

Uses and Misuses of Data on Outcomes for Young Children with Disabilities

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



U.S. Office of Special Education Programs

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

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The word “outcomes” generates numerous reactions—not all of them positive. It also can generate considerable confusion because “outcomes” can take on different meanings depending on the context. The occupational therapist who talks about outcomes for the 3-year-old with whom she is working almost certainly has a different concept of how to use outcome information than does the federal Office of Management and Budget (OMB). The ECO Center has prepared this paper to make explicit some of the diverse ways in which data on outcomes can be used effectively as well as misused. The paper provides background information for stakeholders who are involved in developing outcome measurement systems for young children with disabilities. We hope that the information will assist these stakeholders in:

- Identifying the purposes that an outcomes measurement system can address.
- Understanding distinctions among the many different purposes.
- Understanding what will be gained by having outcome data for a particular purpose or lost by not having those data.
- Alerting them to the possible misuses of outcome data.

From the highest levels of public administration, through service provision, to individual children and families, recognition is increasing of the importance of looking at the outcomes children are attaining. Although the early childhood community remained wary of the outcomes movement for some time, professionals in this field now acknowledge the need to look at appropriate outcomes for young children with disabilities. Not so long ago, some maintained that we should not look at outcomes for these children. Reasons cited included that, because this population is so diverse and goals so individualized, a general outcome framework could not apply; and that Part C is a program to support families in caring for their child with a disability, not one about child outcomes. For some, measuring outcomes is closely linked to assessment, and note that the valid assessment of young children can be challenging. Some worry that the job is too difficult. Moreover, in some instances outcome data have been misused, most notably when assessment results have been used to children’s detriment rather than to their benefit. Although some may still believe that data on child outcomes cannot or should not be collected for children with disabilities, from our work with the ECO Center we conclude that ever-increasing numbers of policy-makers, administrators, service providers, and families are recognizing the importance of good outcome data for this population.

The ECO Center’s mission is to provide leadership and support that will ultimately produce national outcome data on young children with disabilities up to age 5. Not surprisingly, we thoroughly endorse the development and use of outcome measurement systems to improve programs for young children with disabilities. We also recognize the rational trepidation with which many approach the idea of collecting outcome data on young children. Our hope is that by working closely with stakeholder groups as they move forward in developing outcome measurement systems, the resulting systems will achieve their intended purposes in a credible and valid way.

We prepared this paper to serve as an overview of how outcome data can be used at different levels. We identify different purposes for outcome data collection at the following levels:

- Federal/national
- State
- Local (communities, school districts)
- Program/school
- Child/family.

Even within the same level, outcome data can address different purposes. A state agency, for example, could use outcome data to demonstrate for the state legislature that programs for young children with disabilities are effective, or it could use data to identify regions within the state where more support is needed to improve programs. Accordingly, designers of an outcome measurement system need to be clear about the system's purpose(s) because that purpose has implications for data collection. The kind of data that a speech therapist needs to monitor the acquisition of communication skills differ from the data a state agency needs for monitoring to determine whether or not local programs are effectively supporting children's communication development. Some purposes can be addressed with sampling; others cannot. Some purposes require a relatively detailed level of information; others can be addressed with more general outcome data. One implication of so many potential uses for outcome data is that one set of outcome measures is unlikely to be able to address all of the various levels and purposes. The implications of each of the different purposes for the development of outcome measurement systems will be addressed in forthcoming documents issued by the ECO Center.

Table 1 presents possible purposes for uses of outcome data, organized by the level of the user. For each purpose, we list the level of the data (e.g., aggregated across states) and the potential users (e.g., program directors). For each purpose, the table also addresses hypothetical situations related to outcome data: what could happen if the data show good outcomes, what could happen if the data show poor outcomes, and what could happen if the data are not collected, as well as possible misuses of the data. Although support is widespread for the collection of outcome data, the history of good outcome data in any field is so limited that it is difficult to anticipate what will happen once valid data are available. Nevertheless, we believe it is important to anticipate and reflect on some of the likely scenarios as part of the planning process. We hope that by identifying possible misuses of outcome data we can advance the discussions to help stakeholders distinguish between good and bad uses of the data. That outcome data can be misused is not a reason to avoid generating these data, but it is a reason to build safeguards into the systems. We hope that by identifying potential misuses before systems are developed, those misuses can be avoided or minimized.

Realistically, we have no guarantees that outcome data will be used appropriately. Those who fear misuse of the data are thus advised to remain vigilant. A thorough reading of Table 1 at every level suggests to us, however, that at all levels, the potential benefits of having good outcome data outweigh the alternative of not having the data. It is possible that all services currently being provided to young children with disabilities and their families are maximally effective and that all children are achieving the best

possible outcomes. It is possible that public dollars will continue to be spent on programs for which no evidence exists that they are producing their intended benefits. Although possible, these scenarios are not likely, and therefore the development of good systems for producing outcome data is a necessity. Even though different levels have different purposes, all of them are ultimately serving the same goal: ensuring that every one of more than 900,000 young children with disabilities who are receiving services annually through the Individuals with Disabilities Education Act (IDEA) achieves good outcomes.

We hope that you find much food for thought in the table; at the same time we acknowledge that many additional uses, misuses, and other scenarios are also possible. We welcome your comments, and we look forward to revising the paper on the basis of the input we receive. Please send comments to staff@the-eco-center.org.

Table 1
Possible Uses and Misuses of Child Outcome Data at Different Levels

Level: National/Federal

Level of Data	Used by	What happens if . . .			Misuses of the data
		Data show good outcomes	Data show poor outcomes	Data are not collected	
Purpose: To demonstrate the effectiveness of Part C and Section 619; used to meet the GPRA and PART requirements and other needs for outcome data					
Aggregated across all states and territories	OSEP OMB Congress Advocates	<ul style="list-style-type: none"> Funding for program is sustained or increased. 	<ul style="list-style-type: none"> Resources are directed toward improving outcomes. Technical assistance (TA) and guidance increase; IDEA or regulations change. Funding for programs is eliminated or reduced. 	<ul style="list-style-type: none"> Funding for programs is reduced or eliminated. 	<ul style="list-style-type: none"> Making decisions before the data are shown to be valid and reliable Focusing on a narrow set of outcomes or only those outcomes for which data are available Using the data to hold OSEP and states accountable for more than they can reasonably be expected to deal with Misinterpreting the data (e.g., expecting all children with disabilities to function like typically developing children)
Purpose: To examine the effectiveness of OSEP in administering Part C and Section 619; used in combination with information from other sources to determine whether or not OSEP is effectively administering Parts C and Section 619 (e.g., OSEP reviews its own policies and practices)					
Aggregated across all states and territories	OSEP Advocates	<ul style="list-style-type: none"> OSEP is given additional resources. OSEP develops new programs. OSEP is given additional autonomy or responsibility. 	<ul style="list-style-type: none"> OSEP adapts existing strategies or adopts new strategies for how it supports states in implementing Part C and 619 (e.g., new funding priorities, changes in provision of TA, personnel preparation). 	<ul style="list-style-type: none"> Decisions about future investments and strategies are made without knowing whether and where strategies are contributing to good outcomes for children. Effective programs and policies go unrecognized. Ineffective programs and policies continue. 	<ul style="list-style-type: none"> Making decisions before the data are shown to be valid and reliable Making decisions about outcome data alone, in isolation from other information Focusing on a narrow set of outcomes or only those outcomes for which data are available Failing to explore why poor outcomes are occurring

Level: National/Federal Uses (Continued)

Level of Data	Used by	What happens if . . .			Misuses of the data
		Data show good outcomes	Data show poor outcomes	Data not collected	
Purpose: To monitor how states are implementing Part C and Section 619					
Data for each state and territory	OSEP Advocates	<ul style="list-style-type: none"> States with effective programs can be nationally recognized. Proven practices in effective states can be documented and disseminated. Effective states can serve as models for other states Ultimately, outcomes for children with disabilities in all states can improve. 	<ul style="list-style-type: none"> Low-performing states receive focused intervention, develop corrective action plans, or receive sanctions. State improvement strategies are developed and implemented to produce better outcomes. Advocates push for improvements. 	<ul style="list-style-type: none"> OSEP continues to monitor process, rather than results. States achieving good outcomes remain unidentified, as do states achieving poor outcomes. Programs in ineffective states do not improve 	<ul style="list-style-type: none"> Making decisions before the data are shown to be valid or reliable Making decisions on the basis of outcome data alone, in isolation from other information Focusing on a narrow set of outcomes or only those outcomes for which data are available Holding states accountable for more than they can reasonably be expected to deal with Failing to explore why poor outcomes are occurring
Purpose: To monitor the health and well-being of young children with disabilities nationally by determining how young children with disabilities are faring in regard to multiple indicators of health and well-being (probably as compared with typically developing children)					
Aggregated across all states and territories or by state	Advocates All federal agencies concerned with young children with disabilities, including OSEP Interagency groups	<ul style="list-style-type: none"> Funding for current programs is sustained or increased. Changes in future years can be tracked to ensure that good outcomes are maintained year after year. 	<ul style="list-style-type: none"> Advocates and federal agencies explore underlying causes for poor outcomes (e.g., poverty, child abuse, lack of insurance). Funding increases to improve the health and well-being of young children with disabilities. New legislation, new programs, and better coordination across federal and state programs are implemented. 	<ul style="list-style-type: none"> No one knows that children with disabilities are faring poorly. Ineffective policies and programs continue. Policies continue to be set in the absence of information. 	<ul style="list-style-type: none"> Failing to recognize the multiple underlying causes for poor outcomes (e.g., trying to hold one program or funding stream accountable) Failing to act on the information

Level: State

Level of Data	Used by	What happens if . . .			Misuses of the data
		Data show good outcomes	Data show poor outcomes	Data not collected	
Purpose: To demonstrate the degree of effectiveness of Part C and Section 619 in response to requests/demands for data from legislatures, governors' offices, and state budget offices					
Aggregated across all localities in the state	Part C lead agency SEA Advocates	<ul style="list-style-type: none"> State funding is sustained or increased. 	<ul style="list-style-type: none"> The state designs strategies to improve the effectiveness of programs. Program funding is eliminated or reduced. The state withdraws from Part C. 	<ul style="list-style-type: none"> State funding for programs is eliminated or reduced. The state withdraws from Part C. 	<ul style="list-style-type: none"> Making decisions before data are shown to be valid or reliable Focusing on a narrow set of outcomes or only on those outcomes for which data are available Holding the program responsible for more than it can reasonably be expected to deal with Misinterpreting the data (e.g., expecting all children with disabilities to function like typically developing children)
Purpose: To examine state agency effectiveness in administering Parts C or 619; used in combination with information from other sources to determine if the agency is effectively administering Part C or 619 (e.g., the agency reviews its own policies and practices)					
Aggregated across all localities in state	Part C lead agency ICC SEA Advocates	<ul style="list-style-type: none"> The state agency receives recognition for good work. Funding to the agency is sustained or increased. The agency is given more authority or autonomy. 	<ul style="list-style-type: none"> The state agency adapts existing strategies or adopts new strategies for how it supports local entities in implementing Part C and 619 (e.g., new funding priorities, changes in provision of TA, CSPD). 	<ul style="list-style-type: none"> Decisions about future strategies are made without knowing whether current state strategies and investments are effective. Effective practices and policies go unrecognized. Ineffective programs and policies continue. 	<ul style="list-style-type: none"> Making decisions before the data are shown to be valid and reliable Focusing on a narrow set of outcomes or only on those outcomes for which data are available Making decisions on the basis of outcome data alone, in isolation from other information Failing to explore why poor outcomes are occurring

Level: State (Continued)

Level of Data	Used by	What happens if . . .			Misuses of the data
		Data show good outcomes	Data show poor outcomes	Data not collected	
Purpose: To monitor how local entities are implementing Part C or 619					
Data for each locality	Part C agency SEA advocates	<ul style="list-style-type: none"> • Funding to local entities with good outcomes is sustained or increased. • Local programs are recognized as model systems. • Effective practices are documented and disseminated. 	<ul style="list-style-type: none"> • The state develops general strategies to produce better outcomes. • The state takes action to improve programs in localities that show poor outcomes. • Advocates push for changes. 	<ul style="list-style-type: none"> • The state continues to monitor process rather than results. • Communities achieving good outcomes remain unidentified, as do communities achieving poor outcomes. • Programs in ineffective communities do not improve. 	<ul style="list-style-type: none"> • Making decisions before the data are shown to be valid or reliable • Making decisions on the basis of outcome data alone, in isolation from other information • Focusing on a narrow set of outcomes or only those outcomes for which data are available • Holding local agencies accountable for more than they can reasonably be expected to deal with • Failing to explore why poor outcomes are occurring
Purpose: To monitor the health and well-being of young children with disabilities in the state by determining how these children are faring in regard to multiple indicators of health and well-being (probably as compared with typically developing children)					
Aggregated across local jurisdictions or by locality	Advocates All state agencies concerned with young children with disabilities	<ul style="list-style-type: none"> • Funding for current programs is sustained or increased. • Changes in future years can be tracked to ensure that good outcomes are maintained year after year. 	<ul style="list-style-type: none"> • Advocates and state agencies explore underlying causes for poor outcomes (e.g., poverty, child abuse, lack of insurance). • New legislation, new programs, better coordination, and more funding to improve the health and well-being of young children with disabilities result. 	<ul style="list-style-type: none"> • No one knows that children with disabilities are faring poorly. • Ineffective policies and programs continue. • Policies continue to be set in the absence of information. 	<ul style="list-style-type: none"> • Failing to recognize the multiple underlying causes for poor outcomes (e.g., trying to hold one program or funding stream accountable) • Failing to act on the information

Level: Local (Communities, LEAs, etc.)

Level of Data	Used by	What happens if . . .			Misuses of the data
		Data show good outcomes	Data show poor outcomes	Data not collected	
Purpose: To examine the effectiveness of the local agency in administering early intervention or preschool special education; used in combination with information from other sources to determine if the agency is effectively administering early intervention and preschool special education services (i.e., the local agency reviews its own policies and practices)					
Aggregated across all programs/schools	Local administrators LICC Advocates Families	<ul style="list-style-type: none"> The local agency receives recognition for good work. The local agency knows to continue current policies and practices. 	<ul style="list-style-type: none"> The local agency adapts existing strategies or adopts new strategies for supporting programs in providing Part C and 619 (e.g., in-service training, new program options, coordination with other programs or agencies). 	<ul style="list-style-type: none"> Decisions about future directions are made without knowing whether and where programs are effective. 	<ul style="list-style-type: none"> Making decisions before the data are shown to be valid and reliable Making decisions on the basis of outcome data alone, in isolation from other information Focusing on a narrow set of outcomes or only those outcomes for which data are available Failing to explore why poor outcomes are occurring
Purpose: To monitor how effectively programs/schools are providing early intervention or preschool special education					
Data for each program/school	Local administrators LICC Advocates Families	<ul style="list-style-type: none"> Funding to programs with good outcomes is sustained or increased. Programs are recognized as model systems. Effective practices are documented and disseminated. 	<ul style="list-style-type: none"> The local administrator develops strategies to produce better outcomes in programs with poor outcomes. Advocates push for changes. 	<ul style="list-style-type: none"> Administrators continue to monitor programs in regard to process rather than results or do not ask questions about effectiveness. 	<ul style="list-style-type: none"> Making decisions before the data are shown to be valid or reliable; Making decisions on the basis of outcome data alone, in isolation from other information Holding programs accountable for more than they can reasonably be expected to deal with Failing to explore why poor outcomes are occurring Adjusting strategies on the basis of invalid data

Level: Local (Communities, LEAs, etc.) (Continued)

Level of Data	Used by	What happens if . . .			Possible misuses of the data
		Data show good outcomes	Data show poor outcomes	Data not collected	
Purpose: To monitor the health and well-being of young children with disabilities in the locality by determining how these children are faring in regard to multiple indicators of health and well-being (probably as compared with typically developing children)					
Data for the locality (LEA, county)	Advocates Local agencies concerned with young children with disabilities	<ul style="list-style-type: none"> Funding for current programs is sustained or increased. Changes in future years can be tracked to ensure that good outcomes are maintained year after year. 	<ul style="list-style-type: none"> Advocates and agencies explore underlying causes for poor outcomes (e.g., poverty, child abuse, lack of insurance). New programs, better coordination, and targeted funding to improve the health and well-being of young children with disabilities result. 	<ul style="list-style-type: none"> No one knows that children with disabilities are faring poorly. Ineffective policies and programs continue; policies continue to be set in the absence of information. 	<ul style="list-style-type: none"> Failing to recognize the multiple underlying causes for poor outcomes (e.g., trying to hold one program or funding stream accountable) Failing to act on the information

Level: Program/School Uses

Level of Data	Used by	What happens if . . .			Possible misuses of the data
		Data show good outcomes	Data show poor outcomes	Data not collected	
Purpose: To monitor how effectively the program/school is providing early intervention or preschool special education; used in combination with information from other sources to determine if the program/school is doing an effective job of providing early intervention and/or preschool special education services					
Data for all children participating in the program	Program director Policy board Program staff	<ul style="list-style-type: none"> Public and families have evidence that the program is doing a good job. The program knows to continue current practices. 	<ul style="list-style-type: none"> The program adjusts current practices or adopts new practices for early intervention or preschool special education (e.g., in-service training, new program options, coordination with other programs or agencies). 	<ul style="list-style-type: none"> Decisions about the future directions are made without knowing whether and where current practices are effective. 	<ul style="list-style-type: none"> Making decisions before the data are shown to be valid and reliable Making decisions on the basis of outcome data alone, in isolation from other information Failing to explore why poor outcomes are occurring; Adjusting strategies on the basis of invalid data
Purpose: To identify groups of children or families for whom the program is less effective than it should be; used in combination with other sources to determine whether or not the program is doing the best job it can do for all of the children/families it is serving					
Data for each child/family participating in the program	Program director Staff	<ul style="list-style-type: none"> The program knows to continue current practices with some, most, or all children and families. 	<ul style="list-style-type: none"> Program staff discuss alternative approaches that might be more effective. The program convenes an IFSP or IEP meeting to explore alternatives for those with poor outcomes. New interventions are tried. New resources are explored. 	<ul style="list-style-type: none"> Current practices continue or decisions about changes are made in the absence of data on the effectiveness of what is currently being provided. 	<ul style="list-style-type: none"> Making decisions on the basis of invalid or unreliable data Making decisions on the basis of a single assessment Blaming the family for poor outcomes Failing to alter an approach that is not producing good outcomes

Level: Child/Family

Level: Child/Family					
Level of Data	Used by	What happens if . . .			Possible misuses of the data
		Data show good outcomes	Data show poor outcomes	Data not collected	
Purpose: To examine the effectiveness of the approach/intervention being provided by examining data on child progress frequently to determine whether or not the child is making as much progress as expected.					
Data for an individual child/family	Service providers working with the child and family Family	<ul style="list-style-type: none"> Intervention continues. 	<ul style="list-style-type: none"> Intervention is altered in some way. New intervention is tried. 	<ul style="list-style-type: none"> Current practices continue. Decisions about changes in intervention approach are made in the absence of data about the effectiveness of what is currently being provided. 	<ul style="list-style-type: none"> Using data to lower expectations for child performance Using assessment data in isolation from other information Using data to exclude children from opportunities, rather than modifying activities so they can be included <p>NOTE: All invalid practices associated with using assessment data for individual children apply here.</p>