disabilities to stay in school and complete their educational and vocational training.

While we believe that this new policy has very significant implications for this age group, we urge SSA to do aggressive outreach and education to ensure that the regulation realizes its full potential. Although SSA issued EM-99079 [August 10, 1999] to allow young adults at the time of their age-18 redeterminations to continue benefits if they were participating in vocational rehabilitation programs, we understand that this rule is very under-utilized. Providing a new policy that offers even broader protection to age 18 beneficiaries is laudable, but the agency must increase its efforts to educate field staff, disability examiners and hearings officers at all levels.

We believe that SSA should consider a variety of ways to share information with field staff and disability examiners about age-18 redeterminations and special issues for that age group. For example, the agency could consider some or all of the following ideas:

- * Issue POMS;
- * Circulate a DDS Administrators Letter;
- * Circulate a special announcement to ALJs about the rules protecting benefits for age 18 beneficiaries who are participating in a vocational rehabilitation program or an IEP;
- * Offer training about kind of evidence most helpful to document impairment(s) at age 18; and/or
- * Produce a special segment for the Disability Hour.

Thank you for the opportunity to share our observations and suggestions. We can provide additional information and remain available to assist the agency in any way, especially regarding the age-18 redeterminations. We look forward to our continued collaboration with SSA to serve children and young adults with mental retardation and developmental disabilities and their families.

Sincerely,

George Jesien, Ph.D.
Executive Director