MILEmarkers
Bibliographies of practice descriptions and selected evidence-based practices
Tracking, Referral and Assessment Center for Excellence

Sources of Information on Risk Registries Useful for Child Find

Carl J. Dunst, Jill Fromewick, and Shannon M. Lucas

This *Milemarkers* bibliography includes selected references to databases for locating children with or at risk for disabilities and delays and conditions associated with poor developmental outcomes. Five different types of risk registries and population-based surveillance programs that monitor children for the purpose of providing needed supports and resources are included. The information in the bibliography is useful for conducting child find activities to locate infants, toddlers, and preschoolers eligible or potentially eligible for early intervention or preschool special education.

States are required by the Individuals with Disabilities Education Act (1997) to conduct child find to identify and locate infants, toddlers, and preschoolers who are in need of and eligible for early intervention or preschool special education. The Part C regulations state that child find includes, but is not limited to, activities that take full advantage of existing sources of information about eligible children and the use of methods and strategies that establish and identify those children who are most likely to demonstrate developmental delays necessitating early intervention or preschool special education (Early Intervention Program, 2002).

A review of the risk registry literature finds that there are five major types of risk registries that would seem especially useful for child find purposes (Dunst, Trivette, Appl, & Bagnato, 2004). This *Milemarkers* includes selected references to research and practice on risk registries that practitioners responsible for locating eligible children should find informative and useful for conducting and improving child find activities. Risk registries are one type of child find practice (Dunst & Trivette, 2004) that constitute the focus of research and practice at the Tracking, Referral and Assessment Center for Excellence (www.tracecenter.info).

Risk Registries

Birth Defects Surveillance Programs

Birth defects surveillance programs maintain registries of children born or diagnosed with birth defects. A birth defect "encompasses a diversity of conditions including physical malformations, sensory deficits, chromosomal abnormalities, metabolic defects, neurodevelopmental disorders, complications related to prematurity and low birth weight, and other conditions" (Sever, 2004, Chapter 3, p. 3-2). Surveillance programs serve numerous functions, including, but not limited to, "the identification of children who need special education, social services, and other programs" (Lynberg & Edmonds, 1994, p. 223). Dunst, Trivette, Appl, and Bagnato (2004) describe the special value of birth defects surveillance registries for conducting child find activities.

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Milemarkers 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 those of TRACE and do not necessarily reflect 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.

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Montgomery, A., & Miller, L. (2001). Using the Colorado Birth Defects Monitoring Program to connect families with services for children with special needs. *Teratology, 64*, S42-S46.

Sever, L. E. (2004, June). *Guidelines for conducting birth defects surveillance*. Atlanta, GA: National Birth Defects Prevention Network.

Watkins, M. L., Edmonds, L., McClean, A., Mullins, L., Mulinare, J., & Khoury, M. (1996). The surveillance of birth defects: The usefulness of the revised U.S. standard birth certificate. *American Journal of Public Health, 86*, 731-734.

Newborn Medical Screening Programs

Newborn medical screening programs operate much like birth defects surveillance programs but include screening tests for conditions not included in birth defects registries (U.S. General Accounting Office, 2003). Most conditions are metabolic disorders, including, but not limited to, phenylketonuria, sickle cell disease, maple syrup urine disease, and cystic fibrosis. Inasmuch as many "screened" conditions are associated with subsequent developmental delays or disabilities, these databases would seem of special value as sources of child find information. According to the American Academy of Pediatrics (2000), newborn medical screening programs are useful for the "early identification of conditions for which early and timely interventions can lead to the elimination or reduction of associated mortality, morbidity, and disabilities" (p. 389).

American Academy of Pediatrics, Newborn Screening Task Force. (2000). Serving the family from birth to the medical home: Newborn screening: A blueprint for the future. *Pediatrics, 106*, 383-427.

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McCabe, L. L., Therrell, B. L., Jr., & McCabe, E. R. (2002). Newborn screening: Rationale for a comprehensive, fully integrated public health system. *Molecular Genetics and Metabolism, 77*, 267-273.

Stoddard, J. J., & Farrell, P. M. (1997). State-to-state variations in newborn screening policies. *Archives of Pediatrics and Adolescent Medicine, 151*, 561-564.

U.S. General Accounting Office. (2003, March). *Newborn screening: Characteristics of state programs* (GAO-03-449). Washington, DC: Author.

Newborn Hearing Screening Programs

Newborn hearing screening programs specifically involve tests administered at birth or shortly thereafter that involve the early detection of hearing loss or deafness. According to Mehl and Thompson (1998), universal newborn hearing screening is both feasible and justified as a basis for identifying infants who may benefit from early intervention. Newborn hearing screening programs are mandated by law or are implemented voluntarily in the largest majority of states. Most of these programs include a requirement or provision that infants identified with a hearing loss must be referred to appropriate services, including early intervention.

Brackett, D., Maxon, A. B., & Blackwell, P. M. (1993). Intervention issues created by successful universal newborn hearing screening. *Seminars in Hearing, 14*, 88-104.

Davis, A., Bamford, J., Wilson, I., Ramkalawan, T., Forshaw, M., & Wright, S. (1997). A critical review of the role of neonatal hearing screening in the detection of congenital hearing impairment. *Health Technology Assessment, 1*(10), 1-4.

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U.S. Preventive Services Task Force. (2001). Newborn hearing screening: Recommendations and rationale. *American Family Physician, 64*, 1995-1999.
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White, K. R., & Maxon, A. B. (1995). Universal screening for infant hearing impairment: Simple, beneficial, and presently justified. *International Journal of Otorhinolaryngology, 32*, 201-211.
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Child Protective Services Registries

In accordance with the Keeping Children and Families Safe Act (2003), states are now required to develop provisions and procedures for referring children birth to 36 months of age who have been abused or neglected to Part C early intervention programs. Forty-seven (47) states and several jurisdictions maintain central or local registries of children who have been abused or neglected (National Clearinghouse on Child Abuse and Neglect Information, 2004). These registries can be especially useful for identifying children who are eligible for but not receiving early intervention.

Crosse, S. B., Kaye, E., & Ratnofsky, A. C. (1992). *A report on the maltreatment of children with disabilities*. Washington, DC: National Center on Child Abuse and Neglect.
Kotch, J. B., Browne, D. C., Dufort, V., & Winsor, J. (1999). Predicting child maltreatment in the first 4 years of life from characteristics assessed in the neonatal period [Electronic version]. *Child Abuse and Neglect, 23*, 305-319.
Robinson, C. C., & Rosenberg, S. A. (2004). Child welfare referrals to Part C. *Journal of Early Intervention, 26*, 284-291.
Rosenberg, S., & Robinson, C. (2003). Is Part C ready for substantiated child abuse and neglect? *Zero to Three, 24*, 45-47.
Sidebotham, P. (2000). Patterns of child abuse in early childhood, a cohort study of the "children of the nineties". *Child Abuse Review, 9*, 311-320.
Sullivan, P. M., & Knutson, J. F. (2001). Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse and Neglect, 24*, 1257-1273.

Population-Based Registries

Population-based registries include information on individuals who have one or more characteristics or conditions that make them the focus of tracking, monitoring, and outreach for the purpose of providing services, resources, or supports (Boland, 1996; Zeich, 1998). The four different types of registries described above are examples of population-based sources of information about children who may be eligible for early intervention or preschool special education. Knowledge of other kinds of population-based risk registries and research can help broaden the scope of child find activities.

Avchen, R. N., Scott, K. G., & Mason, C. A. (2001). Birth weight and school-age disabilities: A population-based study. *American Journal of Epidemiology, 154*, 895-901.
Cragan, J. D., Roberts, H. E., Edmonds, L. D., Khoury, M. J., Kirby, R. S., Shaw, G. M., Velie, E. M., Merz, R. D., Forrester, M. B., Williamson, R. A., Krishnamurti, D. S., Stevenson, R. E., & Dean, J. H. (1997). Surveillance for anencephaly and spina bifida and the impact of prenatal diagnosis - United

States, 1985-1994. *Teratology, 56*, 37-49.
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Keenan, H. T., Runyan, D. K., Marshall, S. W., Nocera, M. A., & Merten, D. F. (2004). A population-based comparison of clinical and outcome characteristics of young children with serious inflicted and noninflicted traumatic brain injury. *Pediatrics, 114*, 633-639.
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Thorngren-Jerneck, K., & Herbst, A. (2001). Low 5-minute apgar score: A population-based register study of 1 million term births. *Obstetrics and Gynecology, 98*, 65-70.
Torfs, C. P., & Christianson, R. E. (1998). Anomalies in Down syndrome individuals in a large population-based registry. *American Journal of Medical Genetics, 77*, 431-438.
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Summary

Risk registry and surveillance program databases include information about infants, toddlers, and preschoolers who are or may be eligible for early intervention or preschool special education. Knowledge of these databases; close working relationships with registry program personnel responsible for making referrals to supports, resources, and services; and the development and implementation of procedures for mining these databases for child find purposes should improve identification of eligible children. This *Milemarkers* included selected references to risk surveillance databases that practitioners responsible for locating eligible children should find informative for child find.

Acknowledgments

Appreciation is extended to Tharesa Owenby for typing, Teresa Imfeld for editing, and Kaki Roberts for final formatting of the manuscript.

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Authors

Carl J. Dunst, Ph.D., is Co-Principal Investigator of the Tracking, Referral and Assessment Center for Excellence (TRACE) and Research Scientist at the Orelena Hawks Puckett Institute in Asheville, North Carolina (dunst@puckett.org). Jill Fromewick, M.S., is a Research Associate at the Orelena Hawks Puckett Institute (jfromewick@puckett.org). Shannon M. Lucas, M.L.I.S., is Research Librarian at the Puckett Institute (slucas@puckett.org).