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ACCESS TO SPECIALTY SERVICES FOR CHILDREN ON MEDICAID

A BRIEF PREPARED FOR THE CHILDREN'S HEALTH CAUCUS BY THE
COLLABORATIVE FOR CHILDREN'S HEALTH POLICY



The Collaborative
for Children's
Health Policy

Access to Specialty Services for Children on Medicaid

Executive Summary

- Many children and adolescents will need access to child-focused specialty care, including mental health services, regardless of whether they are designated as having ‘special health care needs’.
- A child does not need to be ‘sick’ in order to require access to specialty services.
- Children treated by specialty providers who have training in pediatrics or child health and development have better outcomes than children who are treated by other specialists.
- 19.5% (572,200) of Illinois children have a ‘special health care need’; 37% (or 211,714) are covered by Medicaid.
- Access to primary care is a cornerstone of access to specialty care.
- Illinois children enrolled in Medicaid are less likely to have access to primary care than children insured commercially. Approximately half as many children in Medicaid have a usual source of care as children insured commercially.
- Children of color comprise 48% of all children in Illinois, but 71% of Illinois Medicaid enrollees. Therefore, Medicaid access issues exacerbate racial and ethnic disparities in outcomes.
- Illinois children enrolled in Medicaid are less likely to have access to specialty care than children insured commercially, and access such care later, so that they miss opportunities for services that could potentially improve their developmental outcomes.
- Children in rural areas of Illinois continue to struggle with adequate access to primary and specialty care.
- Medicaid managed care threatens to undermine access to primary and specialty care further.
- Before transitioning children into Medicaid managed care, Illinois Medicaid spent one-third less than the national average on disabled children (\$12,534 compared to \$16,695). The pressure to reduce spending that managed care organizations in Illinois face threatens to limit Medicaid spending for disabled children further.

While it is common to think of children who need specialty services as ‘special needs’ children, many children and adolescents will likely require access to child-focused specialty care at some point in their lives. This care may be delivered in a school, in a community setting, at a doctor’s office, at home or in a hospital or medical center.

All children, whether they are insured by Medicaid, uninsured or insured commercially, may have difficulty accessing specialty services they need because of geographic access issues, low income, insurance-related barriers, inadequate communication about what is needed, wait lists, lack of access to and availability of appropriate primary care, or the fact that our health system remains largely designed around the needs of adult patients.

This brief examines the challenges children enrolled in Illinois Medicaid have in gaining access to and using the specialty services designed for them. One of the great strengths of Medicaid is that it takes the developmental needs of children into account, through an established “early alert” program administered through primary care physicians, which makes access to primary care a cornerstone of children’s access to pediatric specialty care.

Part I: Background on specialty care for children

What are specialty services for children and how do they differ from services for adults?

Box 1. Examples of child-focused specialists:

- Child psychologists and child psychiatrists
- Pediatric dentists
- Pediatric occupational and physical therapists
- Speech therapists
- Pediatric neurologists
- Pediatric surgeons

Child-focused specialty services for children include supports and services from providers who have special training in pediatrics or in child health and development (see Box 1 for some examples). The specialized training focuses on the unique capabilities, physiology, and needs of children as they develop into adulthood. Care provided by specialty providers has repeatedly shown to result in better outcomes for children than care provided by general or adult-focused providers.

A fundamental difference between child-focused specialty care and adult-focused specialty care is that, while providers serving adults typically aim to return their patients to ‘normal’ functioning, child-focused specialty providers also aim to optimize developmental outcomes so that children may achieve their highest potential in life. Thus, a child need not be ‘sick’ in order to require access to specialty services.

Finally, the parent/guardian of the child (rather than the child him- or herself) is the interface with the specialty provider and is responsible for assuring the child receives needed services. While many adults may rely on a family member for help in accessing care, children are entirely dependent on their parents/guardians for accessing care and putting care plans into place. Parents/Guardians provide much of the care children need in the home – from administering medicines to implementing recommended therapeutics, safeguards to prevent injury, special dietary needs, etc. This means that parents/guardians essentially function as co-care providers.

Table 1. Adult- v. child-focused providers

Differences in types of providers	Adult-focused provider	Child-focused provider
Helps to restore health	■	■
Helps to optimize developmental outcomes	□	■
Parents/Guardians are co-care providers	□	■

Which children need access to child-focused specialty services?

As stated at the outset, many children will need access to child-focused specialty services at some point. Their needs for specialty care may be apparent before or soon after birth, upon entry to school, as a result of a preventive visit, after an acute illness, or as a result of an injury. Some children will require access to these services for a very long time, perhaps their whole lives, and some will need access for a very short time, such as to address an acute illness. Some children require the care of many different types of specialists, and others just one type.

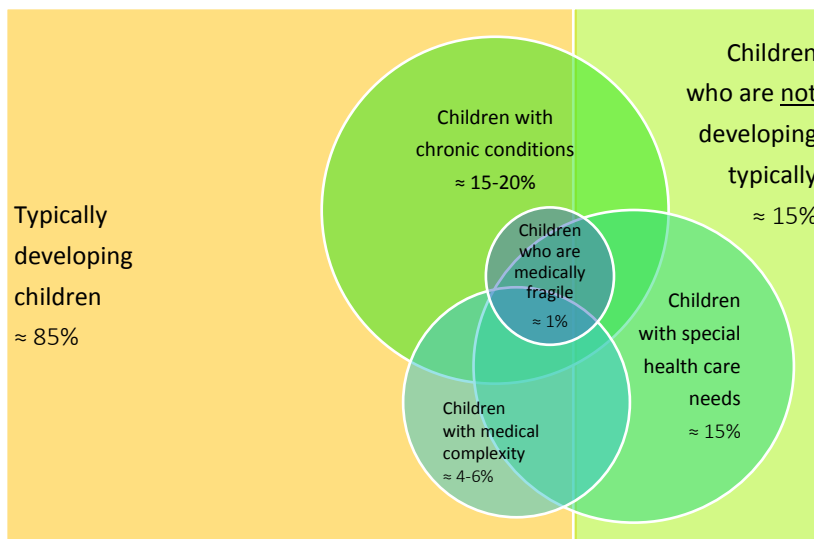
Parents/guardians, the medical community and educators continue to develop ways of talking about children’s needs for specialty care. Over time, they have created a number of classifications of children that do not always align with one another, but that are important to each group. Table 2 presents a

comparison of these classifications. Figure 1 shows how the groups overlap, and reflects the confusion such classifications can sometimes cause.

Table 2: Classifications of children based on their developmental and health care needs

Term:	Used to describe children who require:	Examples:
Typically developing children	No special services (acute care only), or ongoing care for a condition that does not threaten development	Asthma, vision problems that can be corrected with glasses, asthma,
Children with special needs	Educational, health care or other supports that are not typical	Autism, dyslexia, all health care needs
Children with special health care needs	Health services that are not typical (often also need educational supports)	Cerebral palsy, sickle cell, mental health conditions, epilepsy
Children who are medically fragile	Supportive technology	Some cerebral palsy, some epilepsies
Children with chronic conditions	Ongoing care (of any level)	Asthma, diabetes, cerebral palsy
Children with medical complexity	Care across many systems and medical specialties	Cancer, cardiac conditions, cerebral palsy, muscular dystrophy, some epilepsies, severe mental/emotional problems, spina bifida

Figure 1: Overlapping classifications of children based on their developmental and health care needs



Box 2. Key numbers:

(1) 19.5% of Illinois children (or 572,200 children) have “special health care needs.”

(2) 37% of Illinois children with special health care needs (or 211,714) are enrolled in Medicaid.

(3) Illinois spends (\$12,534) less for each child “with a disability” than 44 other states on an annual basis, in the Medicaid program. The mean annual Medicaid spending across the country is \$16,695 per disabled child (or 33% higher than in Illinois).

Source: Kaiser Family Foundation

Part II. Gaining access to child-focused specialty care

The role of primary care in accessing specialty services

Families rely heavily on primary care providers to identify conditions that require specialist care. There are several major ways children are identified as possibly needing specialty services: (1) In a neonatal intensive care unit at birth or shortly after; (2) By parents/guardians who have concerns about their children’s health or development; (3) Through their primary care physician; (4) Through their schools and daycare centers; and (5) Through emergency departments (EDs). (Please see Figure 2 and Table 3, next page.)

(1) Neonatal Intensive Care Units: A small group of children are identified as needing specialty services shortly after they are born. Children are identified through a brief medical screening at birth to assess their health. A portion of these children will be referred immediately to a neonatal intensive care unit for care. In this unit, health issues that are genetic, congenital, or that arise from a traumatic delivery are identified. Some of these issues are medical problems that can be addressed before hospital discharge through surgery or treatment in the neonatal intensive care unit, some problems will need ongoing care, and some will require additional screenings as the child develops and grows.

In addition, the State of Illinois has an excellent screening program called the Adverse Pregnancy Outcomes Reporting System (APORS) carried out in neonatal intensive care units. APORS screens certain children for conditions that can compromise their ongoing health and development. If the hospital believes the infant may have a condition that will threaten their developmental outcomes, a referral is made to the Early Intervention program (EI), the primary care physician is contacted, and other specialists may be engaged during the hospital stay.

Box 3. Key Illinois programs

APORS – Adverse Pregnancy Outcomes Reporting System – Screening conducted after birth in neonatal intensive care units for children who have congenital or perinatal conditions.

EPSDT – The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit mandates the provision of all comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid. EPSDT is key to ensuring that children and adolescents receive appropriate preventive, dental, mental health, and developmental, and specialty services. This is a federally protected program within Medicaid.





EI – Early Intervention – A federal-state program that offers therapeutic and care coordination services in the first three years of life (until 36 months of age, or the child’s 3rd birthday) to address developmental delays.

EI provides services and care coordination for children who need developmental therapies. It is free for Medicaid recipients and it is designed to provide intensive therapeutic services early in life, when the child’s developmental trajectory is still being shaped.

Table 3. Identification of children who need access to specialty care

Age of child	Triggering event	Where screening occurs	Screening and evaluation	As needed, child is referred to
Birth	Traumatic birth or initial screening at birth	Neonatal intensive care unit	APORS and/or neonatologist	Early Intervention <u>Primary Care Physician</u> Other specialist providers
Until 3 rd birthday	Parent concern, routine well child visit, ED visit, or child care center concern	<u>Primary care physician</u>	EPSDT Medical evaluation	Early Intervention Other specialist providers
3 rd birthday through start of kindergarten	Parent concern, routine well child visit, ED visit, or child care center concern	<u>Primary care physician</u>	EPSDT Medical evaluation	Other specialist providers School-based providers
Kindergarten through grade 12	Parent concern, routine well child visit, ED visit, or academic performance	<u>Primary care physician</u>	EPSDT Medical evaluation	Other specialist providers School-based providers

Figure 2. How and when most children are identified as requiring child-focused specialty care

	Triggers for screening			As needed, child is referred to		
	Well child assessment (primary care)	Parent concern	School or day care concern	Medical and behavioral specialty providers	Early Intervention	School-based providers
 Birth and shortly after	■	■	□	■	■	□
 Until age 3	■	■	■	■	■	□
 Age 3 to Kindergarten	■	■	■	■	□	□
 Kindergarten through High School	■	■	■	■	□	■

(2) Primary Care Physicians. If the screening at birth does not identify any health problems, EPSDT screenings are provided by a primary care provider. Primary care physicians screen children for developmental problems and refer them to medical specialists or EI if needed. The goal is to screen regularly and thoroughly so that services can start early, during the period when the child can benefit most.

If a developmental delay does not surface in a screening before age three, the primary care physician will pick it up in later well-child checks, but EI services

will not be available to the child once he or she reaches age 3. When a delay or a health problem is identified through screening, the primary care physician refers the child to specialty care.

(3) Parents/guardians. Parents/guardians often observe that their child is not developing in a way they might expect and will often ask the primary care provider to assess their child’s health and development. Research shows that parents/guardians are very good at identifying ‘that there seems to be a problem,’ but need a physician to help identify what the actual problem is.

(4) Schools and child care centers. If a child begins to have difficulties at school or in child care, the school or center may do an evaluation and will reach out to the family to ask them to have the child screened for learning disabilities or behavioral needs by their primary care physician. If the physician determines that the child would benefit from a specialist assessment or services, a referral will be made.

(5) Emergency departments. Children and adolescents may gain access to specialty services through emergency departments. Sometimes this occurs because a child has repeat ED visits for an emerging chronic condition (such as many visits for wheezing that would trigger concerns about asthma). Sometimes this occurs because a child has an injury that is initially treated in an ED and that requires follow-up care by specialty providers (e.g., a concussion).

Finally, when parents/guardians have difficulty accessing specialty care, they may use an ED to gain access. For example, challenges in accessing mental health services may lead a parent to bring their child with severe behavioral issues to the ED for care. Typically, the ED will notify the primary care provider so that he/she can help the family with follow up care.

Access to primary care for Medicaid children

In each of these ways of accessing specialty services, the primary care physician is at the center of the process. Thus, access to primary care is a critical component of access to specialty services.

In Illinois, access to good primary care is not equal for children insured by Medicaid. Table 4 demonstrates that children insured by Medicaid are much less likely to: (1) have a nurse or doctor that their parent considers the child’s personal provider, (2) have a usual source of care for preventive services, (3) have a usual source of care for sick care, and (4) have a primary care provider who meets the standards of a medical home. Thus, Medicaid children have less access to primary care providers in Illinois than do their commercially-insured counterparts. This severely limits their access to specialty services.

Table 4: Primary care and medical homes for Illinois children, 2016

	Children in Medicaid/ AllKids	Children with private insurance	Difference is statistically significant at 95%
Do NOT have one or more persons you think of as this child’s personal doctor or nurse	37.4%	18.4%	■
Do NOT have a usual source of care for preventive care	9.1%	2.9%	■
Do NOT have a usual source of care for sick care	25.3%	13.6%	■
Care does NOT meet standard of medical home	62.7%	40.2%	■

Source: 2016 National Survey of Children's Health

Indeed, Table 5 indicates that Medicaid children have a harder time getting referrals and that they begin specialty services later in life than do children who are commercially insured. Children insured by Medicaid are almost 20% less likely (in relative terms) than children insured by commercial insurance to begin specialty services before the age of 3, when children age-out of EI services. Most children who are insured by Medicaid begin services later, around the age they begin preschool or kindergarten, long past the age at which these services are most effective.

Table 5: Access to specialty care for Illinois children, 2016

	Children in Medicaid/ AllKids	Children with private insurance	Difference is statistically significant at 95%
Had problems getting referrals to see any doctors or receive any service (of those who needed a referral).	22.0%	16.7%	■
Child receives special services to meet his/her developmental needs (such as speech, occupational or behavioral therapy).	10.5%	6.7%	□
Child began special services to meet his/her developmental needs.			
Before age 3 (when EI services are available)	26.2%	32.3%	■
Age 3-5	55.2%	35.1%	
Later than age 5	18.6%	32.6%	

Source: 2016 National Survey of Children's Health

Additional factors affecting access to specialty services for children

(1) Geographic access. Specialty providers are not available equally across Illinois. Rural areas, in particular, have significant gaps in service. Telemedicine is one way to make specialty services more accessible.

(2) Chronic workforce shortages. There are fewer child-focused specialty providers for a number of reasons:

- (a) There are fewer training programs for child-focused providers, so fewer providers choose pediatrics or child health as a focus.
- (b) Medicaid pays less than Medicare, and a far greater proportion of children are covered by Medicaid than for any other age group, making it harder for child-focused providers to pay back student loans, keep a viable business open, or make ends meet.
- (c) The difficulties of working in the Medicaid system in Illinois (as a fee-for-service provider or as part of a managed care network) make it more difficult to run a practice than if providers only accept commercially-insured children into their practice.

Some specialists are in particularly short supply in Illinois. These include, for instance: masters-trained mental health providers, child psychologists, child psychiatrists, pediatric cardiologists, pediatric neurologists and pediatric physical therapists.

(3) Difficulties for families. Families themselves face a number of difficulties in accessing specialty services once their child is identified as needing them. For example:

(a) Services for children are offered through a range of agencies and providers that are not always easy to navigate. For example, it is not unusual for a parent to have to shuttle information between specialty providers and schools in order for school-based services to begin.

(b) Parents/guardians have different levels of health literacy and so different levels of ability to understand their child's problem and which services to access, and how to implement care plans in the home.

(c) Parents/guardians have different resources, including time, to manage the care of their children. Research shows that parents/guardians of children with medical complexity are more likely to lose a job or reduce their work hours to assure their child's access to needed services.

(d) The lack of culturally and linguistically-diverse providers make it challenging for parents/guardians with limited English language skills to get appropriate, timely care.

The role of Medicaid managed care

In January 2015, the State of Illinois began moving children insured by Medicaid into managed care. This change has both the potential to increase access to primary and pediatric specialty care and to undermine it. It depends on how well it is implemented. Even though managed care organizations are paying for services, the State of Illinois has the capacity to improve access to primary and specialty care by implementing robust standards for managed care plans.

There are key ways in which a poor or inconsistent implementation of Medicaid managed care threatens access to child-focused specialty services:

(1) **By further undermining access to primary care.** As noted above, children in Medicaid already have less access to primary care providers. Transitions to managed care may endanger the relationship between the child and his or her primary care provider, because not only must the child enroll in a managed care plan, but the provider must also enroll in that plan as well. If, during the enrollment into a managed care plan, the family is placed into a plan that excludes the child's primary care provider, the family must start over with a new provider or switch managed care plans within a short time window.

(2) **By not assuring network adequacy.** The managed care plan may not include in its network the range of specialists the child needs. Since families cannot always anticipate their children's need for specialty care, narrow networks threaten to add more delays or reduce access to specialty care. Plans can meet some of the specialty requirements by using specialists without certifications in pediatrics or child health.

(3) **By undermining relationships between primary care and specialty providers.** In managed care arrangements, primary care providers are often prevented from referring children to specialty providers they know and trust. Severing these established relationships may compromise necessary care coordination and specialty provider expertise.

(4) **By underpaying primary care and specialty providers.** Managed care organizations have fee structures that might reduce the fees paid to child-focused providers and thus drive them out of

Medicaid. This would exacerbate the disparity in access to specialty care that already exists between Medicaid- and commercially-insured children in Illinois.

(5) **By placing too many administrative burdens on providers.** Administrative burdens have always been part of Illinois Medicaid and have historically made participating in the Medicaid program challenging. With the advent of managed care, additional burdens are experienced by providers. For example, specialty providers must contract and negotiate successfully with each different Medicaid managed care plan in order to be reimbursed adequately and thereby sustain access to services.

(6) **By limiting services that are covered by Medicaid.** Medicaid managed care plans can refuse to pay covered services that children need because they have an incentive to reduce expenditures (and therefore service use). Examples include long-term therapies, specialized wheelchairs and other durable medical equipment, splints and casts, and specialized drugs. EPSDT is designed to assure access to screening, diagnosis and treatment, so that children may develop optimally, but not all managed care plans have experience with this type of program and many are focused on reducing costs. While parents/guardians may appeal these decisions, having to do so increases the burden on them and results in delayed care.

Conclusion

Medicaid offers great potential to address access barriers to specialty care for children. Because of workforce shortages and other factors that the Illinois Medicaid program cannot control, there is a limit to what Illinois can do. However, Medicaid can make progress toward achieving health equity for all the children of Illinois by:

- (1) assuring adequate payment for child-focused primary care and specialty providers,
- (2) reducing administrative burdens on providers participating in Medicaid,
- (3) protecting relationships that exist between primary care and specialty care providers,
- (4) assuring network adequacy in managed care contracts, and
- (5) adding quality of care measures to managed care contracts that focus on access to specialty services for children and that help the State of Illinois identify service gaps as proactively as possible.

The repeated screening for children's health and other service needs in Medicaid has been a key component of decreasing the gap in health and developmental outcomes. For that reason, the screenings and any treatment required as a result receive unique protections in federal law. Illinois Medicaid has a key role to play in safeguarding access to child-focused primary care providers and pediatric-trained specialists.

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