



## CHILDREN WHO EXPERIENCE HEALTH COMPLEXITY MUST BE A PRIMARY FOCUS OF OREGON HEALTH AUTHORITY'S HEALTH EQUITY EFFORTS

### *A Public Comment to the Oregon Health Policy Board: June 2022*

The Oregon Pediatric Improvement Partnership (OPIP) staff wholeheartedly support Oregon Health Authority's (OHA) urgent and transformative goal to eliminate health inequities by the year 2030, which creates a catalyst to focus on priority populations and activities that will achieve progress towards that goal. Health disparities for children have been illuminated and exacerbated during the pandemic, the call for health equity is even more pressing today<sup>1</sup>.

The purpose of this memo is **to outline why a focus on children must be an intentional and explicit priority** in order for this goal to be achieved in a meaningful way. Childhood is one of the most predictive elements of health, and inequities experienced in childhood have multi-generational impacts. Nearly 40% of Oregon's Medicaid-insured are children<sup>2</sup>, and Medicaid provides insurance for the majority of children of color in our state (60% of Black children, 65% of Latino children, and 57% of AI/AN children)<sup>3</sup>. Additionally, many children who have experienced adverse childhood experiences (ACEs) have parents who are also insured through Oregon's Medicaid/CHIP. However, our systems, policies and payments do not consistently address the needs of the family unit, thus missing opportunities to use the dyadic or family approach to care which evidence tells us is the best way to support intergenerational healing.

### **Focusing on Health Complexity is Critical to Achieving Equity**

Health complexity is a concept that combines and then quantifies the degree to which children have both **medical and/or social complexity**. Since 2018, Oregon has led the nation in the development and dissemination of system-level data to understand the challenges faced by publicly-insured children<sup>4,5</sup>. In direct alignment with OHA's health equity goals, the data identifies children who have experienced medical and/or social challenges that may lead to disadvantage, such as disability, poverty, language barrier, parental incarceration, parental death, foster care, or child abuse. **One in four children in Oregon** face some level of both medical and social complexity. This health complexity data shows that the magnitude

Oregon is the only state to produce annual reports of the child health complexity data, displaying data at the state-, county-, and CCO-level<sup>6</sup>. This data has been provided since 2019 and is publicly available on the [Oregon Health Authority Transformation Center website](#).

- 1 in 20 Oregon children have complex and chronic **medical conditions** AND 3 or more criteria signaling significant **social complexity**, both of which impact health and health care costs.
- Among Oregon children **without** a known medical condition, **over half have some level of social complexity** and almost a quarter already have **3 or more social complexity factors**, which research has shown often leads to poor health outcomes later in life.

of children who likely need additional supports is great, which should drive investments to build and improve our systems.

However, the data could be better used to galvanize the meaningful system and ground-level improvement efforts needed and to evaluate and track the impact of those efforts on the children who most need our support in order to achieve health equity. Identifying and supporting children with health complexity directly aligns with efforts to eliminate health disparities by putting the most vulnerable in the center of system redesign. When we design our systems to meet their needs, we will support every Oregonian to achieve full health potential and lifelong well-being. By identifying children whose families are likely to face significant barriers, the data can help us fast-track families into programs and services to address their needs before they lead to increasing health complexity<sup>7</sup>. Behavioral Health are that are dyadic, including the child and parent/caregiver, are critical to intergenerational healing and ensuring a healthy trajectory for children<sup>8,9</sup>. Without the right interventions, our data tells us that the number of social complexity factors will increase across the lifespan, and that racial, class and other intersectional disparities will persist.

### **The Complex Medical Needs of Children Must be Met**

Within health complexity, there are children facing early adversity due to disability or chronic medical conditions who are at high risk for inequitable outcomes. **Families of children with complex chronic health conditions**

**are disproportionately impacted** by the high cost of their child's medical care. As nearly two-thirds of Medicaid/CHIP children with special health care needs live at or below the poverty level, these costs can further exacerbate economic disparities<sup>10,11</sup>. Our healthcare system **must fully support children and youth with special health needs** in order for them to thrive and reach their full potential. By providing adequate network adequacy to serve this

Within OHA's and OHPB health equity definition and aims, a key component we see for children in **Medicaid/CHIP is the intentional inclusion of "disability"**.

- For children with special health care needs in Oregon, OHP **is the safety net** for addressing and covering their medical, behavioral, oral and care coordination needs.
- According to the 2021 Child Health Complexity data, there are **145,000 children enrolled in Medicaid/CHIP** who have some level of medical complexity (more than 1 in four enrolled children), with 50,000 having a complex, chronic condition.<sup>6</sup>

priority population, proper equipment, medications, support services, specialists, skilled caregivers, and case managers, we could **reduce** Emergency Department visits, inpatient stays, missed school days, parental mental health and job loss, and health complications - thereby promoting and attaining health equity for the full spectrum of children with health complexity.

### **The Complex Social Needs of Children Must be Met**

Childhood experiences are a predictor of a child's future adult health and of the health of future generations. Significant literature shows the impact of just one adverse childhood experience (ACE) and the magnified impact for children who endure multiple ACEs. Social complexity, as defined by the Center for Excellence for Children with Chronic Conditions, is a set of co-occurring

individual, family or community characteristics that can have a direct impact on health outcomes or an indirect impact by affecting a child’s access to care and/or a family’s ability to engage in recommended medical and mental health treatments. In order to address factors that drive inequitable health outcomes-, these social complexity factors need to be addressed through improvement efforts that focus on family centered, trauma informed practices. Priority efforts include listening to families of children with social complexity about what they need and how systems don’t work for them. Throughout OPIP’s projects parents have shared about the need to support 1) trauma-informed approaches of care for children with social complexity, 2) dyadic and family-based models of care that incorporate the needs of both the child(ren) and adult(s) while considering the impact that they have on health and health care use, and 3) behavioral health services and supports that are engaging and safe for children and their families with social complexity.

In Oregon, nearly **two in five (38%)**<sup>6</sup> – or **197,860** publicly insured children - have three or more social complexity factors, the majority of which align with adverse childhood experiences, for which behavioral health is an essential service requiring equitable access and quality care.

### **The Path Forward Must be Driven and Informed by Families and Communities**

We are excited that the new equity vision emphasizes community voice and design. Families of **children facing high levels of health complexity should be a primary and priority partnership**, as their meaningful involvement will be critical to moving this work forward. In our experience partnering with families across the state, several important themes about their needs consistently arise: addressing the critical financial impact when parents must become full time caregivers; making health systems accessible; supporting family navigation needs; and increasing accessibility of skilled behavioral health supports for children and families.

The voices of lived experience echo the data - children facing significant inequity-based stressors will experience medical and behavioral health impacts if their parents, community, health care teams, and state do not have the right resources in place to buffer and eradicate those stressors.<sup>12</sup> The experiences of childhood build our brains, bodies and behavior<sup>13</sup>. By uniting together we can build systems of care and connection that help children be ready to learn, grow and thrive. **If we ensure our equity work meets the needs for prevention and intervention in childhood, we engage a critical and time-sensitive opportunity to break down inequities and move towards justice.**

#### ***Voices of Oregon’s Parents from OPIP Focus Groups and Parent Advisors***

**On Navigation** - *“The right hand doesn’t know what the left hand is doing. But we are supposed to know where to go for help.”*

**On Caregivers** - *“I feel like I was my child’s therapist and case manager and advocate and medical researcher, and I just wanted to be her mom.”*

**On Health Systems** - *“They keep trying to reinforce a system that doesn’t work for us. The system is doing exactly what it is designed to do. It’s the design we need to look at!”*<sup>14</sup>

### **Actionable Steps to Prioritize a Focus on Children as a Core Component of Health Equity:**

We appreciate the policies and priorities that articulate the vision and lay the groundwork for transformation to happen (*Coordinated Care Organization 2.0 recommendations, Patient Centered Primary Care Home Standards, Primary Care Payment Reform Collaborative, Raise Up Oregon & Behavioral Health Investments*). Yet, we are time and time again **not seeing those policies result in meaningful change** to our systems and practices to improve outcomes **for children with health complexity**. Broad population-level policies applied across all age spans nearly always lead to an inequitable lack of focus on children, their unique needs, and the specific approaches and strategies required. Our systems, policies and payments do not consistently address the needs of the family unit, thus missing opportunities to use the dyadic or family approach to care which evidence tells us is the best way to support healing.

Some **actionable steps to consider include:**

1. OHA should staff a **child health team** to ensure appropriate focus & supports within and across OHA efforts and ensure appropriate subject matter technical assistance are engaged.
2. OHA should **continue & sustain the dissemination of child health complexity data** and support **maximal use of the data** through data provision, technical assistance, learning communities, and requirements around use. This includes using the **health complexity indicator as stratifiers** and as a target population for benchmarks and incentives. From dissemination of the health complexity data, to examination and use of the data, to assessment of quality of care by these indicators available for all publicly insured children, thoughtful and strategic use of the data will be a critical first step to eliminating health disparities by putting the most vulnerable in the center. This is particularly important given the magnitude of missing data related to race-ethnicity currently, while health complexity data is available for all publicly insured children birth to 20 in Oregon. Recognizing that children with health complexity have often been disproportionately impacted by the intersections of race & ethnicity, language, disability status, gender, gender identity, sexual orientation and social class, this data allows for a prime opportunity to start action for populations with current and historical injustices for whom other data is not available.
3. OHA should provide support and guidance, and ensure accountability, for the **data to be used in trauma-informed, strength-based ways** to address the inequities that children with health complexity experience. These supports could be targeted to state policy makers, community partners with shared goals and visions, and Coordinated Care Organizations.
4. OHA should examine **relevant and meaningful CCO 2.0 requirements specifically for the health complex population**, and then obtain information about whether these policies impact this population specifically. This could include assessments of whether children with health complexity have received physical, behavioral, and oral health care. OHA should then provide technical assistance and learning supports to CCOs to address gaps identified and create safe learning spaces to address root cause barriers.
5. OHA should **ensure appropriate investments are made to provide access to intensive case coordination and wraparound services** that are commensurate with the magnitude of need indicated by the health complexity data, with a focus on models of care that are best matched to the needs and experiences of children and families with health complexity.
6. OHA should prioritize **behavioral health resources and investments** to children AND their families given the multi-generational impact lack of services will have on the family and communities in which they reside.

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