

## Sources of Information About Possible Early Identification Activities During the Health Care Planning Process

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This *Milemarkers* bibliography includes selected references to sources of information about various health care planning processes for children eligible or potentially eligible for early intervention or preschool special education. The development of hospital discharge plans, hospital-to-home transition plans, continuity of care plans, and coordinated care within medical homes constitute opportunities for early intervention and preschool special education staff to work with health care providers to identify children eligible or potentially eligible for Part C or Part B(619) services. The sources of information should be useful to practitioners responsible for increasing referrals to early intervention or preschool special education programs.

As part of meeting the requirements of the Individuals with Disabilities Education Act (IDEA) regulations (Early Intervention Program, 34 C.F.R. § 303, 2002), practitioners are expected to institute procedures to promote referrals from primary referral sources (e.g., medical personnel, hospitals) to early intervention or preschool special education programs. Influencing the health care planning process used by hospitals and private practices constitutes one way of increasing referrals to Part C early intervention or Part B(619) preschool special education personnel. Important components of this process are activities and efforts that influence the decision-making processes of primary referral sources within the health care system to recommend or “prescribe” early intervention or special education services for children eligible or potentially eligible for services.

This *Milemarkers* bibliography includes selected references to sources of information pertaining to efforts of Part C early intervention and Part B(619) preschool special education practitioners to have health care professionals include early intervention or preschool special education as prescribed or recommended services on health care plans (Krehbiel, Munsick-Bruno, & Lowe, 1991). A review of health care planning literature identified four opportunities for practitioners to influence the health care planning process: (1) hospital discharge plans, (2) hospital/home transition plans, (3) continuity of care plans, and (4) medical homes. When health care plans are being written regarding discharge requirements, transitions out of the hospital setting, movement of children into the community, and identification of possible community resources, it is advantageous for early intervention or special education personnel to be involved in the planning process to ensure these services are part of the plans (Browne, Lan-

glois, Ross, & Smith-Sharp, 2001). Health care planning practices are one type of referral activity (Dunst & Trivette, 2004) that constitutes the focus of research and practices at the Tracking, Referral and Assessment Center for Excellence ([www.tracecenter.info](http://www.tracecenter.info)).

### Health Care Planning Process

#### *Hospital Discharge Planning*

Hospital discharge planning has traditionally been viewed by health care professionals as the process hospital staff use to identify what must occur in order for the child to be released from the hospital. For example, within the Neonatal Intensive Care Unit (NICU), this planning process typically focused on what the parents needed to learn to care for their child at home and what the child’s developmental status (e.g., weight level) must be before the child is discharged (American Academy of Pediatrics, 1998). Historically this planning was done with minimal connection to or involvement with community resources that might be available to the child or parents following

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discharge. In the early 1990s, this view began to change and many hospital staff and families now jointly plan with community partners during the hospital discharge process, with the goal of a smooth discharge and transition to the community (Bruns & Steeples, 2001). The sources of information in this section of the bibliography focus on collaborations among hospital staff and early intervention or preschool special education personnel during the discharge planning process. The reader will find it helpful to review the sources of information in this and the next section (*Hospital to Home Transition Plans*) because many of the resources address both hospital discharge planning and transition planning.

- Browne, J. V., Langlois, A., Ross, E. S., & Smith-Sharp, S. (2001). Beginnings: An interim individualized family service plan for use in the intensive care nursery. *Infants and Young Children, 14*(2), 19-30.
- Bruns, D. A., & Steeples, T. (2001). Partners from the beginning: Guidelines for encouraging partnerships between parents and NICU and EI professionals. *Infant-Toddler Intervention: The Transdisciplinary Journal, 11*, 237-247.
- Gamblian, V., Hess, D. J., & Kenner, C. (1998). Early discharge from the NICU [Review]. *Journal of Pediatric Nursing, 13*, 296-301.
- Katz, K. S. (1993). Project Headed Home: Intervention in the pediatric intensive care unit for infants and their families. *Infants and Young Children, 5*(3), 67-75.
- Krehbiel, R., Munsick-Bruno, G., & Lowe, J. R. (1991). NICU infants born at developmental risk and the Individualized Family Service Plan/process (IFSP). *Children's Health Care, 20*, 26-33.
- Wyly, M. V., Allen, J., Pfalzer, S. M., & Wilson, J. R. (1996). Providing a seamless service system from hospital to home: The NICU Training Project. *Infants and Young Children, 8*(3), 77-84.

### **Hospital-to Home Transition Plans**

For parents of infants cared for in the NICU, leaving the hospital is often the beginning of the family's relationship with community supports, services, and resources. It is important to the health of the child and well-being of the parents for hospital transition plans to focus on the services, resources, and supports that will be needed to help the child and family successfully move from the hospital back home (Affleck, Tennen, Rowe, Roscher, & Walker, 1989; Kotagal et al., 1997; Rieger & Henderson-Smart, 1995). The resources in this section provide early intervention and preschool special education personnel information about strategies for developing with family members and hospital staff transition plans that

focus on child services and family supports needed to ensure a successful transition.

- Amato-Bowden, C. (1997). Neonatal follow-up care: Implications for home health care. *Home Health Care Management and Practice, 9*(3), 52-62.
- Bruder, M. B., & Cole, M. (1991). Critical elements of transition from NICU to home and follow-up [Electronic version]. *Children's Health Care, 20*, 40-49.
- Bruder, M. B., & Walker, L. (1990). Discharge planning: Hospital to home transitions for infants. *Topics in Early Childhood Education, 9*(4), 26-42.
- Gillette, Y., Hansen, N. B., Robinson, J. L., Kirkpatrick, K., & Grywalski, R. (1991). Hospital-based case management for medically fragile infants: Program design. *Patient Education and Counseling, 17*(1), 49-58.
- Hussey-Gardner, B., McNinch, A., Anastasi, J. M., & Miller, M. (2002). Early intervention best practice: Collaboration among an NICU, an early intervention program, and an NICU follow-up program. *Neonatal Network: The Journal of Neonatal Nursing, 21*(3), 15-22.
- Kotagal, U. R., Perlstein, P. H., Gamblian, V., Donovan, E. F., & Atherton, H. D. (1995). Description and evaluation of a program for the early discharge of infants from a neonatal intensive care unit. *Journal of Pediatrics, 127*, 285-290.
- Shotts, C. E. (1995). *Hospital to home: A guide for transition planners*. Topeka, KS: Associated Colleges of Central Kansas & Kansas State Department of Health and Environment, Kansas Coordinating Council on Early Childhood Developmental Services. (ERIC Document Reproduction Service No. ED397584).
- Tien, C.-L., Peterson, C. A., & Shelley, M. C., II. (2002). Postdischarge service use by families of neonatal intensive care unit graduates. *Journal of Early Intervention, 25*, 42-57.

### **Continuity of Care Plans**

Continuity of care plans are mechanisms for generating the necessary flow of information between medical care providers and community providers to ensure appropriate clinical management of a patient's needs (Haggerty et al., 2003). Continuity of care is the desired outcome of a patient's move between medical systems and community resources, and the development of a continuity of care plan can help ensure this outcome is accomplished (Cameron, 1994). This section of the bibliography includes sources of information about various characteristics and models of continuity of care that provide opportunities for practitioners from early intervention or preschool special

education to work with medical care providers to ensure the identification of children eligible or potentially eligible for early intervention or special education services.

- Gilkerson, L., Gorski, P. A., & Panitz, P. (1990). Hospital-based intervention for preterm infants and their families. In S. J. Meisels & J. P. Shonkoff (Eds.), *Handbook of early childhood intervention* (pp. 445-468). New York: Cambridge University Press.
- Girard, N. J. (1976). Home visits give continuity of care. *AORN Journal*, *24*, 1057-1062.
- Godchaux, C. W., Travioli, J., & Hughes, L. A. (1997). A continuum of care model. *Nursing Management*, *28*(11), 73-76.
- Haggerty, J. L., Reid, R. J., Freeman, G. K., Starfield, B. H., Adair, C. E., & McKendry, R. (2003). Continuity of care: A multidisciplinary review (education and debate). *British Medical Journal*, *327*, 1219-1221.
- Inkelas, M., Schuster, M. A., Olson, L. M., Park, C. H., & Halfon, N. (2004). Continuity of primary care clinician in early childhood. *Pediatrics*, *113*, 1917-1925.
- Jackson, B., Finkler, D., & Robinson, C. (1992). A case management system for infants with chronic illnesses and developmental disabilities [Electronic version]. *Children's Health Care*, *21*, 224-232.
- Miller, L. P., Greenspan, B., & Dowd, J. S. (1999). The medical database as a tool for improving maternal/infant continuity of care. *Journal of Medical Systems*, *23*, 219-225.

### Medical Home

In the early 1990s, the American Academy of Pediatrics (AAP) began to define what they considered the essential characteristics of a medical home. The AAP (2004) operationally defines a medical home as a place where care provided to children is accessible (e.g., provided in the child's community), family-centered (e.g., recognition of the primary role of the parent), continuous (e.g., same primary health care professional from infancy to adolescence), comprehensive (e.g., preventive, primary, and tertiary care needs addressed), coordinated (e.g., linkages to support, educational, and community-based services), compassionate (e.g., concern for well-being of child and family expressed), and culturally competent (e.g., family's cultural background is recognized, valued, and respected). Though the Academy believes every child should have a medical home, much of the work around this concept has focused on children with special health care needs or disabilities (Cooley, 2003; Starfield, 2003). This section of the bibliography provides the reader with sources of information concerning the role of the physician as coordinator of local educational and support

services for children with special health care needs or disabilities as well as general information about the medical home and how well it is working.

- American Academy of Pediatrics, Medical Home Initiatives for Children With Special Needs Project Advisory Committee. (2004). The medical home. *Pediatrics*, *113*, 1545-1547.
- Burstein, K., & Bryan, T. (2000, August). Parents as partners in the medical home: Helping children with special healthcare needs: Introduction to a special series. *Exceptional Parent*, *30*(8), 29-31.
- Cooley, W. C., & McAllister, J. W. (2004). Building medical homes: Improvement strategies in primary care for children with special health care needs. *Pediatrics*, *113*, 1499-1506.
- Nickel, R. E., Cooley, W. C., McAllister, J. W., & Samson-Fang, L. (2003). Building medical homes for children with special health care needs. *Infants and Young Children*, *16*, 331-341.
- Sia, C., Tonniges, T. F., Osterhus, E., & Taba, S. (2004). History of the medical home concept. *Pediatrics*, *113*, 1473-1478.
- Starfield, B., & Shi, L. (2004). The medical home, access to care, and insurance: A review of evidence [Review]. *Pediatrics*, *113*(5 Suppl.).
- Strickland, B., McPherson, M., Weissman, G., Van Dyck, P., Huang, Z. J., & Newacheck, P. (2004). Access to the medical home: Results of the national survey of children with special health needs. *Pediatrics*, *113*, 1485-1492.
- Wehr, E. (2002). Vermont parent doctor team designs a medical home for children with special healthcare needs. *Exceptional Parent*, *32*(6), 72-78.
- Ziring, P. R., Brazdziunas, D., Cooley, W. C., Kastner, T. A., Kummer, M. E., Gonzalez de Pijem, L., et al. (1999). Care coordination: Integrating health and related systems of care for children with special health care needs. *Pediatrics*, *104*, 978-981.

### Summary

Transition planning by health care practitioners and early intervention or preschool special education personnel is one approach to increasing referrals of eligible or potentially eligible children to Part C or Part B(619) programs. This *Milemarkers* includes selected references to planning processes and research findings for taking advantage of these medical transitions to help eligible children become involved in appropriate services. The material in this bibliography should be useful to practitioners responsible for developing and implementing referral activities.

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## References

- Affleck, G., Tennen, H., Rowe, J., Roscher, B., & Walker, L. (1989). Effects of formal support on mothers' adaptation to the hospital-to-home transition of high-risk infants: The benefits and costs of helping. *Child Development, 60*, 488-501.
- American Academy of Pediatrics, Committee on Fetus and Newborn. (1998). Hospital discharge of the high-risk neonate: Proposed guidelines [Electronic version]. *Pediatrics, 102*, 411-417.
- American Academy of Pediatrics, Medical Home Initiatives for Children With Special Needs Project Advisory Committee. (2004). The medical home. *Pediatrics, 113*, 1545-1547.
- Browne, J. V., Langlois, A., Ross, E. S., & Smith-Sharp, S. (2001). Beginnings: An interim individualized family service plan for use in the intensive care nursery. *Infants and Young Children, 14*(2), 19-30.
- Bruns, D. A., & Steeples, T. (2001). Partners from the beginning: Guidelines for encouraging partnerships between parents and NICU and EI professionals. *Infant-Toddler Intervention: The Transdisciplinary Journal, 11*, 237-247.
- Cameron, B. (1994). The impact of pharmacy discharge planning on continuity of care. *Canadian Journal of Hospital Pharmacy, 47*(3), 101-109.
- Cooley, W. C. (2003). The medical home: Improving primary care for children with special needs. *Advances in Family-Centered Care, 9*(1), 4-7.
- Dunst, C. J., & Trivette, C. M. (2004). Toward a categorization scheme of child find, referral, early identification and eligibility determination practices. *Tracelines, 1*(2), 1-18. Available from <http://www.tracecenter.info/products.php>.
- Early Intervention Program for Infants and Toddlers with Disabilities, 34 C.F.R. § 303 (2002).
- Haggerty, J. L., Reid, R. J., Freeman, G. K., Starfield, B. H., Adair, C. E., & McKendry, R. (2003). Continuity of care: A multidisciplinary review (education and debate). *British Medical Journal, 327*, 1219-1221.
- Kotagal, U. R., Atherton, H. D., Bragg, E., Lippert, C., Donovan, E. F., & Perlstein, P. H. (1997). Use of hospital-based services in the first three months of life: Impact of an early discharge program. *Journal of Pediatrics, 130*, 250-256.
- Krehbiel, R., Munsick-Bruno, G., & Lowe, J. R. (1991). NICU infants born at developmental risk and the Individualized Family Service Plan/process (IFSP). *Children's Health Care, 20*, 26-33.
- Rieger, I. D., & Henderson-Smart, D. J. (1995). A neonatal early discharge and home health support programme: Shifting care into the community. *Journal of Paediatrics and Child Health, 31*(1), 33-37.
- Starfield, B. (2003). The Medical Home Index applies primarily to children with special health care needs. *Ambulatory Pediatrics, 3*, 173-180.

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