

WHAT COUNTS: MEASURING THE BENEFITS OF EARLY INTERVENTION

Frequently Asked Questions

Concerning the Child Goal Summary Reporting **Protocols**

1. *What children should we rate?*

All children at least 4 months old, with current IFSPs, except children who enroll at the age of 31 months or older.

2. *How long should a child be in an EI program before s/he is rated?*

Initial rating is created at the first IFSP meeting at which child is at least 4 months old

3. *How do we handle children served by more than one EI program?*

The care coordinator facilitates the rating process and submits data. All IFSP team members participate in the rating discussion.

4. *For children born prematurely, do we compare to a typical child of the same chronological age, or of the same corrected age?*

- If you are rating a child less than two years old, compare to a typical child the same corrected age.
- If you are rating a child two years old or older, compare to a typical child the same chronological age.

5. *If we know a child is exiting the program before age 3, should we complete another What Counts measurement at the exit meeting? Does this depend on how recently the child was rated?*

Complete a What Counts rating at the last meeting with the family, no matter when the most recent rating was done. Try to get information from all members of the IFSP team to support the exit rating.

Concerning the Three **Child Goals**

1. *What does it mean to understand the physical and social worlds?*

Understanding the physical world includes things like knowing about gravity (not the word but anticipating that things will fall or roll downhill but not uphill), rain as a natural phenomenon that your mom can't turn off and that won't hurt you but will get you wet; light switch controls lights; etc. Understanding the social world includes knowing that some people (family, "aunties") have a special relationship to you; empathy - comforting baby brother when he's crying; asking for attention in "acceptable" ways likely to produce positive attention; being "cute" on purpose for other people, etc.

2. *What does it mean to understand symbols?*

Knowing about symbols might be like knowing a STOP sign means stop; using the correct button on the remote control to start a video; knowing that when someone picks up their keys it means going out; that the door bell ring means someone is outside the door; etc. By three, many children have the essential preliterate understanding that printed words can be read and make sense; recognize their written name; quite a few can read several words - of course letters and words are symbols.

Concerning the Child Goal Summary Reporting **Tool**

1. *How do we know a child's true potential, what s/he could be expected to achieve?*

Each goal rating compares a child to a typically developing child, not to the child's individual potential; the child's initial rating will be used to look at progress achieved during participation in the program.

2. *Can the form be modified?*

The form has been modified based on input from pilot and initial implementation programs. We are still interested in improving the form in the future: email comments to beppie@hawaii.edu, or call Beppie at 973-9644.

3. *Could there be different forms for different children — for children with developmental delays of various severity or children at risk, for example?*

We are not doing this for three reasons: 1) It would be hard to decide how many different forms to produce; 2) The process would be more complex; 3) The data on different forms might not mean the same “thing” for all children – this is critical if summaries across children are to be meaningful.

4. *The tool and process seem very subjective, so data may not be valid, reliable, or meaningful.*

There is no existing “objective” assessment based on the three functional Child Goals. In the future one or many will probably be created. For the time being we hope that a Team's thorough discussion of the child's skills and behaviors across a variety of settings and situations, and of child development expectations, will result in a relatively valid and reliable rating. We are working on quality assurance (QA) processes to identify needs for support in the future.

5. *The box for describing progress (next to the “a” question) isn't big enough to include all the child has learned to do since the last rating.*

There is no requirement to enter a lot of examples of progress for the “a” question. This description will not be entered into the database for summarization. The box allows the IFSP team to acknowledge progress the child is making, especially if the child is not “catching up” to typical functioning or is very atypical (e.g. in the “Emerging” or “Not

Yet” categories in the “b” question). Detailed information on child progress should probably be written into the PLOD section; if the information on child progress is in the PLOD, just write “see PLOD” in the box next to the “a” question on the Child Goals Summary Form.

Concerning the **Team Process**

1. *What should providers do if there is disagreement among team members as to what rating category to assign to a child on one of the Goals?*

In order to minimize disagreements, we suggest Teams start by talking about the Functional Goal and the various ways, settings, and situations in which the child demonstrates skills and behaviors related to the Goal. The Team should refer back to the PLOD and maybe add new information to the PLOD to describe the child’s progress toward each Goal. At the same time, it is recommended that Team members who are more familiar with child development provide examples of skills or behaviors typical of a child the same age and those typical of a younger child. We also suggest providers ask parents whether they know other children the same age as their child and what they see those children doing in the Goal area.

After this discussion, the person who is facilitating the meeting should summarize what has been said and suggest a rating, reading the description of the rating. If there is agreement, the facilitator can just check the category related to the description. If team members disagree only between adjacent categories, the team can choose any method they like to pick which one to check: for instance, “majority rules” or “let the parent choose”, or the Team may agree to average the ratings.

If, however, one person feels a very different rating is appropriate, the facilitator should ask that person to describe the child’s behaviors or skills and in what settings they are seen, which led them to choose that rating.

Write what the person says on the PLOD – that will show the group is really listening. The facilitator should then ask other members of the team why they chose the ratings they felt were appropriate, when they have seen the behaviors/skills in what settings, and what they know about typical behaviors/skills for a child this age, and younger children, in this Goal area. Write this evidence in the PLOD, too. Then, look at all the evidence together. Through this discussion the Team may come to a closer agreement. If the disagreement is only between two adjacent categories, the Team may agree to average the ratings or choose one or the other.

If the Team cannot reach agreement within a reasonable amount of time, the Care Coordinator can record the discussion in notes and not choose a rating at the meeting. In this case, the Care Coordinator needs to discuss the situation with his or her supervisor. The supervisor can decide to not record a rating at this IFSP. The supervisor and/or Care Coordinator can ask for support and technical assistance to discuss other ways the IFSP meeting and What Counts discussion might have been more successful. These requests should be emailed to kathy.kubo@fhsd.health.state.hi.us and she will forward the request to the appropriate person if she cannot answer it herself.

6. *Some children will never show typical behavior/skills. Due to their disability, disease or condition, their behavior will remain far below typical or even regress. How can the Team approach the What Counts rating without upsetting the parent?*
 - If the Team has just finished reviewing the assessment results and writing the PLOD, the parent may already be dealing with this issue so it won't be overwhelming.
 - However, if the facilitator feels the rating process would be upsetting for the parent, s/he can explain to the parent that this kind of rating needs to be done for every child in EI to satisfy a federal requirement from OSEP. The facilitator can ask the parent if s/he wants to participate in the rating, or just let the provider do it from the discussion of assessment and PLOD. Parents can decide not to participate.

Concerning **Relationship** of Benefits/Goals Measurement to **Other Assessments**

1. *How is What Counts different from existing quality improvement initiatives, e.g. Internal Monitoring, Johns Hopkins project for Healthy Start, Legislative report on EI...*
 - Every child in EI will be measured at regular intervals – no sampling
 - Focus is on the three functional Child Goals, which are related to but not the same as standards used in other initiatives
 - Focus is only on progress on three Child Goals, not on process (how program interacts with child/family)
2. *How is What Counts different from data we are already collecting and reporting for OSEP?*

What Counts data focuses on what child has actually achieved during program participation; other OSEP data involves only process data (how program interacts with child/family, keeps records, etc.)

3. *How is What Counts rating different from assessment on HELP, EIDP, or ASQ?*
 - The purpose differs: *What Counts* ratings support program improvement and funding; HELP and other assessments support understanding of child's status and design of services to enhance development.
 - *What Counts* ratings compare child's behavior and skills in **the three functional Goal areas** across multiple situations and settings, to a typical child; HELP and other assessments compare a small sample of the child's behavior and skills in each of the **five domains** to typical development.
4. *For a child exiting EI and moving into 619 preschool, can the final rating on the Summary Tool be used as the intake measurement for 619?*

The DOE 619 program is using a very different process and timing, so they are currently not going to accept the *What Counts* rating as the initial 619 rating.

Concerning **Relationship** to **IFSP**

1. *Will every child be required to have an objective related to one or more Goals?*

No. IFSP Outcomes and objectives should still reflect the IFSP team members' sense of what is most important for the family and child, and what the next steps are in addressing those important areas. However, IFSP teams **may** want to consider the three Goal areas while discussing what functional areas are important.

2. *At what point in IFSP meeting will the rating occur?*

Pilot programs found it was easiest to do it right after completing the Present Levels of Development (PLOD) section of the IFSP. That is what we are recommending, but any IFSP team can choose to do it another way that seems to work better for that Team.

Concerning **Staff Overload**

1. *Can we use existing forms and data?*

Unfortunately, no. No current data directly addresses the three functional Goal areas and compares the child to a typically developing child in those areas. OSEP requires us to report data on child progress in the three Goal areas. Also, we have wanted a measure of how children and families benefit from early intervention for a long time, but never had one.

Concerning **Interpretation** of the **Goals data**

1. *Will state/OSEP be looking at length of time child is served to explain benefit or lack of benefit? How will the measurement system include how much the child/family actually participated in services?*

OSEP has not requested any data on length of enrollment or participation in services. Presumably they believe that when averaged over all the children in the state, these differences will disappear – this may or may not be accurate. For Hawai'i, we are collecting the date of each measurement. The range from first to last date of measurement will approximate the duration of enrollment.

2. *How is this data on child and family related to Program Evaluation?*

Since EI programs are designed to benefit children and families, we can only evaluate how successful programs are by looking at the extent to which children and families benefited. At the moment, we (nationally, as well as in Hawai'i), do not know what to expect in terms of child progress during participation in EI. As data accumulates however we expect to identify service models/intensities which are more effective than others; we may be able to tailor certain service models/intensities to children with certain developmental or environmental profiles.

3. *Children who enter EI because of risk criteria look typical at entry. Their ratings can only go down, which will look like regression. Will state/OSEP understand this context?*

There is already discussion at the national level about how to communicate this important observation to OSEP and other federal agencies looking at the data. In Hawai`i, we hope to borrow language developed nationally for state and local communication about the summarized Goals data.

4. *If State/OSEP see poor child outcomes, will they then take away dollars from programs when the problem may be bigger than a program can effect (e.g. a systems problem, a societal problem, etc.)?*

We can't predict how the state/OSEP will use the Goals data, but we are discussing how to report the data to help policy makers understand the complexity which underlies benefits achieved. Comparisons among types of programs and states could be made. It is possible the data will help funders understand and address systemic /societal problems. On the other hand, if a program finds that children do not seem to be making progress on the three Goals during their participation in the program, staff at that program will probably want to find out more about what may be getting in the way of progress.

5. *Will state/OSEP understand the kinds of intense, complex needs families have?*

Many state and federal officials clearly understand this; others will need to be educated. Eventually some qualitative descriptions may be helpful to enhance understanding of the data.

6. *Will state/OSEP understand program realities like inability to recruit staff, turnover, multiple demands, etc.?*

Understanding variations in caseloads, staffing, turnover, etc. will be important to interpreting variations in data. This is where the design of reports from agencies and DOH to state and OSEP will be critical. These reports have not been discussed yet. Data from Child Count, OSEP compliance, internal monitoring etc. will be very useful.

Concerning **Data Submission**

1. *Where will rating data go?*

Each "Agency" (Healthy Start, PHNB, Infant/Toddler Development Programs under EIS) is modifying an existing data system so information from the Child Goals Summary Form can be entered into the enhanced data system. Data will be entered at the local program, and transmitted electronically to the Agency. Agencies will summarize data and send summaries to EIS. At EIS, all data will be combined into a report to OSEP. The individual Agencies and EIS will analyze the data and report appropriate summaries to individual programs, and to Agencies. These reports have not been discussed yet. Of course, if and when we finally get an EI tracking system, it will include What Counts data with less effort!

Concerning **Implementation in Hawai`i**

1. What are the timelines?

Pilot: January 1 – February 28, 2006

(Leeward PHNs; Waianae Healthy Start; and Kailua Easter Seals)

Initial implementation: April 1 – September 30, 2006

(All EI programs in Ko`olauloa, East Honolulu, and West Hawai`i are participating)

Roll-out to full implementation:

Starting June 1, 2006, What Counts training will be provided communities around the state. As each program is trained, it will start implementing the measurement process and reporting data. We are currently finalizing the training schedule. By October 1, 2006, all EI programs will be using the What Counts rating process.