

June 10, 2005

Commissioner of Social Security  
P.O. Box 17703  
Baltimore, Maryland 21235-7703

By e-mail: [regulations@ssa.gov](mailto:regulations@ssa.gov)

Dear Commissioner:

We are responding to the Advance Notice of Proposed Rulemaking [4/13/05, Federal Register] requesting comments and suggestions about establishing a new body system listing for speech and language impairments.

We represent 61 University Centers for Excellence in Developmental Disabilities [UCEDD] and 35 Leadership Education in Neurodevelopmental Disabilities [LEND] programs. Thirty-one of the LEND programs are located at a UCEDD. The UCEDD/LEND programs are interdisciplinary centers that provide clinical services, 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. UCEDDs provide training and technical assistance, conduct research, perform diagnostic and assessment services, and link individuals and families to community services and supports.

We understand that the Social Security Administration [SSA] will consider information about advances in medical knowledge, treatment and methods of evaluating language and speech disorders, along with its program experience. We believe that our comments may be of special interest based on our unique perspective on how SSA and the Disability Determination Service [DDS] offices respond to the challenging issues presented by speech and language impairments.

For the past seven years, our Centers/programs have conducted interdisciplinary assessments of selected children for disability benefits and provided related technical assistance and training through contracts from SSA. Specifically, our network members:

- Provided over 700 evaluations at all levels of the adjudicative process including: continuing disability reviews of low birth weight infants; initial applications for school age and adolescents; age 18 re-determinations. These evaluations included both full interdisciplinary and targeted assessments in areas of special concern, including speech/language, cognitive functioning and adaptive functioning.
- Participated in four national case reviews with representatives from SSA and DDS offices to analyze case outcomes and themes from the interdisciplinary and targeted assessments.

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- Developed a three-part program on “Children’s Language and Speech: Consequences of Communication Problems” for SSA to broadcast as a national interactive video training.

We offer our observations and recommendations based on our work with DDS offices across the country as well as our members’ extensive clinical expertise with childhood disabilities.

### Observations

Our interdisciplinary assessment teams found undetected speech and language disorders in every age cohort [early childhood, school age, adolescents and age 18 re-determinations] when we assessed children in person or reviewed their case files. In fact, language limitations were among the top two most frequently undetected issues in our assessment of over 700 children. These functional limitations are a special concern because they have a significant impact on all domains of children’s daily activities, especially their ability to learn.

Participating DDS offices reported that our assessment teams regularly recognized the presence and severity of potential language disorders in children referred to them. Furthermore, the DDS offices acknowledged that our assessment reports provided critical information regarding the functional impact of these limitations in all developmental domains.

Our interdisciplinary assessment teams reported these specific findings:

- Files may have sufficient information, but adjudicators had difficulty recognizing underlying language problems. Examples: underlying problems not picked up by IQ scores or children failing in school, but not because of any reported behavioral problems.
- Files may not have any evidence about potential language limitations, but once uncovered in the assessment, they were material factors for the DDS adjudication.
- Files usually have little or no language test results from other sources.
- Files usually have little or no description regarding the impact of language disorders on children’s behavior and their learning or social functioning. Example: Parents who apply for SSI for children because they suspect ADHD, but adjudicators overlook the possibility of learning disorders caused by serious language deficits.
- Files may have strong clues for possible speech/language disorders, but adjudicators in numerous instances failed understand the significance of these “red flags.” Examples: developmental language delays; hearing screens; large spreads between verbal and performance scores; boys ages 5-12 with ADHD who often have undiagnosed language disorders.
- Adjudicators do not know what specific evidence is most useful to request from a consultative examiner, or even from teachers, regarding potential language impairments.

### Recommendations

We believe that SSA should establish a new body system to describe disability at the listing level for individuals who have very serious language or speech problems. We believe that this approach will provide a more comprehensive way for adjudicators at all levels to evaluate language and speech problems than current listings.

In particular, we refer you to the comments submitted by The UCLID Center at the University of Pittsburgh, one of our LEND program members. UCLID proposes a listing for SSA to consider for language and speech disorders in children. It includes age-specific indications to guide evaluation, uses terms to reflect the severity of the disorder and includes medical conditions that commonly occur with language and speech disorders. We believe that their proposed listing is worthy of your serious consideration given their extensive work with our Children's SSI Project and their DDS office.

We also suggest that you seriously explore the option of adding Autism and possibly Aspergers Syndrome or Autism Spectrum Disorder given the strong connection between these disorders and children's language and communication difficulties.

As you move forward reviewing responses to the ANPRM, and possibly publishing a Notice of Proposed Rulemaking [NPRM], please do not hesitate to contact us if we can provide any assistance.

We look forward to working with SSA as you address this very significant area of functional limitations for children and adults.

Sincerely,

George Jesien, PhD, Executive Director  
Rhoda Schulzinger, Esquire, Children's SSI Project Director