

**Policy Forum**

**Child and Family Outcome Measures for  
Infants, Toddlers and Preschoolers with Disabilities**

**Convened**

October 17-18, 2004

**Proceedings Document**

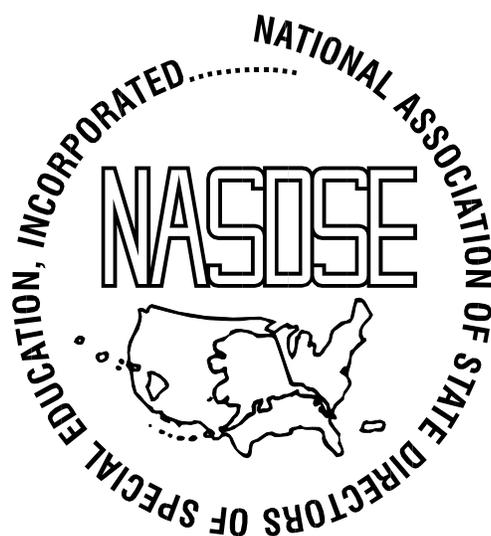
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# **Child and Family Outcome Measures for Infants, Toddlers and Preschoolers with Disabilities**

Project Forum at NASDSE & Early Childhood Outcomes (ECO) Center  
October 17 & 18, 2004

## **Background and Purpose of Meeting**

On October 17 and 18, 2004, Project Forum at the National Association of State Directors of Special Education (NASDSE) convened a meeting in Arlington, Virginia to obtain feedback from a range of stakeholders on the development of child and family outcomes for the Part C and Part B-Section 619 programs of the Individuals with Disabilities Education Act (IDEA). This meeting was part of the work of Project Forum under its cooperative agreement with the U.S. Department of Education's Office of Special Education Programs (OSEP).

Project Forum planned and carried out this meeting in collaboration with the Early Childhood Outcomes (ECO) Center. A copy of the agenda can be found in Appendix A. ECO was funded by OSEP in October 2003 to promote the development and implementation of child and family outcomes measures for infants, toddlers and preschoolers with disabilities that can be used in local, state and national accountability systems. The meeting provided an opportunity to have face-to-face dialogue with a cross section of individuals at a critical juncture in the work of ECO. The group of participants included eight of the nine-member ECO Family Workgroup (parents and parent advocates) and six other stakeholders (two state directors of special education, two 619 coordinators, one Part C coordinator and one Part C health lead agency administrator). Also participating were staff members from OSEP's divisions of Monitoring and State Improvement Planning (MSIP) and Research to Practice (RTP), as well as ECO and NASDSE staff. A list of participants can be found in Appendix B.

During its first year of funding, the ECO Center convened small workgroups of like stakeholders (e.g., Part C coordinators, Section 619 coordinators, family member and advocates) and conferred with researchers on technical issues related to the measurement of child and family outcomes. The purpose of this policy forum was to seek broader stakeholder input and build consensus on components of an early childhood outcomes system, especially the draft child and family outcome statements. (The most current version of the child and family outcomes can be found at [www.the.eco-center.org](http://www.the.eco-center.org).)

## **Background Information from OSEP**

Jennifer Tschantz, ECO's OSEP Project Officer, described the federal impetus for early childhood outcomes and initial OSEP work in this area. This description included a review of the Government Performance and Results Act (GPRA) and the Program Assessment Rating Tool (PART). GPRA requires that a set of indicators be established for all federal programs in order to judge the effectiveness of programs in meeting their goals. GPRA goals and indicators for IDEA have been established, but indicators and data collection are further along for the school-age population than for younger children. The PART is a program evaluation tool that was

introduced by the Office of Management and Budget (OMB) in 2002 to promote performance-based budgeting of federal programs. There are four critical assessment areas—purpose and design, strategic planning, management, and results and accountability.

The most recent PART evaluation of the IDEA formula grant programs, both Part C and Section 619 of Part B, were found to have process performance measures, but lack child outcome data and long-term child outcomes. As a result, OSEP was required to establish long-term outcome-oriented objectives and develop a strategy to collect performance data. Current child outcome performance goals are as follows:

- Section 619: All preschoolers with disabilities receiving special education and related services will improve their early language/communication, pre-reading and social-emotional skills;
- Part C: All infants and toddlers with disabilities will exhibit improved and sustained functional abilities.

At this point in time, there is more pressure to measure child outcomes than family outcomes.

OSEP's previous activities on early childhood outcomes included a focus group meeting, discussions with other federal programs, presentations at national meetings to gather input, synthesis work and funding of the ECO Center. Stakeholder input is essential to the success of these efforts. There are short-term and long-term components of this work. The short-term approach focuses on generating data from states on a limited number of outcome indicators to be used for program accountability at the federal level. The long-term approach focuses on supporting the development of state early childhood data collections for program improvement.

## **Overview of ECO and Timelines**

Kathy Hebbeler, ECO Project Director, provided an overview of ECO's structure and mission, communication/input strategies, first year accomplishments, current activities and next steps.<sup>1</sup>

The immediate next steps of the project are to review and revise a draft set of child and family outcome statements, post them on the ECO website and invite input from a wide variety of individuals and groups through listservs and existing groups (e.g., parents on the state Interagency Coordinating Councils, etc.). It is anticipated that the recommended child and family outcome statements will be sent to OSEP by December 31, 2004.<sup>2</sup>

Input on the measurement approach for the child and family outcomes will be gathered through January 2005. The measurement approach and accompanying materials will be developed in the spring of 2005 through work with 6-8 states, with many of these likely to be states that received General Supervision Enhancement Grants (GSEGs) from OSEP. Large-scale field testing will occur in the fall of 2005 and revisions will be made in early 2006. By the spring of 2006,

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<sup>1</sup> For a Powerpoint presentation on the ECO Center and it's work, go to [http://www.fpg.unc.edu/~eco/pdfs/CEC\\_Baltimore\\_2005.pdf](http://www.fpg.unc.edu/~eco/pdfs/CEC_Baltimore_2005.pdf)

<sup>2</sup> Note that this Project Forum's policy forum took place prior to this deadline.

materials and procedures will be released for use by states. However, there will be ongoing revision of materials based on implementation research and ongoing development of training materials.

It is important to note that these timelines are very tentative and ambitious. Each step depends on the completion of the previous step and acceptance of recommendations from ECO to OSEP.

### **Measurement System and Evidence Statements**

Kathy Hebbeler summarized a paper written by ECO, “Considerations Related to Developing a System for Measuring Outcomes for Young Children with Disabilities and Their Families,” which was mailed to meeting participants. [This paper can be found on the ECO website by clicking on the publications button on the ECO website ([www.the-ECO-center.org](http://www.the-ECO-center.org)).]

The following bullets summarize some of the possible purposes of such a *measurement system* as presented by Dr. Hebbeler:

- examine the effectiveness of Part C and Section 619 nationally, within a state, within a community and within a program;
- monitor the implementation of Part C and Section 619 by OSEP and states;
- monitor the status of young children with disabilities;
- provide information for program improvement at the federal, state and local levels; and
- provide data on child progress that can be used to adjust services or curriculum.

It was noted, however, that it is unlikely that one system will be able to address all the purposes above.

An *evidence statement* is a statement that provides quantifiable evidence as to whether or not an outcome has been achieved. States will submit such statements to OSEP. All states must submit the same kind of evidence in the same form in order for the data to be aggregated across states. There are four categories of evidence statements listed below, each accompanied by a hypothetical example.

- Achievement of goals (e.g., 85% of children who received Section 619 services achieved all of their Individualized Education Program [IEP] goals in language).
- Any degree of positive change (e.g., 90% of children who received Section 619 services made gains in language).
- Positive change compared to some kind of benchmark (e.g., 45% percent of children who received Section 619 services moved closer to typical development in language).
- Change in status of different waves or cohorts (e.g., children who received Section 619 services in 2007 gained an average of 2.5 months in language skills over a three-month period).

## Feedback from Forum Participants on Measurement and Evidence Statements<sup>3</sup>

- *How should we document progress and outcomes for young children who are never “ready” for kindergarten by conventional standards and are a very heterogeneous population in terms of skills? The goal should not be for all children to be “typical” because children with disabilities are by definition not “typical” and will not reach all benchmarks.*
- *For some children, although a small group, a positive outcome is the maintenance of skills (i.e., the child does not regress).*
- *Family satisfaction data are powerful, but we need more than this. In some states, legislators do not want to hear only about family satisfaction data because it is not the intent of the law to make families happy.*
- *Child and family outcomes cannot be separated because a child’s progress is reflected in the family outcomes and vice versa. A well-functioning family has a positive impact on the child’s progress. What about a family that from outward appearances seems to be functioning adequately, but the child does not make measurable progress?*
- *Will child outcomes segregate children with disabilities more than they currently are segregated?*
- *We want outcome data to represent the progress children and families are making as a result of good program improvement strategies. The focus should be on programs, not individual children.*
- *If percentages are used in evidence statements, will this make stakeholders think about a grading system? For example – 60% of children make gains in language – will people equate this to a “D” grade?*
- *Expected outcomes should be high. Years ago we would never have expected so much progress in young children with disabilities.*
- *How can we ensure that all programs and states document outcomes in the same way so that we are not comparing apples to oranges? Could this be a system similar to the National Assessment of Educational Progress (NAEP)?*
- *Outcomes should reflect readiness to transition from Part C to 619 programs because this transition is a critical event.*
- *Should we use more than one type of evidence statement since there are pros and cons for each type?*

### Child Outcome Statements

ECO staff members Kathy Hebbeler and Dale Walker, Associate Research Professor, Juniper Gardens Children’s Project, Kansas City, KS, provided background information on the development of the child outcome statements prior to soliciting input from participants.

“Child outcome” is defined as a measurable condition desired for all children with disabilities after participation in early intervention or special education programs. The outcomes refer to

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<sup>3</sup> Please note: Feedback from the policy forum participants is summarized in this section and several other sections of this document, grouped by topic and italicized. The summarized feedback reflects the range of comments articulated during the meeting. There was no systematic effort made to reach consensus.

knowledge, skills and behaviors that children acquire and display. They are based on the assumption that the goal for all young children with disabilities is to function successfully in their homes, in kindergarten with typically developing peers and in their community. The outcomes reflect skills learned in infancy that serve as a foundation for later learning; skills that are truly important for children to acquire throughout the early childhood years and beyond; and skills that children develop in ways appropriate for their age and individuality. Based on input received previously from stakeholders, ECO's approach to development of outcomes has been to formulate the outcomes based on an integrated view of child development, rather than one bound by discrete developmental domains (e.g., fine motor, gross motor, cognitive, etc.) and to emphasize functional skills used across settings.

ECO staff presented some general questions/considerations in developing child outcomes, including the following:

- How should child outcomes for Part C and Part B-Section 619 be aligned?
- How should early childhood outcomes and K-12 outcomes be aligned considering the emphasis on academics in the K-12 years?
- How do we reflect the diverse abilities of children with disabilities in the outcomes?
- How do we develop a system that will allow child outcomes to be aggregated across children and states?

The child outcome statements presented by ECO staff were developed to reflect the following criteria:

- be consistent with IDEA and legislative intent;
- describe the most important behaviors and skills desired for children as a result of participating in early intervention and preschool special education services;
- incorporate what is known about development and learning;
- use phrasing that reflects "universal design" (i.e., phrasing that implies outcomes can be accomplished in more than one way);
- be applicable to the entire birth-to-five age span;
- be concise;
- be readily understood with a minimum of jargon or specialized phrases; and
- have the potential to influence practice in a positive way.

### **Feedback from Forum Participants on Outcomes, Questions/Considerations and Criteria**

- *There was support for the integration of Part C and Section 619 outcomes and alignment with K-12 outcomes, but acknowledgement that these will both be a challenge.*
- *It is good that the goals, considerations and criteria reflect inclusion.*
- *Emphasis on kindergarten is not necessary. Children should function successfully at home and in all parts of their community (this would include school for preschool-age children).*

- *Emphasis on “typically developing peers” is not necessary. Children should interact successfully with ALL peers and adults.*
- *It is not clear that the outcomes will adequately reflect the critical social-emotional skills that young children must acquire between birth and five years of age.*
- *Two additional criteria should be “reflect family’s goals for child” and “be acceptable to stakeholder groups.”*
- *Should we be looking at more sustainable outcomes, such as progress at grade 3?*
- *Concern was voiced about use of the phrase “reasonable targets.” A particular target may not be reasonable for an individual child, but it might be reasonable for children as a group. These are to be child outcomes that reflect programs, not individuals.*

### **Draft Child Outcome Statements Presented by ECO Staff at Policy Forum**

#### **Child Outcome Statement 1: Children have positive social relationships.**

This means that:

- ~ The child demonstrates attachment with the significant caregivers in his/her life.
- ~ The child initiates and maintains positive social interactions.
- ~ The child behaves in a way that allows him/her to participate successfully in a variety of settings and situations, for example, on the playground, at dinner, at the grocery store, in child care, etc.
- ~ The child communicates wants and needs effectively.
- ~ The child builds and maintains relationships with other children.
- ~ The child regulates his or her emotions.
- ~ The child understands and follows rules.

(This outcome reflects competencies in the social-emotional and communication domains.)

#### **Child Outcome Statement 2: Children acquire knowledge and skills as active participants in their home, school and community.**

This means that:

- ~ The child displays an eagerness for learning and is actively engaged in daily learning opportunities.
- ~ The child has the necessary knowledge and skills (i.e., vocabulary, complexity of language, problem-solving skills, general knowledge, pre-literacy, pre-numeracy, etc.) and uses them to participate successfully in a variety of everyday routines and activities.
- ~ The child shows imagination and creativity in play.

(This outcome reflects competencies in cognition, language and communication, and social-emotional domains.)

#### **Child Outcome Statement 3: Children move around and explore and manipulate objects in their environment.**

This means that:

- ~ The child manipulates objects to explore their properties or to use the object to meet his/her own needs.
- ~ The child independently uses objects as tools such as forks, sticks, pencils, crayons and scissors in appropriate ways.
- ~ The child can move independently from place to place to participate in everyday routines and activities.

(This outcome reflects competencies in the fine motor, gross motor and cognitive domains.)

**Child Outcome Statement 4: Children tend to their basic care needs.**

This means that:

- ~ The child displays independence with regard to basic care needs (i.e., feeding, dressing, toileting, etc.).
- ~ The child seeks help when necessary to assist with basic care.
- ~ The child's ability to meet his or her basic care needs allows him or her to participate successfully in everyday routines and activities.

(This outcome reflects competencies in the adaptive, fine motor, gross motor, cognitive and communication domains.)

**Child Outcome Statement 5: Children are healthy.**

This means that:

- ~ The child is in good physical health.
- ~ The child is active and physically fit.
- ~ The child's diet reflects good nutrition.
- ~ The child understands and follows rules related to health and safety.

(This outcome reflects physical health, and competencies in cognitive, adaptive and social domains.)

Note: These outcomes were the outcomes discussed at the meeting. Subsequent revisions to these outcomes can be found at [www.the-eco-center.org](http://www.the-eco-center.org).

**Feedback from Participants on Child Outcome Statements**

General comments:

- *A domain-integrated approach looks more like a real child than a domain-specific approach and seems more applicable to ALL children.*
- *Domains constrain rather than facilitate discussion about a child.*
- *All outcome statements must refer to knowledge and skills that are part of everyday routines and activities across home, school and community.*
- *A concern was raised about the domain-integrated approach because eligibility is mostly domain specific.*
- *Consider an outcome statement related to self advocacy and choice, or perhaps this fits into outcome statement 2 or 4.*
- *A question was raised about how soon states could realistically address all the child outcome statements in their Annual Performance Report (APR).*
- *It must be made clear that bullets elaborate on an outcome statement, but are not meant to be a checklist and not all bullets are appropriate for every age group.*

Child Outcome Statement 1:

- *This outcome statement should reflect relationships with a variety of adults, not only caregivers.*
- *Does this outcome statement adequately capture mental health issues – and should it?*

- *There should be a bullet about negotiating social challenges.*
- *Consider replacing the word “regulates” with “controls” or “displays.”*

Child Outcome Statement 2:

- *There is support for bullet three about play.*
- *Consider using the word “member” rather than “participant.”*
- *Consider separating bullets one and two because they seem like different constructs.*
- *Consider moving bullet one to outcome statement 1.*
- *Are the words “active” and “eager” too subjective?*
- *We must be clear that language and vocabulary include all means of communication (e.g., sign language, communication boards).*
- *Add more bullets that reflect the birth-to-three age range and learning outside a school setting.*
- *Should attention skills be included in this outcome statement?*
- *Remove “successfully” from bullet two.*

Child Outcome Statement 3:

- *Many concerns were raised about this outcome statement. It does not reflect the principles of universal design as well as the others because children with severe motor disabilities may never reach this outcome.*
- *This outcome statement must reflect the importance of learning to use technology and equipment for mobility, exploration and manipulation of objects.*
- *Use of the word “independently” is not appropriate here because young children may learn to use caregivers to help them be mobile, explore and manipulate objects.*
- *It seems like a challenge to combine fine motor, gross motor and cognitive skills into one outcome statement.*

Child Outcome Statement 4:

- *This outcome statement should reflect cognitive skills more than motor skills.*
- *Concern was raised about use of the word “independence” and how this outcome statement would reflect skills of children with severe motor disabilities.*
- *Add more bullets that reflect the birth-to-three age range.*
- *Consider using the word “meets” rather than “tends” in regard to basic care needs.*

Child Outcome Statement 5:

- *Although good health is very important and is related to early childhood outcomes, should this be an outcome for Part C and Section 619 programs?*
- *Consider moving the last bullet to outcome statement 4.*
- *There are no developmental markers for this outcome.*
- *Consider focusing on healthy choices in regard to everyday routines and activities.*

## Measurement of Child Outcomes:

- *Measurement of child outcomes will provide families with valuable information and will help them set meaningful goals for their children.*
- *States will not have all the information necessary to provide a rating for all outcome statements, at least at the beginning.*
- *Measurement of child outcomes will result in increased work for the IEP or Individualized Family Service Plan (IFSP) team.*
- *A question was raised about benefit to the individual child.*
- *Concern was raised about the ability of programs to measure all five child outcomes on the “fast track.”*
- *A question was raised about the point(s) of measurement – annual or exit from Part C or Section 619.*

## Family Outcome Statements

Don Bailey, ECO staff member based at the Frank Porter Graham Child Development Center in Chapel Hill, North Carolina, provided background information on development of the family outcome statements prior to soliciting input from participants.

“Family outcome” is defined as a benefit experienced by families as a result of early intervention or special education services received. It is not the receipt of service or satisfaction with services, but something that happens because services are provided.

ECO’s rationale for the development of family outcomes is as follows:

- Federal legislation is predicated on the assumption of benefit to families.
- Research documents the critical role of families in child development.
- Parents are affected by having a child with a disability and early intervention services should promote positive adaptation and reduce potential negative impacts.
- Family outcomes may be especially important for families whose children, despite intensive early intervention, make relatively little measurable progress and suffer serious health or developmental challenges.

ECO staff raised some questions/considerations in developing family outcomes including the following:

- Should family outcomes be linked directly to child outcomes?
- Should family outcomes for Part C and Part B-Section 619 be the same and if not, how should they be aligned?
- Do *all* family outcomes impact the child in some way?
- Family outcomes are more cyclical and child outcomes are more linear (e.g., families may experience periods of more or less stress from one year to the next, whereas most children achieve higher skill levels with each passing year).

## **Draft Family Outcome Statements Presented by ECO Staff at Policy Forum**

### **Family Outcome Statement 1: Families know their rights and advocate effectively for services.**

This outcome may include:

- ~ The family understands its rights and responsibilities.
- ~ The family is able to access services in its community.
- ~ The family is familiar with service options and the types of services offered by different providers.
- ~ The family feels comfortable talking with professionals or asking questions.
- ~ The family is able to access the Internet or other sources to find out about rights and services.
- ~ The family is able to participate effectively in team meetings to plan goals and services.
- ~ The family advocates for services that are important.
- ~ The family is able to advocate for needed services that are not being provided.

### **Family Outcome Statement 2: Families understand their child's abilities and special needs.**

This outcome may include:

- ~ The family is able to describe expectations for typical development at different ages and stages.
- ~ The family is aware of how its child with, or at-risk for, a disability is developing and what might be the next developmental abilities that could be encouraged.
- ~ The family is able to observe the child's behavior and notice whether changes occur as a result of services, medication, changes in parenting or alterations in the home environment.
- ~ The family understands the special risk factors, conditions or disability its child might have.
- ~ The family is able to access information about child development or its child's special needs through resources such as other parents, reading materials, professionals or the Internet.

### **Family Outcome Statement 3: Families help their child develop, learn and behave appropriately.**

This outcome may include:

- ~ The family demonstrates general styles of effective parenting.
- ~ The family demonstrates special techniques that might be effective in enhancing learning or managing special behavior problems.
- ~ The family modifies the home environment or routines to more closely match their child's learning style or needs for adaptive environments.
- ~ The family is able to help their child use special adaptive equipment.
- ~ The family is able to access and evaluate the validity of recommendations for dealing with particular learning or behavior challenges.

### **Family Outcome Statement 4: Families have the support they want from other family members, friends, neighbors or others.**

This outcome may include:

- ~ Spouses/partners communicate about their child's needs.
- ~ The family maintains friendships and makes new friends.
- ~ The family talks to friends and neighbors about disability-related issues.
- ~ The family continues to participate in desired neighborhood activities, family functions and social outings with spouse/partner or friends.
- ~ The family meets and gets to know other families of children with disabilities.
- ~ The family has neighbors, friends or family who can serve as trusted babysitters.

**Family Outcome Statement 5: Families access desired services, programs and activities that are available to other families in their community.**

This outcome may include:

- ~ The family accesses specialized services that assist the child to participate and learn in everyday activities and routines.
- ~ The family has a physician and dentist who can provide care that is sensitive and responsive to its child's special needs.
- ~ The family belongs to parent organizations or support groups relevant to its child's disability and the family's style and priorities.
- ~ The family finds acceptable and trustworthy babysitting and respite services when informal care is not available.
- ~ The family is able to participate in religious or recreational groups that the family ordinarily would have participated in had its child not had a disability.
- ~ The family accesses and participates in programs for children, such as Gymboree.
- ~ The family uses inclusive child care so that the parents can work.
- ~ The family is able to take the child grocery shopping, to the mall or out to a restaurant.
- ~ The family uses the neighborhood playground.

**Family Outcome Statement 6: Families are satisfied with their quality of life.**

This outcome may include:

- ~ There is a sense of wellbeing within the family.
- ~ The family feels confident that they have done what is needed to get the services they want.
- ~ The family finds a sense of meaning or fulfillment in life.
- ~ The family is able to do the things that are important.
- ~ There is economic self sufficiency within the family.

Note: These outcomes were the outcomes discussed at the meeting. Subsequent revisions to these outcomes can be found at [www.the-eco-center.org](http://www.the-eco-center.org).

## **Feedback from Forum Participants on Family Outcomes Statements**

General comments:

- *Family outcomes for Part C and Part B-Section 619 should be the same. This will help to increase the much needed connections between the two programs; however, this raises some concern because of the different family inputs for the two programs.*
- *Having family outcomes will help emphasize the importance of family-focused services.*
- *Concern was voiced about the program resources needed to yield good family outcomes.*
- *The work of ECO should be aligned with the family survey work being done by the National Center for Special Education Accountability Monitoring (NCSEAM).*
- *If the Annual Performance Reports for Part C and Part B-Section 619 address family issues, development of family outcomes is essential.*
- *Perhaps there is a need for an overall statement about racial/cultural sensitivity in regard to family outcomes.*
- *The importance of partnerships between families and professionals may not be adequately addressed in the family outcome statements.*

- *The family outcomes do not address transitions and this is such a critical time for families.*

#### Family Outcome Statement 1:

- *This outcome statement is good for both Part C and Part B-Section 619.*
- *Change “advocate...for services” to “advocate for its child.”*
- *Omit “effectively” from this outcome statement due to concerns about its measurement.*
- *Include in bullets a reference to accessing information—not just services—and evaluating information (e.g., finding a “trusted resource”).*
- *Consider a bullet regarding understanding of eligibility for Part C and Part B-Section 619.*
- *Make separate bullets for rights and responsibilities.*
- *Consider including in the narrative the differences between Part C and Part B-Section 619 in regard to the family role.*

#### Family Outcome Statement 2:

- *This outcome statement is good for both Part C and Part B-Section 619.*
- *Add reference to varying learning styles in the narrative section.*
- *Add reference to social/emotional issues and mental health of child in the narrative section.*
- *Include a bullet that addresses the family’s awareness of the child’s strengths/assets.*
- *Concern was raised about whether this outcome statement might limit the expectations families have for their children.*
- *Concern was raised about measurement of this outcome.*

#### Family Outcome Statement 3:

- *This outcome statement must be consistent with the child outcome statements.*
- *Consider whether “develop” can stand alone in this statement because learning and behaving are part of developing.*
- *Omit “behave appropriately” and consider changing to “demonstrate positive behaviors” or “interact in the community in a positive way.”*
- *Consider adding a bullet regarding setting challenging goals and helping children obtain those goals.*

#### Family Outcome Statement 4:

- *It is good that this outcome statement includes the phrase “they want” referring to the families.*
- *This outcome statement must reflect the fact that families have different wants and needs and this should be respected.*
- *Consider using the phrase “are supported” or “feel supported” rather than “have the support” because the perception of support is important.*

- *Consider using the phrase “informal support” in the outcome statement.*
- *Might this outcome statement be worded differently if families do the rating?*
- *Concern was expressed about the impact that programs can have on informal support; maybe this is really part of quality of life that is covered in Family Outcome Statement 6.*

#### Family Outcome Statement 5:

- *Change “other families” to “all families.”*
- *Change “access” to “participates.”*
- *Include reference to siblings in narrative and bullets.*

#### Family Outcome Statement 6:

- *This outcome statement may not be necessary because it is really the “gestalt” of the other statements.*
- *Concern was raised because “quality of life” means something different to everyone.*
- *The bullet on economic self sufficiency is problematic in regard to measurement.*
- *If this outcome statement is retained, the bullets must be developed better.*

#### Measurement of Family Outcomes:

- *Support was expressed for the phrase “one member of our family...”*
- *The rating scale must be clear and concise (simple wording), but have enough markers for each rating.*
- *Consider adding a “do not know” rating option.*
- *The rating scales suggest more linearity than exists.*
- *Concern was expressed about data collection because the program staff is already overburdened.*
- *Measurement of these family outcomes must be able to mesh with other family measurement currently being done in states.*
- *Consider involving other agencies in addition to Part C and Section 619 lead agencies in the measurement of family outcomes.*

### **Steps to be Taken Following the Meeting**

Following the October policy forum, the ECO staff will consider all feedback provided by the participants. Clarifications and revisions will be made to the background/narrative sections, the child outcome statements and the family outcome statements. These revised drafts will be discussed with smaller workgroups (e.g., researchers, Part C coordinators, Section 619 coordinators) in the final months of 2004. Feedback will then be solicited from the general public through listservs, conference calls and the ECO website. After review of all feedback from the general public and possible revision, a set of child and family outcome statements will be submitted to OSEP for consideration.

**Appendix A:**  
**Agenda**

## Appendix A - Agenda

### Child and Family Outcome Measures for Infants, Toddlers and Preschoolers with Disabilities

#### Policy Forum October 17 & 18, 2004

##### Sunday, October 17

- |               |   |
|---------------|---|
| 8:30 – 9:00   | Breakfast   |
| 9:00 – 9:15   | Opening & review of meeting objectives                                |
|               | Welcome from OSEP   |
| 9:15 – 9:40   | Introductions by participants   |
| 9:40 – 10:00  | OSEP background<br>(Initial work on EC outcomes, GPRA, PART & APR)    |
| 10:00 – 10:30 | ECO overview  |
| 10:30 – 10:45 | Break   |
| 10:45 – 11:30 | Framework/considerations<br>Evidence statements                       |
| 11:30 – 12:00 | Questions/discussion about nature and purpose of outcomes             |
| 12:00 – 1:00  | Lunch   |
| 1:00 – 1:20   | GSEGs and the ECO Center  |
| 1:20 – 1:50   | Child outcomes – background   |
| 1:50 – 3:00   | Child outcomes – discussion<br>- areas<br>- measurement/rating system |
| 3:00 – 3:15   | Break   |
| 3:15 – 5:00   | Child outcomes - discussion (continued)                               |
| 5:00          | Adjourn for day   |

Monday, October 18

- |               |  |
|---------------|--|
| 8:30 – 9:00   | Breakfast  |
| 9:00 – 9:15   | Opening and introduction of newcomers  |
| 9:15 – 9:45   | Comments/questions from previous day   |
| 9:45 – 10:30  | Family outcomes – background   |
| 10:30 – 10:45 | Break  |
| 10:45 – 10:55 | Remarks from OSEP  |
| 10:55 – 12:00 | Family outcomes – discussion <ul style="list-style-type: none"><li>- areas</li><li>- measurement/rating system</li></ul> |
| 12:00 – 1:00  | Lunch  |
| 1:00 - 2:45   | Family outcomes – discussion (continued)   |
| 2:45 – 3:00   | Break  |
| 3:00 – 3:45   | Concluding reflections from participants   |
| 3:45 – 4:00   | Next steps   |
| 4:00          | Adjourn  |

**Appendix B:  
Participant List**

## Appendix B – Participant List

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