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ABSTRACT

This document is the outcome of a conference that examined promising practices in services for children with developmental delays (DD) and gathered input for making policy recommendations related to the implementation of DD as a specific disability category for children ages 3 through 9. It begins by discussing changes to the Individuals with Disabilities Education Act (IDEA) in 1997 that allows states to serve children with developmental delays ages 3-9, and then summarizes presentations that address use of the DD category, the developmental delay project at the Frank Porter Graham Child Development Center at the University of North Carolina, state eligibility definitions, and findings from a state director survey on the DD category. The perspectives of different stakeholders are included and recommendations for further research are provided. Recommendations include: (1) monitor the percentages of children served under the DD label and changes over time, (2) coordinate national efforts to review assessment procedures for DD, (3) examine the use of the DD label across state and local education agencies, (4) conduct research on parent/student perspectives of DD classification, (5) compare eligibility criteria across states, and (6) conduct research on the effect of eligibility criteria on the number of children served. (CR)

Policy Forum

Developmental Delay: Review of Research And Future Directions

Convened
July 19 – 21, 2000

Proceedings Document

prepared by:

Patrice Linehan
Project FORUM at NASDSE

NATIONAL ASSOCIATION OF STATE DIRECTORS OF SPECIAL EDUCATION, INCORPORATED..........

NASDSE

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IDEAs that Work

U.S. Office of Special Education Programs

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Developmental Delay: Review of Research And Future Directions

Background

There has been much concern among educators surrounding the use of disability labels to describe young children (e.g., miscategorization, inaccurate testing in early years). In response to the concern, educators and policymakers have established other options to labeling and categorizing children at an early age. In 1986, Federal special education law (P.L. 99-457) was amended to include the eligibility category of *developmental delay* (DD) for children birth through 2 years. While this broader label could not be applied to older children covered under Part B of this law, states were exempted from reporting 3-5-year-olds by specific disability category as part of the 1986 Amendments. In 1991, the law was revised again (P.L. 102-119) to allow states to add DD as an eligibility category for children 3-5 years.

In 1997, this issue was addressed in more detail when Congress reauthorized P.L. 94-142, now known as the Individuals with Disabilities Education Act (IDEA). The 1997 amendments to IDEA, along with the Part B regulations, allow states and local districts to extend the use of DD in order to deliver appropriate services to young children:

> *b. Children aged 3 through 9 experiencing developmental delays ... may, at the discretion of the State and LEA [local education agency] ..., include a child --*
>
> *(1) ... experiencing developmental delays, as defined by the State and as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas: physical development, cognitive development, communication development, social or emotional development, or adaptive development and*
>
> *(2) who, by reason thereof, needs special education and related services* (20 U.S.C. 1401(3)(A) and (B) §300.7)

During the reauthorization process, comments indicated a need to clarify the use of the term. The main questions and concerns addressed under the "Analysis of Comments and Changes" section of the *Federal Register* (March, 1999) were related to the following:

- the application of the term DD and the respective roles of the state and local education agencies (SEA and LEA) in implementing the provision;
- the need for defining the term consistently under both Part B and the early intervention program under Part C of the Act; and
- the impact that the term would have for children with sensory disabilities or significant cognitive disabilities. (Federal Register Vol. 64, No. 48, March 12, 1999, p. 12540)

The conditions for using DD and specified disability categories were clarified in response to public comments. The regulations specify that:

> *(1) A State that adopts the term developmental delay ... determines whether it applies to children aged 3 through 9, or to a subset of that age range (e.g., ages 3 through 5).*
> *(2) A State may not require an LEA to adopt and use the term ....*
> *(3) If an LEA uses the term ..., the LEA must conform to both the State's definition of that term and to the age range that has been adopted by the State.* [ages 3 through 9, or a subset of that range]
> *(4) If a State does not adopt the term ..., an LEA may not independently use that term as the basis for establishing a child's eligibility .... (20 U.S.C. 1401 (3)(A) and (B) §300.313)*

If a specific disability is diagnosed, the revisions clarified that it is still appropriate to use the more descriptive category for those children (§§300.7(b) and 300.313). A state may also choose to adopt a common definition of the term DD under both Part B and Part C of IDEA.

Purpose of the Meeting

As part of its cooperative agreement with the U.S. Department of Education's Office of Special Education Programs (OSEP), Project FORUM at the National Association of State Directors of Special Education (NASDSE) collaborated with the North Carolina Office on Disability and Health, Frank Porter Graham (FPG) Child Development Center, and the School of Education at the University of North Carolina (UNC) at Chapel Hill to convene a meeting on the issue of Developmental Delay (DD).

One of Project FORUM's goals is to facilitate communication among a broad range of stakeholders on critical issues and to obtain input on particular topics or program information needs. The Frank Porter Graham Child Development Center is one of the nation's oldest multidisciplinary centers for the study of young children and their families. Research and education activities focus on child development and health, especially factors that may put children at risk for developmental problems.

The FPG Child Development Center project was funded by OSEP and the Center for Disease Control and Prevention (CDC), to undertake several tasks related to DD:

- conducting a survey of state practices;
- undertaking a review of the literature;
- making policy recommendations; and,
- developing a research agenda that might be used to set priorities by those implementing Part B of IDEA .

In order to enhance the work of these two federally-sponsored projects, Project FORUM and FPG Child Development Center hosted a meeting to examine promising practices in serving children with DD, and gather input for making policy recommendations related to the implementation of DD. The meeting focused on assisting the FPG Child Development Center in accomplishing the following goals:

- review the current research related to DD;
- generate policy and practice recommendations; and
- develop a research agenda for OSEP's consideration.

This joint meeting provided the FPG Child Development Center an opportunity to present its preliminary work toward the goals outlined above. Although the work is still in the early stage, participants were able to review state activities currently being implemented in the area of DD, and the FPG staff was able to receive input from various stakeholders on the initial findings being presented.

Preparation for the Meeting

Planning and Selection of Participants

In preparation for this meeting, several conference calls were held with representatives from the FPG Child Development Center, OSEP project officers, and Project FORUM staff. The agenda and format for the meeting were developed by Project FORUM and FPG staff, with input from OSEP. Participants then were selected to represent the diversity of stakeholders interested in the issue of DD.

Location and Process of the Meeting

The meeting was convened in Alexandria, Virginia July 19-21, 2000, and opened with a summary of the issues related to DD presented by OSEP. This was followed by an overview of the DD project at the FPG Child Development Center. The meeting was divided into three main sections: the first morning focused on policy issues; the afternoon focused on research; and, the next morning, input was garnered in respect to establishing recommendations. Details of the agenda can be found in Appendix B.

From the beginning, it was emphasized that discussions of policies, research, and practice were of a tentative nature because use of the DD category is still evolving. The option for states to use the DD category for children through age nine was not available until the 1997 reauthorization of IDEA, and it takes time for states to establish and implement such policies.

Summary of Presentations

Opening Remarks *by Lou Danielson, Director, Research to Practice, OSEP*

The history of the Developmental Delay (DD) category was explained from a federal perspective, and an overview of issues related to DD was presented for later discussion. The main issues raised are outlined below.

Use of Developmental Delay Category

OSEP became interested in learning whether the DD category has fundamentally changed the way educators think about children and identification, or whether the additional label is simply used as an alternative way of reporting students who would be eligible for services under another category (e.g. mental retardation or learning disability) if DD did not exist. If DD is used as a separate category used to make judgments about students, there are implications for research and development and the delivery of technical assistance. Some of the questions related to this topic are:

- How do we assess and make judgments about student eligibility?
- How do we organize services for students identified under DD?
- Will the use of DD expand the population of special education students?
- Are students identified as DD the same students who are being identified later under a specific disability category, or do they represent a different population of children?

Due to the concern that using DD could potentially expand the population of children served under IDEA, states may be reluctant to adopt the DD category. There are already concerns about the cost of special education services, and increasing the population served would logically increase the cost of providing services. Although states and schools seem to be moving cautiously on this issue, there may be some changes occurring within states as a result of reauthorization. In the past, states were not required to report 3-5-year-olds by specific disability category. Thus, the number of children being reported simply represented aggregate data on the number of students with disabilities in preschool. However, the federal statute now requires states to report the number of preschool-aged children by disability category, which may lead states to define and adopt the DD category in order to comply with federal reporting requirements.

Interface between Education and Medical Communities

Recently, there has been publicity about the number of 3- and 4-year-old children receiving psychotropic medication to treat certain disabling conditions. This public debate has resulted in discussions between OSEP and other federal human service agencies on issues related to the diagnosis and treatment of such conditions. While these discussions and the resulting increased collaboration were extremely valuable, it is clear that the medical and education communities operate from very different models of identification and service delivery. Despite the use of categories for reporting data on students with disabilities, educators have generally taken a more individualized approach to service delivery than medical personnel. In fact, IDEA requires programming to be based on individual needs rather than labels, and a functional approach to definition and assessment is compatible with developing an Individualized Education Plan (IEP). As the education community continues to interface with the medical and health communities, finding ways to effectively communicate differing "world views" and reconciling contrasting approaches becomes increasingly important.

Disparity between IDEA Philosophy and Local Services Based on Disability Category

The IDEA philosophy recognizes and appreciates individual differences. Programming should not be prescribed based on a specific disability label. In practice, however, local services are often delivered on such a categorical basis. Parents are told that their child cannot receive services without a specific diagnosis, which leads them to seek a specific disability label in order for their child to access needed services. Moreover, professional organizations and parent groups tend to organize around specific disability issues, which is contrary to the IDEA belief that services should be delivered according to the needs of the individual child. This disparity between the spirit of the law and how it is being considered by some disability groups and implemented in local schools raises questions about service delivery and funding options. Some questions include:

- Will the use of DD eliminate the problem of services being driven by disability label?
- What is the vision for the use of the DD category?

Overview of Project at University of North Carolina (UNC) *by Rune J. Simeonsson, Principal Investigator, Frank Porter Graham Child Development Center*

Developmental delay (DD) is a concept embedded in the principles of early education and intervention. Historically, early intervention has relied on interdisciplinary collaboration between professionals and close contact with families to improve individual growth or treat disabling conditions. The use of the DD category may allow for identification and earlier intervention to enhance developmental progress. This classification takes individual differences into account and recognizes the complexity of childhood disability.

The DD project underway at the Frank Porter Graham (FPG) Child Development Center at UNC is examining some key questions related to extending DD from ages 6 through 9. The following activities are part of FPG's examination:

- survey of various stakeholders on DD practices in states;
- research of the policy options for DD, as well as options for research to practice; and,
- synthesis of "promising" practices.

In addition, three ad hoc groups, which included representatives from NASDSE, DEC (Council of Exceptional Children's Division of Early Childhood), OSEP, and the National Early Childhood Technical Assistance System (NEC*TAS), were convened between 1999-2000 to:

- identify stakeholders who need to be involved in the discussion of DD;
- discuss how use of the DD category affects eligibility for special education; and,
- identify potential special education implementation issues resulting from the use of DD.

Editor's note: More information about FPG's activities and findings was presented later in the policy forum and can be found on subsequent pages of this document.

Introductory Comments *by Don Lollar, Centers for Disease Control and Prevention*

The Centers for Disease Control and Prevention's (CDC) National Center for Environmental Health has been focusing on health promotion and the prevention of secondary conditions that occur as a result of a disability. Current practices and programs for children with DD are based on an interdisciplinary framework. This approach values the complexity of each individual within the context of the family. Remediation of skill deficits is considered along with primary and secondary prevention. The importance of the health and education fields working together to serve these children and families was stressed. This cooperation is vital to ensure the coordination of services necessary for treating "whole people."

State Data Report *by Scott Brown, OSEP*

State-reported data from 1997-98 and 1998-99, submitted to fulfill the federal child count requirement, was reviewed to see if any patterns could be discerned in relation to DD since the reauthorization of IDEA. These preliminary data were presented and discussed with participants, but are not available for dissemination. It is important to note that states were not permitted to use DD for 9-year-olds until the regulations were adopted following the 1997 reauthorization of IDEA. In addition, states may or may not opt to use DD for children through age 9; therefore data are not easily comparable across states. And because the number of new DD identifications are relatively small compared to the number of children in other disability categories, it will be difficult to distinguish the degree of change within other disability categories.

While the number of students with disabilities grows each year in the 6- to 9-year age range, the percentage of students under the DD classification within this age group is decreasing. Thus, it appears as though states are implementing a DD policy that allows them to classify younger children, and they are less likely to use DD at a later age when the specific nature of a disability is clearer. After age 9, a student must be identified under a specific disability category in order to continue receiving special education services under IDEA. For example, a student classified as DD at age 9 may move into the mental retardation (MR) or some other category the following year. Once data have been collected for a number of years, specific identification patterns may emerge.

Although there is no federal policy requiring states to use the DD classification, OSEP is informing states that the use of DD is one way to serve younger children without having to use a specific disability category. Some states are keeping data records on the categories used for children who *age out* of the DD category.

State Eligibility Definitions *by Joan Danaher, NECTAS*

The NECTAS, has been following state policy development on pre-school age eligibility for about 12 years. Detailed information and data can be accessed by referring to the NECTAS web site at http://www.nectas.unc.edu/devdelay/devdelay.html. The most recent information received from states on the use of the DD category shows that 33 states use the term DD or SDD (severe developmental delay) for their early childhood-specific category. Eighteen states use other terms that function as DD. Most of these terms were in place before the reauthorization of IDEA. Some examples include: *preschool child with a disability*; *early childhood disability*; and *eligible for essential early education.* The most common age range used by states for their early childhood specific category is age 3 through 5. This is true for states that use DD as well as those that use another disability term. Since children ages 3 through 5 will have to be reported by specific disability categories in order to continue receiving services, soon DD may be adopted by states that are not using the term currently.

Most states (31 of 34) that measure a child's status in one of five areas of development (cognitive, language, physical, psychosocial and self-help) quantitatively use the criteria 2.0 standard deviations (SD) below the mean in one developmental area, and/or 1.5 SD below the mean in two developmental areas. Some states use percent delay criteria. In these states, 25-30 percent delay in one or two developmental areas meets the criteria for DD. Some states do not require quantitative data and permit informed team consensus, clinical opinion or professional judgment in determining eligibility. Other states permit the diagnosis of a condition that is associated with a disability (e.g., Down's Syndrome) to qualify for special education services under the DD category. Several states have not established criteria for DD, but allow the LEA to make the determination and the state may provide guidance.

At the time of the policy forum, 16 states were using the DD category beyond age 5—five states through age 9, seven states through age 8, two states through age 7, and two through age 6. Nine states reported they were *considering* or were *in the process of* extending the age limit for this category, and two states were piloting an extension of the age range for DD at the time of the forum. Four states were *adopting* or *considering the use of* both the DD category and an established age range. At least two of these states were using another disability term at this time, but were discussing the use of DD instead.

Some states have a policy that a 6- or 7-year-old child cannot be newly identified as DD. However, if the child was initially identified as DD between the ages of 3 and 5, he or she can continue to receive services under the DD classification. Some states mandate that the DD category can be used by states only *if a child did not qualify under another disability category.*

Local education agencies (LEAs) were granted some additional control over use of the DD category in the 1997 reauthorization of IDEA. Now, an LEA can decide if it wants to follow its state-established DD category. However, the LEA cannot decide to use its own definition of DD. If the LEA decides to use the state DD category, it must abide by the state-established definition and age range. Originally, states were concerned about the LEA option to refuse use of the DD category, but some of these states have since reported that most LEAs are adopting the state DD definition. Still, the use of a specific category, as well as the definition and criteria used to determine eligibility for services, has many implications for individuals and their families. For example, a specific diagnosis may be needed in order for an individual to receive services from other agencies.

State Director Survey Findings *by Valerie Jarvis McMillan and Harriet Able-Boone, UNC*

In 1999, the ad hoc workgroup convened by UNC as part of its research recommended surveying state directors of special education and Section 619 Coordinators to learn how this change in policy affected practice within states. UNC staff interviewed individuals about the changes in DD federal policy and important issues, and asked them to identify key stakeholders. All 50 state directors were contacted and 35 agreed to participate in the telephone survey.

In the discussions of state eligibility definitions and state director survey findings, four main policy strands emerged:

1) DD is considered to be a different disability category than the Part B disability categories;
2) DD encompasses all Part B categories;
3) DD is thought to be an early manifestation of one of the disability categories; and
4) DD provides the option of a functional approach.

In the first strand, children being identified as DD are those who need services but do not qualify under another category. Respondents describe these children as those who "might fall through the cracks" if services are not provided. The second strand responds to the need to ensure compliance with the law while allowing a less stigmatizing label to be used. The third strand describes students who are thought to fall into one of the existing categories, but are difficult to identify because the source of their disability is not clear at an early age. And, the fourth strand addresses the issue of providing a "non-categorical" option to ensure that services are not based solely on a disability label.

These policy issues raise a fundamental question about the number of students being served under IDEA. Does the DD option provide for the use of a different label for young children without increasing the number of children identified, or does the DD category allow more children who need services to be identified and served? States have raised concerns about over-identification and increased costs associated with more children being identified. States also worry about inconsistency across districts due to confusion over the definition and criteria used to determine DD.

Because of the high degree of variability among states, it is difficult to assess whether inappropriate referrals are being made or not. In one state that carefully tracked student data, 95 percent of children identified as DD in preschool qualified for special education services at age 5.

Other state concerns raised during the survey interviews include the following:

- Need for training and technical assistance
- Professional preparation and licensure
- Implementation issues
- Changing nature of special education
- Monitoring
- Transition at age 10
- Eligibility assessments
- Implications for families

Participant Discussion of Policy Issues

Editor's note: At various points throughout the course of the policy forum, participants contributed to open discussion on policy issues related to Developmental Delay (DD). Their comments were organized into themes by Project FORUM staff and are summarized below.

Philosophy

The ways in which society views developmental delay and disabling conditions was at the core of participant discussion. On one hand, early intervention services that were once viewed skeptically by families are now welcome. As a result, children are entering programs earlier. On the other hand, we have to think about the assumptions we make when classifying individuals and defining disability through a deficit model. There are natural variations in child development and the system must be responsive to that. Labels can help us describe conditions and are not always negative. However, the language that is used along with a label is often troubling. All children need individualized services to enhance their strengths and support or address their weaknesses.

Evolution of the Term Developmental Delay

The history and evolution of the term Developmental Delay was considered during this discussion also. Prior to the 1997 reauthorization of IDEA, there was much debate over the use of disability categories. Some groups wanted to eliminate the use of categories altogether, while others wanted to revamp them. Participants discussed different purposes of DD (e.g., bring services to younger children while avoiding mislabeling or bring services to a new population of students), and the role of the SEA and LEA in implementing this option. It was decided that an appropriate definition for DD could be developed if the purpose of using the term was clear.

Definition

Many policy forum participants were concerned about confusion over definitions and eligibility criteria used for DD. In some LEAs, DD is used for every child in a designated early childhood age group regardless of specific evidence that the child would clearly qualify for another category. Participants reported that people in the field are worried that too broad a definition will significantly increase the number of children referred to special education , while too narrow a definition will "leave children behind," or just become "one more way to sort students." The label should not be driving the service, so DD should not act simply as a "re-labeling." If a child will be served under a different category at age ten, the number of identifications should not increase. Rather, services will be provided earlier, or be less intense later. One participant suggested three distinctions: 1) a chronic condition that leads to DD; 2) at-risk for DD; and 3) developmental delay. This approach is the same as the one defining Part C eligibility.

Identification

For developmental delay to be a useful category, it will be important that children who really need help, but who would not qualify under other categories, get services through the use of DD. Informal comments from SEA staff indicate that DD is "a way to pick up children who might fall through the cracks." One participant questioned whether DD is expanding the special education population inappropriately or whether it is necessary due to the toxic environment to which some children are exposed. Environmental issues – such as poverty, pesticide exposure, and substance abuse – should be considered in connection with issues of definition and identification.

Assessment

Participants expressed concern that there are no data on assessments being used to determine eligibility under DD. In fact, there may be a lack of appropriate assessment instruments, and assessments may not look at the whole child. In one environment (e.g., school) a child may be identified as disabled, while in another (e.g., home) s/he may be viewed as typical. The focus needs to be on the needs of the individual rather than the particular label, and the label should not determine services. Those who believe in functional assessment and diagnosis appreciate the use of DD because they acknowledge that individuals do not fall neatly into categories.

Responsibility

The global effects of economics, health and the environment impact DD. While the public often assigns the responsibility of addressing DD to school systems, some forum participants felt there should be a more collective responsibility. However, others stated that the school system has the best capacity to address this issue. One perspective was that universal early childhood education would eliminate much of the debate about responsibility; however, this was considered cost prohibitive. At the national level, there must be agreement among agencies and fields about the meaning and use of the term DD, and more cost-sharing is needed.

Systems Change

Increased collaboration and shared costs may lead to systems change according to some forum participants. Moreover, the philosophical shift, from focusing on a disability to viewing delay as part of a continuum of development that can be enhanced by enriching the environment, would be a major transformation. Use of the term DD could be the catalyst for these changes, but much work needs to be done.

Presentation of Research Being Conducted at UNC *by Rune J. Simeonsson*

Context for Use of the Term Developmental Delay

A review of the literature on early intervention over the past decade demonstrates the widespread use of an interdisciplinary framework that stresses a "whole child" approach to identifying and providing appropriate services. It is thought that the use of the term Developmental Delay (DD) could promote systemic intervention and prevention using this family-oriented, "whole child" approach. Children are constantly influencing and being influenced by interaction with their caregivers. The extent to which the child and family make contact with support systems, as well as the quality of that interaction, determines the degree to which child outcomes are enhanced. Strengthening the knowledge and skills of families is an important part of service provision.

The use of DD in a coordinated context is thought to provide services that are more directly related to the individual needs of the child. Also, it may prevent the child from being put into an inappropriate or incorrect category, and eliminate the practice of delivering services greater than the child needs due to the use of a label. Identifying young children by the term DD also may reduce later referrals by correcting the disabling condition through early intervention.

Issues of Classifying Childhood Disability

One of the most important issues in the classification of children with disabilities is the confusion over definitions. It is difficult to know how many children are in need of services because there is so much confusion about defining terms. This impacts identification, eligibility determinations, and inclusion efforts since common terms can be interpreted differently by individuals or groups. While it is generally accepted that a child with DD needs support in the general education environment, descriptions of DD often vary depending on the perspective of the person conducting the assessment.

In some cases, a particular measurement tool is used to determine eligibility. While one child may score in the range associated with DD, another child may score only slightly lower and qualify for services under a different category (e.g., mental retardation). The same child evaluated in different environments (e.g., at home or in school) may also be given two different labels. Within a medical model, it is important to determine the etiology of a condition; however, many medical classifications are not indicators of individual functioning or academic performance. For example, traumatic brain injury results in a range of school needs.

When a functional definition is used rather than a categorical definition, identification differs. Since categorization often is influenced by the socio-political context, children may be miscategorized or receive inappropriate services. The law specifies 13 special education categories, and also allows the option of using DD, but DD is not clearly stated as a category of classification.

The concept of framing disability in categorical rather than classification terms was also discussed. Classifications should focus on the characteristics of disabling conditions instead of on individuals. Inclusion and exclusion criteria, measurement tools, and clinical decision-making are some of the issues that need to be reviewed in relation to the classification of children, and the use of DD in this process. It was suggested that classification of children in schools should be based mainly on ability to participate in instruction and progress in curriculum. A functional definition (rather than disability categories) and a framework of dimensions also were considered as a way of thinking about classification.

Alternative Approaches to Identification and Service Provision

Three main approaches for identifying and serving children ages 6 through 9 in special education programs were discussed:

- Extension of Part C definition and approach;
- Additional category (14th category); and,
- Functional, "non-categorical" approach.

Each of these approaches is rooted in a differing conceptual base and would focus on distinct intervention activities. For example, using DD as an extension of Part C implies that variation in performance levels is expected as a part of development, while adding it as a fourteenth category means that unique etiologies can be found. Thus, one approach attempts to reduce or eliminate the disability and its consequences, and the other seeks to manage the disability in a comprehensive manner. The functional approach focuses on accommodations and skill acquisition. This is a complex issue and will need further discussion. It was noted that it is possible to have combinations of the three approaches as well.

Research priorities to inform policy and practice

A number of considerations for both policy and practice were presented by the FPG Child Development Center project staff. These considerations will be disseminated along with the results of their research once their project is complete. Some of the research priorities highlighted by the FPG Child Development Center project are:

- Examine conceptual and empirical bases for defining developmental delay;
- Test specificity and sensitivity of eligibility criteria;
- Estimate incidence and prevalence;
- Establish correspondence of assessment with intervention; and,
- Establish resource needs.

Participant Discussion of Research Implications and Research Agenda

A Parent's Perspective *by Carmen Sanchez*

While many LEAs are moving toward use of the DD label through age nine, services are often determined by a more specific label. Although labels should not determine eligibility or service delivery, parents may see the label as the entry point to services. However, the label should not determine the services once the child receives access to programs. Often, the use of a particular label may limit placement options. For example, children are immediately placed in more restrictive environments based on a label rather than individual need. These children sometimes have strengths that are overlooked, which affects their potential inclusion.

It is important to insure that children are assessed properly. It can be a struggle for a child to demonstrate what s/he knows and is able to do because of inappropriate assessments and non-adapted tests. For example, one typical task on early childhood tests is stacking blocks. Although a child may have the cognitive functioning to attempt this task, his motor skills may prevent him from completing the task, which is not a reflection of his intelligence level. Rigid testing procedures need to be evaluated and a broad range of assessments, from informal to formal, is needed.

A mechanism other than DD should be established to meet the needs of students who would not fall under a specific Part B disability category at age ten. Some of the most progressive practices are introduced in Part C programs and then carried into schools as these young children move through the system. This is an effective systems change approach in many ways. But, while these "best practices" are beneficial to the children they serve, Part C programs are carrying the burden of implementing these innovative initiatives. Legislators need to be informed that additional resources are needed for early intervention, since Part C of the Act is very critical.

A Service Provider's Perspective *by JoAnn Edelin*

Service providers find that DD often is used as a deferred diagnosis, when a specific diagnosis cannot be made. However, generally, practitioners feel that a child should be identified within a specific disability category whenever possible. The developmental delay classification should be used only when the problem cannot be diagnosed easily. This can be difficult when parents disagree with the use of a particular label. A consensus approach should be used to determine the appropriate label for a child when the family does not agree with the practitioner's diagnosis, but agrees that services are needed.

According to people in the field, the diagnostic process must improve. There is a need for comprehensive assessments that are timely and practical (e.g., provide functional information), and diagnostic tests should be appropriate for assessing children in natural settings, such as at home and play. Children who live in poverty and those with cultural and linguistic differences, must be considered in any discussion of assessment. While accommodations can be used in the administration of many tests, it is important to review the whole diagnostic process to ensure that a language acquisition issue is not diagnosed as a disability. It is also important to increase communication and involvement with less-informed parents. Parents and professionals outside of the education field -- such as those in health, social services, and recreation -- often see conditions that are not documented in reports. More awareness and preparation is needed to get them involved in the process. Training for general educators, who often request such support, was recommended too. Although determining eligibility is an important step toward accessing programs, it is only the beginning. Other assessments are needed to find the most appropriate program plan for children.

Practitioners also need assistance in serving children with challenging behavior. Often times, these children are not able to function in an environment despite being at the appropriate level cognitively and verbally. While these children may be considered eligible for services, because they meet the criteria for identification under the social/emotional domain, the educational practitioner may struggle in providing the appropriate services. Some LEAs consider the social/emotional domain to be the responsibility of the human services or medical community rather than that of education.

A Psychologist's Perspective *by Sally Flagler*

Although most practitioners have little input on policy issues, the legal stance on the issue of extending the use of DD is important because it determines what is done in the field. A number of practitioners who have been trained in the past ten years have incorporated both play and alternative assessment techniques and strategies to the assessment of young children. Few early childhood assessment specialists use standardized instruments alone. Many readily incorporate parent and preschool information, observations in naturalistic settings, and structured and unstructured play routines as standard parts of their repertoires.

On the other hand, policy does not always guide services the way it should. Some examples were given of practitioners who follow rigid assessment procedures despite the existence of a flexible policy. A study addressing how psychologists currently assess/evaluate young children would be useful. The Early Childhood Interest Group of the National Association of School Psychologists (NASP) is conducting a small preliminary study on this topic. It would be interesting to see whether other personnel are using similar techniques.

While policy issues may not be considered relevant to many practitioners, the practice of classifying a child with a disability is very germane to the work of psychologists. This is a broad, complex issue. The early childhood field has made much progress in assessing young children, birth to age 5, but some psychologists (e.g., those prepared solely in psychometric testing rather than a family-oriented approach) have not had the comprehensive training or opportunity to work with non-standardized testing procedures. States need to examine the extended use of DD in the context of comparing the results of assessment by practitioners trained in traditional school-age assessment with those trained in early childhood assessment. The results of such research would have implications for policy and personnel preparation at the university level.

Another major question is whether use of the DD label modifies assessment procedures to the extent that children who traditionally have not been served under IDEA (e.g., those in poverty or affected by substance abuse) are now eligible for services. Present practice has allowed practitioners to include children at-risk for potential delays (e.g., those children with social and emotional difficulties who might not meet standard criteria). Changes in the law allow this flexibility. Many children with challenging behaviors have made substantial progress in preschool which has benefited them later in school. If a child needs related services, a special education label is necessary. A study is needed to examine what happens to children who do not qualify for special education services once they reach school age following a DD label in preschool.

A State Director's Perspective *by Virginia Beridon*

In Louisiana, 26 LEAs took part in a pilot study of DD. The results of the study showed that approximately ten percent of students identified under the DD category would not have met the criteria for a disability in the non-categorical pre-school programs or a specific category within Louisiana's other programs.

Editor's note: The following paragraphs summarize broader state issues discussed by the speaker.

Educational reform efforts (e.g., accountability mandates, high-stakes testing, and school ranking based on performance) are increasing the pressure on special education. While higher expectations and an increased focus on instruction are positive results of these efforts, inclusion efforts may suffer. Depending on how students with disabilities are factored into accountability systems, referrals to special education programs may increase. In addition, general education teachers, who often are under pressure to increase student achievement, may resist taking the time to provide differentiated instruction to serve students with disabilities.

Another issue related to access to the general education curriculum is the overrepresentation of minorities in special education programs. Because, historically, some groups of children have been excluded from the general education system, extensive documentation now is needed to demonstrate the need for a particular label. The strong emphasis on labels can lead to other problems, too. For instance, services are sometimes attached to a label, regardless of need. Some children receive services that are not needed because these services are part of the prescribed treatment that accompanies a particular label, while children without a label are perceived as ineligible for education-related services. Moreover, the unwritten policy of many local school systems is to fund services in accordance with a label. So, while it is important to avoid unnecessary labeling of children, the labels sometimes are viewed as essential to receiving services.

Personnel issues (e.g., teacher quality and availability of personnel) are important to consider when examining the use of labels. Severe shortages of certified personnel are a concern nationwide. While certification does not always indicate quality, the dearth of qualified personnel – particularly among those serving students with the most severe needs – is one of the many factors states are confronting. Sometimes particular labels are used as a procedural safeguard to ensure that students are being served. If all students received the individualized services they needed, either through general education programs or specialized programs, there would be a diminished need to categorize children. The ideal situation would be to have teachers who delivered services based on the strengths and weaknesses of their students, regardless of the labels used to identify them. However, since all teachers do not possess the knowledge and skills necessary to deliver appropriate services (e.g., discipline, diverse instruction) some protections have been built into the system in the form of labels. While states prefer to work toward the spirit of the law, the threat of litigation often drives many of the policies at the state level.

Recommendations for UNC Project

Participants were asked to give input and make recommendations to the staff of the FPG Child Development Center as part of the policy forum. Although many of the recommendations are beyond the scope of the work on DD assigned to the FPG researchers, the issues are important to consider in future work on this topic. The following recommendations were distilled and organized into themes by Project FORUM staff:

Identification and Eligibility

- Monitor the percentage of children served under the DD label and other labels through age 9 and changes over time.
- Examine the percentage of children served under DD who later qualify under "learning disability."
- Coordinate a national effort to review assessment procedures for DD.
- Research on what disability classifications would be used if DD was not an option.
- Examine the use of the DD label across SEAs and LEAs.
- Conduct research on parent/student perceptions of DD classification.
- Examine and compare eligibility criteria across states, as well as application of criteria at different ages.
- Conduct research on the effect of eligibility criteria on the number of children served through age 9, as well as the number of children whose eligibility continues after age 9 under a different category.

Implementation Issues

- Describe programs that effectively serve children with the DD label.

- Conduct research on the impact of transition at age 10 when non-DD label is assigned.
- Examine strategies used for implementing the local option of using DD.

Personnel Issues

- Conduct research on the preparedness of general educators to work with children identified as DD.
- Explore and clarify issues regarding cross-categorical preparation of special education personnel.

Next Steps

The FPG Child Development Center will use the information gathered through this policy forum to focus its work over the remaining months of the study. Although many of the recommendations generated from this meeting are beyond the scope of the DD project at the FPG Child Development Center, the issues and recommendations that emerged will inform the Center's remaining work. Some of the recommendations also may be pursued by other researchers and organizations.

Information from NECTAS (reported on pages 7-8 on this document) and the policy forum participants indicate that state policies related to use of the term DD is in flux. Many states are considering policy changes related to the option of identifying and serving young children through age 9 under the term DD. Thus, the work of this policy forum should be viewed as a starting point upon which the work of other federal- and state-initiated projects can build.

Appendix A

Participant List

Appendix A
Participant List

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Project FORUM at NASDSE

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Appendix B

Agenda

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Agenda

Wednesday Evening – July 19, 2000

5:00 - 5:10	Welcome from Project FORUM and overview of agenda	*Joy Markowitz*
5:10 - 5:30	Welcome from OSEP and overview of issues	*Lou Danielson*
5:30 - 6:00	Participant introductions	
6:00 - 6:45	Dinner	
6:45 - 7:30	Overview of project at University of North Carolina	*Rune Simeonsson*
7:30 - 7:45	Logistics and announcements	*Project FORUM staff*
7:45	Adjourn	

Thursday – July 20, 2000

8:30	Coffee and other beverages	
9:00 - 9:15	Introductory comments	*Don Lollar, Centers for Disease Control*
9:15 - 9:45	State data report	*Scott Brown, OSEP*
9:45 - 10:15	State eligibility definitions	*Joan Danaher, NECTAS*
10:15 - 10:30	Break	
10:30 - 11:00	State director survey findings	*UNC Project staff*
11:00 - 12:00	Discussion with participants about policy issues (e.g., definitions, identification, assessment)	
12:00 - 1:30	Lunch on your own	
1:30 - 2:15	Conceptual and empirical issues	*UNC Project staff*
2:15 - 3:00	Review of findings	*UNC Project staff*
3:00 - 3:15	Break	
3:15 - 4:00	Synthesis of key issues	*UNC Project staff*
4:00 - 5:00	Discussion with participants about research implications and research agenda	

Friday – July 21, 2000

8:30	Coffee and other beverages	
9:00 - 9:30	Overview of previous day's accomplishments	
9:30 - 10:15	Feedback from different constituencies	*Participants*
10:15 - 10:30	Break	
10:30 - 12:00	Recommendations for UNC Project	
12:00	Adjourn	