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An Overview of Policy Issues in Access to Care for Children with Disabilities*

Deborah Spitalnik**

This article presents a brief overview of the policy issues affecting access to health care for children with disabilities.

I. Who are Children with Disabilities?

Children with disabilities are among the most vulnerable children in our country. Based on estimates from the 1994 Disability Supplement from the National Health Interview Survey, 6.1 million children under the age of 17 are considered disabled.¹ Children with developmental disabilities, those severe disabilities that originate in childhood and persist throughout the life span, represent some 1.3 million or 21% of the population of children with disabilities.² The population of children who are eligible for Special Education services is larger than the group of children who have developmental disabilities.³ Children with developmental disabilities represent only a subset of children eligible for Special Education.

Developmental disabilities accrue from mental or physical impairments or a combination thereof. Developmental disabilities can be described functionally or categorically by disease en-

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1. See Michele Adler, *People With Disabilities: Who Are They?*, Presented at *Beyond the Water's Edge: Charting the Course of Managed Care for People with Disabilities 1* (Nov. 20-22 1996) (Copies available from the Office of Disability, Aging and Long Term Care Policy/ASPE/DHHS).

2. See *id.* at 6.

3. See *id.* at 2. There are 4.7 million children are eligible for Special Education. See *id.*

tity or diagnostic groupings. Functionally, the developmental disabilities in children may include, in varying constellations, severe limitations in cognition, self-care, mobility, communication, social development, and learning. Moreover, developmental disabilities include such diagnostic categories as mental retardation, cerebral palsy, epilepsy, autism, Spina Bifida and severe sensory disabilities.⁴ From the array of conditions and range of functioning within these conditions, as well as the overlap of many of these conditions and potential combination of functional impairments, it is evident that children with developmental disabilities represent a very heterogenous population. Planning for health care for children with disabilities is complicated by the diversity in this population of children.

Disability in children, in whatever diagnostic or classification descriptive frameworks utilized, must also be recognized as a social condition. Societal factors play a significant role in who is born disabled or becomes disabled, as well as the type and severity of their disabilities.⁵ Fujiura and Yamaki at the University of Illinois have clearly established that poverty is a central dynamic in mental retardation and developmental disabilities.⁶ The occurrence of mental retardation and developmental disabilities is not random in the population.⁷ If you are poor, you are more likely to have a child with mental retardation or developmental disabilities.⁸ If you have mental retardation or other developmental disabilities, you are more likely to be poor as an adult.⁹

As the population changes, the risks for long-term disability also undergoes changes. According to the survey of Income and Program Participation (SIPP), people with developmental disabilities constitute 1.1% of the population.¹⁰ Fujiura, in analyzing the SIPP data, demonstrated a real variation in the

4. See PAMELA LOPREST AND GREGORY ACS, THE HENRY J. KAISER FAMILY FOUNDATION, *Press Release for PROFILE OF DISABILITY AMONG FAMILIES ON AFDC* (August 22, 1996).

5. See Glenn T. Fujiura and Kiyoshi Yamaki, "Analysis of Ethnic Variations in Developmental Disability Prevalence and Household Economic Status," 35 *MENTAL RETARDATION* 286, 290 (1997).

6. See *id.*

7. See *id.*

8. See *id.* at 291-292.

9. See *id.*

10. See Fujiura and Yamaki, *supra* note 5, at 286, 289.

prevalence of developmental disabilities by race and ethnic group.¹¹ For Latinos, the prevalence of developmental disabilities is .82%, for African-Americans it is 1.36% and for Whites the rate is .90%.¹²

Having a child with mental retardation or developmental disabilities can have a very inhibiting effect on families' economic mobility and their access to other services. The mean monthly household income is lower for families of children with developmental disabilities than for families whose children do not have developmental disabilities.¹³ For African-American and Latino households with children who have developmental disabilities, the mean monthly income is lower than it is for White households with children who have developmental disabilities.¹⁴

II. The Nature of Disabilities which Originate in Childhood

Developmental disabilities which originate in childhood not only change the child's life trajectory, but also the life trajectory of the family. The nature of parenting a child with a disability is often different than parenting a child without developmental problems. The responsibilities of parenthood and actual caregiving often last longer into and even throughout the adulthood of the developmentally disabled child. It is not unusual to see families of young children with disabilities experiencing a type of premature aging, exhibiting concerns about issues that usually plague older adults.¹⁵ Parents of young children with disabilities, aware of the extended period and nature of the care their children need, worry about what will happen to their children, if they, the parent, become incapacitated or die. Children with disabilities are often isolated from peers their age because of the ways that services are organized and may segregate children with disabilities or stigmatize them further. Families are

11. *See id.* at 289.

12. *See id.*

13. *See id.* at 291.

14. *See id.*

15. *See* Michele Adler, *People With Disabilities: Who Are They?*, Presented at *Beyond the Water's Edge: Charting the Course of Managed Care for People with Disabilities 1* (Nov. 20-22 1996) (Copies available from the Office of Disability, Aging and Long Term Care Policy/ASPE/DHHS).

often isolated from their extended family, their neighbors, colleagues and communities.

III. Different World Views: Health Care and Disabilities

Children with disabilities, as with their adult counterparts, are faced not just with medical and health issues, but also social issues and life challenges. The Children's Supplemental Security Income (SSI) Program, under the Social Security Administration, tends to medicalize disability. Health care providers are inclined to be trained and view disability only in terms of the medical aspects of the child's condition. Children with disabilities need primary health care, as do all children. They may also require specialty care to address some of the aspects of their disabilities. Children with disabilities and their families also need certain services and support, including education and social services, which may even be more extensive than their medical needs. These needs vary by the child's age, the nature of the disabilities and their family and community context.

Accessible services that are coordinated across systems are essential for the well-being of children with disabilities and their families. Families' experiences with case management or care coordination within a maternal and child health system or developmental disabilities service agency may enable families to draw on the services they want for their child. Within the health care system, particularly within managed care, care coordination is utilized with condition-specific protocols, to improve care, but also to strictly control resources.

A health care perspective tends to view disabilities in terms of cure or remediation, weighing the consideration for providing services against the standard or judgment of medical necessity. The disability movement is a fight for the rights of full inclusion and participation in community life, and attaining and maintaining functioning and is responding to different imperatives than those of health care systems.

IV. Health Care Needs of Children with Disabilities

All children need a medical home: a place where they are known, where they receive primary care and where their medical records reside. For the child with disabilities, who may need

the care of multiple specialists, a medical home is perhaps even more critical. Health care providers, in particular, often perceive disabled children only in terms of the health consequences of their disabilities. A medical home enables children with disabilities to be seen as children, who, as all other children, have age-specific health care needs, including the need for immunizations, checkups and screenings or family guidance.

Children with disabilities need knowledgeable, skilled and sensitive health care practitioners. While medical providers should not see the child only in terms of their disability, they must also understand issues of co-morbidity and the implications of typical childhood illnesses in children with particular disabilities.

Children with disabilities and their families need health care providers who value them, who see children with disabilities not as mistakes or casualties, but as full human beings to whom they will provide assistance for their development. These needs raise many policy issues about how we train health care providers. Many of the medical students I teach value mental ability as the hallmark of personhood, and technology leading to cure as the primary role of the physician. Children with disabilities often do not fit that mold, so it is very easy for them to be ignored or devalued by the health care system.

Access to specialty networks and durable medical equipment (DME) is also important for children with disabilities. Health care services, in addition to being age-appropriate, also need to be developmentally appropriate. Wheelchairs and other equipment need to be upgraded to keep pace with the growth of the child. Frequently, limitations in benefits packages for equipment and the need for frequent replacement impede the availability of developmentally appropriate equipment. Limitations on the amount of DME or supplies, such as limiting the number of catheters supplied for children with Spina Bifida, can have adverse effects on health for the child, and eventually result in the need for more extensive and expensive health care services downstream. Children with disabilities need significant access to allied health therapies, including physical, occupational and speech and language therapies. It is difficult to ensure that benefits packages for disabled children, particularly

under managed care, are adequate because of the lack of research on the advantages of these therapies.

Coordination of care across systems is essential. Physicians must work in partnership with families, with schools, with allied health therapists, with durable medical equipment and assistive technology providers to enhance and maintain functioning in children with disabilities.

V. Managed Care and the Needs of Children with Disabilities

Most states have made Medicaid managed care mandatory for Temporary Assistance to Needy Families (TANF) recipients, (formerly Aid to Families with Dependent Children [AFDC]), and voluntary, at least up until recently, for children and adults whose disabilities are recognized by their status as SSI beneficiaries.¹⁶ Although the data is incomplete, we know that within the TANF population there are significant numbers of adults and children with disabilities, who, because of their TANF status, are now in mandatory Medicaid managed care, without the contract requirements that many states are considering to protect the rights and address the needs of children and adults with disabilities.¹⁷ The Kaiser Foundation estimates that 27-29.5% of the former AFDC population is thought to be either a mother or a child with disabilities and 18-21% is a mother with a disability or a child with a severe disability.¹⁸ Within this very poor population, there are competing social policies and inequities: economic independence for families, and the difficulty in finding available, adequate day care for children with disabilities.

The gatekeeper function within managed care, typically performed by the primary care physician, is particularly critical for kids with disabilities. Children with disabilities need gatekeepers who are knowledgeable and sensitive about their needs and the types of services that are necessary to maintain and enhance their functioning. The demands of managed care have

16. See PAMELA LOPREST AND GREGORY ACS, THE HENRY J. KAISER FAMILY FOUNDATION, PROFILE OF DISABILITY AMONG FAMILIES ON AFDC 15 (1996).

17. See *id.*

18. See *id.* at 15.

created changes in the way that primary care physicians are trained. These changes are not necessarily conducive to the development of the skills necessary to address the needs of children with disabilities. Residency training requirements have changed for both pediatricians and family practitioners. The expectations of what primary care providers will be able to do in the managed care setting have increased, including providing more experience with radiology and other kinds of generic functions. Our concern is that as these generic skills stretch primary care providers, and that there will be less time to devote to developing the skills necessary to properly care for children with disabilities.

The existence and adequacy of specialty care networks within a managed care organization is of great concern for children with disabilities. Not only does there have to be a network available, it has to be accessible. The anecdotal experience of families of children with disabilities who have joined managed care plans, particularly commercial plans, is that they may have joined the plan because of a particular specialist(s), only to find that the patient panel of the specialist they want is closed. Many families of children with disabilities, particularly those with complex or low incidence conditions, have pieced together a specialty network for their child and want and need to be able to utilize that set of practitioners in a coordinated way. That may not be possible in many plans.

The nature of the benefit package for children with special health care needs and disabilities is very important. Advocates should be looking at Medicaid managed care contracts in terms of what benefits and services are specified. Paradoxically, children who are Medicaid beneficiaries, receive more protections, at least theoretically, than children who have private, commercial insurance. These protections include, for as long as it continues, the Early Periodic Screening, Diagnosis and Treatment Program (EPSDT) which are, in effect, standards of care. The Medicaid contract with the specificity of its provisions, and the benefits packages with its mechanisms for addressing the rights of beneficiaries also provide additional protection to children with disabilities and their families who are Medicaid recipients. In commercially purchased managed care, there are no standards of care for children with special health care needs and

disabilities, and no real mechanisms for influencing that directly.

The State Child Health Insurance Program (SCHIP), while enhancing access to health care coverage for uninsured children, may not be adequate coverage for children with special health care needs and disabilities. Whether SCHIP meets the needs of disabled children will hinge upon the nature of the benefit package. Although many states have created in effect, a buy-in to the Medicaid program, it is unlikely that states will be willing to create or replicate the richness of the Medicaid program benefit package and protections.

The complexity of need and the vulnerabilities of children with disabilities are almost a litmus for how well managed care can perform for any of us. There are entitlements and protections for children with disabilities that Professor Fentiman will address.¹⁹ Whether the promise inherent in these laws comes to pass for children with disabilities will depend on our advocacy and the political will of our country.

19. See Linda C. Fentiman, *Health Care Access for Children with Disabilities*, 19 PACE L.REV. 245 (1998).