

# Universality, Inclusion, and Continuity: Implications for Pediatrics

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ABBREVIATION. SSI, Supplemental Security Income.

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Generalists tend to be broad, universal, and holistic in how they view children and communities, more lumpers than splitters. Universality, inclusion, and continuity are three concepts that help inform the work of academic general pediatricians in policy and research. Webster's defines universality as "the quality or state of including or covering all. . . without limit or notable exception." Inclusion is defined as "to take in, enfold, or comprise. . . as a part of a larger aggregate," the opposite of exclusion. Continuity is an "uninterrupted connection or succession; close union of parts." This article addresses applications of these concepts in four areas: 1) eligibility for programs and services; 2) continuities in the health of children; 3) program coordination, consolidation, and demonstrations; and 4) the implications for general pediatric research and policy.

## ELIGIBILITY FOR PROGRAMS AND SERVICES

Determining program eligibility requires finding ways to include and exclude people, unless programs are universal. The strong American tradition has been to set up exclusionary eligibility categories and distinctions for most public programs. Consider first health insurance. Debates on universal health insurance in the United States began more than 75 years ago. The Ambulatory Pediatric Association and other general pediatric groups have long argued for universal coverage for America's children and adolescents. Yet, the United States remains one of the few industrialized countries lacking universal access to health insurance.

The lack of universal inclusion and the presence of multiple eligibility categories make access to services difficult for families. Changes in Medicaid law in the 1980s broke the link between welfare and Medicaid eligibility.<sup>1,2</sup> Yet, of the millions of children who became eligible under new Medicaid categories, only one third have enrolled over the last 10 to 15 years, partly because many families

never understood the new and different categories and states never developed effective strategies to market them.<sup>3</sup> With the advent of SCHIP, the new state child health insurance programs, many states fear that a simple expansion of Medicaid will "crowd children out" of private insurance, that is, many children and adolescents would forego private insurance for more generous public insurance. Thus, states have developed still more eligibility categories, again complex and difficult for potential enrollees to understand. Continuing this process to its natural conclusion could result in an individual eligibility category for every American child and adolescent. Colleagues in almost all other nations know that universality in health insurance makes sense and that parceling out different programs for different populations increases administrative costs and sets up artificial barriers. Worrisome is the trend in countries such as New Zealand to Americanize health insurance, decreasing universality and inclusion by limiting services covered by national health insurance. Will eligibility definitions become another American export?

What of the debates about universal coverage for all household members versus coverage of children and adolescents first? Many advocates have supported a Children First legislative approach, but can one really justify the notion of ill parents lacking preventive and treatment services raising healthy children who have health insurance? The United States must achieve fully universal coverage, and other nations should maintain strong trade barriers to prevent the infusion of American eligibility systems into their health care programs.

The Supplemental Security Income (SSI) program provides additional insight into categories. The SSI program has grown tremendously in the last several years, now covering more than 1 million children and adolescents under age 18 years.<sup>4</sup> SSI provides cash and, in most states, access to Medicaid for low income people with severe mental, physical, or developmental disabilities.<sup>5</sup> Program growth engendered a flurry of public, media, and congressional attention and concern, especially after a Bob Woodward article in the *Washington Post* in 1994 asked whether most of these children deserved benefits.<sup>6</sup> Much of the debate revolved around "deserving" and "undeserving populations."<sup>7,8</sup> Many politicians felt it appropriate to reimburse families if having a child with a disability caused a major decrease in family income or forced them into poverty. Families who began poor and whose child was born with or developed a

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disabling condition were considered less deserving of public support. During these debates, pediatricians were asked whether attention deficit hyperactivity disorder is a behavioral disorder or a neurologic condition, with the latter deserving cash but not the former. Parents were viewed as responsible for the *behavior* of their children but not for the consequences of a neurologic abnormality. Although there has been debate regarding the appropriateness of attention deficit hyperactivity disorder for cash benefits, the important point here is the categorization into deserving and undeserving.

The SSI debate came down to which conditions or diagnoses merit the label of “severely disabling,” distinguishing children included and excluded. SSI is an on–off program without gradation of eligibility, and the categories assume similar levels of severity whether a person has mental retardation or lung or kidney disease. The SSI program thus recognizes that diverse conditions cause similar needs for families. (In contrast, hospitals tend to organize increasingly specialized services that increasingly subdivide children into multiple condition categories.) The notion of commonalities, that similarities across classes of children and their families overshadow the diagnostic diversity of their health conditions, comes from work of Barry Pless and Nick Hobbs years ago.<sup>9</sup> Conversations with parents of children with a diverse group of chronic conditions in the context of a policy research project in those years led to the formulation of the 85/15 rule.<sup>10</sup> This rule acknowledges that most issues (perhaps 85%) families face raising a child with a chronic condition have little to do with the specific diagnosis but rather reflect universal issues encountered in dealing with a chronic condition requiring specialized services and changes in family activities. The other 15% does reflect specific diagnoses, treatment, and outcomes.

It is instructive to compare the history in the United States with that in other countries. Almost every country provides some disability-related benefit, rarely means-tested and rarely based on specific diagnosis.<sup>11</sup> In Scandinavia, parents whose children have major disabilities have an increase in approved sick-leave days, with the social contract recognizing that the care of these children requires additional time from parents. England provides cash benefits when a person in the household has a mobility impairment or requires caretaking. These benefits apply universally, without regard to socioeconomic status, and provide resources to the entire household rather than only to the child. Unfortunately, England faces increasing political demands to limit benefits to lower income populations, again emulating the American way.

Categories are of course not all bad. They often are essential for allocating resources or for research purposes. When used to enhance inclusion and improve monitoring for special populations, they may benefit many people. Where resources are scarce (and they always are), categories provide ways to ensure that services go to those most in need or most likely to benefit from them. At some

point, decisions must be made to determine who does get SSI benefits. But the construction of categories in the absence of differential effectiveness can create real barriers to services and artificial boundaries that may do substantial harm in the long run. Intellectually, multiple categories recognizing the diversity of children’s needs might make sense; administratively, multiple categories are a nightmare. Having many categories causes administrative complexity, which wastes money. And risks of categorizing include providing labels that constrain a child’s opportunity or characterizing some groups as deserving or undeserving. Categories also affect opportunities for advocacy. Consider the political history of Medicare and Medicaid. Medicare, a universal program for elderly populations, has tremendous political support. Medicaid, viewed somewhat inaccurately as a poor people’s program, has much less support.

#### CONTINUITIES IN THE SYSTEM OF HEALTH SERVICES FOR CHILDREN

The notion of universality applies also to systems of health care—how inclusive they are, how they integrate across services and child health problems. Three continuities seem particularly important: public health and personal health care; primary care and subspecialty care; and behavioral symptoms in children. Improving the health of young children and their families requires a collaboration between public health efforts and personal health services.<sup>12</sup> Most agree that the provision of immunizations should be integrated into ongoing comprehensive primary care, yet the availability and distribution of immunizations require substantial public health efforts. Emergency medical services are important in the management of accidents once they occur, and primary care should address injury prevention. But necessary public responsibilities include monitoring and improving the safety of environments, hand gun control, diminishing access to hazards and toxins, and developing community awareness and prevention campaigns. Programs to improve child health related to tobacco use, domestic violence, unwanted pregnancies, or the development of healthy physical lifestyle during adolescence require active collaboration between personal health and public health.

Almost all industrialized countries and many without strong industrial bases invest in a universal preventive public health program. Methods vary greatly. The health visitor in Great Britain assesses community needs, links services within communities, provides street-based health prevention, and does home visiting.<sup>13</sup> At child health stations in Belgium and France, families receive cash payments if they bring their children for preventive care, including immunizations. Community health centers in Scandinavia provide physician and nursing services in virtually every community. These programs all are universally available to all citizens, without means testing (at least not yet). A recent examination of the effects of type of universal health program in several European coun-

tries—a national health system versus universal health insurance alone—on health status found better perinatal outcomes in those countries with strong investment in public health and a national health system.<sup>14</sup> The data also indicated that the unit costs of improving health outcomes were lower in countries with national health systems. Thus, investments that link public health with personal health services appear to lower costs and improve health outcomes.

Academic generalist pediatricians typically think in ways that reflect a public health and population-based orientation, often linked with great sensitivity to what they learn from or do in the clinical encounter. They think more clearly in public health ways than do most other health providers and recognize the continuities that affect the health and wellbeing of young people. Of concern is the decline in support for public health in America, especially maternal and child health, over the last 20 years. Given their deep interests in the essential nature of this relationship, generalists must recognize the limitation of health insurance alone in meeting child health needs and stress the importance of synergy with public health to improve child health. Generalist pediatricians must reforge links with the public health community.

However, other and related strategies also are needed to improve the health of populations. Consider the central role of comprehensive primary care in the continuum from primary to subspecialty care. Barbara Starfield's leadership in exploring all facets of primary care has documented the relationship between health status and a nation's commitment to primary care. Starfield's rule is that nations that emphasize primary care have better health status and satisfaction with care. Her provocative paper in *JAMA* in 1991 documented these findings across studies in several industrialized countries and gave the lowest primary care score to the United States.<sup>15</sup> In her Martha May Eliot address to the American Public Health Association, Starfield added consideration of France, a nation not included in her 1991 paper.<sup>16</sup> Here she noted improved health outcomes for young populations, despite relatively little emphasis on primary care in a system of personal health services similar to that in the United States. She attributed these results to the remarkable publicly funded maternal and child health programs in that country.

These two notions—serious investment in public health and strong commitment to primary care—operate together to lower expenditures and improve health status. Of interest, Canada rates high on measures of primary care but lacks a universal preventive or public health system. Although Canada rates high on health outcomes, the United States and Canada are the countries with the highest percentage of their gross domestic product spent on health care.

A brief comment about continuities in child behavior and general pediatric practice: The Diagnostic and Statistical Manual for Primary Care for children and adolescents, developed by the American

Academy of Pediatrics with strong support from the Ambulatory Pediatric Association, describes the continuum or spectrum of child and adolescent behavior.<sup>17</sup> The Diagnostic and Statistical Manual for Primary Care considers that pediatricians commonly work with families around a continuum of child behaviors, including variations, problems, and disorders, without attempting to provide sharp demarcation among the categories. Nonetheless, insurance companies, Medicaid, and managed care operations generally have been loath to recognize the breadth of child and adolescent health and rather pay only for care for diagnosed mental health disorders, subverting preventive mental health care and encouraging the mental health community to overpathologize behaviors.

#### PROGRAM COORDINATION, CONSOLIDATION, AND DEMONSTRATIONS

Governments in market-driven economies typically spawn a multitude of programs, often with overlapping jurisdictions and concerns but, as with Darwin's finches, a tendency to shy away from courting nearby neighbors. In the 1970s, the federal government tallied 23 different federal programs for migrant farm workers, each with a different definition of farm worker. Among programs for children with disabilities in the United States, the definitions used by early intervention, special education, the SSI program, the Title V Maternal and Child Health Programs for Children with Special Health Care Needs, the Centers for Disease Control, the Americans with Disabilities Act, and the National Health Interview Survey, all are different. And foundations, so important (primarily in the United States) to fill gaps in public programs, also compete with each other to carve out their niche, focusing attention on specific populations, hoping to do something unique.

For families and the communities in which they live, the logic behind definitions that demarcate distinctions makes little sense. Easier to understand would be integrated programs, providing coordinated services meeting the needs of families. Yet families in the United States typically endure a bewildering plethora of services, with different sites for primary health care, immunizations, nutrition, or adolescent services. Community agencies attempting to integrate programs face complex arrays of reporting requirements, definitions of eligibility, or program periods. Common conflicts over land and turf create disincentives for program collaboration. Consolidating funding resources can be particularly difficult.

Many pediatricians have tried to bring change to their communities. America is a land of demonstrations, investing in imaginative programs that often provide real solutions to community needs. Yet, the nation has less capacity to engage the much more difficult task of bringing demonstrations to universal application. Policymakers often use the great diversity of populations in the United States to justify different demonstrations in different communities, overlooking the universal concepts that

might support serious policy changes affecting the lives of larger numbers of children and families. Although America “demonstrates” more than most other industrialized countries, France, Britain, and other countries increasingly have joined this effort, allowing a proliferation of demonstrations to limit more fundamental change in public policy to improve family health.

Important exceptions to this rule exist. An examination of five state maternal and child health programs that began as local demonstrations of coordinated integrated service delivery systems and then were implemented statewide indicated that necessary components generally included forward-thinking bureaucrats in high positions who had the authority to make state agencies collaborate, defined a collaborative mission, changed the incentives for midlevel employees, and made pooling of resources a central and common theme, all strategies promoted currently by the Milbank Memorial Fund in its Reforming State Government program.<sup>18</sup> These programs aimed to improve pregnancy outcomes, primary care for young children, or services for children with special health care needs.<sup>19</sup> Interestingly, research data had little to do with the statewide implementation of any of these projects.

The Robert Wood Johnson Foundation Child Health Initiative attempted to coordinate multiple funding streams in several communities. Although projects succeeded primarily in linking only two or three sources, the program’s evaluation offers lessons for future work and provides evidence that fragmentation of services prevents effective health care; fragmentation can be reduced, with care coordination and home visiting as key elements; health financing reforms follow service delivery innovations; significant improvements take time; technical assistance helps; small investments go a long way, and communities will embrace care coordination. These issues provide a reminder that the tasks involved in integrating services are complex and require a good deal of thought and preparation, along with an understanding of the power structures that exist and of effective methods to develop a commitment to change.

Lee Schorr’s work identifying programs that improve outcomes for children and households in complex high risk situations also provides guidance for change. In *Common Purpose*, Schorr describes seven attributes of highly effective programs: they are comprehensive, flexible, and responsive; they deal with children in their family and community contexts; they have a preventive orientation and a clear mission; they have high standards and an accountable staff; they operate with intensity and perseverance; staff have flexibility in their jobs and develop strong relationships with families; and they recognize limits of a service strategy and build community and economic opportunity. We know a great deal about what works, but less about methods of implementing what works universally. Schorr notes the complexity of this effort and the tendency to miss key lessons:

“Part of this gap between knowledge and action springs from traditions which segregate bodies of information. . . . Complex, intertwined problems are sliced into manageable but trivial parts. . . . Academics burrow for what remains unknown but often fail to herald what is known. . . . Successes achieved by health centers, schools, and family service agencies have common characteristics which form patterns that are rarely perceived.”<sup>20</sup>

### Implications for General Pediatric Research and Policy

The notions of universality and continuities have long directed academic generalists to research focusing on children rather than on diseases and on populations rather than on individuals. This focus is more consistent with the efforts of the Maternal and Child Health Bureau and the Agency for Health Care Policy and Research than those of the National Institutes for Health, although concepts of universality and generalism surely deserve more attention within traditional National Institutes of Health funding as well. Physicians trained in pathology and disease still may find difficult the recognition of the research issues arising from a noncategorical or universal approach to the definition of children, adolescents, and their lives.

Many of the outcomes that interest generalists particularly have complex antecedents, and unitary hypotheses typical in some biologic systems will be hard to find in these areas of research. Generalists often address messy and complex social and biologic interactions. Think about the plasticity of the developing brain and the amazing interaction of biology and environment in this remarkable structure. Poverty is associated negatively with almost every measure of health. Yet, what are the specific mechanisms by which poverty affects health? What are the biologic substrates, the social and environmental mechanisms, the effects of health care access, and the opportunities to improve the health status of poor children?

This lack of unitary hypotheses means that almost all research by generalists must include multiple variables and require difficult choices among variables of key interest. The need to find overarching concepts and theories to guide this work and to help choose wisely among variables is critical. Researchers may need to borrow from social and behavioral sciences, but our clinical acumen also should have a role in developing and testing theory. Julie Richmond describes the development of public policy as requiring an adequate knowledge base, efficacious and effective social strategies, and political will.<sup>21</sup> How can these elements be measured in the context of child health improvement? Furthermore, the complex nature of the causes and outcomes for health and development of children should encourage generalists to work with colleagues who view the world through different lenses. Good behavioral and social scientists bring different perspectives, methods of assessment, and much wisdom to many of the same questions generalists address. Working together will improve the research effort greatly. Where interdisciplinary for the National Institutes of Health may mean physi-

ologists and biochemists working together, for academic generalists, it means clinicians, economists, psychologists, biostatisticians, sociologists, and others. Notions of universality and continuity will help researchers to make the important associations and frame the questions well within a broad theoretic context.

Universality also should underlie advocacy by academic generalists in attempts to integrate children any number of clinically interesting situations with all other children and with finding the kinds of services that children need. The principles developed by the Ambulatory Pediatric Association 4 to 5 years ago regarding health care reform remain relevant today. Universality is crucial, that is, reform should involve every child and family; provide coverage that is comprehensive and child-specific; and have an appropriate infrastructure with an integrated delivery system. The health care workforce should have an appropriate mix of generalists and subspecialists, and performance measurement should use child-specific standards and guidelines.

Academic generalists are at a defining period in child and adolescent health in which policy, research, and advocacy can come together to benefit families and society in remarkable ways. New knowledge at the molecular level, at the social and environmental level, and at the systems level provides great opportunities for academic generalists and the communities with which they work. The challenge requires a vigorous, imaginative, and coordinated approach.

## REFERENCES

1. Pear R. Expanded right to medicaid shatters the link to welfare. *New York Times*, March 6, 1988
2. Newacheck PW, Hughes DC, English A, Fox HB, Perrin JM, Halfon N. The effect on children of curtailing Medicaid spending. *JAMA*. 1995; 274:1468–1471
3. US Government Printing Office. *Medicaid Source Book: Background Data and Analysis*. 1993 Update. Washington, DC: US GPO; 1993
4. Social Security Administration. *Annual Statistical Supplement, 1997*. SSA Publication No 13-11700. SSA: Washington, DC; 1997
5. Mashaw JL, Perrin JM, Reno VP, eds. *Restructuring the SSI Disability Program for Children and Adolescents*. Washington, DC: National Academy of Social Insurance; 1996
6. Woodward B, Weiser B. Costs soar for children's disability program. *Washington Post*. Feb 4, 1994:1
7. Katz MB. *The Undeserving Poor*. New York, NY: Pantheon Books; 1989
8. National Commission on Childhood Disability. *Supplemental Security Income for Children with Disabilities*. Report to Congress. Washington, DC: October 1995
9. Pless IB, Perrin JM. Issues common to a variety of illnesses. In: N Hobbs, J Perrin, eds. *Issues In the Care of Children with Chronic Illness*. San Francisco, CA: Jossey-Bass; 1985:41–60
10. Hobbs N, Perrin JM, Ireys HT. *Chronically Ill Children and Their Families*. San Francisco, CA: Jossey-Bass; 1985
11. Perrin JM. Children with special health needs: a US perspective. *Pediatrics*. 1990;86:1120–1123
12. Perrin JM, Kahn RS, Bloom SR, et al. Health care reform and the special needs of children. *Pediatrics*. 1994;93:504–506
13. Goodwin S. Children with special needs: their care in England and Wales. *Pediatrics*. 1990;86:1112–1116
14. Elola J, Daponte A, Navarro V. Health indicators and the organization of health care systems in western Europe. *Am J Public Health*. 1995; 85:1397–1401
15. Starfield B. Primary care and health: a cross-national comparison. *JAMA*. 1991;266:2268–2271
16. Starfield B. Public health and primary care: a framework for proposed linkages. *Am J Public Health*. 1996;86:1365–1369
17. American Academy of Pediatrics. *The Classification of Child and Adolescent Mental Diagnoses in Primary Care*. Elk Grove Village, IL: AAP; 1996
18. The Reforming States Group. *State Oversight of Integrated Health Systems*. New York, NY: Milbank Memorial Fund; 1997
19. Bruner C, Perrin JM. *More Than Health Insurance: State Initiatives to Improve Maternal and Child Health*. New York, NY: Milbank Memorial Fund; 1995
20. Schorr LB, Schorr D. *Within Our Reach: Breaking the Cycle of Disadvantage*. New York, NY: Anchor Press/Doubleday; 1988
21. Richmond JB, Kotelchuck M. Co-ordination and development of strategies and policy—the United States example. In: *Textbook of Public Health*. Oxford, UK: Oxford University Press; 1984

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