# Guidance for States in Documenting Family Outcomes for Early Intervention and Early Childhood Special Education

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Demonstrating Results for Infants, Toddlers and Preschoolers with Disabilities and Their Families

IDEAs thatWork U.S. Office of Special Education Programs

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For more information about the ECO Center, including other products, see the website at www.the-eco-center.org.

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# Background

The Early Childhood Outcomes (ECO) Center was established in 2003 by the U.S. Department of Education, Office of Special Education Programs (OSEP), to provide leadership and assistance related to the collection of data on outcomes for infants, toddlers, and preschoolers with disabilities and their families. Among other responsibilities, the Center was charged with the task of "working directly with State educational agencies, local educational agencies, local agencies, technical assistance providers, parent organizations, parent trainers, other relevant organizations, and researchers to build consensus among stakeholders on what is important to measure, how the measurement should be conducted, the importance of using outcome indicators in early intervention and preschool special education, and the selection of child outcomes and indicators and family outcomes and indicators" (*Federal Register 68*, July 28, 2003, p. 44320).

A preliminary step in developing an outcomes measurement system is identifying the outcomes to be measured. Accordingly, the initial work of the ECO Center focused on identifying a set of family outcomes for early intervention and early childhood special education. A large number of stakeholders were involved in generating, reviewing, and modifying proposed family outcomes, and as a result, five outcomes were identified:

- 1. Families understand their child's strengths, abilities, and special needs.
- 2. Families know their rights and advocate effectively for their children.
- 3. Families help their child develop and learn.
- 4. Families have support systems.
- 5. Families access desired services, programs, and activities in their community.

Additional information about what is meant by each of the family outcomes identified through the ECO stakeholder process is available in *Family and Child Outcomes for Early Intervention and Early Childhood Special Education* (ECO, 2005). Background information related to the selection of family outcomes can be found in *Family Outcomes of Early Intervention and Early Childhood Special Education: Issues and Considerations* (Bailey & Bruder, 2005). This paper provides a rationale for documenting family outcomes, addresses selected issues associated with family outcome assessment, and reviews a number of existing frameworks that have suggested various outcomes for families of children with special needs. Both documents can be accessed at the ECO Center website at www.the-eco-center.org.

In the summer of 2005, OSEP released the indicators related to families for which all states must provide data. For Part C, these indicators are:

- Percent of families participating in Part C who report that early intervention services have helped the family
  - Know their rights
  - Effectively communicate their children's needs
  - Help their children develop and learn

The family indicator for early childhood special education applies to all children and youth receiving special education ages 3 to 21. It is:

• Percent of parents with a child receiving special education services who report that schools facilitated parent involvement as a means of improving services and results for children with disabilities

States are now moving forward to build the infrastructure that will allow them to collect regular data from families. We have written this document to provide guidance to states as they undertake this important activity. Much of the guidance in this document is germane to any kind of information that states are planning to collect from families. The primary purpose of this document, however, is to provide guidance related to the collection of data on family outcomes, since this is a new area for statewide data collections.

We know that many states have already gathered some kind of information from families participating in early intervention or early childhood special education programs. To date, much of that information has focused on satisfaction with these services rather than outcomes achieved by families. The distinction between family outcomes and family satisfaction is critical. An outcome is a *benefit* experienced by families as a result of services and supports received. It is what happens to families as a result of participating in a service or program. It is not receipt of the service or satisfaction with the service. Some states will want to collect family outcome data in addition to currently collected data on satisfaction with services. For other states, both of these areas could be new data collections.

The family outcomes to be measured could be the five listed above but could also include other family outcomes. Many states have been working with stakeholder groups to identify the important family outcomes in their state. Some have adapted the five ECO-recommended outcomes or have expanded the list. If states have not yet engaged stakeholders in thinking about what family outcomes are important in their state, we strongly encourage them to do so.

States are facing many decisions related to collecting data from families. In this document, we identify a set of state decisions related to measuring family outcomes, discuss some of the considerations related to each decision, and make one or more recommendations. We recognize that each state will need to make decisions in these areas based on factors unique to their population, history, and resources. We encourage states to consult with key stakeholder groups, especially family members of young children with disabilities, as they prepare to make decisions that ultimately will result in a measurement system for family outcomes.

An overarching decision is whether a state wants to collect information about families in addition to what is being required by the Office of Special Education Programs. We strongly encourage states to collect data on family outcomes in addition to the indicators

required by OSEP.<sup>1.</sup>Information on family outcomes will be needed if the state wants to examine the extent to which its programs are supporting families in caring for their children. Additional information also will permit states to identify areas where local programs may need more assistance to strengthen their capabilities in meeting the needs of children and families. The achievement of child and family outcomes are thoroughly intertwined for young children, and it is unrealistic to expect that child outcomes will be achieved without achieving family outcomes. Without good data on family outcomes, states will lack key information on whether or not they are providing quality programs.

There is almost no research on the statewide measurement of family outcomes, so our recommendations are based on our understanding of related research and our team's collective input and experience with large-scale data collections. The recommendations outlined in this document do not constitute official recommendations from OSEP, but are entirely those of the ECO Center. There is much to be learned about how to assess family outcomes statewide. We encourage states to conduct pilot studies to examine the validity and reliability of the measurement strategies they select. Sharing what they have learned with the ECO Center and other states will increase our collective knowledge. For a general overview of issues in designing state accountability systems, states may want to consult a recent article by Harbin, Rous, and McLean (2005), with invited commentaries by Hebbeler (2005), Roberts (2005), and Lesko (2005).

#### **ECO Center Recommendations:**

- States develop meaningful mechanisms to include parents, service providers, and program coordinators to assist in making decisions about the outcomes to be measured in addition to measurement and implementation decisions. Of special importance is the inclusion of families that represent the state's cultural and socioeconomic diversity.
- States collect data about family outcomes in addition to the required OSEP family indicators.
- States conduct pilot studies to identify strategies that maximize the validity and usefulness of the data being collected, and share what they learn through this process with ECO Center staff, OSEP, and other states.

This report consists of three sections. We begin by discussing a series of measurement decisions that need to be made when documenting family outcomes. In the second

<sup>&</sup>lt;sup>1</sup> The National Association of State Directors of Special Education (NASDSE), one of the ECO Center's partner organizations, recognizes the importance of data collection and analysis in order to improve outcomes for all infants, toddlers, children, and youth with disabilities. However, the data collection and reporting requirements of IDEA are substantial and therefore NASDSE does not agree with the recommendation of the ECO Center that states collect more data than is required by the federal government.

section, we address implementation decisions. In the final section, we describe options for states to select an instrument to measure family outcomes. Additional information about specific instruments is available at www.the-eco-center.org.

## **Section 1: Measurement Decisions**

Here we discuss six decisions states need to make with regard to the measurement process. Assuming states have determined the nature and range of outcomes to be documented, the next set of decisions relates to how these outcomes will be measured. These decisions relate to the characteristics of the data collection instrument that will be used to collect the information on family outcomes. If states are considering developing their own instrument, these decisions can be considered in that development process. If states are selecting a tool from one of the tools summarized in the final section of this document, then the information can be used as criteria in making a selection.

#### What data collection mechanism will be used?

The basic choices for data collection mechanisms are direct observation, interview, and survey methods. *Direct observation* methods require one or more individuals to actually observe families or family members. The most common example of this approach is the case in which parent-child interaction is observed and rated on such dimensions as amount, quality, or appropriateness, but observation also could be used to document such outcomes as parent participation in team meetings, follow-through on IEP/IFSP goals, or advocacy efforts. Direct observation has the advantage of directly assessing behavior; as a result, some may consider it to be more objective and thus more valid than self-report. However, direct observation suffers from major limitations for statewide data collection. It is an extremely expensive and labor-intensive approach, both to collect the data and then to code and summarize it. Some outcome areas (e.g., support, community inclusion) would be almost impossible to assess through direct observation since it would not be possible for an observer to sample enough settings to obtain a reasonable estimate of the presence or absence of outcomes. Many parents would likely view such an assessment as an attempt by professionals to judge or evaluate them, and to the extent that this perception occurs, it will compromise the ultimate intent of family outcomes assessment. Finally, there is considerable consensus in the field that family outcome attainment is an inherently subjective phenomenon. According to this perspective, families' perceptions of their own outcomes are more valid than nonfamily members' judgments about the presence or absence of an outcome.

Interview methods involve one person talking with another person to determine outcome attainment. Interviews can be structured, semistructured, or open-ended, and could be conducted in-person or by phone. Interviews almost always involve sampling (addressed later). A state would never try to interview all families participating in a program, although a smaller program might. Interviews have the advantage of allowing for a more thorough understanding of a phenomenon than is possible through a survey. Interviews can be highly flexible, allowing questions to be tailored to a family's communication style and comfort levels, and adjusted "midstream" as the conversation proceeds. Interviews also can be useful for families who have difficulty completing a written survey. One of the

biggest advantages of interviews over surveys is response rate. It is much easier with interviews to get responses from many of the families identified in the sample. A primary disadvantage of the interview is the time and labor required; as a result, interviews can be expensive. An additional cost involves the training and supervision of interviewers. Conducting a valid and appropriate interview requires considerable skill. Another concern is the analysis of interview data from open-ended questions. For these questions, the analyst is left with the challenging task of sorting through interview data to determine how to code responses so they can be summarized across families. Finally, an interview can make some families uncomfortable or some may feel pressure to give an answer that they think the interviewer will approve of.

Survey methods usually involve a "paper and pencil" approach, primarily in the form of written instruments to which families provide a written response, although computerized or web-based versions are possible as well, the major advantage of survey methods is their cost efficiency. The labor cost of distributing and collecting surveys is usually much lower than costs associated with direct observation or interviews. Scanning or other automated data entry procedures can further reduce the cost of data analysis. Also, families can complete the survey at a time and location convenient to their schedules, can review and consider responses, and can take as long or as short a time as they wish. Disadvantages of survey methods include the challenge of getting respondents to complete and return the survey. Consequently, return rates of less than 50% are common. (More on return rates later in this document.) Another disadvantage of surveys that is closely linked to return rate are problems related to literacy and primary language. Some families may not be able to read well, and increasing cultural diversity in the U.S. means that a significant number of families may not speak English as their primary language. This means the additional cost of translating the survey into multiple languages, although many immigrant families may still not be able to read it.

We should also note that *focus groups* have been effectively used as a way of gathering information about families' perceptions of early intervention or preschool special education. A focus group typically involves assembling a small number (5 to 10) of participants and, using a guided discussion format, eliciting ideas and opinions from individuals participating in early intervention or preschool programs. This methodology has the advantages of a face-to-face format, allowing for open discussion and interactions where one participant can build on the comments of another. Focus groups may be especially useful for families who have difficulty reading or completing a written survey. Also, some families who may not feel comfortable sharing their true feelings in a one-on-one interview may be more comfortable speaking when in the company of other families. However, measuring outcomes is fundamentally different from measuring perceptions of programs or services, in that it seeks to determine where an *individual family* stands with respect to a predetermined set of outcomes. A focus group format would not generally be appropriate for documenting individual outcome attainment.

#### **ECO Center Recommendation:**

• States use a survey to collect data on family outcomes, primarily for reasons of cost efficiency. As discussed below, however, careful attention

needs to be paid to the selection or construction of an instrument, and the process by which it is described, distributed, and reported will have a major influence on the return rate.

#### Who will provide the data?

Who will provide the information for the measurement of family outcomes is another decision that must be made. Any of the described data collection mechanisms could be used with one or more parents, caregivers, extended family members, or professionals serving each family. Deciding who provides information for family outcomes is less straightforward than for child outcomes. For documentation of child outcomes, one or more assessments typically is done by professionals familiar with the child. Information from families is incorporated, but the process almost always would involve professionals playing a key role in the measurement of child outcomes.

Should a professional or a team of professionals rate the extent to which a family outcome has been attained? Some would argue that professional ratings may be more "objective," as professionals typically have worked with a large number of families and could rate a family in the context of this broader set of experiences. Some precedent exists for this approach in the form of observational scales used to rate parenting skills or parent-child interactions.

We suggest, however, that states not use professional ratings as the source of information on family outcomes, for two primary reasons. First, families are not likely to respond favorably to a system in which they perceive themselves as being evaluated or measured by a professional. For many families, this would be offensive, and the result would compromise the ultimate intent of measuring family outcomes, which is to determine the benefits experienced by families as a result of early intervention or preschool special education programs. Second, much research suggests that family outcomes have an inherently subjective component to them that is of value and, in fact, is likely to be strongly related to whether a benefit has been received. For any given outcome there are likely to be components that are relatively objective and others that are relatively subjective. For example, a parent may be able to describe all of the rights she has with respect to early intervention and, from an outsider's perspective, may seem aware of those rights and capable of communicating effectively with professionals and advocating for her child's needs. But what if she is not happy with her communication or advocacy skills, and interactions with professionals are highly stressful for her? Professionals would not be able to determine a family's perceptions of skills, support, or community inclusion, because they can rate only what they can observe. The ECO Center recommends that families be the source of information about family outcomes.

If families themselves are to be the source of information for data on family outcome attainment, who within the family should provide that information? We know that families differ with regard to the number of adults who care for the child and their relationships to the child and each other. The term "family outcome" suggests outcomes for the family as a whole, but often data are collected from a single family member, usually the mother. One strategy is to identify that the survey is to be completed by the child's primary caregiver. Another strategy is to address the survey to the child's parents or guardians, assuming that each couple will make a choice as to the best person to complete the survey. A variation of this approach would ask that the "most knowledgeable family member" provide the information, thus allowing for the possibility of grandparents or other significant family members serving as respondents. Finally, states can suggest or encourage that caregiving adults discuss the items among themselves and come to joint agreement as to the status of each outcome.

Providing precise directions about who is to complete the survey might give the appearance of controlling for unwanted variation in responses, assuming for example, that fathers would answer questions differently from mothers. In reality, regardless of the instructions given, families are likely to make their own choices about who responds, since families vary in composition, role distribution, communication styles, and preferences. For a statewide data collection, prescribed directions about who should complete the survey are not a good idea. If families actually follow such directions, it is likely to negatively impact return rates because families may be offended by directions, for example, in the case that directions ask mothers to complete the survey. Even among families returning surveys, some will follow directions and some will not, resulting in variations in respondents anyway.

#### ECO Center Recommendations:

- States collect information directly from families to measure family outcomes.
- States give families considerable flexibility about who provides information about family outcomes, since it is unlikely that any one approach will work well for every family.
- States include a question on the survey asking who completed it (mother alone, father alone, and so on) so responses can be analyzed by type of respondent.

### Whose outcomes are being reported?

A closely related question is whose outcomes are being reported. When a family is made up of more than one adult, it is possible that those adults do not share the same perceptions with regard to each of the family outcomes. At least three options are possible. First, the respondent could be asked to report on outcomes that he or she individually has experienced (e.g., "I am confident in his or her ability to incorporate my child's IFSP goals into her daily activities"). Alternatively, the respondent could report outcomes experienced by their whole family (e.g., "Our family is confident in our ability to incorporate our child's IFSP goals into her daily activities"). In a third option, the respondent could report outcomes experienced by at least one family member (e.g., "At least one member of our family is confident in their ability to incorporate our child's IFSP goals into her daily activities").

Each option has obvious advantages and limitations. Asking the respondent to describe only his or her outcomes is the most straightforward and direct approach. It assumes that the person responding is both the primary person who would know about family outcomes and the person who has indeed experienced these outcomes. It is quite possible, however, that many families will have shared or perhaps divided responsibilities. For example, the father may be the primary spokesperson in IEP meetings and the mother may have primary responsibility for implementing IEP goals in the home and daily routines. It would be confusing to ask for some information from some family members and other information from others.

Option B ("our family...") could be problematic in the case of families where one family member is experiencing outcomes (e.g., feels supported or confident) but another family member is not. However, this option is most consistent with the current OSEP Part C indicator that refers to "family" as the recipient of outcomes (e.g., percent of families who report that early intervention services have helped the family). Option C ("at least one member of our family...) allows families the greatest flexibility and more likely reflects the division of responsibilities, needs, and priorities that likely exist within families. Although not worded in as precise a format as the OSEP reporting requirements, it is likely that this approach would be both acceptable and valid, as it does not require all family members to attain an outcome but that at least one person in the family do so.

There is a fourth possibility that is used in research studies and that is to have each family member provide the information separately. We do not consider that option feasible for a statewide data collection. As stated in the conclusion to the previous section, regardless of the state's preferences, it is likely that families will respond in a way that best suits their needs and circumstances at the time they are providing the information.

#### **ECO Center Recommendations:**

- States be clear in the initial instructions to respondents about whose outcomes are to be considered in answering the questions.
- States use a format that asks about the family as a whole rather than about the individual respondent's outcomes (unless multiple family members are given the opportunity to individually provide information regarding outcome attainment). We can see advantages of both asking about "our family" (Option B above) and asking about "at least one member of our family" (Option C), and both options will likely work for learning about family outcomes and reporting on the OSEP performance indicators.

#### Should the items be open- or closed-ended?

A basic decision required about the format of items is whether to use open- or closedended questions. An *open-ended question* is one that asks about an outcome and leaves it to the respondent to determine what he or she will say in response. For example, "How would you describe how well you understand your child's strengths, abilities, and special needs?" This approach has a clear advantage in giving flexibility to the respondent and allowing for a personalized indication of outcome attainment. Its primary disadvantage is that aggregating data from open-ended questions requires considerable resources because a coding system has to be developed and the responses have to be coded so they can be analyzed. A *closed-ended question* is one that asks about an outcome and presents a limited set of responses from which the respondent can choose. Although the responses are constrained, they are much easier to compile, to summarize at a local or state level, and to compare across programs or regions.

A combination of closed- and open-ended responses is optimal. This allows easy aggregation of data across a large number of program participants, while at the same time providing for a fuller and more individualized expression of the extent to which outcomes have been attained, showing what families actually mean when they indicate an outcome has been realized, and perhaps even providing information about the program factors that contributed. Also, having only closed-ended items can sometimes be frustrating to respondents. The open-ended items provide families an opportunity to provide information they want to share about their experiences and their program.

One last factor to consider in this decision is the extent of resources the state has available to analyze the data. If the state does not have the resources to read and analyze what families write in response to open-ended items on a survey, these items should not be included. Many families will invest considerable time in responding to open-ended questions, and their time should not be wasted if those responses will not be analyzed.

#### **ECO Center Recommendation:**

 States use a combination of open- and closed-ended items, using a core set of closed-ended questions to facilitate data aggregation and the openended items to supplement the information, provided they have the resources to analyze the responses to open-ended questions.

#### What should be the content of the items?

Most measures will consist of statements such as "Our family knows how to help our child learn new skills." How are those statements generated? Ideally, the content of a survey instrument should be developed based on a combination of theoretical, practical, empirical information. Theories about families—how they develop, change, and cope—provide one source of information about item content. Practical considerations, such as input from consumers, federal or state reporting requirements, and acceptability to respondents, constitute a second set of relevant factors. Finally, research on item scaling and how items cluster together also provides critical information regarding instrument utility. Ultimately, states need to assure themselves that any measure used to document family outcomes has a high degree of *content validity*. Evidence for content validity is typically based on expert and consumer opinion as to whether the items in an instrument are directly tied to the family outcomes a state wants to achieve.

A core distinction is whether the statements should be in a format that describes the status of families (e.g., "Our family knows how to help our child learn new skills") or alternatively, in a format that attributes family outcome attainment to early intervention or preschool special education (e.g., "As a result of early intervention, our family knows how to help our child learn new skills"). Both formats are legitimate and both have been used in various instruments. The OSEP family indicators for Part C and Preschool/Part B imply the use of the latter kind of format. For example, the Part C indicator asks states to report the "percent of families participating in Part C who report that early intervention services have helped the family...," so states obviously need to gather data in a manner that provides this information.

However, presenting items in an attributional format has several potential limitations. First, an attributional format is inconsistent with the OSEP reporting format for children, which focuses directly on improvement in skills without attributing that improvement to services. We would argue for a more parallel approach where child and family outcome measurements are done in comparable formats. Second, the most important thing to be learned about a family outcome is where the family is with regard to the outcome. Attributional statements are not descriptive of a family's status with respect to an outcome; rather they ask about the family's opinion as to whether early intervention has influenced their status. In the most extreme example, a family could feel that they are still far from where they would like to be with regard to an outcome, but they would nevertheless say that early intervention has provided them some help with the outcome. Having been provided with help and having achieved an outcome are not the same thing. Because attribution questions shift the focus to early intervention, they come closer to being statements related to the receipt of services rather than statements about actual skills, confidence, or resources. The attributional format makes it difficult to show change over time in outcomes, since changes in ratings from Time 1 to Time 2 only reflect changes in the respondent's opinion about the effects of services rather than changes in skills, confidence or resources. Finally, what happens in the case of a family who feels that it has attained a high level of a given family outcome, but does not attribute this attainment to early intervention, either at all or in part? Following a strict interpretation of the item, the family respondents would give a low rating of early intervention service impact, even though they have a high level of outcome attainment.

#### **ECO Center Recommendations:**

- States use measures for which adequate content validity has been demonstrated, both with respect to the indicators required by OSEP and additional outcomes states wish to document.
- States use a set of items that measures family outcomes. To provide the OSEP-required data, states will need to ask a separate set of questions.

#### What will be the format of the closed-ended responses?

Most surveys used by states will consist of a series of statements to which families respond. There are several response formats possible. Probably the most commonly used is a *Likert-type scale*, one that presents a continuum of responses from which the respondent can choose to indicate the extent to which their perceptions correspond to the statement presented. A typical (probably the most common) format is one in which a statement is presented (e.g., "We have a strong network of support from friends, neighbors, or family members"), and the responses are on a continuum of agreement with the statement. For example, a 5-point Likert-type agreement scale might be:

- 1 = Strongly disagree 2 = Disagree 3 = Unsure
- 4 = Agree
- 5 = Strongly Agree

One alternative to the agreement continuum is a continuum of satisfaction. For example, the statement presented could be altered slightly to read "How satisfied are you with your network of support from friends, neighbors, or family members?" with a response continuum ranging from Very Satisfied to Very Dissatisfied. Another alternative has been suggested recently by Harbin and Neal (2004), whose Family Benefits Inventory consists of a series of items rated on a 6-point scale ranging from "Not at All Like My Family" to "Very Much Like My Family." A final variation is a continuum in which the responses are directly tied to the specific content of the outcome statement. For example, the item could read "How strong is your network of support from friends, neighbors, or family members?" with a response continuum ranging from Very Strong to Not Strong at All. Unlike the previous alternatives, however, this approach requires a slightly different set of responses to each item, and thus might limit direct comparability of responses across items.

A different approach to responses is to use a scale with more detailed, anchored descriptors at selected points on a continuum. This format has been used successfully with the Early Childhood Environment Rating Scale–Revised (Harms, Clifford, & Cryer, 2004). This scale addresses 37 aspects of the preschool environment (e.g., the block center). Each item is rated on a scale from 1 (inadequate) to 7 (excellent), with detailed descriptors specific to each environmental dimension provided for ratings of 1, 3, 5, and 7. Intermediate scores (2, 4, 6) are used when some but not all of the descriptors presented apply. The ECO Center has developed a family outcomes survey that uses this format to document family outcomes. The survey is available on the website at www.the-eco-center.org.

Once a response format is selected (e.g., agree-disagree), other decisions to be made include the number of responses possible, and whether descriptors are provided for each. One general rule is to have enough response options to maximize variability in responses and to show change over time. For example, a two-item response format

(e.g., agree or disagree) is simple to use but cannot reflect the range of perceptions experienced by families and would not likely show change over time. Improvement could only be documented at one point in time (the point at which ratings shift from disagree to agree), after which additional positive change could not be documented. Generally, it is recommended that the number of choices presented should be a minimum of 4 and probably a maximum of 7.

Presenting a number of possible responses may be especially important in documenting family outcomes so that any variation that does exist can be captured in the data. Although there is not yet enough research on statewide measurement of family outcomes to draw on, we know from related research that families have traditionally been positive when responding to surveys related to services for young children with disabilities (McNaughton, 1994). Although the lower points on a scale may rarely be used, if there are three upper points, families may distribute themselves across these points. A survey with only one upper or positive point runs the risk of nearly all of the families choosing this response even when there are differences across families.

Should there be an odd or even number of response choices? Presenting an odd number of choices for respondents usually results in a middle number sometimes described as neutral or unsure. Instrument developers sometimes recommend using an even number of choices with Likert-type scales to force respondents to attach a positive or negative valence to each item.

Most scales have words attached to each numerical response. However, some respondents feel that no set of words precisely describes their own unique situation. Furthermore, as the scale length increases, it becomes difficult to come up with a set of words that adequately captures in a quantitative way the distinctions between each rating. One way to solve these problems is to provide a scale with words anchoring some of the choices along the continuum, with the option for respondents to circle an intermediate number if the words used do not capture their perceptions.

Here is an example of how this approach could be used with a 7-point agreement scale:

1 = strongly disagree
3 = disagree
4
5 = agree
6
7 = strongly agree

For any of the response formats, states will need to make decisions about how to analyze their data to produce the required OSEP data and any other data they want for state purposes. If states use scales such as those described above, they need to develop a rule for deciding which families are considered to have achieved the outcomes and which are in the category requested by OSEP (for e.g., those who report they agree or strongly agree are in the category reported to OSEP). Similarly, with a numerical scale, a cut-off score can be used. For example, if the possible responses range from 1 to 7, a state might decide that a rating of 5 or higher would be needed for the family to be considered to have achieved an outcome.

The decision about format becomes complicated when states use scales that have multiple items for each outcome domain. To reduce the data, the state needs a procedure for combining responses across the several items addressing the same outcome. Alternative procedures could be to average the responses, to require that 2 out of three items be a "5" or higher, or some other rule. A clear formula or set of decision rules are needed to combine the data from multiple items into a single conclusion about whether a given family should be considered to have achieved the outcome.

## ECO Center Recommendations:

- Each of the response formats discussed in this section could be appropriate for documenting family outcomes, as long as there are sufficient response choices.
- States develop rules for converting item data to statements about outcome attainment early in the construction of the measurement system. These decision rules should be discussed and shared with stakeholders.
- States use the same surveys and same rules from year to year to allow comparisons across time.

### How long will the instrument be?

A final measurement issue to be decided is the overall length of the instrument. How many questions will the instrument include? The general rule to keep in mind is that the longer the survey, the lower the response rate. From a research and measurement perspective, it is important to have a sufficient number of items to assure adequate coverage of an area. In the case of outcome assessment, this usually means multiple items for each outcome assessed. From a practical perspective, however, a shorter measure maximizes families' willingness to complete and return surveys.

### ECO Center Recommendations:

- States include multiple items to address each outcome area.
- States select or develop instruments that are short. The total amount of time to complete the survey should be no more than 20 minutes, with 10 to 15 minutes being ideal.

# Section II: Implementation Decisions

In addition to making decisions regarding measurement, states also will need to make decisions related to the implementation of the data collection.

#### How will the assessment of family outcomes fit with other needs for information?

Many states have at least one existing mechanism for gathering information from families, such a survey of family satisfaction with early intervention or preschool special education programs. States need to combine questions about outcomes with other information they want to learn from families, such as information about satisfaction with services. From an efficiency perspective, combining family outcome assessment with other data-gathering efforts would seem logical, minimizing costs associated with data collection and limiting the number of things that are asked of families. Also, from a data-analysis perspective, there may be some utility to asking everything at the same time so that any cross-item comparisons (e.g., relationships between service satisfaction and perceived outcomes) are based on perceptions measured at the same time.

However, several potential disadvantages may limit the usefulness of simultaneous data collection. First, combining efforts can result in a packet of materials or a lengthy survey that will be too much to ask of many parents. As noted above, a long survey negatively impacts the response rate. This is especially true for families for whom reading is difficult. Second, the analytic advantages of having an outcome assessment distributed at the same time as a satisfaction with services assessment can be outweighed by possibly having one influence the other. For example, it is possible that some families might see the survey as one big satisfaction with services or because of a desire to make sure that decision makers have a positive impression about the program that has provided services to them and their child.

One way to keep surveys short and to keep satisfaction items distinct from outcome items is to use different surveys with different samples of families. For example, one sample of families could receive a satisfaction survey and a second sample could receive the outcomes survey. In many states and districts, the number of families being served is sufficient to allow this approach. (See the discussion about sampling below.)

#### **ECO Center Recommendation:**

 States conduct outcome assessment separately from the assessment of satisfaction with services, to minimize the response burden on families and create a clear separation of the different purposes of the two assessments. However, this might not be feasible for many states. In such cases, states can minimize the response burden on families by designing the survey in a way that there is a clear distinction between questions about services and questions about outcomes.

# Should states use a sample of families or request information from all program participants?

If it is feasible for a state to sample, contacting a sample of families will be more cost effective than contacting all program participants. States are required by IDEA to produce data for school districts for the federally required Part B information and by

service regions for Part C information, so any sampling strategy needs to produce valid information at these levels as well. Designing an appropriate sampling plan requires specialized expertise and is beyond the scope of this paper. States are advised to consult a sampling statistician.

#### **ECO Center Recommendation:**

• States consult with a sampling statistician to examine the feasibility of sampling and to develop an appropriate sampling plan, when they are interested in sampling for measuring family outcomes.

#### When and how often will data be collected?

The answer to this question depends on how the state plans to use the information. At a minimum, the survey should be administered once near the end of the family's time in early intervention or preschool services. This presents two logistical challenges: (1) not all families indicate they are leaving services, and those who depart suddenly may be experiencing different family outcomes than those who stay through transition; if this is the case, the survey results will be biased and not adequately represent family outcomes; (2) families leave services throughout the year, and surveys would need to be sent out and received continuously, a process that could be labor intensive. A related consideration is whether assessing family outcomes too near the end of time in service might capture some of the stress associated with transition and result in an accurate representation of the family's status at less stressful times.

A more efficient way to send the surveys is to send the surveys to subsets of families at a designated month or months of the year. For example, families who entered services between January and June could receive a survey a year later in May, and families who entered July through December could receive a survey the following November. Such a distribution schedule would still mean some families would be missed, but not nearly as many as would be missed if the survey was not sent out until the child's scheduled transition out of early intervention or preschool.

An even simpler plan would be to survey families every year in a designated month, e.g., April. Some families would still be missed because they would enter and leave between survey administrations. Some families only will have been in services a short time (although the state could establish rules for a minimum time, e.g., surveys are sent only to families who were enrolled by December). From a data management standpoint, an administration at the same time every year is probably the most straightforward way to schedule the data collection.

If a state wants to track changes in family responses over time (an approach that requires linking identification numbers, see discussion below), then it will be interested in collecting data on the family near the time when they begin services, and at designated intervals thereafter. These intervals could be the entire time in service, which would mean the second data collection would be near exit, or the data collection could take place more frequently, for example, annually.

As more information becomes available on how family outcomes change over time, it will be possible to make more informed recommendations as to what states can expect to see when outcomes data are collected at different times or at varying intervals. We know and expect that almost all children will show positive change in outcomes over time but we know little about how family outcomes change over time. It is reasonable to suspect that some outcomes may fluctuate depending on what a family is experiencing at a given point in time.

### **ECO Center Recommendation:**

• States need to consider both what they want to learn from the data and what distribution survey is feasible given available resources.

## Should surveys be anonymous?

States have a choice about placing identification numbers on their family surveys or keeping them anonymous. A survey that is *anonymous* contains no identifying information about the respondent and it cannot be linked by names or identification number to any other information. There is almost never a reason to have names attached to surveys, and we would not recommend it (although there might be a reason for families to submit their names as discussed below about increasing return rates). If a state plans to use an identification number, these numbers can be preprinted on the surveys themselves, added through preprinted labels, or, as a last resort, handwritten on the surveys.

Having an identification number on a survey presents a number of advantages. Identification numbers are necessary if the state plans to administer the survey more than once to the same families and is interested in tracking change over time. If the state already has a data base with unique identifiers, the family survey data can be linked to other information such as family demographic information, child disability information, and even child outcome data. Linking with other data sets will allow the state to answer a variety of important and useful questions such as the following:

- Do outcomes differ for families from different income or racial/ethnic groups?
- Do outcomes differ for families whose children are developmentally delayed compared to those with diagnosed conditions?
- Are family outcomes more positive for families whose children have the best outcomes?

Identification numbers linked to other information also are important for providing information about which families did and did not return the surveys. For example, if fewer minority families returned the survey, and there are differences between responses of minority and majority families, then their data can be presented separately, and these differences can be explored and understood. If the state cannot tell who returned the survey, then any important differences between responders and non responders cannot be identified or examined. If the state does not have the capability to link the family b

outcomes data to any other data and is not planning to link one administration of the survey to another, then the identification numbers are of less value.

If the state is interested in how family outcomes relate to other factors, such as family education or length of time the family has been receiving services, but cannot link to other databases, then questions on these factors must be added to the family survey, which add to the length of the survey. At a minimum, states need to be able to examine family outcome data by the program, local agency, or region. In the absence of datalinking capability, this identifying information can be put on surveys before they are distributed in much the same way identification numbers are put on surveys.

Some states might be concerned that the use of an identification number will deter families from responding. In our focus group work with families as part of the development of the ECO Family Outcomes Survey, families reported that they were not bothered by the surveys being identifiable as long as they were returned to the state agency and not to their local program. The concepts of *anonymous* and *confidential* are sometimes confused. Even if a survey is not anonymous, completed surveys always should be treated as confidential, meaning that a limited number of people will have access to the *individual* or identifiable survey results. Local programs should be provided the aggregated data for their families but should not have access to individual data if the surveys are returned to a state agency.

#### **ECO Center Recommendation:**

• States need to consider whether there is a need to link survey data with other databases or surveys in deciding whether to place unique identifiers on family outcomes surveys.

#### How should surveys be distributed to families?

Surveys generally are distributed to families in envelopes containing a cover letter, the survey itself, and, if the survey is to be returned by mail, a stamped and addressed envelope. The cover letter should use straightforward language to provide information about the survey process, such as why information is being collected, how to return the survey, and when to return the survey. The cover letter also should explain who will see the family's responses and how the information will be used. If a state uses identification numbers on the survey, the cover letter should explain in simple terms why the identification number is there.

Survey packets can be handed to families by someone from the program or sent in the mail, either from the state agency or from the local program. If the state does not have a current file of the names and addresses of families participating in the program, then the surveys must be distributed by the local agency or program.

If the state has the capability to mail the survey, this relieves local programs of the responsibility and burden. When the survey comes from the state agency, families might be less likely to feel the need to respond positively to make sure their programs know

they appreciate the services. Alternatively, families might feel that because the survey comes from the state, they need to make sure the state knows how much they appreciate their local program. Generally, survey responses are increased by techniques that make the survey as personal or as close to the recipient as possible, which argue for having the survey come from the local program, an entity much closer to the family than the state agency. Another technique for making the survey more personal is to include a cover letter from the local program even if the survey is being mailed by the state.

If a local program distributes the survey, should they mail it or hand deliver it to the family? Using the same logic just explained, handing a survey to a family is much more personalized than mailing it. The families in our focus groups indicated they thought surveys should be handed to them because a survey that came in the mail could easily go unnoticed or be thrown away without being opened.

To relieve burden on local programs, states with access to the data could prepare the packets of surveys for local programs and then distribute them to local programs, where the local providers, teachers, and service coordinators would hand them to the families they work with.

A related issue is making sure the family gets a survey in an appropriate language. Some states have this information in their databases already and can prepare survey packets accordingly (and states that do not have language information now can add it for future data collections). If the information is not readily available at the state level, the responsibility falls to the local program either to communicate to the state which families need a survey in a language other than English or to prepare the survey packets for non-English speaking families themselves. This process, of course, assumes that the state has the survey available in the main languages that are spoken by families in the state.

If there is a need to give non-English versions of the survey to some families, provisions must be made to insure that the identification number appears on this version. For example, if the local program substitutes a Spanish version of the survey for some families based on their knowledge of home language and the identification numbers were placed on an English version of the survey by the state agency, the program staff needs to make sure the identifications numbers are correctly transferred to the Spanish survey. Some programs with large numbers of speakers of a non-English language may find it more feasible to send all families the survey in two languages.

#### **ECO Center Recommendation:**

• States distribute the surveys to families by having a local provider hand the survey to the family. If this is not feasible, mailing the survey from the state agency with a cover letter from the local program personalizes the survey while minimizing responsibilities of the local program.

#### How do families return the survey?

Possible options include handing the survey to a provider who works with the family, mailing the survey to the local program, or mailing it to the state. Mailing the survey to the state is the preferred option because it relieves local programs of the burden of handling and housing the returned surveys, which, in most states, will ultimately be going to the state for analysis anyway. Also, our focus group work suggested families would be comfortable with the survey information being identifiable as long as it was not returned to their program.

### **ECO Center Recommendation:**

• Families should mail the survey back to the state agency.

#### What can be done to maximize the return rate?

Return rate refers to the percentage of families who return the survey. If 1000 surveys are sent out and 200 are returned, the response rate is 20% (200/1000). Ideally, surveys should have return rates in the 70% and above range, although response rates as low as 20% are not uncommon. The problem with a low response rate is not just the number of surveys returned; it also involves who returned them. With low response rates, it is highly likely that those who returned the surveys are not a good cross-section of all the families who were sent the surveys. This means the findings do not apply to all of the families being served. For example, if highly educated families were more likely to return the survey, the findings will reflect outcomes for these families. It takes extra effort to get good return rates on surveys, but the payoff is worth it because the findings will apply to the full range of families being served.

There are a number of strategies that can be used to increase return rate. In general, the more effort the state is willing to put into getting a good return rate, the higher it will be. The strategies listed below can be used alone or in combination:

- Actively promote the importance of the survey and survey return with families. Service providers should talk about the survey to families before families receive it so families know the survey is coming. If the survey is to be mailed from the state, the provider can make sure the survey arrived and repeatedly stress the importance of returning it. The providers represent the most personal and therefore most powerful voice for encouraging families to complete the survey, but even flyers left or sent to the family and posters at the program (for programs where families come to the program) can help alert families that the survey is coming, and that completing it is important.
- 2. Make sure the families notice the survey. The state can used brightly colored envelopes or paper to make sure the survey stands out and is easily recognizable. As noted above, our focus groups told us that a provider handing the survey to a family would be a better way for the family to notice the survey than having it come in the mail.

- 3. Remind families to complete the survey. Surveys sent in the mail can be followed by a postcard a week later to make sure families have received the survey and to encourage them to complete it. This can be followed by a second postcard a week or two later with a similar reminder. An alternative to the postcard is to resend the survey two weeks later to make it even easier for families to return it. Providers working with the family also should provide reminders.
- 4. Build in incentives for the family to return the survey. Most states cannot afford to include a cash incentive in the survey, but this is an effective strategy for increasing return rates. Including a dollar bill with the survey helps the survey to get noticed and does encourage returning it. Another type of incentive is to provide an opportunity for a family to be chosen for a gift of higher value (e.g., a \$100 gift certificate) if it returns the survey. This can be done by including a card with space for the family's name, address, and phone number that gets returned with the survey. The cost to the state or program is minimal with this kind of incentive.
- 5. Build a system that allows tracking of return rates while the surveys are being collected. If programs can be given feedback about their own (and possibly other programs' return rates) as the surveys are being collected, it serves as an incentive to encourage programs to try a little harder to get more surveys in during the survey collection process. No program wants to have a 25% return rate when other programs have 80%.
- 6. Implement a system of supports for families who have difficulty completing the survey. Every family's survey is important. Families who have difficulty completing the survey can have the survey questions read to them. Programs can assemble a list of parent volunteers willing to serve as readers to other parents or work with a local parent organization to identify readers. Similarly, parents or others can serve as translators for those parents who speak a language other than the language of the survey. The person reading a survey to a parent or doing a translation should never be a provider or other employee associated with the program, because the parent may feel obligated to be overly positive in his or her answers.

### **ECO Center Recommendation:**

• States need to implement a variety of strategies to maximize return rate.

# Section III: Instrument Options

There are several options for states to use in documenting family outcomes. One option is to use existing measures that relate to individual outcome areas. For example, if a state wants to assess the extent to which families have supports (outcome 4), there are a number of scales that have been developed and validated to specifically assess family support and resources, and these existing measures can be used to assess each of the

outcome domains. This approach has the advantage of using instruments that have been specifically developed to assess the constructs of interest. Each instrument usually contains a number of items and so can thoroughly document various aspects of outcome attainment. However, there are two possible disadvantages. First, the length of the scales may be daunting for families, especially if multiple scales are used (e.g., one scale per family outcome), and the total response burden may mean that some families will choose not to complete the measures. Second, the existing scales represent a range of ways of summarizing responses, none of which are directly related to what states are required to report to OSEP. Thus, states need to develop ways of converting summary or subscale scores to outcome statements or to add additional items to address the OSEP indicators.

A second approach is for states to develop their own instruments. This approach has the advantage of allowing states to tailor the assessments to meet their own needs in addition to meeting national reporting demands. An additional benefit occurs when states involve stakeholders in the instrument development process itself, because doing so increases the likelihood that the instrument reflects the issues that stakeholders in that state consider to be important and maximizes "buy-in", and, hopefully, participation rates. However, instrument development, especially when done well, can take a considerable amount of time, and adequate research needs to be done to assure that the scale does what it is intended to do. As noted earlier in the document, we do not recommend that states develop their own instruments.

A third approach is for states to use already developed measures that have been aligned with the set of outcomes that states want to examine, that have the capability to provide the required OSEP information, and that have already been well researched. Few such measures currently exist, in part because the OSEP reporting requirements were just released in July 2005. Information about surveys that states might be interested in using can be found at www.the-eco-center.org.

#### Conclusion

The discussion about design, implementation, and instrument options leads to one conclusion: obtaining meaningful data on family outcomes requires that a state carefully weigh its options to make decisions that best reflect its priorities and available resources. An extremely important implementation activity is building the infrastructure to support data collection. Infrastructure refers to the staff, the resources, and the procedures to effectively implement a statewide data collection on a regular basis. Collection of the data is only part of the effort. Decisions also will need to be made about how to analyze the data and what kinds of reports to produce for what audiences. The benefit to the state of a well-designed and implemented system for measuring family outcomes will be the acquisition of valuable information for program improvement. The reward to children and families when the information is used effectively will be better programs, better services, and ultimately, better outcomes.

#### References

- Bailey, D., & Bruder, M.B. (2005). *Family outcomes of early intervention and early childhood special education: Issues and considerations.* Menlo Park, CA: Early Childhood Outcomes Center. Available at http://www.fpg.unc.edu/~eco/pdfs/Family Outcomes Issues 01-17-05.pdf
- Early Childhood Outcomes Center. (2005). *Family and child outcomes for early intervention and early childhood special education.* Menlo Park, CA: Author. Available at http://www.fpg.unc.edu/~eco/pdfs/eco-outcomes-4-13-05.pdf
- Harbin, G., Rous, B., & Mclean, M. (2005). Issues in designing state accountability systems. *Journal of Early Intervention, 27*, 137-164.
- Harbin, G., & Neal, P. (2004). *Family benefits inventory*. Unpublished instrument, University of North Carolina at Chapel Hill, FPG Child Development Institute.
- Harms, T., Clifford, R. M., & Cryer, D. (2004). *Early childhood environment rating scale.* New York: Teachers College Press.
- Hebbeler, K. (2005). Aligning outcomes across multiple systems, attribution, and the Fea factor. *Journal of Early Intervention,* 27, 165-166.
- Lesko, J. (2005). Where the rubber meets the road: Reaction to Harbin, Rous, and McLean, *Journal of Early Intervention*, 27, 170-172.
- McNaughton, D. (1994). Measuring parent satisfaction with early intervention programs. Current practices, problems, and future perspectives. *Topics in Early Childhood Special Education, 14*, 26-28.
- Roberts, R. (2005). Delivering on the promise of early intervention: Accountability as the keystone. *Journal of Early Intervention*, *27*, 167-169.