Developmental Screening in Your Community

An Integrated Approach for Connecting Children with Services

by

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Dr. Bricker has an abiding interest in the preparation of early intervention leadership personnel. For more than three decades, the Early Intervention Program has graduated students who now fill leadership positions in institutions of higher education, who contribute to research efforts in the field, and who, in turn, prepare the next generation of early intervention personnel.

Dr. Bricker's distinctions include the Division of Early Childhood, Council for Exceptional Children Service to the Field Award, December 1992, and the Peabody College Distinguished Alumna Award, May 1995.

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Dr. Squires has served as principal investigator on numerous research studies focused on assessment in social-emotional competence, parent-completed developmental screening processes, personnel training, and systems change related to early identification and treatment of infants exposed prenatally to drugs and alcohol. She is a professor of special education, focusing on early intervention and early childhood special education. Dr. Squires has directed national outreach training activities related to developmental screening and the involvement of parents in the assessment and monitoring of their child's development, and on systems change related to early identification and treatment of infants exposed prenatally to drugs and alcohol.

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Dr. Marks has authored numerous journal articles and textbook chapters on the early identification, prevention, treatment, and ongoing monitoring of children with developmental and behavioral challenges. He has been a stalwart and enthusiastic "screening champion" in his own medical group, which blazed quality improvement trails by being "early adopters" of multiple screening tools, one of them being the Ages & Stages Questionnaires®, Third Edition (ASQ-3™), and then employed these tools in combination with the Reach Out and Read (ROR) program, which promotes early literacy and school readiness.

Dr. Marks was a key member behind Oregon's Assuring Better Child Development (ABCD) leadership team that spread the use of evidence-based screening tools statewide to other primary care practices. He participated in Oregon's Help Me Grow (HMG) project to improve care coordination services for children identified with suspected developmental delays and/or mental health problems. He has been involved in Oregon's Screening Tools and Referral Training (START) project, and is also a health advisor board member for his county's Head Start program.

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A Framework for Early Detection/Child Find

A Systems Approach

As noted in Chapter 1, this volume has two important goals. The first is to emphasize the importance of early detection as the most effective way to minimize the effects of physical or developmental problems on young children and to discuss the array of available data and information associated with early detection/Child Find activities in the United States. The second is to present a framework for early detection/Child Find based on a systems approach that offers a flexible structure that can be adapted to accommodate variations in community settings, personnel, populations, and resources. The ensuing chapters provide examples of how this approach to early detection/Child Find can be employed under a range of conditions and in medical, educational, and social services settings.

A scan of the professional literature in the field of pediatrics, early intervention/early childhood special education, and child development might suggest that there is broad support for the conduct of early detection/Child Find activities across communities in the United States (e.g., American Academy of Pediatrics, Committee on Children with Disabilities, 2001; Conroy & Brown, 2004). This may be accurate; however, as discussed earlier, developmental surveillance and screening activities in this country are hugely variable in terms of target populations, measures and procedures used, implementing personnel, comprehensiveness, feedback, and follow-up. Some health care practices and community agencies engage in systematic and comprehensive screening of young children for physical and developmental problems, whereas other states, regions, or localities rarely, if ever, offer parents or other caregivers any opportunity to formally examine their child's developmental status until the child is preparing to enter kindergarten.

The significant diversity of early detection/Child Find activities across the country may be due in large part to the absence of flexible and thus appropriate and applicable models or approaches that can be adopted and adapted to fit individual community needs. The absence of such models may also explain the many communities that have only rudimentary screening programs or procedures in place that often do not offer systems that include other components necessary for a comprehensive approach.

Although models exist for developmental surveillance and screening, these models tend to be developed for specific settings or practices. For example, the American Academy of Pediatrics has offered an algorithm for developmental surveillance and screening for pediatric practices (2006). This algorithm and its expansion by Marks, Glascoe, and Macias (2011), discussed in detail in Chapter 6, offers flexibility and does encourage cooperation across professionals and services; however, it is designed for use in pediatric practices. The aim of this chapter is to offer an early detection/Child Find approach that can be applied across the multitude of settings and by the various professionals in the United States responsible for the early identification of problems in young children.

The approach we propose has two basic processes and a series of critical content components derived from the pertinent literature and our experience working with the personnel who conduct early detection/Child Find programs throughout the nation. Strategies for adapting the approach to meet the varying needs of small, large, rural, urban, well-resourced, and poorly resourced communities are described in subsequent chapters. To meet this variability, we offer a flexible systems approach for the conduct of early detection/Child Find activities.

The systems approach we are advocating is centralized and emphasizes coordination across all components. By centralized we mean that communities funnel

their resources into a single service entity that offers coordinated early detection/Child Find services to all children. Such centralization reduces administrative costs and uses limited resources efficiently. In addition, such centralization should eliminate misunderstanding by parents and the general community about where and how screening is conducted, and by whom. Consistency in the measures being used and the uniformity of norms is assured. Although we advocate a centralized, single-service entity to conduct activities in each defined community, we understand that many communities have a variety of services and programs that offer early detection/Child Find services, including medical practices, health departments, and education programs. Such variability requires that the model we are proposing be flexible and adaptable so that communities with decentralized or multiple-service delivery units can use the approach but with the necessary adjustments and adaptations.

When applying the approach to communities with multiple services or agencies that are conducting early detection/Child Find activities, adaptations are required. The nature of the adjustments to the systems approach depends upon the multiple services being offered in each particular community as well as the available resources. To facilitate such adjustments, we strongly recommend the formation of a communitywide council that can coordinate activities across the participating services so that they complement rather than compete with each other. Coordination should produce better coverage (i.e., more children being served), more efficient use of resources, and greater community acceptance and understanding.

This chapter begins by presenting definitions of early detection/Child Find, developmental-behavioral screening, and the systems approach. Next, the important concepts of surveillance and follow-up are addressed and their use reviewed. Then, the two processes and six content components that make up the systems approach are defined and their parameters set. Finally, we discuss how the two fundamental processes of coordinating and checking guide the operation of the system's six components.

DEFINITIONS

As noted in Chapter 1, we have chosen to use early detection/Child Find as the umbrella terms to refer to the entire process of informing, finding, screening, and following up children who may have a physical or developmental-behavioral problem(s). Many authorities use *developmental screening* or other terms such as *developmental surveillance* to refer to the entire process; however, we have chosen to use early detection/Child Find to refer to all associated activities. We define *developmental-behavioral screening* as "a brief, formal evaluation of developmental skills intended to identify those children with potential problems who should be referred for a more in-depth assessment" (Squires & Bricker, 2007, p. 55). This definition captures the appropriate usage of developmental-behavioral screening for the systems approach described in this chapter, with two caveats. First, in our approach we are referring to a first-level or initial screening for children. That is, this approach is designed for first-level assessments of children's developmental status and should not be seen as a more comprehensive, in-depth evaluation. Second, "To be useful, first level screening programs need to assess large numbers of children and, therefore, require screening measures or procedures that are easy to administer, at low cost, and appropriate for diverse populations" (Squires, Twombly, Bricker, & Potter,

2009). Therefore, our systems approach offers a first-level, brief, low-cost developmental-behavioral screening procedure appropriate for a diverse range of children that reliably identifies children in need of further, more comprehensive evaluation. In addition, the approach incorporates the components of program goals, community awareness, contact and referral, follow-up, and overall evaluation.

Our view is that available screening models or approaches are relatively inefficient and ineffective for two important reasons: their inflexibility and their patchwork of disconnected services. The systems approach offered here is designed specifically to overcome these deficiencies. Because developmental-behavioral screening is conducted by an array of personnel and agencies with vastly different resources—and these conditions are likely to persist—this approach offers flexibility to the user. That is, the flexibility of the approach permits its adaptation to the assets and resources, whether modest or plentiful, of individual communities and works whether the system is centralized or incorporates multiple sites and services.

The systems approach coordinates its six components into a cohesive system of services. *Random House Webster's College Dictionary* (1992) defines a system as "An assemblage or combination of things or parts forming a complex or unitary whole." This definition reflects well our use of the term *systems* to modify the approach, in that we offer a series of components (i.e., things or parts) that work together to form a coordinated whole. Further, the checking/verifying process of the approach is designed to ensure the activities assigned to each component are completed.

PRECURSORS TO CONDUCTING EARLY DETECTION/CHILD FIND

Our years of experience with early detection/Child Find activities have made clear the need for a set of preliminary decisions surrounding key factors that are instrumental in shaping the approach adopted by a community. These factors include goals of the screening program, target population, and resources. To arrive at sound decisions about these factors, we recommend representatives from all relevant agencies meet for discussion and arrive at mutually acceptable decisions. Players are likely to include representatives from the public schools, medical/health practices, child development and social-welfare programs, and early intervention/early childhood special education programs. It may also be useful to have a parent representative(s) as a member of the planning group.

Often the most useful starting point is a discussion of available resources. Understanding potentially available staff and facilities will likely shape the selected goals. For example, resource-rich communities may be able to have a goal that encourages screening of all children at periodic intervals, whereas communities with limited resources may only be able to screen high-risk groups. It may be unwise to let

resource-limited communities select goals that are too narrow and unimaginative. Perhaps these communities can select modest goals with an eye toward increasingly comprehensive communitywide screening as resources permit.

PROCESSES AND CONTENT OF THE SYSTEMS APPROACH

As noted, the systems approach described in this chapter is composed of two processes and six content components. The content is embedded in the components of the approach, whereas the approach's processes shape its operation or function. Figure 5.1 provides a schematic of the proposed systems approach to early detection/Child Find that should be applicable across a wide range of communities with varying goals and resources.

The two processes, coordinating and checking/verifying, appear above the six content components in Figure 5.1, and the lines depict the continuous functioning of these two processes across components. The connecting lines and arrows between each component reflect the forward movement of data and information as the system unfolds. Finally, the returning arrows from the Overall Evaluation component indicate that outcome data are meant to inform each of the other components.

The remaining sections of this chapter discuss the two essential processes and the six content components and how each is guided by the coordinating and checking/verifying process.

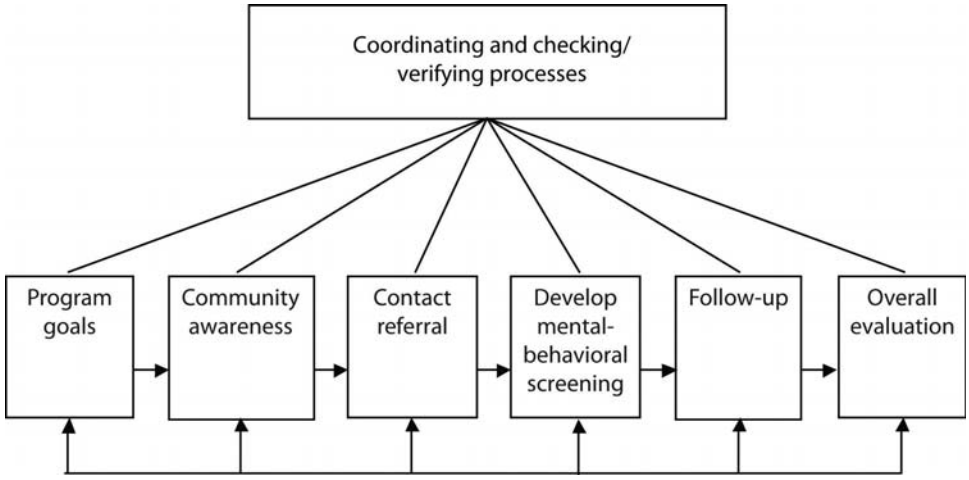

Figure 5.1. A schematic of the systems approach to developmental screening.

SYSTEMS APPROACH PROCESSES

The two essential processes of the proposed systems approach for early detection/Child Find are the coordinating and checking/verifying processes. The coordinating process addresses the need for connecting and aligning activities to help ensure all parts of the system work together to pass along information. The checking or verifying process addresses the need to ensure adequate action and follow-up occur as required.

The coordination process is the systems connection between its components because the initial content component is directly linked to subsequent components in two important ways. First, the initial component serves as a base for subsequent components, and second, information acquired during the initial component is moved to subsequent components. This linking process occurs with the ensuing systems components in that they serve as a base or platform for the actions associated with subsequent components. Information and findings are passed forward and directly infused into subsequent components. Thus, outcomes from the first component, Program Goals, directly affect component 2 and serve as the basis of action to be accomplished in component 2 and subsequent components. Data or information acquired during component 2 is likewise passed on to component 3, which in turn transmits information to component 4 and finally on to component 5. The final component—Overall Evaluation—passes its outcomes to all previous components to assist in verifying their effectiveness.

Checking/verifying is the second process associated with the proposed systems approach and refers to the requirement that some form of action and follow-up occur as the end point for each system component. Each component has associated actions or activities that must be undertaken and completed by the assigned personnel. For example, after referral to the screening component, the referring source is required to ensure the referral was received and is being acted upon. The screening component is, in turn, required to follow up by alerting the referring source that the screening has been completed and conveys the subsequent form of action recommended to the family.

The functioning of this system is guided by the coordinating and checking/verifying processes. The embedding of these processes throughout the system helps ensure information/data are passed along in a meaningful and efficient manner and that necessary actions are undertaken for each component (i.e., verified). In the next section, examples of the coordinating and checking processes are provided for each of the six components.

SYSTEMS APPROACH CONTENT COMPONENTS

As shown in Figure 5.1, the proposed systems approach is composed of six distinct but linked content components: 1) Program Goals, 2) Community Awareness, 3) Contact and Referral, 4) Developmental-Behavioral Screening, 5) Follow-up, and 6) Overall Evaluation. Each component has a specifically designed mechanism for checking on required actions or following up. In the next section, each component is covered: 1) definitions and purpose specified, 2) expected outcomes noted, 3) issues that may impact the creation and functioning of the component identified, 4) descriptions of the component's operational parameters provided and how the processes of coordinating and checking/verifying are embedded into the component, and 5) the type of data collected and passed on to the next component addressed.

This chapter describes a flexible approach to the creation and operation of a community-based system to ensure universal developmental-behavioral screening of all children birth through age 5. The requirement that the approach can be adopted to and adapted by a diverse range of communities and resources mandates that it be described in broad strokes rather than in specific detail.

Subsequent chapters are designed to assist potential users in the approach's application based on varying conditions and settings (e.g., an education or social services setting). In addition, it is important to note that the goal of the approach is universal early detection/Child Find for a community. Yet many communities lack the necessary resources for large-scale screening efforts and must initiate a Child Find program that targets only the most vulnerable children. This more modest goal is acceptable so long as the implementers maintain the long-term goal of universal screening for all children in the community and move toward that goal as resources and strategies permit.

We have stressed that the approach be community-based, which encompasses two important concepts. First, to be community-based, the approach must operate within and across a specific geographic region. Consequently, in relatively small population areas (e.g., small towns, rural settings), the community should be composed of all residents, even if great distances are involved. In larger population areas (e.g., large cities), several geographic communities may exist, for example, the east side versus the west side of town or the downtown area versus the suburbs. Finally, metropolitan areas that include millions of people can be usefully divided into many smaller geographic regions that comprise smaller communities. Early detection/Child Find programs should be designed to reach all members of a community so all eligible children can be recruited as resources allow. In areas where more than one screening program operates, the geographic boundaries should be clear and agreed upon so that children are not missed and services not duplicated. Thus, it is important that early detection/Child Find programs carefully specify their geographic target community.

The second concept associated with being community-based focuses on early detection/Child Find efforts as an integral part of the designated community. In this sense, *community-based* refers to creation and operation of the early detection/Child Find program by individuals and agencies/entities within a given geographic area that comprises a recognized community. The most effective early detection/Child Find efforts are likely to occur when members of the target community are intimately involved in the development of the program and its administration over time.

The remainder of this chapter discusses in detail the six content components of the systems approach that are guided by the processes of coordinating and checking/verifying. For each component presented in Figure 5.1, information on purpose, outcome, associated issues, operational parameters, the associated coordinating and checking processes, and the type of data to be collected is provided.

Component 1: Program Goals

We have included the development of program goals as a component because of the importance we assign to having a set of agreed-upon program aims or objectives to be addressed and hopefully accomplished. Program goals should guide and direct all subsequent decision making, action, and use of resources. It is important that program goals be selected by the community players central to early detection/Child Find activities.

Purpose In the present systems approach framework, the Program Goals component refers to the overriding accomplishments to be achieved through the

various actions undertaken by program personnel. The purpose of this component is to provide the necessary guidance for the selection and implementation of activities associated with the other five components of the approach.

Outcome The outcome for component 1 is a written document that contains clearly stated goals, the associated resources necessary to conduct the actions associated with each goal, and how these actions are to be evaluated.

Issues A number of issues may arise around the selection of program goals, including 1) who determines the goals, 2) determination of cost associated with actions or activities necessary to address the goal, and 3) mechanisms to evaluate progress toward goal acquisition. We believe the first step in the creation of an early detection/Child Find program is the selection of three to five program goals that guide all subsequent activities.

If the early detection/Child Find program is to be communitywide, it is essential to include all the critical players in the development and selection of program goals. Most likely, representatives from medical/health, social services, and educational agencies should be involved. It is probably better to err on the side of including too many rather than too few community representatives as program planners.

Once the critical players have been assembled, the next step is to determine what community resources are available to develop and operate the program. Identifying the available resources is of vital importance because it allows the planners to select attainable goals. It is also essential to estimate the potential cost associated with meeting each goal. For example, if a possible goal is to offer developmental screening to 100 children ages 12–36 months per year, the potential costs associated with that particular goal should be assembled. The number of personnel required to conduct the screening, the cost of materials, space requirements, and so forth should be evaluated so the planners can gauge the appropriateness and reasonableness of the selected goals. If costs appear to far exceed available resources, adjustments need to be made to program goals, or additional resources located.

Finally, selected goals should be examined to determine if they can be objectively evaluated. A goal of improving community awareness must be stated in a verifiable manner. For example, tracking the number of community agencies that have been contacted and/or tracking the number of public service announcements that occurred over a specified time period can offer objective information about the dissemination of information to the community.

Operation As suggested earlier, program goals should be determined by personnel who represent the critical agencies that may be associated with the development and implementation of an early detection/Child Find program as well as other important players (e.g., parent representative) in a designated community.

These critical players need to be assembled and program goals and an associated game plan created that is generally acceptable to most participants. Once program goals are chosen and the necessary resources identified, planners are ready to move forward.

Coordinating and Checking/Verifying The first component of the approach, Program Goals, sets the parameters and guidelines for the remaining components; therefore, each subsequent component should link back to the particular goals associated with the component's activities. Program goals should be agreed upon by all constituents who plan to participate in communitywide early detection/Child Find, and should be made known to all elements of the community. The checking/verifying process is conducted by reviewing the activities assigned to each component to determine if they are consistent with an associated program goal. In addition, the subsequent results should be compared carefully with the goal that served to originate the activity and to evaluate its success in addressing that specific goal.

Type of Data The type of data to be collected for this component is discussed in the Overall Evaluation component. In this final component a range of information and data should be collected to determine if program personnel are addressing and meeting the program goals developed in the first component.

Component 2: Community Awareness

Of all the approach's content components, Community Awareness may appear to be the least vital; however, without effective communication about the need for early detection/Child Find programs and their availability, the remainder of the approach is likely to be only modestly successful. For communitywide Child Find to occur, there must be in place mechanisms for informing parents/caregivers and relevant agencies about the importance of developmental-behavioral screening prior to school entry and how and where developmental screening can be accessed. The establishment of this component so that it functions effectively is one of the significant challenges to the creation of a systems approach for communitywide early detection/Child Find.

Purpose In the present framework, Community Awareness refers to procedures, mechanisms, or strategies developed and used to transmit information or to alert the general community as well as important players (e.g., parents of young children, agency personnel) about the importance of developmental-behavioral screening for young children, what the process entails, and how to obtain relevant information about accessing screening or have questions addressed. In other words, the purpose of this component is to disseminate essential information about early detection/Child Find to the community at large in a way that produces the desired

outcome (i.e., young children being referred for developmental-behavioral screening in a timely manner).

Outcome The desired outcome for this component is that parents/caregivers and agencies/organizations contact the personnel who operate component 3, Contact and Referral, to enroll children for developmental-behavioral screening. Component 2's success is a well-informed community of both individuals and organizations that refer or provide contact information for all young children eligible for screening in their community.

Issues A number of issues or conditions may affect the development and success of this component. At first, conveying information communitywide to parents/caregivers of young children may not appear challenging; however, a closer inspection reveals significant challenges inherent in establishing an information dissemination strategy that consistently is able to access families and to move them to action. The problem is largely that groups of children most at risk have parents or other caregivers who may be least able to recognize the benefits of early detection and intervention and least able (for a variety of often legitimate reasons) to access sources that would assist them in seeking developmental-behavioral screening for their child. Consequently, it may take considerable thought and effort to devise a community awareness plan that produces the desired outcomes (i.e., early detection of problems in young children).

A second issue or challenge is which personnel, agency, or resources are to be responsible for creating and communicating the outreach/awareness information. In order to ensure adequate functioning of this component, some personnel and/or entity must be responsible for at least three activities. First, the type of information to be disseminated needs to be developed or adopted and should match the resources available in the community for conducting developmental-behavioral screening. Second, dissemination of the information needs to be done so that the community becomes aware of this service and how to access it. Third, follow-up to determine the effectiveness of the awareness activities is essential. Is the information reaching the appropriate audiences and is it producing action (i.e., is a referral agency contacted)? If not, what adjustments are necessary?

An associated issue is cost, that is, what agency or group provides the funds or manpower to get the word out that developmental-behavioral screening is available. With some consideration, it may be possible to operate this component with little fiscal investment by accessing community resources such as public service announcements, or information transmission by agencies that offer services to the target children (e.g., Special Supplemental Nutrition Program for Women, Infants, and Children [WIC]; Child Protective Services [CPS]; volunteers).

How to ensure parents, caregivers, and relevant agencies (i.e., public schools, WIC) receive Community Awareness information in a timely manner is another important issue associated with this component. Having available essential information may be of little value if it does not reach the target audience in a timely fashion. If children eligible for early intervention are not identified until kindergarten,

it is likely that the problem(s) have worsened and that valuable intervention time has been lost.

A final issue concerns how communities with limited resources choose a target population that is to be the recipient of developmental-behavioral screening. Although we advocate the screening of all young children at periodic intervals, many communities do not have the necessary resources to offer screening to all children birth through age 5. In this event, careful consideration needs to be given to those children who are targeted initially (e.g., medically or environmentally high-risk infants). The awareness information needs to make clear what groups of children are eligible for community-based developmental-behavioral screening so the time of the parent/caregiver and the agency is not wasted. If it is necessary to focus screening efforts on specific populations, thought should be given to how more comprehensive screening could be accomplished in the future.

Operation There are probably many different but effective strategies for implementing the Community Awareness component. In most cases, using a variety of mechanisms to transmit information about developmental-behavioral screening results in a greater number of appropriate referrals. For example, encouraging public service announcements on local media, using information boards at libraries or other community agencies, and providing information to public school or child welfare personnel as well as health care practices yields desired outcomes. All potential fertile avenues for information dissemination should be explored.

The content of the information to be disseminated is important. The content should be relatively brief and simple to understand, with directions for contacting the referral group crystal clear. In effect, the message should be specific: developmental-behavioral screening is important, certain groups of children are eligible for screening, and this is the agency to contact for the service or further information.

We believe success of this component is substantially enhanced by having one central location and phone number. Personnel should be available on a regular basis, and when not present, some clear mechanism must be in place for taking and providing information (e.g., phone answering and messaging). In addition, personnel should have an intake form that guides gathering all necessary information so a complete referral can be made. Having a form in duplicate may facilitate referral to the Developmental-Behavioral Screening component. Finally, personnel associated with the operation of this component are responsible for ensuring that the referral was received and that appropriate and timely action was taken for each referred family. If multiple sites or groups are involved in the dissemination component, careful consideration should be given to the coordination of these sites/groups.

Coordinating and Checking/Verifying The two processes of coordinating and checking associated with the systems approach can and should be executed in this component. There should be a direct link between providing awareness information to the community and contacting personnel who operate the Contact

and Referral component. Thus, the information disseminated should make clear who is to be contacted and how to do it. The personnel responsible for component 2 activities are also obligated to check or verify with personnel assigned to component 3 the number and type of calls or contacts received, their timeliness, and appropriateness for offered services.

Type of Data The data to be collected for this component may include noting the number and type of community announcements made during a specific time and/or specific groups contacted and provided information. The response to the community awareness information is then determined in component 3 by assessing the number and type of referrals made semiannually or annually.

Component 3: Contact and Referral

Once strategies for dissemination of information are determined, the next component is Contact and Referral. As should be clear from the previous description, component 1 serves as the platform for component 2. So, too, a direct link exists between the information generated in component 2 and action taken by the personnel who operate the Contact and Referral component. That action should be a careful assessment of parent/caregiver and/or agency/program information and requests, followed by personal contact that provides the necessary information for connection to the appropriate resource (i.e., screening program or other more appropriate program).

The present approach advocates only one agency, site, or group be responsible for receiving requests for developmental-behavioral screening and for making appropriate and timely referrals. In many communities in the United States, multiple groups, sites, or agencies are responsible for receiving and dealing with referrals for screening. For example, Head Start, health clinics, and public schools may all have personnel assigned to conduct developmental-behavioral screening.

The involvement of multiple agencies in screening often creates problems and redundancy, both of which result in the poor use of limited resources. For example, there may be confusion about whom parents should contact if multiple agencies are conducting developmental screening. Having one clear central contact and referral agency in a designated community should reduce ambiguity and uncertainty and enhance the efficiency of the process. In addition, paying personnel to carry out the same function is very likely not the best use of limited resources. In most cases, it makes more sense to pool community resources to create a centralized site equipped to manage all incoming referrals. Even in communities where newborn screening programs or other programs with specialized target populations are available, a central site can be used to contact all eligible parents. However, if multiple sites/groups are involved, coordination is essential.

Purpose The purpose of the Contact and Referral component is to accept all calls and contacts asking for information on developmental-behavioral screening

and/or how to access the available screening program or programs. The Contact and Referral component is also responsible for making the appropriate referral for child and family in a timely manner and for following up the referral to ensure the appropriate action (i.e., an appointment for screening) has occurred.

Outcome The desired outcome for this component is that all parent/caregiver and/or agency queries about developmental-behavioral screening or further information about developmental-behavioral screening in the community are addressed in a timely manner that results in an appropriate referral. By appropriate, we mean that the child is directed to the program that can render the necessary assessment. By timely, we mean that queries or concerns are addressed within 1 or 2 days.

Issues Perhaps the most challenging issue associated with this component is its centralization. As noted, we believe creation of a central site and staff leads to the most effective use of resources. In the first place, consolidation should result in a more efficient operation because it permits the elimination of redundancy across agencies offering similar referral services. Second, a centralized staff should offer more consistent information to all callers, resulting in a coherent message to the designated community. Over time, most community residents should understand where developmental-behavioral screening information can be obtained. Third, confusion about whom to approach for developmental-behavioral screening information should be minimized because all referrals are made to a central site.

A second issue is how a community with limited resources can develop and maintain a centralized site and staff. Plans are needed for how relevant community agencies can work together to offer a centralized contact and referral service. Agencies may have to pool resources or one agency may have to accept the responsibility to provide this service—if this activity is consistent with its funding base. It is possible that some communities can only offer limited access to a contact and referral service, and although not ideal, this solution is superior to having no centralized site. Finally, some communities may need to search for new funds or resources to develop and maintain a centralized contact and referral source. Exploring federal, state, or local options may be necessary to identify resources for the creation of this service.

A final issue associated with this component concerns community agreement about the nature of the referrals made. This issue may not be a concern in communities where developmental-behavioral screening is only offered by one agency, and consequently, parents/caregivers or agencies can only be referred to one program. In these cases, the contact and referral group needs to work together with the developmental-behavioral screening program to ensure a smooth referral process. In communities where more than one agency or program offers developmental-behavioral screening, the referral staff have two important responsibilities. First, if programs differ—as well they might—in terms of target population or other variables (e.g., geographic location, income

level), the referral staff must ensure parents/caregivers are referred to the appropriate program. Second, if community programs offer similar services, the referral staff must be evenhanded in making referrals. Success will likely depend upon the referral staff meeting with screening staff and developing clear and comprehensive guidelines about referrals to maximize community resources and maintain professional collaboration and cooperation.

Operation The operation of this component can vary widely depending on community goals and the contact and referral agency and staff; however, in general, this component must oversee three important activities. First, it must have the capacity to accept incoming referrals or information-seeking on a regular basis. Thus, staff need to have time (or at least specified times) to answer queries of all sorts. Queries may be focused on obtaining information about what agency does developmental-behavioral screening and how to contact that agency. Queries can also be more general, so staff should be prepared to address a wide range of queries in order to be helpful.

The second staff activity is to evaluate the query and provide accurate and useful information. Thus, for caregivers exploring screening options for their child, staff need to gather the necessary information to make an appropriate referral. The third activity entails follow-up. Parent/caregiver or agency contact information should be collected, and at an appropriate time interval, the parent/caregiver or agency should be called to ascertain if the appropriate action has been taken and in most cases, the screening scheduled.

Coordinating and Checking/Verifying The two processes of coordinating and checking that underlie this systems approach also are operational in component 3. As component 2 serves as a platform for component 3, the Contact and Referral component serves as a platform for the Developmental-Behavioral Screening component. That is, there is a direct link between these components because the information acquired during component 3 drives the activity in component 4. The children referred from component 3 are the children for whom developmental-behavioral screening is provided in component 4.

The checking/verifying process occurs as staff in component 3 follow up to ensure parents/caregivers or agency personnel have contacted the appropriate developmental-behavioral screening program, an appointment has been arranged, and the screening has been completed. If follow-through has not occurred, contact and referral staff are responsible for contacting the parent/caregiver (or agency) to offer further assistance to ensure the screening occurs.

Type of Data The data collected for this component is of two types. First, careful records of referral should be kept. These data should include name, birthday, age, address, phone number, and reason for referral. The other data tracked should cover follow-up on referrals made to the Developmental-Behavioral

Screening component. Information on verifying if the referral was received, subsequent action taken (e.g., date of appointment for screening, mailing of screening measure to parent), and if the screening was successfully completed should also be kept.

Component 4: Developmental-Behavioral Screening

The initial components are designed to ensure targeted children receive timely developmental-behavioral screening. The major activity of this component is to complete an accurate and timely developmental-behavioral screening on each referred child. As we have emphasized, the ultimate goal for each community is universal screening of all children from birth through age 5.

Purpose The purpose of this component is to offer a brief, first-level determination of children's developmental/behavioral status using a formal procedure. The results should indicate if the child's development appears to be typical for his or her chronological age or if more comprehensive assessment is in order.

Outcome The obvious outcome for this component is that an appropriate and timely screening procedure is completed on all referred children. Therefore, when a referral is made, an appointment for screening should be made as quickly as convenient for parents/caregivers and the community screening program.

Issues Most small communities will likely have the necessary resources to support only one screening program and that program initially may have to be directed to specific high-risk populations. However, for large and/or diverse communities with ample resources, the first issue associated with this component may be a decision about the number and type of screening programs the community should create or support. The number and type of screening programs should be guided by the early detection/Child Find goals the community selected. Some communities may choose (and have the necessary resources) to have screening efforts conducted by all medical practices and clinics, as well as have early education and social services agencies screen specifically identified groups (e.g., young children in foster care). Other communities may be able to pool resources and create one central site and staff that conducts all developmental screening. This last option is usually the most cost-effective and reliable. In any event, if a community operates multiple screening efforts, it is essential that these efforts be coordinated to eliminate overlap, redundancy, and confusion in the community about appropriate referrals.

A second issue associated with this component is the choice of a developmental-behavioral screening measure. As noted in Chapter 4, screening measures can be categorized as either parent-completed or professionally completed.

Parent-completed measures are less expensive to use and usually offer more options for completion. For example, parent-completed measures can be mailed out, can be completed by phone or interview, can be completed while waiting for a medical appointment, or can be completed by child care workers who are familiar with a child's behavior. In addition, parent-completed measures address the recommended practice of including parents/caregivers in assessment activities for their children. However, the selection of a screening measure should be based on community goals. In addition, communities may choose to use a variety of measures depending on the target population chosen by specific screening programs.

A third issue concerns logistical decisions about who conducts the screenings; where the screenings occur, how appointments, if necessary, are set up; how screening intervals for children are tracked; and how to ensure appropriate measures are available (Clifford, Squires, Yockelson, Twombly, & Bricker, 2011).

Operation As can be deduced from a discussion of issues above, the operation of a screening program is dependent upon its goals and resources; however, there are certain requirements for this component that must be met by any group conducting developmental-behavioral screening, such as having a physical site and sufficient personnel to accomplish designated tasks: distributing screening measures, answering questions, tracking returns/completions, and following up. (The last is addressed in the next component.)

A developmental-behavioral screening program must have a site that houses staff, office materials, and test protocols. If a mail-out format or completion in existing clinics is used, it is not necessary to have child assessment space available. In most cases, it is necessary for parents or other agency personnel to make phone contact with screening personnel. Ideally, the program would have staff available on a predictable schedule so queries can be answered and assessment appointments scheduled in a timely manner. If the selected screening strategy is parent- or caregiver-completed, staff must be available to disseminate assessment protocols, answer questions, and score the child's performance on the screening measure. In addition, it is important to have a mechanism that ensures parents/caregivers received the screening measure or made an appointment to have the child assessed by screening personnel.

Required activities associated with this component include receiving a referral, providing information as necessary to parents/caregivers or agency personnel, ensuring the screening is completed by the parent or a professional, scoring the protocol, recording and disseminating findings to the appropriate entities, and conducting follow-up to ensure identified children receive an in-depth evaluation.

Coordinating and Checking/Verifying In this component, the coordinating process begins by receiving a referral from staff who operate the Contact and Referral component and ends with ensuring that the screening results are passed on to the Follow-up component. This component links to the next component by

passing on each child's screening results to ensure appropriate action is being undertaken.

The checking process for this component centers on developing strategies to first ensure all referrals are addressed in an appropriate and timely manner, that is, the referral is acknowledged and the necessary actions undertaken to conduct the screening. The checking/verifying process centers on creating a follow-up strategy that ensures the results of the developmental-behavioral screening are shared with the parents and the appropriate evaluation agency.

Type of Data The primary data collected by personnel in this component are number of referrals and outcomes from the screenings that are completed. It is important to keep track of the number of referrals and their geographic/demographic data in order to determine if the activities undertaken by the Community Awareness and Contact and Referral components are effective. Of course, it is essential that screening outcome data are tracked as well. It is important for personnel to know how many children are being identified as questionable and those not meeting age expectations.

Component 5: Follow-up

In many communities, the activities assigned to this component in the present approach may be assumed by the personnel who are conducting the developmental-behavioral screening. We have chosen to create a separate component to emphasize the importance of follow-up activities.

Purpose In our systems approach, the purpose of the present component is captured in the three distinct actions associated with follow-up. The first action is taken by personnel following the completion of the screening assessment, whether professionally or parent completed. Feedback is usually required by two or often three entities, including the 1) parents or the primary caregiver, 2) referring agency (if there is one), and 3) child's primary health care professional or clinic. Generally, the information or feedback shared addresses the child's performance on the screening measure. The feedback is generally one of three outcomes: the child's performance is similar to his or her chronological peer group, the child's performance is significantly different from his or her chronological peer group, or the child's performance shows some evidence of being below age expectations in one or more developmental areas. In addition, information on the reliability of the child's performance on the screening measure may be addressed (e.g., the child was cooperative, the parent appeared to grasp how to assess the child's performance).

Outcomes One outcome for this component is that the parent and the appropriate agency receive information in a timely manner and understand what the feedback means. A second outcome is that parents take the appropriate steps

based on the feedback received. For children whose performance on the screening measure appears to be typical, no subsequent action may be required; but for children whose performance was questionable or clearly below age expectations, concrete action is required. For children with questionable performance, follow-up screening should be scheduled and parents/caregivers encouraged to undertake a range of developmental activities to stimulate learning and growth in targeted areas. For children whose performance is below age expectations, a comprehensive developmental assessment is required.

Issues At least three important issues are associated with this component: responsibility for follow-up, nature of and process for sharing the information, and process for ensuring appropriate actions are undertaken.

In most cases, the personnel who manage the actual screening are responsible for sharing feedback with parents and other appropriate agencies. However, this responsibility should be made explicit as should the type of content to be shared and the procedure for doing so. In resource-rich programs, personnel may be able to call all parents to relay feedback, but in programs with limited resources, more cost-effective strategies, such as mail, may be used. If at all possible, we recommend caregivers be contacted directly for the few children who are identified as performing below age expectations. This personal contact is important to address parental unease and potential concerns, as well as to provide an opportunity to encourage subsequent appropriate action. As noted, for children who appear to be functioning at age expectations, personal contact is not essential. Contacting referring or health agencies to provide feedback can be done through cost-efficient means such as mail.

A second issue is the nature of the message delivered to parents or other primary caregivers, particularly when a child's performance is below age expectation or in the questionable range. It is important to remember that screening measures—even the very best ones—make errors. Thus the sharing of a child's performance must be couched in terms that emphasize that the results are only the first step and further verification is essential. Whether feedback is verbal or written, the content should be carefully formulated to present clear and accurate information about a child's performance. Of course, feedback to agencies should also be accurate and carefully constructed to reflect what is known about the child.

A final issue is how to ensure parents/caregivers take the necessary subsequent action. If feedback suggests further evaluation is essential, parents should be encouraged to seek a timely, comprehensive assessment of their child. In many cases, personnel who conduct the developmental-behavioral screening are also responsible for referring the family for more comprehensive evaluation. It is essential that follow-up activities ensure the proper referral is made and the appropriate action is taken by the evaluation agency (e.g., schedule a comprehensive evaluation in a timely manner).

Operation The operation of this component is highly dependent upon community resources and assignment of responsibility to agencies. If community resources are limited, it may be important to begin the screening program focused on very high-risk populations in order to keep screening numbers at manageable levels. We believe it is more important to serve a small group of children and families appropriately than to try to serve a larger group in ways that do not lead to accurate assessment, timely referral, and necessary follow-up. Each community and participating entity must determine how many children can be adequately managed, given available resources. It is better to begin small and do an efficient and effective job than to try to manage larger groups than resources comfortably permit.

Given the above caveat, essentials of the component's operation include assignment of responsibility for follow-up, the form and process for conducting follow-up, and a mechanism for assuring that the necessary information has been received and acted upon.

The operation of the Follow-up component is conducted by the professional or paraprofessionals who have been assigned the responsibility of informing parents and interested agencies (e.g., the child's primary health care provider) about the outcome of the screening. If personnel responsible for managing the screening are different from personnel responsible for follow-up, it is essential that a clear understanding exists about the division of labor between personnel. If different groups are involved, it may be wise to develop a written set of assignments and responsibilities.

In addition to assigning follow-up responsibility, the operation of this component requires specifying the form and process for disseminating the screening outcomes. As noted earlier, generally one of three outcomes describing the child's performance is possible: similar to age peers, in the questionable range, or below expectations. Also as noted earlier, we recommend that for all children whose performance is suspect, parents or other caregivers be contacted personally. Mailing feedback (e.g., a form letter) to parents whose children appear to be functioning within normal limits is acceptable. However, whether follow-up is personal or by mail, we strongly recommend that it be made clear whom parents can contact if they have concerns or questions.

The final operation of this component requires establishing a mechanism to ensure, to the extent possible, parents/caregivers have acted appropriately if they receive feedback that suggests their child's performance is questionable or clearly below developmental expectations.

At least two strategies are available for personnel to ensure parents have scheduled follow-up assessments. Personnel can call back parents at specified intervals to ensure an appointment has been made and the evaluation undertaken. Personnel can also check with the designated follow-up evaluation entity to ensure an appointment has been made and—most importantly—kept.

Coordinating and Checking/Verifying The actions to be taken in the Follow-up component are directly linked to the previous component, Developmental-Behavioral Screening. Results from the screenings of children are transmitted

to parents/caregivers and other designated agencies along with recommendations for subsequent action if needed. The data derived from the Developmental-Behavioral Screening component is directly linked to actions assigned to the Follow-up component.

In addition to a direct linkage between the Developmental-Behavioral Screening and Follow-up components, checking actions for this component entail having personnel verify progress toward subsequent evaluation of children whose performance is below age expectations. So as with previous components, actions inherent in this component are directly linked to previous component actions and procedures for verifying specified actions.

Type of Data Three important types of information should be assembled by personnel who operate this component. First, data should be kept on caregivers' follow-through on making and keeping appointments for further assessment. Second, data should be kept on the outcomes from the more comprehensive assessment (e.g., was the child identified as needing further services?). Third, subsequent action taken by caregivers should be tracked (e.g., was the child enrolled in an early intervention program?).

Component 6: Overall Evaluation

The final component of the systems approach described in this chapter is Overall Evaluation. It refers to the collection of information to verify the system is functioning as prescribed, targeting appropriate groups of children, accurately identifying children who are both typically developing and in need of further assessment, and producing general user satisfaction for both parents/caregivers and those implementing the system.

Purpose The Overall Evaluation component is composed of a range of actions whose purpose is to collect and analyze the necessary data and information to ensure the system is meeting its stated goals in an acceptable and timely manner.

Outcomes The activities conducted by personnel assigned to this component should produce outcomes that address how well program goals are being met. As an example, Table 5.1 contains a list of six possible goals for an early detection/Child Find program, with their associated data collection strategy.

Issues At least four issues are associated with the Overall Evaluation component. The first concerns the identification of funds to conduct the specified evaluation activities dictated by the program goals. Conducting evaluation usually requires a range of resources, with the most expensive being the personnel necessary to plan and execute the evaluation. Thus, at the stage when program goals are being developed

Table 5.1. Examples of possible program goals and their associated data collection strategy

Goal	Data collection strategy
At least 50 children from ages 6–32 months who have been identified as high-risk by the local child protection agency will be screened each year.	The number of children screened each month will be tracked.
Screening will be conducted by foster parents if possible.	Date, type of screening, and who conducted the screening will be tracked.
Following screening, all foster parents, social workers, and each child's health care entity will be provided feedback within 2 weeks.	Records of date, type of feedback, and receiving entities will be noted.
Follow-up evaluation will be conducted for all identified children within 30 days; other children will be screened at 6-month intervals until age 3.	Child, date, type of evaluation, and results will be tracked.
Screening results will be examined annually.	Screening data will be compared with comprehensive evaluation and with follow-up as appropriate.
User satisfaction will be assessed.	Caregivers and systems approach personnel will complete a user survey once per year.

(i.e., component 1), it is essential that resources and mechanisms for collecting and analyzing evaluation data are discussed and plans for doing so developed. Personnel need to be assigned to execute the data/information collection activities, analyze results, and disseminate outcomes to appropriate audiences. Evaluation plans do not have to be complex and expensive, but they do need to specify the essential activities to determine if program goals are being met in a timely and appropriate fashion. That requires thoughtful and careful planning and execution.

A second issue associated with this component involves the expertise necessary to formulate the questions appropriately, analyze results to answer the selected questions, and disseminate outcomes to designated parties. This requirement does not necessarily mandate the addition of staff with extensive evaluation expertise. An alternative is to recruit an outside evaluation expert(s) who can assist program staff in creating low-cost strategies to adequately address and answer the evaluation questions. Often, institutions of higher education have staff with evaluation expertise who are willing to assist in program evaluation efforts at little or no cost to projects that have limited funds.

A third issue concerns the type and number of evaluation activities proposed. As noted above, program goals should drive the evaluation activities. Thus, when personnel are considering program goals, they must simultaneously consider how each goal can be evaluated and if the program has the necessary resources to conduct the proposed evaluation activities. Programs with limited resources may have to consider and adopt modest evaluation efforts. Programs that have access to a more extensive resource base have the option to pose more extensive and complex data collection activities. It is essential that program goals, evaluation activities, and analysis are congruent with available resources and expertise.

A final issue associated with this component is how to disseminate the collected information. There are at least four important audiences that should receive evaluation information on a regular basis (e.g., semiannually, annually). These include parents/caregivers, program staff, interested/involved community agencies, and the general public. The nature of the disseminated information should vary by audience and should be designed to meet their needs and level of expertise. For example, an evaluation report that provides an overview of the findings may be appropriate for the general public, whereas a more in-depth report may be essential for both program personnel and community agencies. Reports to parents/caregivers should use straightforward language that can be understood by individuals with modest levels of education. Brief reports are often appropriate for parents and the general public, whereas reports for staff and community/state agencies may need to contain more detail on how data were collected and analyzed.

Operation As we have tried to make clear, the operation of each component is highly dependent upon program goals and available resources—so, too, with the Overall Evaluation component. The operation of this component is dependent on decisions made about program goals and the evaluation activities associated with each goal. With that caveat in mind, program staff should be prepared to undertake several important activities to help ensure the efficient and effective operation of this component: assignment of responsibility for conducting data collection activities, meeting timelines, undertaking data entry, performing data analysis, and preparing reports.

Assignment of data collection activities should be clear and may vary across program personnel. It may be most efficient for the personnel responsible for the developmental-behavioral screening to keep track of referred children, assessment outcomes, and the type of follow-up that occurs. These same personnel may be able to track subsequent evaluations, or it may be more efficient for the staff assigned this responsibility to record and keep these data. It may be necessary to have an administrator or manager be given the responsibility of ensuring that timelines are being met. Finally, the responsibility for data entry, analysis, and report writing may fall to program service staff or be assigned to specialized personnel, depending upon program resources. Regardless of program resources, assignment of the operational responsibilities associated with evaluation activities should be clear and monitored.

Coordinating and Checking/Verifying The evaluation activities conducted as part of this component should provide data that inform each of the previous components. Thus this component's, outcomes are directly linked to all previous system components as shown in Figure 5.1. Collected data and information should assist in determining if

- Program goals are being met.
- Community awareness is progressing as specified.

- Contact and referral is operating satisfactorily.
- Developmental-behavioral screening is being conducted on referred children.
- Follow-up is occurring in a timely manner.

In addition, the evaluation information and data collected should assist in checking the extent to which each component is meeting its stated expectations. Thus, the proposed approach composed of six separate but directly linked components is designed to operate as a unified system in which each component's activities can be checked by examining how well each meets its stated outcomes.

Type of Data As noted earlier, the type of data and information collected during the Overall Evaluation component is highly dependent upon program goals and resources. However, regardless of the type of information assembled, it is important that it be objective and address the specific goal with which it is associated. For example, if a program goal includes assessing parent/caregiver satisfaction, then personnel should formulate an objective means (e.g., written survey, focus group conducted by a third party) to assess parent/caregiver satisfaction with services offered, timeliness, and quality of feedback. Informal discussion will likely not yield substantial, verifiable information about how satisfied clientele have been.

SUMMARY

The authors of this volume are committed to the development of a universal early detection/Child Find system for all children birth through age 5 who reside in the United States—of course, we strongly support all international efforts to undertake universal Child Find as well. As we have argued in prior chapters, one of the most effective ways to assist young children with developmental problems is through early detection and early intervention. Accurate and widespread developmental-behavioral screening is fundamental to this goal.

To reach the goal of universal developmental-behavioral screening, approaches must be created that are easy to implement and cost-effective, and that produce desired outcomes. The purpose of this chapter has been to present a unified systems approach to early detection/Child Find that, we believe, is straightforward to implement, relatively low-cost because of its coordinating and checking/verifying processes, and can accurately identify children in need of further assessment. The system is composed of six components that are linked by directly sharing outcomes and checking that required actions have been taken. Flexibility is a hallmark of the approach to ensure its appropriateness and applicability to a wide range of programs located across our nation—programs that may have different goals and available resources and expertise.

Subsequent chapters apply variations of the systems approach framework in a range of settings (e.g., medical, education, social service). The goal is to assist personnel throughout the country in the development and implementation of efficient and effective screening programs that identify children in need of EI/ECSE services.