

November 7, 2005

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

Dear Commissioner Barnhart:

We write regarding the interest of the Social Security Administration [SSA] to update and revise rules used to evaluate growth impairments of individuals under age 18 who apply for or receive disability benefits under Title II and Title XVI of the Social Security Act. These rules now appear in Section 100.00 in the Listing of Impairments in Appendix 1 to Subpart P of Part 404 of the regulations (the listings).

In the Advance Notice of Proposed Rulemaking [ANPRM], published in the Federal Register [9/8/05], the agency requested information from individuals who may have concerns about any of the current growth impairment listing provisions, including possibly changing any current criteria or expanding the growth impairment listings to include new information.

The Association of University Centers [AUCD] represents the 64 University Centers for Excellence in Developmental Disabilities (UCEDD) and 35 Leadership Education in Neurodevelopmental Disabilities (LEND) programs across the country. UCEDD and LEND programs are interdisciplinary centers (hereafter called the “Centers”) that provide pre-service and continuing education as well as technical support to professionals working in the field of developmental disabilities, individuals who have developmental disabilities, and their families. The Centers provide training and technical assistance, conduct research, perform diagnostic and assessment services and link families to community services and supports.

AUCD submits these comments based on our unique work for SSA over the past six years. During that time period, we have operated the Children’s SSI Program in collaboration with the SSA’s Office of Disability Policy that has included efforts to: conduct interdisciplinary assessments for almost 850 infant, school age and age 18-disability claimants; preparing and presenting training for adjudicators at all levels of the agency; create tools and protocols for state agency decision makers; and implement collaborations with state Disability Determination Services (DDS).

To reply to this ANPRM, we draw upon work conducted for our Children’s SSI Project as well as our clinical expertise assessing low birth weight children and treating conditions that result from their growth or developmental impairments. We present our response in three parts:

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1. Policy recommendations for the legally mandated continuing disability reviews for low birth weight infants.
2. Case data from interdisciplinary assessments conducted by our Centers in 2000 and 2004 for selected state DDS offices.
3. Conditions that may signal high risk of developmental complications for low birth weight infants [i.e. “red flags” for adjudicators to note].

## **Part One: Policy Recommendations**

We offer a series of policy recommendations that we first shared with SSA in February 2003. We base these suggestions on our first set of interdisciplinary assessments and other discussions with SSA and DDS staff. Our observations and recommendations remain unchanged after further assessments. We organize our recommendations around three areas: use of tests and their interpretation; procedures to address prematurity; and special considerations to assess premature infants.

### 1. Extend the re-adjudication process until 36 months for all LBW infants. If this is not possible, extend the period for at least VLBW (very low birth weight) and ELBW (extremely low birth weight) infants

Using a later diary date would allow SSA to use standardized, well-validated IQ and speech and language tests that are commonly used for preschoolers. This could simplify the evaluation process because there are more qualified professionals available to perform the necessary consultative evaluations and often, schools assess many children who have developmental delays. The later date would also provide time for children to benefit from any positive effects of early intervention and provide SSA with a more accurate and complete depiction of the children’s ability to function compared to others the same age who do not have disabilities. Our work has shown that the more premature the infant, the greater the difficulty basing “true” functional performance on the very few test items that are used to assess children at that age. Many of the language, behavioral and developmental problems are not accessible to testing and diagnostic procedures until the child is older. Thus, waiting until 36 months for at least the VLBW and ELBW could overcome many of the missed conditions we observed and more accurately evaluate the child’s level of functioning.

### 2. Require adaptive testing for all LBW infants as part of their re-determinations unless they qualify on some other basis

Evaluations of all LBW infants should include a measure of adaptive behavior unless they qualify on some other basis. Adaptive behavior integrates many distinct constituents and reflects overall functional status. We suggest that each LBW re-evaluation include results from a recent Vineland, the Scales of Independent Behavior or an equivalent test such as the Pediatric

Evaluation of Disability Inventory (PEDI). These tests provide a composite measure of functional limitations that is not limited to the clinical setting.

3. Require speech and language testing or a review of existing communication assessments for all LBW infants as part of their re-determinations unless they qualify on some other basis

We believe it is necessary to measure speech and language competence for all LBW children unless they continue to qualify on some other basis. According to the research, over half of children who are born with very low birth weights experience significant school problems later and many have underlying language disorders. The complex interplay of cognitive, emotional, motor, linguistic, and attentional skills means that speech and language skills serve as an appropriately sensitive indicator of functional difficulties.

4. Issue Special Guidance for disability adjudicators about testing LBW young children

The Special Guidance would provide an overview on LBW infants and particular issues to consider when reviewing these cases. The guidance would do the following: (a) describe a valid consultation for the youngest children that includes measurement of speech/language competence and adaptive functioning; (b) describe tests, what they measure, common questions and errors (c) explain special considerations for this age group including how to review their file evidence and how to reconcile common discrepancies without arbitrarily excluding discrepant data and (d) provide basic information about federal, state and local infant and toddler programs so adjudicators understand what assessment information they can typically request from these programs.

5. Provide adjudicators with specific guidance on how to evaluate the health function of all LBW children because the frequency of medical visits is not a sole indicator of functional limitations

We had difficulty assessing the “health and physical well-being” domain when reviewing the case files. It is not uncommon for these infants to see medical or health-related professionals many times each month. The purpose of these visits may be to receive “well-baby” checkups, early intervention services and/or treatment for a continuing problem. Applying this domain to children with LBW is challenging because the frequency of visits does not necessarily reveal the infants’ health. Often LBW children have multiple medical visits that are not usually associated with hospitalization, but are far more frequent than those made by “typical” infants and toddlers. These frequent medical visits impact quality of life and the young child’s ability to function in addition to creating an added burden for the family.

We provide more details about these policy recommendations in **Attachment 1: Technical Appendix**. Although we prepared this Appendix in 2003, we believe that the information is still relevant for your deliberations.

## Part Two: Case Assessments in 2000 and 2004

In general, we learned roughly one-third or more of the children who received an interdisciplinary assessment qualified to continue receiving SSI benefits. This is a significant number and a very important factor in the lives of these children and their families because without this additional information, the DDS would have denied continued eligibility. All referrals to our participating Centers were children who would not have received benefits any longer based upon the existing DDS file evidence. We provide explanations below for some of our additional findings.

1. The primary sources of file evidence were from medical records. While these records are very useful for adjudicators, they do not necessarily provide the full picture of potential developmental delays. We are especially concerned about the need to assess speech and language skills and adaptive behaviors to obtain a complete picture of the functional status of children who are born with low birth weight (particularly those born with extremely low or very low birth weights).
2. Most children are not receiving the full array of early intervention services that could help them overcome potentially disabling physical or developmental conditions as they move from infancy to toddler years. We found that compared to our work in 2000, the number of children and families receiving services and supports declined in 2004. We are quite concerned that less than one-quarter of the children we saw were receiving services at the time of their assessments, though a greater proportion was felt to be in need of these services.
3. File records are generally deficient for this age group. Of special concern is the lack of information regarding adaptive functioning, cognitive development and speech-language skills. Relying upon gross measures of development fails to capture the complexity or adequately represent the developmental level of the young child.

See **Attachment 2** for the supporting data for these conclusions. We base our conclusions on internal data forms and Family Services Reports that participating Centers completed to help SSA gain insights into this population. Although we changed some data fields in 2004, most were similar enough so we could compare the two years and prepare composite data. Our data provides both descriptive and diagnostic information as well as information about developmental status across domains and assessments results across functional areas. Centers also reported what types of services and supports they recommended for children and families. Our data is based on 42 assessments in 2000 and 48 in 2004.

Case data shows that 14 of the 48 children in 2004 received continued benefits compared to 15 of the 42 in 2000. However, when joint teams of AUCD/SSA professionals reviewed a selection of these cases in July 2004, they disagreed with five cessations. See **Attachment 3** for a chart that shows assessment age, birth weight, gestational age and length of stay data for 2004 cases organized by birth weight. We are unable to show a comparison with the 2000 cases because we did not collect similar data at that time.

**Part Three:** Conditions that may signal high risk of developmental complications for low birth weight infants

We developed a “red flag” list of conditions that may signal a high risk of developmental complications for low birth weight infants. This list is based on extensive medical and developmental work conducted by Centers, including specialized clinics to follow low birth weight infants, and their interdisciplinary assessments conducted for SSA. Conditions marked with an asterisk represent those that we believe pose an even higher risk for developmental complications. The conditions fall into three groups: prenatal, neonatal and infancy.

#### Prenatal

- Maternal infection/chorioamnionitis
- Multiple gestation, especially if death of co-twin or twin-to-twin transfusion
- Intrauterine growth retardation (IUGR), small for gestational age (SGA)

#### Neonatal

- Prematurity, especially for Extremely Low Birthweight (less than 1000 grams) \*
- Intraventricular hemorrhage (IVH), all grades but particularly Grades III & IV \*
- Periventricular leukomalacia (PVL)/periventricular cysts \*
- Hydrocephalus \*
- Neonatal stroke/infarction \*
- Seizures, especially if uncontrolled/prolonged status epilepticus, with abnormal EEG or on anti-epileptic medication \*
- Perinatal asphyxia \*
- Hypoxic Ischemic Encephalopathy (HIE) \*
- Encephalopathy \*
- Microcephaly \*
- Neonatal sepsis/meningitis \*
- Retinopathy of prematurity, especially if Stage 3/greater or if laser surgery required \*
- Hypotonia
- Hypertonia
- Congenital anomalies (especially cardiac), genetic syndrome diagnosis
- Congenital infections (i.e., cytomegalovirus [CMV], toxoplasmosis, herpes, syphilis, HIV, rubella)
- Prolonged hypoglycemia (such as > 24 hours with symptoms)
- Recurrent episodes apnea & bradycardia, especially if require intervention
- Prolonged oxygen use (such as >28 days)
- Hyperbilirubinemia
- Fail newborn hearing screen
- Prolonged Neonatal Intensive Care Unit stay, especially if longer than expected to reach appropriate gestational age

## Infancy

- Recurrent or chronic otitis media, especially if hearing loss associated
- Persistent feeding difficulties, severe reflux, chronic gastrointestinal difficulties
- Failure to thrive/poor growth
- Recurrent use of urgent care/emergency medical services
- High frequency of illnesses requiring medical intervention

Some of these conditions may be appropriate to include in an expanded listing for growth impairments. We recognize that other items may be more appropriate to include in a comprehensive training for adjudicators if you revise or expand the listing for growth impairments. However, we include the complete “red flag” list so that you can decide how to best use these insights.

A second part of our proposed “red flag” list includes certain functional behaviors that may indicate developmental delays or disabilities that warrant further attention by adjudicators. Depending on the severity of these behaviors, the children may have functional limitations that meet eligibility requirements for SSI benefits:

- Deficit(s) in social referencing, gestures, communicative attempts, responsiveness to verbal directions, and/or engagement in routine "games" (e.g., peek-a-boo) in age-appropriate ways
- Motoric imbalance and/or lack of age-appropriate coordination
- Hypertonia or hypotonia resulting in inability to navigate the environment in an age-appropriate way or in accidental injury
- Extreme overactivity and/or inattentiveness as evidenced by inability to attend to tasks long enough to engage in meaningful problem solving or enjoy activities in age-appropriate ways
- Consistent pattern of motor overactivity and/or lack of inhibition combined with poor judgment that may lead to reckless or self-endangering behavior that requires intensive safety monitoring beyond what is age appropriate

## **Conclusion**

We support revising the listing for growth impairments because we believe that an expanded listing would provide greater guidance to adjudicators and result in greater uniformity of decisions, especially for infants born with low birth weights. These infants may have significant complications from medical conditions and/or neurodevelopmental disabilities. In fact, over time, these complications may become more important to the children’s ability to function compared to other children the same age.

We remain available to provide further assistance as you proceed with deliberations regarding the growth impairment listing, especially if you prepare a Notice of Proposed Rulemaking for public comment. Thank you for your attention to our comments.

Sincerely,

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Attachment 1: Technical Appendix, Low Birth Weight Infants, prepared February 2003

Attachment 2: AUCD Case Assessment Data, 2000 and 2004

Attachment 3: AUCD Case Outcomes for Interdisciplinary Assessments, 2004

**Attachment 1**  
**Technical Appendix, Low Birth Weight Infants**  
**Prepared by AUCD in February 2003**

**General Background: Low Birth Weight Infants**

Current pediatric practice is to use three categories of low birth weight infants (Subramanian, Yoon & Toral, 2001), these include:

Low Birth Weight (LBW) = Less than 2500 grams = 5 lbs. 8 oz. or less

Very Low Birth Weight (VLBW) = Less than 1500 grams = 3 lbs. 4 oz. or less

Extremely Low Birth Weight (ELBW) = Less than 1000 grams = 2 lbs. 3 oz. or less

These birth weight categories are somewhat different from those employed by SSA to establish functional equivalence. SSA regulations provide for allowances (until one year of age) for two categories: (a) infants with birth weights less than 1200 grams and (b) infants with birth weights from 1200 to 2000 grams who are small for gestational age (SGA). SGA is defined as a birth weight that is at least two standard deviations below the mean for the infant's gestational age (i.e., less than third percentile) (See 20 CFR Sections 416.926(a)(m)(7) and (8)) Although there is a difference between commonly used categories and SSA parameters for establishing presumptive eligibility, this difference should not pose a problem in viewing or implementing the suggested recommendations.

Approximately 7.5% of all births are low birth weight and 1.4% very low birth weight. Nearly one-in-ten low birth weight infants (<2500 g) are ELBW (27,988 births in the United States in 1997). Risk of developmental delay and disability increases as the birth weight decreases. For example, an estimated 48% of VLBW children will have some type of neurosensory or neurodevelopmental impairment by school age (Subramanian, Yoon & Toral, 2001).

Survival has significantly improved for ELBW infants. With the widespread use of special treatments (e.g. surfactant and maternal steroids), the minimum gestational age of viability is now reduced to as young as 23 weeks gestation (17 weeks pre-term). However, nearly all these infants require neurodevelopmental follow-up in order to track their progress and identify disorders that were not apparent during the hospital stay. The lowest-weight infants typically have complicated medical histories and many often go home with multiple treatments and medications. In addition to following their immediate medical needs upon discharge, it is important to evaluate their cognitive and language development, vision and hearing ability, and overall neurodevelopmental progress as they develop.

We organized our observations and recommendations around three areas: (1) prematurity correction procedures (2) use of tests and their interpretation and (3) special considerations to assess premature infants.

## I. Adjustment for degree of prematurity

### Background

Children who are born prematurely usually perform at a level that is more typical of a chronologically younger child. Experts call the process of making allowances for the degree of prematurity “correction.” It remains a problem for children who are extremely premature, partly because our review of the literature reveals that most studies of the issue date from the mid-1980s. Consequently, more modern advances in neonatology that now allow much more immature infants to survive are not reflected in the literature. It is not unusual now to see babies of 24-30 weeks survive, i.e. 10-16 weeks early. In 2000, there were 56,000 babies with birth weight of <1500 grams (3 pounds, 4 ounces) of whom over 85% survived with weights of 750-1500 grams. The problem for very and extremely low birth weight children is due to the fact that the correction – which is greatest for the earliest born infants (e.g. 3 months for an infant born at 28 weeks) – can have such a large impact on a child’s test scores just prior to or just after the typical cut off age for correction – 24 months.

Currently, experts do not agree on how to deal with correction in VLBW and ELBW premature infants. Past standards called for correction until 24 months of age and not correcting afterward. Although this practice may have previously served its purpose for LBW children, it is now questioned - especially for VLBW and ELBW infants. The following example may shed light on the impact of correction.

- Baby #1 was born at 26 weeks' gestation. He is 23 months and 13 days old. On a speech and language battery he scored at the 14-month level. His language quotient is 70 [14 months/(23 months- corrected age)]. If his other skills were at similar level, he would not be far enough behind to merit SSI.
- Baby #2 was born at 26 weeks' gestation. She is 23 months and 16 days old. On a speech and language battery she scored at the 14-month level. Her language quotient is 58.3 (14 months/24months - uncorrected). If her other skills were at similar level, she would lag enough behind to qualify for SSI.

The chart below further illustrates the problem.

**Table 1: Summary of Clinical Data**

	<b>Baby 1</b>	<b>Baby 2</b>
<b>Gestational age</b>	26 weeks	26 weeks
<b>Chronologic age</b>	23 months 13 days (round to 23 months)	23 months 16 days (round to 24 months)
<b>Correction</b>	3 months	None
<b>Speech and Language Age</b>	14 months	14 months
<b>Speech and Language Quotient</b>	70	58.3

Thus a difference of 3 days has a significant impact on the outcome score – a speech and language quotient of 70 versus 58. However, this difference most likely does not reflect a difference in function but rather, is an artifact of the test and the use of the correction procedure.

### Possible Alternatives

This is not an easy issue to resolve, so the Work Group provides several alternatives for SSA to consider:

Determine the best current practices based on the extant data. This determination could use information from the National Institute of Child Health and Human Development's (NICHD) Neonatal Research Network, the Vermont-Oxford Network neonatal database or Infant Health and Development Project. (We can provide specific references for each data source.) The issues to address include, but are not limited to: the amount and length of time of correction; validity; misclassification rates (false positives and false negatives); and how often correction delays diagnosis. SSA may want to consider making a formal request to NICHD to determine the current advisability of using correction procedures and until what age. SSA could incorporate these recommendations into its re-determination procedures for LBW children.

Extend the age of coverage of LBW infants as long as possible. Although some members of our Work Group proposed extending until 42 months, we understand that this would require statutory change. Therefore, we recommend extending coverage until 36 months especially for the VLBW and ELBW infants. Although it may be appropriate to correct to 24 months for the heaviest infants, it is most problematic for those in the lower birth weight groups.

Using a later diary date would allow SSA to use IQ and speech and language tests that are commonly used for preschoolers. This could simplify the evaluation process because there are more qualified professionals available to perform the necessary consultative evaluations and often, schools assess many children who have developmental delays. The later date would also provide time for the child to benefit from any positive effects of early intervention and provide SSA with a more accurate and complete depiction of the child's ability to function compared to children the same age who do not have disabilities.

Evaluating children at 36 months is more accurate than that at age two because the child provides more behaviors to sample and they are better able to participate in structured tasks. Given these differences, the effects of the prematurity should diminish to a level that it has only minor effects on the decision regarding disability. In fact, the later diary date would eliminate the need to correct for prematurity when evaluating LBW infants.

Continue to apply correction indefinitely. The practice of ceasing to correct has not been validated experimentally. If correction is justified under two years of age, some members of our Work Group believe that it is consistent to apply correction after two years. Alternatively, some task force members suggested developing scores for chronological and "corrected" age (post term equivalent) and that adjudicators use the lower scores. These approaches are conceptually valid but were not endorsed by the majority of the task force. We present these approaches to demonstrate the wide range of alternatives to deal with the issue of correction.

Recommendation 1: Extend the re-adjudication process until 36 months for all LBW infants. If this is not possible, extend the period for at least VLBW and ELBW infants.

## **II. Tests and Their Interpretation**

### Psychometric Measures

Tests have variable psychometric properties at the low age ranges. Two examples illustrate this point:

- The Stanford Binet, IV Edition has been shown to under-identify mental retardation in young children because of the low number of items available at the very early ages.
- The Bayley Scales of Infant Development, 2<sup>nd</sup> edition, may generate misleading scores under a variety of conditions: unlike most other tests, it can yield less favorable results when the corrected age is employed for premature infants (Ross & Lawson, 1997); and it can also generate multiple sets of competing results (Washington, Scott, Johnson, et al 1998). Additionally, the Bayley Mental Development Index relies heavily on expressive and receptive language skills such that children who have language delays will score lower on the Mental Development Index regardless of their problem solving abilities.

Similarly, in assessing adaptive behavior (i.e., functional status) scores may vary as a function of how information is collected (e.g., spontaneous parent report, direct observation, elicited response). There may be standardization differences: e.g., for young children with developmental delays, the Vineland Adaptive Behavior Scales often yield standardized scores that are eight or ten points higher than other standardized scores. Measures of adaptive functioning also have very few items at younger ages making it difficult to assess true adaptive functioning. Further, children with developmental delays may receive credit for items irrespective of the quality of their performance, the amount of scaffolding they require in order to accomplish the task, or the consistency with which they perform it. Thus, measures of adaptive functioning often fail to capture the burden of care experienced by families.

Behavioral testing of very young children is challenging at best. Results can vary, especially at very young ages (i.e., one - three years), due to situational factors such as comfort and health of child, rapport with examiner, and the examiner's skill eliciting behavior from infants.

### Standard Deviations

Although psychometric properties are important, disability adjudicators should know about the range of behavior in LBW infants that various tests can assess. In very young children, many tests do not measure behavior that is more than three standard deviations below the mean and thus, may fail to identify children with extreme dysfunction. Almost no test gives reliable and valid distinctions more than three standard deviations below the mean. Scores at this level encompass less than 0.13% of the population. Many tests are based on a standardization sample of about 100 children in each age group. Even if that number were increased to 1000 children in

each group, there would only be 1 or 2 children functioning at this level. Clearly, this sample size will not support reliable distinctions more than 3 standard deviations below the mean.

In addition, distinguishing behavior that is marked, between two and three deviations below the mean, is difficult and questionable in very young children because of the limited repertoire of behavior that is sampled in a testing situation. At very young ages, a small number of items have a great impact on actual scores. Issues of cooperation frequently affect the reliability of the score. Thus, scores in young children should be viewed with caution. As children grow older, and it becomes possible to sample a broader range of performance, tests tend to have less measurement error overall, yielding scores with narrower confidence limits. Disability adjudicators who review claims for LBW infants should know about these limitations and not expect that tests will show extreme functional limitations.

### Speech/Language Competence

We believe it is necessary to measure speech and language competence for all LBW children unless they continue to qualify on some other basis. According to the research, over half of children who are born with very low birth weights experience significant school problems later and many have underlying language disorders. The complex interplay of cognitive, emotional, motor, linguistic and attentional skills means that speech and language skills serve as an appropriately sensitive indicator of functional difficulties.

Our review of case files indicates that disability examiners most commonly request a psychological consultative examination for this age group. Psychological cognitive testing is not a sufficient proxy for speech and language testing because it does not measure all the important aspects of development. Our review of LBW children showed that information provided by the UCEDD assessment about speech/language disorders affected the outcome of a significant number of decisions. Speech and language testing is not intended to replace measures of cognitive function, but rather to provide additional information to determine if language delays are present. Speech and language testing should be conducted by a therapist specializing in work with young children and should use appropriate, validated instruments that directly test the child's ability rather than relying on parental report.

### Adaptive Functioning

Evaluations of all LBW infants should include a measure of adaptive behavior unless they qualify on some other basis. Adaptive behavior integrates many distinct constituents and reflects overall functional status. We suggest that each LBW re-evaluation include results from a recent Vineland, the Scales of Independent Behavior, or an equivalent test such as the Pediatric Evaluation of Disability Inventory (PEDI). These tests provide a composite measure of functional limitations that is not limited to the clinic setting.

### Testing Variation

Disability adjudicators should incorporate all testing data for each LBW infant. They should not interpret one score to outweigh others in the assessment process. For example, when a child

scores better on an IQ test than on a speech-language measure, this may or may not indicate the presence of a significant functional limitation. At the same time, adjudicators must address individual scores. For example, when assessing a child with VLBW status, it is not unusual to have a child with a cognitive standard score of 75 (normal 100+/- 15), a language score of 65, and motor score of 70. A child may score 65 in the self-care domain of adaptive skills, but have a total adaptive composite of 71. Disability adjudicators need instruction to understand that, just as with IQ, a stronger area does not override the contribution of an area of substantial delay (ss <70). Although this is current SSA policy, we were concerned in our case reviews in that we came across files where discrepant scores were not appropriately factored into the determination.

Our recommendations for tests and their interpretation:

Recommendation 2. Require adaptive testing for all LBW as part of their re-determinations unless they qualify on some other basis.

Recommendation 3. Require speech and language testing or a review of existing communication assessments for all LBW as part of their re-determinations unless they qualify on some other basis.

Recommendation 4. Issue Special Guidance for disability adjudicators about testing LBW young children

The Special Guidance would provide an overview on LBW infants and particular issues to consider when reviewing these cases. The guidance would do the following:

- Describe a valid consultation for the youngest children that includes measuring speech/language competence and adaptive functioning;
- Describe tests, what they measure, common questions and errors, and special considerations for this age group;
- Suggest how to review file evidence for the youngest children;
- Suggest how to reconcile common discrepancies without arbitrarily excluding discrepant data;
- Provide basic information about federal, state and local infant and toddler programs under Part C of IDEA and Early Head Start so adjudicators understand what assessment information they can typically request from these programs.
- Utilize professionals experienced in assessing young children when requesting additional evaluations. Reports from these professionals must address the above issues and explain discrepancies in findings in light of their impact on child functioning.

### **III. Conditions That Frequently Affect Or Are Unique To LBW**

We had difficulty assessing the “health and physical well-being” domain when we reviewed these case files. It is not uncommon for these infants to see medical or health-related professionals many times each month. The purpose of these visits may be to receive “well-baby” checkups, early intervention services, and/or treatment for a continuing problem. Applying this domain to children with LBW is challenging because the frequency of visits does not necessarily

reveal the infants' health. Often LBW children have multiple medical visits that are not usually associated with hospitalization, but are far more frequent than those made by "typical" infants and toddlers. Examples of situations that require special attention by disability adjudicators include:

- One child had eight medical visits to monitor her continuing problems and four physical therapy visits in one month. However, it was difficult to determine the severity of her medical conditions from the DDS file evidence.
- One child saw her primary care provider (not a specialist) as frequently as once a month for recurrent wheezing. She did not meet the asthma listing, but the impact of her disorder did not raise a "red flag." In the interim, she was well and the condition did not affect her performance on a developmental assessment.

Some medical disorders are much more likely to appear in LBW infants, such as deficient growth or microcephaly.

Recommendation 5: Provide adjudicators with specific guidance on how to evaluate the health function of all LBW children because the frequency of medical visits is not a sole indicator of their functional limitations. Evaluating health also requires an understanding of the burden of care required by these additional medical and therapy visits and the impact of constant interaction with providers on the young child.

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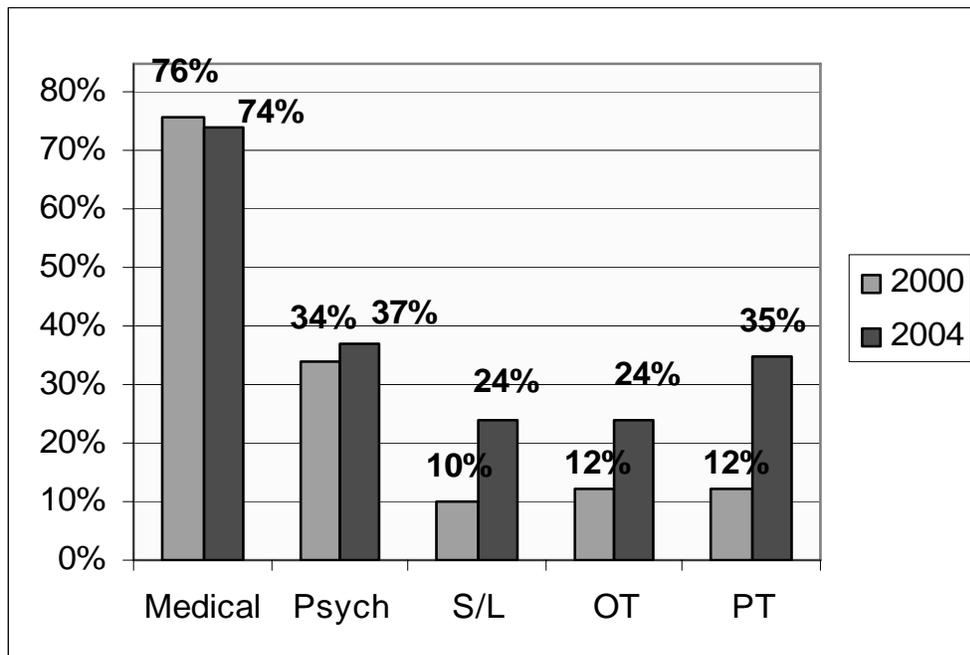
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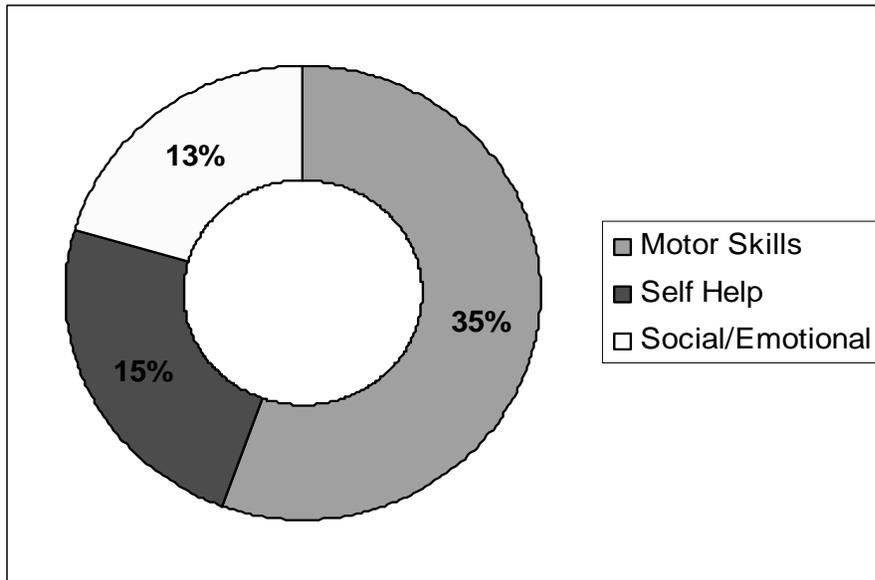
## Attachment 2 AUCD Case Assessment Data, 2000 and 2004

AUCD bases its conclusions on internal data forms and Family Services Reports that participating Centers completed to help SSA gain insights into this population. Although we changed some data fields in 2004, most were similar enough so we could compare the two years and prepare composite data. Our data provides both descriptive and diagnostic information as well as information about developmental status across domains and assessments results across functional areas. Centers also reported what types of services and supports they recommended for children and families. Our data is based on 42 assessments in 2000 and 45 in 2004.

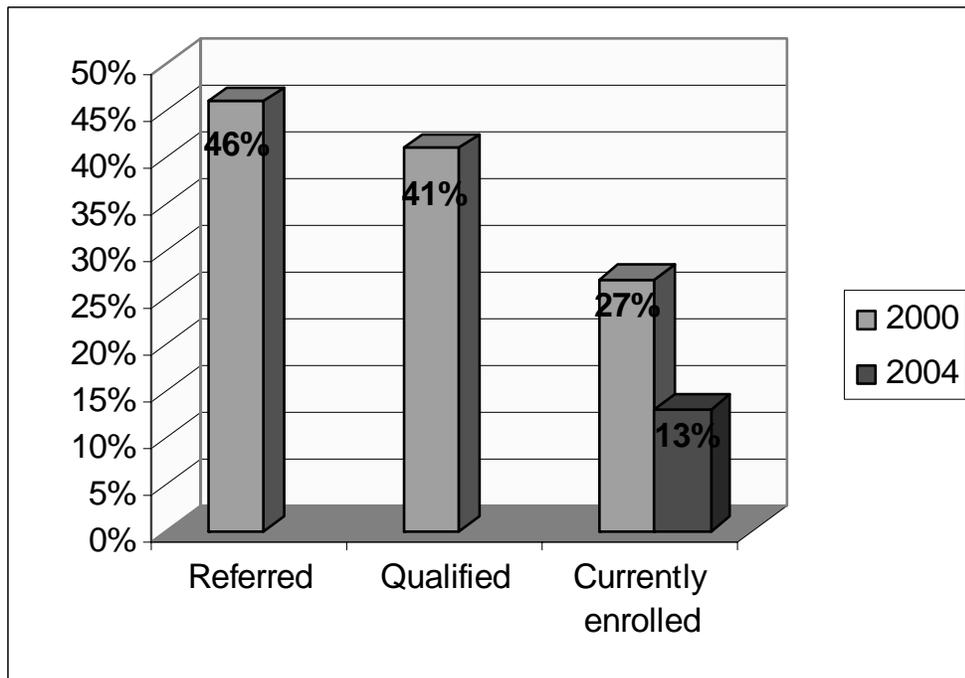
File Data Available: The initial step for our Center clinicians was to conduct a comprehensive review of available records in the DDS file and note file inconsistencies or areas in which additional information may have helped DDS adjudicators to make decisions. The charts below indicate the kind of information that the Centers saw in files referred by participating DDSs. The data indicates that approximately three-quarters of the files contained medical information in both years. The Centers found that generally the 2004 cases files contained more information than 2000 files. This difference may reflect the new children's regulations that took effect during that time period. Our data shows that among files: 37% had psychological information, 24% had speech-language and occupational therapy records and 35% had physical therapy records. Motor skills, self help and social/emotional data was collected only in 2004.



## 2004 Data



Early Intervention Records: In 2000, 46% of files showed that the children were previously referred for EI services: 41% qualified, but only 27% were currently enrolled in EI. In 2004, we only collected information about who was “currently enrolled.” The Centers recommended EI services for 80% of the children in 2004, but only 13% were “currently enrolled.” This enrollment data shows a worrisome decline from the 27% figure in 2000 and far below the 80% recommended by the Centers.

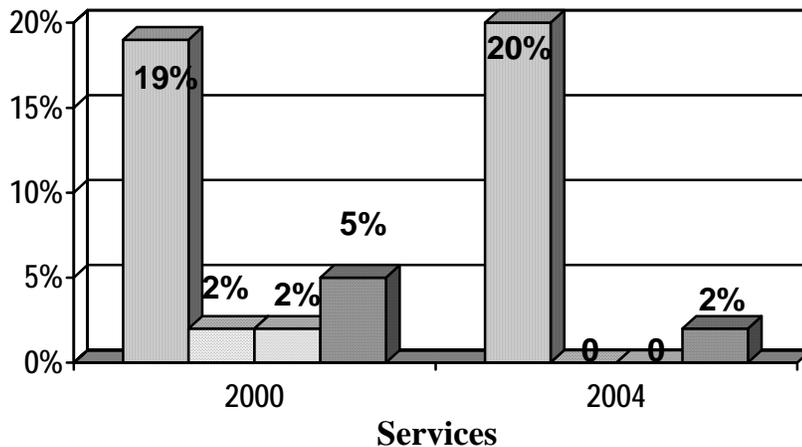


File Information: The Centers indicated the need for additional information in the following areas, in order of frequency requested:

<b>2000</b>	<b>2004</b>
Speech-Language	Adaptive Function
Adaptive Behavior	Cognitive
Cognition	Speech-Language
Dev. Pediatrics	PT
Audiology	Psychological
Psychological	OT

Overview of Family Services Reports: AUCD designed Family Services Reports to ask participating Centers to record services that families were receiving at the time of evaluation and the referrals made by the participating Centers. We noted, with deep concern, that fewer infants and families were receiving services in 2004 than in 2000. The percentage dropped from 29% in 2000 to only 22% of 2004 cases receiving services. The number of families receiving referrals for additional or expanded services remained about the same, 88% in 2000 cases and 87% in 2004. The frequency of referrals for additional or expanded services included, in this order: early intervention, medical, community, mental health and family services.

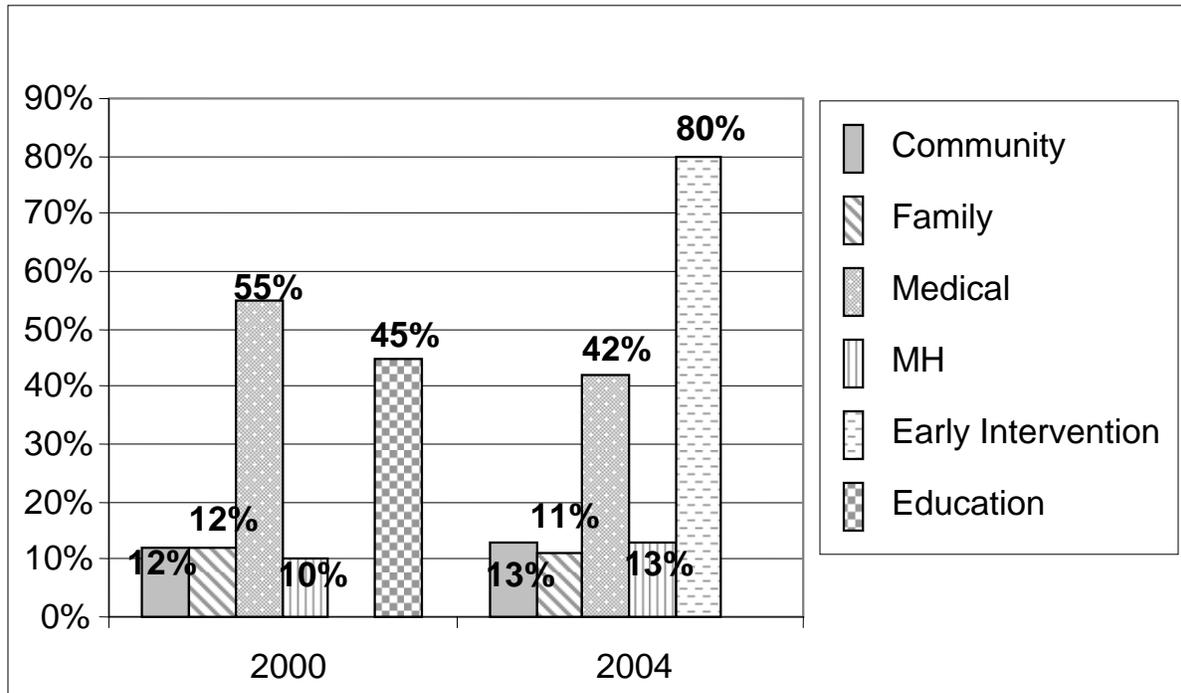
Current Services: At time of the interdisciplinary evaluation, 12 of 42 children (29%) in 2000 and 10 of 45 children (22%) in 2004 were receiving services. The state birth-three programs were the most common providers, with approximately 20% of children receiving such services.



■ Birth-3 Program   ■ School District   ■ Other Public Sources   ■ Private Orgs.

Centers clearly recognized the need to refer children and families for a broad range of services and supports. Among the children assessed for our project, 37 of 42 (88%) in 2000 and 39 of 45 (87%) in 2004 were referred for services. We did not collect data for early intervention services

in 2000 or education services in 2004. In 2004, the Centers most frequently suggested early intervention services for families, referring 80% of the children they saw for the project. In both years, the Centers referred about half of all children (55% in 2000 and 42% in 2004) for medical services. Other major needs were community, family and mental health services and these referral rates were relatively consistent between the two years.



## Outcomes

According to the Centers, the assessments provided new information for the DDS in 80% of the cases in 2000, but only 42% in 2004. Again, this decrease may reflect changes in SSA's rules and regulations that now provide more specific guidance for adjudicators. In addition, Centers felt that they were able to:

- Augment available information about the extent, severity or impact of a child's disability in 32% of cases in 2000 and 35% in 2004;
- Confirm existing information with new findings in 22% of cases in 2000 and 0% in 2004;
- Resolve conflicting information in 7% of cases in 2000 cases and 17% in 2004; and
- Provide information for new treatment in 83% of the 2004 cases (not asked in 2000).

**Attachment 3**  
**AUCD Case Outcomes for Interdisciplinary Assessments, 2004**

<b>ID#</b>	<b>Age at Assess</b>	<b>Birth Wt</b>	<b>GA</b>	<b>LOS</b>	<b>Decision - Post-AUCD</b>
MS-7	2 yr 8 mo	539 g <sup>+</sup>	25 wks		CEASE
MS-1	3 yr 5 mo	624 g <sup>+</sup>	25 wks		CEASE
MS-5	1 yr 11 mo	624 g <sup>+</sup>	27 wks		CEASE
NC-10	2 yr 7 mo	718 g	24 wks	8 weeks	CEASE
WI-12	1 yr 10 mo	725 g	28 wks	2 mo	CONTINUE
IN-7	2 yr 4 mo	765 g <sup>+</sup>	26 wks	4 mos	CEASE
PA-15	1 yr 6 mo	775 g	28 wks	56 days	CEASE
PA-16	1 yr 11 mo	791 g	26 wks	?	CONTINUE
IN-6	1 yr 8 mo	794 g <sup>+</sup>	26 wks	2 mos, 1 wk	CEASE
CO-9	1 yr 11 mo	819 g	25 4/7 wks	3 mo 6 days	CONTINUE
PA-14	2 yr 3 mo	822 g <sup>+</sup>	26 wks		CEASE
IN-4	1 yr 10 mo	822 g <sup>+</sup>	27 3/7 wks	3 mos	CEASE
PA-9	1 yr 8 mo	834 g	27 wks	61/88 <sup>2</sup>	CONTINUE
NC-5	2 yr 3 mo	843 g	27 wks	64 days	CEASE
WI-4	1 yr 9 mo	855 g	29 wks	2 mo	CEASE
CO-2	1 yr 9 mo	859 g	25 4/7 wks	> 64 Days	CONTINUE
OH-1	2 yr 1mo	877 g	27 wks	7 weeks	CEASE
CO-7	1 yr 8 mo	890 g	26 6/7 wks	>70 Days	CEASE*
MS-11	2 yr 0 mo	907 g <sup>+</sup>	23 wks		CEASE
MS-8	2 yr 1 mo	907 g <sup>+</sup>	26 wks		**
CO-12	1 yr 7 mo	920 g	32 wks	~2 months	CEASE
PA-11	2 yr 5 mo	935 g <sup>+</sup>	32 wks		CONTINUE
WI-1	2 yr 4 mo	960 g	27 2/7 wks	56 days	CONTINUE
CO-10	1 yr 9 mo	964 g	26 wks	? Days	CEASE*
CO-8	1 yr 8 mo	964 g	25 wks	87 days	CONTINUE
CO-3	1 yr 7 mo	975 g	30 6/7 wks	37 days	CEASE
WI-3	1 yr 9 mo	982 g	27 3/7 wks	2 mos.	CONTINUE
CO-6	1 yr 9 mo	983 g	27 4/7 wks	52 days	CEASE*
TN-1	2 yr 1 mo	992 g <sup>+</sup>	27 wks	5 wks	CEASE
PA-6	2 yr 6 mo	1010 g	30 1/7 wks	18/32 <sup>2</sup>	CONTINUE
CO-1	2 yr 1 mo	1079 g	27 wks	47 days	CONTINUE
PA-12	1 yr mo	1105 g <sup>+</sup>			CONTINUE
PA-18	1 yr 6 mo	1105 g <sup>+</sup>			CONTINUE
MS-9	2 yr 4 mo	1105 g <sup>+</sup>	32 wks		CEASE
CO-4	1 yr 8 mo	1118 g	28 wks	<52 Days <sup>1</sup>	CEASE*
WI-8	1 yr 10 mo	1120 g	32 wks	5 weeks	CEASE
IN-1	2 yr 8 mo	1134 g <sup>+</sup>	30 wks	2 mos	CEASE
WI-6	1 yr 11 mo	1165 g	28 wks	51 days	CEASE
WI-11	2 yrs 6 mo	1174 g	29 wks	82 days	CEASE

<b>ID#</b>	<b>Age at Assess</b>	<b>Birth Wt</b>	<b>GA</b>	<b>LOS</b>	<b>Decision - Post-AUCD</b>
PA-7	1 yr 8 mo	1180 g	29 wks	?	CEASE
CO-5	1 yr 8 mo	1190 g	28 wks	? Days	CEASE*
WI-2	2 yr 6 mo	1196 g	30 wks	~1 month	CEASE
NC-8	2 yr 0 mo	1200 g	29 wks	14 weeks	CEASE
NC-8	2 yr 0 mo	1200 g	28 wks	14 wks	CEASE
PA-17	2 yr 0 mo	1219 g <sup>+</sup>			CONTINUE
NC-1	2 yr 6 mo	1311 g	29 wks	42 days	CEASE
MS-6	1 yr 8 mo	1360 g <sup>+</sup>	35 wks		CEASE
WI-7	1 yr 9 mo	1873 g	37 wks	1 week	CEASE

<sup>1</sup> Unable to determine discharge date – but at home on day 52

<sup>2</sup> Days in NICU, total days hospitalized (additional days in transitional infant care)

<sup>+</sup> Converted from ounces to grams

<sup>\*</sup> Cessations disputed by review team

<sup>\*\*</sup> Decision pending in DDS