



Snapshots

Tracking Pathways of Referrals to Early Intervention

Carol M. Trivette and Carl J. Dunst

Abstract

The study described in this paper examined the extent to which contacts with different health-care professionals influenced referrals of 16 children with various diagnoses to early intervention. Information was gathered from interviews with the children's parent(s) and from records maintained as part of each child's participation in early intervention. Findings showed that for children who were seen by health-care professionals in hospital settings, referrals to early intervention were more likely to be made at the time of a child's diagnosis or at the time of recognition of a developmental problem. In contrast, the larger the number of contacts with nonhospital health-care providers, the longer it took for a child to become involved in early intervention. Implications for child find are described.

Introduction

The study described in this *Snapshots* investigated the pathways children traversed from the time they were diagnosed with an identified condition or disability to the time they were enrolled in an early childhood intervention program. We specifically examined the extent to which contact with health-care professionals working in different capacities made or did not make referrals for early intervention.

Young children with disabilities and identified conditions often have contact with non-early intervention professionals prior to enrollment in early intervention including, but not limited to, hospital staff (NICUs, specialty and follow-up clinics, etc.), primary care and specialty providers (pediatricians, cardiac specialists, orthopedists, etc.), and other human and social-service system practitioners, that facilitate or impede timely referral to Part C early intervention. The manner in which contact with hospital and nonhospital health-care providers influenced timely enrollment in early intervention constituted the focus of data analysis reported in this paper.

IDEA (1997) and the regulations for the Act (Early

Intervention Program for Infants and Toddlers with Disabilities, 34 C.F.R. § 303, 2002) both include explicit reference to the terms child find and referral. According to IDEA, states must not only develop and implement a comprehensive child-find system to locate eligible children, but must also develop procedures that professionals or parents can use to refer children to early intervention programs.

As used in this *Snapshots*, the referral process is defined as the "procedures or steps taken by an individual or group on behalf of an infant, toddler, or preschooler to obtain the opinions, supports, or services of another individual or group for a child" (Dunst & Trivette, 2004). Most, but not all, children with disabilities or developmental delays enrolled in early intervention or preschool special education programs are referred to early childhood intervention by physicians or other health-care providers. A referral includes a decision-making process used by primary referral sources (e.g., physicians, therapists, NICU nurses) to recommend or suggest the provision of early intervention services. Implicit in this process are both the reason for a referral and the need for a service or intervention to address a concern or treat a problem. The extent to which the focus of health-care professionals' concerns influenced a decision about a referral to early intervention was a secondary purpose of this study.

The study was conducted at the Tracking, Referral and Assessment Center for Excellence (TRACE). The major purpose of TRACE is to identify and promote the use of evidence-based practices for improving child find, referral, early identification, and eligibility determination of infants, toddlers, and preschool children with

Snapshots is a publication of the Tracking, Referral and Assessment Center for Excellence (TRACE) funded by the U.S. Department of Education, Office of Special Education Programs (H324G020002). Opinions expressed in this publication are the responsibility of TRACE and are not necessarily the views of the U.S. Department of Education. TRACE is a major initiative of the Center for Improving Community Linkages, Orelena Hawks Puckett Institute, www.puckett.org. Copyright © 2006 by the Orelena Hawks Puckett Institute. All rights reserved.

disabilities or developmental delays eligible for IDEA Part C early intervention or Part B(619) preschool special education (Dunst & Trivette, 2004; Dunst, Trivette, Appl, & Bagnato, 2004). The study was implemented at the Family, Infant and Preschool Program (FIPP) located in western North Carolina (www.fipp.org). FIPP is an early childhood intervention and family support program serving young children birth to eight years of age (Dunst & Trivette, 2005).

Method

Participants

Sixteen children enrolled in FIPP were the study participants. The children were purposely selected so that they had a wide range of disabilities and identified conditions. Six of the children had a chromosomal abnormality (five with Down syndrome and one with Cornelia de Lange syndrome). Four of the children had identified motor delays (two with cerebral palsy and two with spina bifida). Two of the children had identified developmental delays (one with global delays and one with autism). One child had a cleft palate and another child had visual and hearing impairments. Two of the children were born prematurely and had a number of associated developmental complications.

Data Collection

Information was obtained from two sources to develop pathway maps that chronicled the events and contacts the children had with professionals from the time of each child's birth to the referral of the children to early intervention. An interview process was used to gather information from the parent most involved in this stage of each child's life. This structured interview process included probes to ensure that parents provided as much detail as possible concerning the professionals with whom they had contact concerning their child's care prior to his or her referral to early intervention. During the interview, parents were asked to recall how they first learned about their child's diagnosis or developmental delay; the names and roles of professionals with whom the family had contact concerning their child; the content of the contact including what referrals, if any, resulted from the contact; and to whom referrals were made.

Information also was obtained through a review of all the records maintained as part of the enrollment process used by FIPP. These records included hospital birth records, records from primary and specialty medical personnel, and assessment and therapeutic reports from individuals and programs the parents encountered prior to enrollment in FIPP. This information was cross-referenced with the information gathered from the parents to ensure the information was as accurate and complete as

possible. When neither source included information that was deemed relevant, an attempt was made to obtain the necessary records with the parents' permission.

The information obtained from all sources was used to construct a timeline of events and contacts with different professionals and organizations. In most situations, the timeline began at the child's birth. However, when there was information suspecting or identifying a problem prior to the child's birth, the timeline began earlier. A chronology with dates of contacts, the name and profession of the contact person, and whether a referral to another agency or professional was made as a result of the contact, was developed using the information provided by the parent and abstracted from each child's chart.

Both independent and dependent measures were constructed from the pathways data. The independent variables were the number of contacts each child and family had with: (1) medical personnel from local and regional hospitals (e.g., NICU staff, referral personnel, specialty clinics) and (2) nonhospital medical personnel (e.g., family physician, pediatrician, cardiologist). The dependent variable was the number of days between (a) the time a child was first suspected of or it was known that the child had a disability or developmental concern and (b) the time when the child was actually referred to or enrolled in FIPP. Preliminary analysis indicated that the data for one child had outliers on both independent variables, and another child's data was an outlier on the dependent variable. Data for these two children were not included in the analyses described next.

Results

The number of days between the time a child was identified or suspected of having a disability or identified condition and the time a referral was made to early childhood intervention ranged from 1 to 376 days ($M = 134$, $SD = 26.60$). The number of contacts with hospital staff ranged from 0 to 4 ($M = 1.80$, $SD = 1.47$), and the number of contacts with nonhospital medical personnel ranged from 0 to 5 ($M = 1.87$, $SD = 1.72$).

The extent to which the number of contacts with hospital and nonhospital medical personnel was associated with differences on the dependent measure was determined by two regression analyses, one for the hospital staff contacts and one for the nonhospital staff contacts. The number of days between the time of identification of a child's disability or condition and the time of referral to early childhood intervention was regressed on the two independent measures, and the results were used to calculate Cohen's d effect sizes for the two linear trends. The findings are shown in Figure 1. As can be seen, the more contacts a child had with hospital personnel, the sooner a referral was made to early intervention ($ES =$

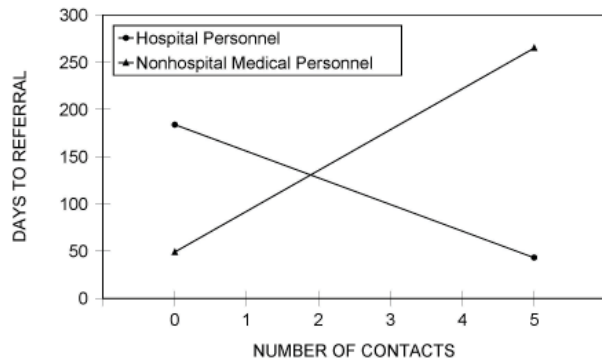


Figure 1 Linear trends between the number of contacts with hospital staff and nonhospital medical personnel and the number of days until a referral was made to early childhood intervention.

0.77). In contrast, the more contacts a child had with nonhospital medical personnel, the longer it took for a child to be enrolled in early intervention ($ES = 1.81$).

Discussion

The reasons for the divergent results found in this study, although not readily apparent, could be identified by close inspection of the focus of health-care providers' care of the children. Hospital staff tended to focus on disability or development related issues that, by definition, made the children eligible for early intervention. This included, but was not limited to, prematurity, specialty clinics for children with spina bifida, and genetic counseling. In contrast, many of the children seen by nonhospital staff were seen for medical but not disability or developmental reasons (e.g., a child with Down syndrome being treated for a heart condition). In these cases, the children's conditions constituting the focus of attention apparently were not seen as something warranting a referral to early intervention.

A lesson learned at TRACE regarding the conditions under which physicians make or do not make referrals to early intervention is that the focus of attention or concern by health-care providers influences when and to whom referrals are made. If the concern (disability, identified condition, etc.) is one that, at least in part, can be addressed by early intervention program staff, the likelihood that a referral will be made is generally high. In contrast, if the primary focus of attention or concern is a diagnosis that requires medical treatment, even if a child has a condition making him or her eligible for early intervention, the likelihood of a referral to early intervention is low.

Results from a recently completed review of physician referral practices (Dunst & Gorman, 2006), as well as several other research reviews (Faulkner et al., 2003;

Grimshaw et al., 2005), indicates that physician referrals are triggered by the condition that is of primary concern, which also influences when and to whom a referral is made. This has at least one important implication for child find practices. Taking the time to understand how primary referral sources "conceptualize" a child's needs can help identify how to focus child find efforts.

Acknowledgments

Appreciation is extended to Abigail Underwood for typing, Teresa Imfeld for editing, and Kaki Roberts for final layout of the manuscript.

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