2022 - 2025
Oregon System of Care Strategic Plan

System of Care Advisory Council (SOCAC)

Updated December 2023

(Originally released November 2021)

Dear System of Care Community:

The System of Care Advisory Council (SOCAC) was established in 2019 by the Oregon legislature to provide oversight for Oregon's System of Care. Central to the formation of the Council was the creation of a vision and a strategic plan to guide our system improvements. Oregon's first System of Care Strategic Plan was originally released in late 2021 as a two-year plan. In spring of 2023, the legislature granted the Council a two-year extension for strategic planning, affording the Council time to complete a comprehensive assessment of the system and undertake robust community engagement to inform the next strategic plan, now due in January of 2026. In the meantime, the Council is pleased to offer this updated plan, ensuring it is a livable, working document for the next two years. Outcomes of our implementation progress can be found in the [legislative reports we submit annually to the legislature](#).

The Council is continually humbled by the young people and their families who bravely step into the work of the SOCAC. Youth and family voices advocate for better services and supports, not only for themselves, but for those who will be entering the system for years to come. The Council is also grateful for the state agency partners, providers and advocates who prioritize this work. While the Council is a convener and holder of accountability, system improvement is multi-faceted and requires commitment from hundreds of people across this state. We humbly thank all partners and parties who are aligning with the vision and the strategic priorities identified in this plan.

We need and invite everyone into the work of the Council; here are some ways you can get involved:

- [Attend or listen in to a Council or Committee meeting](#). All meetings are open to the public, and public comment is needed and welcome.
- [Become a voting member of a committee](#). The only thing we ask is your regular participation. Youth and family members may be eligible for compensation.
- [Sign up for our listserve](#) where we send out monthly updates about the Council and other system of care related efforts.
- [Regional Systems of Care](#) exist in every county of the state. Learn more and get connected to what's happening in your part of the state.

While the Council is proud of our system improvement efforts, we recognize there is still much work to do, especially for Black and Brown youth, Tribal youth, and those who identify as LGBTQ+. We reaffirm this strategic plan as a foundational blueprint for building an equitable system of care.

Sincerely,
Adam Rodakowski and Annette Majekodunmi
SOCAC Co-chairs

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Executive Summary

The System of Care (SOC) Strategic Plan supports the overarching goal that Oregon's system of care is, in partnership with youth and families, developing and implementing a coordinated, collaborative, and comprehensive system of services and supports that are family driven, youth guided, community based and culturally and linguistically responsive. This strategic plan provides direction for development of a robust system of care for Oregon.

The plan follows the values and principles of national best practice in system of care and reflects the state's commitment to racial equity. It is a living document that will evolve as tasks are accomplished, strategies are honed, and new needs arise.

> ### *System of Care Vision*
> *A future where young people from all backgrounds are healthy, safe, learning and thriving at home and in their communities.*
>
> ### *Outcomes[1]*
> - All youth have connections to their community.
> - All children and youth have a permanent home.
> - Families know about available services and supports.
> - Youth can access care when they need it.
> - Youth have access to culturally and linguistically responsive care.
> - System involved youth graduate from high school.
> - System involved youth have necessary independent living skills.
> - System involved youth have a plan to continue with their education or have a vocational plan and related identified services and supports.
> - Children in child welfare custody are served in home, wherever safety permits.
> - The juvenile justice system is not used as a gateway to behavioral health services.
> - Young people involved in multiple systems do not, after the age of 21, enter the adult correctional system.

Engaging diverse youth and families involved in Oregon's child-serving systems was the foundation of the planning process, and strategic planning followed their priorities. Intentional communication and use of consistent feedback loops ensure that the work of the Council remains grounded in and informed by youth and families across the state. The Council has chosen to focus on the smaller population of youth identified by the SOC Data Dashboard: those involved with three or more systems. The Council's efforts will expand to the larger population as structures, processes and services are improved.

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[1] Several outcomes have been revised since original strategic plan released in 2021. See the 2023 SOC Data Report for more information.

Introduction

SOC philosophy and the System of Care Advisory Council (SOCAC)

The SOCAC was established by Senate Bill 1 (2019) to improve the effectiveness and efficacy of the system of care[2] that provides services to youth, from infancy to 25 years old, by providing a centralized and impartial forum for statewide policy development, planning and funding strategy recommendations.

The primary duty of the Council is to recommend policy and develop and implement a comprehensive, long-range plan for a coordinated system of care encompassing all child-serving systems, including public health, health systems, child welfare, education, juvenile justice, and services and supports for mental and behavioral health and people with intellectual or developmental disabilities. Under this approach, services and supports are family-driven and youth guided, with the strengths and needs of the family determining the types and mix of services and supports provided.

A system of care is community-based, with the locus of services and supports, as well as systems management resting within a supportive, adaptive infrastructure of structures, processes, and relationships at the community level. Additionally, all systems are culturally and linguistically responsive with agencies, programs and services that reflect the cultural, racial, ethnic, linguistic, and unique differences of the populations they serve, to facilitate access to utilization of appropriate services and supports. In Oregon, it is especially important to address the unique strengths and needs of rural communities, as these areas present geographic challenges and cultural nuances not found in more populated areas of the state. Oregon's system for children and families is in crisis and under resourced, with longstanding issues exacerbated by the difficulties resulting from the COVID-19 pandemic.

> A system of care is defined as a coordinated network of services and supports for children and youth/young adults that:
> - Integrates planning and management across multiple levels of care
> - Is culturally and linguistically responsive
> - Is designed through meaningful partnerships with families and youth in the planning, delivery, management and evaluation of services and the development of policy
> - Is supported by policy and governance at the local and state levels
> - Is community based with relationships at the local level
> - Is data driven
> - Is rooted in the System of Care philosophy and approach

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[2] The term "system of care" is capitalized when one is referring to the philosophy or model with defined principles and values (System of Care). It is not capitalized when referring to a coordinated system of services and supports (system of care) in a community or state. It is commonly abbreviated as SOC.

Purpose of Oregon's SOC Strategic Plan

Senate Bill 1 (2019) required the SOCAC to develop an initial strategic plan by 2021, followed by biennial updates. Senate Bill 968 (2023) extended SOCAC's strategic planning to a four-year cycle, with the next strategic plan now due to the legislature in 2026. The strategic plan details the Council's vision and provides direction for the full development of a robust system of care for Oregon. The plan aligns with the values and principles of national best practices in system of care and incorporates foundational steps needed to establish a more coordinated, comprehensive system for Oregon's children, youth, and families It is meant to be a living document that will evolve as tasks are accomplished, strategies are honed, and new needs arise. The Council strives to be data driven in its work, and relies on data from state agencies who must approve the use and analysis of available data in accordance with HIPAA and FERPA[3] privacy laws.

Strategic Planning Process

Youth and family engagement

The Council centers the voices of youth, young adults, and family throughout its work. To build trust with Tribes and communities of color and to thoroughly embed SOC principles and values across the state, a greater focus on equity was included in the strategic planning process. Slowing down to meaningfully engage those served and impacted by systems and to allow for two-way engagement resulted in a plan grounded in the voices of youth and families involved in Oregon's child-serving systems.

> *"We need a system that understands what we need – that has empathy."*
>
> *"The system is doing exactly what it is designed to do. It's the design we need to look at!"*

The Council engaged youth- and family-led organizations to gather input on system issues, strengths, and priorities directly from youth and families involved in systems across the state. Feedback collection was organized under the four Pillars and asked youth and families to prioritize the most immediate areas on which the Council must focus.

Youth- and family-led organizations outreached to a variety of groups, programs, agencies, and organizations across the state to invite youth/young adults and families into the   strategic planning process. Approximately 300 young people participated in youth led "Think Tanks" or responded to an online survey. Approximately 170 families, including 16 monolingual Spanish-speaking families, participated in family-led discussion groups.

Discussions were also initiated with Tribal liaisons to illuminate the unique strengths, needs and priorities of Tribal communities. Although there is far more to discuss with Tribal leaders, the strategic plan includes their initial input around inclusion of Tribal communities and development of ongoing mechanisms for communication and engagement in the work of the Council. The Council strives to build more intentional and effective communication and connection with Tribal communities.

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[3] Health Insurance Portability and Accountability Act; Family Educational Rights and Privacy Act

Engaging diverse youth and families involved in Oregon's child-serving systems was the foundation of the strategic planning process undertaken with agencies and local systems of care. Broader community input followed the priorities illuminated by youth and families. The strategic planning process is outlined in the graphic below. Intentional communication and use of a consistent feedback loop with youth and families is a primary strategy woven throughout the plan, ensuring that the work of the Council remains grounded in and informed by youth and families across the state.

Desired outcomes expressed by youth/young adults and families

Youth and families clarified the outcomes they wish to see from the implementation of a more coordinated, collaborative, and comprehensive system of care.

The three most important outcomes identified are:
- Recognition of their expertise and the need for true partnership between youth, families, and providers.
- Access to culturally and linguistically responsive services and supports that are available where and when they are needed and offered in a way that fits the individual youth and family need or situation.
- Collaboration and coordination between and across systems and providers, especially during points of transition in care.

"I always wonder how the loss of a family's wholeness is an acceptable loss."

"No one listens to me, but they tell me everything I'm not doing right."

Population of Focus

The Council's legislatively defined focus is improving systems that serve children and youth, infancy through age 25, who have or are at increased risk for complex behavioral (including substance use disorders), emotional, physical, or developmental conditions, and who are under supervision by or engaged with multiple systems or are at risk for involvement in those systems. Of particular concern for the Council are Black and Brown families of historically marginalized communities, LGBTQ+ youth, and Tribal children and families. Because of inequity and racist systems, these communities are less likely to be served by upstream systems and services like behavioral health and I/DD, and more likely to be involved in downstream services like child welfare and juvenile justice.

In the short term, the Council is initially focused on a smaller population of system involved youth, those involved in three or more child serving systems (Medicaid funded behavioral health, Child Welfare, Intellectual/Developmental Disability services, and juvenile justice). According to the SOC Data Dashboard, the number of children and youth involved in three or more systems is declining. The Council's efforts will expand to larger populations of children as structures, processes and services are developed or implemented.

Young people involved in 3 more systems
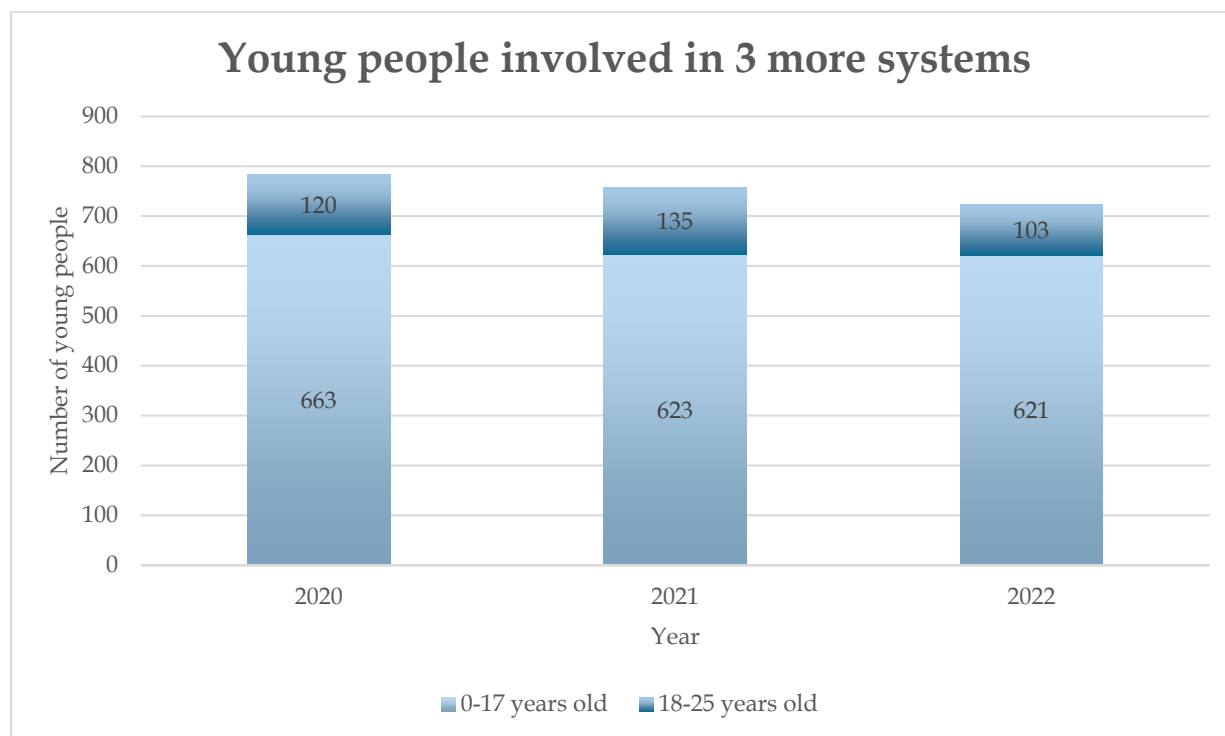
Strategic Plan

The SOC Strategic Plan is organized around four Pillars, with corresponding objectives and strategies. The strategies are sorted into thematic areas of Cultural Responsiveness and Equity, Workforce, Policy and Funding, Coordination, and Education and Information.

Pillar I: Youth and family centered

Youth and Family are full partners in care at the individual, program and policy levels with strengths and needs of the child and family determining the types and mix of services and supports provided.

Core Objectives:

- Ease of service use
- diverse services statewide
- Planful transitions
- Services match needs
- Natural and community supports
- Youth and family feedback
- Youth- and family-led system change
- Early assessment of needs
- Peer support services
- Health prevention and promotion services

Policy and Funding

1.Center youth and family in all groups with power, leadership, and voice, including governance, policy making, and other decision-making groups.

2. Develop a consistent structure or processes for listening to, hearing from and engagement with youth and families, including providing safe places for sharing.

"I can't go to meetings. I'm exhausted. Besides, it's not about meetings, I need providers to listen to what I have to say."

"If doctors would listen to my experience instead of acting like they lived it and invalidating it."

Coordination

1. Establish and implement processes to coordinate ongoing training across systems and communities in youth and family driven practices and in meaningful engagement strategies.

Pillar II: Integrated and collaborative

Child and youth serving systems are integrated and collaborative with shared initiatives, funding, processes, and policies that are youth and family driven, transparent and grounded in the System of Care philosophy.

Core Objectives:

- Diverse access and array of services
- Youth and family rights
- Increase diversity of service providers
- Services match needs
- System coordination
- Effective and responsive services
- Prevention and early intervention
- Service entry available to all
- Shared responsibility

Coordination

1. Identify and build a statewide structure to support system of care capacity and services.

"It's not even that systems are separate. It seems like every organization is in its own box."

"Nobody wants access to DHS. Let's get capacity where it's needed instead of where the system creates a need."

- Funding: Identify and implement more effective funding structures for Oregon's system of care.
- Communication: Develop a robust communication system across systems and providers.
- Coordination: Improve coordination across systems and providers at the state and local levels.
- State level collaboration: Develop a process to increase collaboration across state agencies in strategic planning, joint funding, and joint policy legislation packages.

Pillar III: Culturally and linguistically Responsive

Services and supports are developmentally appropriate, culturally and linguistically responsive, and trauma informed.

Core Objectives:

- Responsive and informed services
- Youth- and family-led equitable change
- Diverse service providers trained and retained
- Diverse service providers statewide
- Youth and family informed data

1. The system of care will center equity in all efforts to improve access and service delivery across systems.

2. The Council will center equity within the System of Care governance structures.

3. Increase culturally and linguistically responsive services and supports across systems.

4. Engagement efforts will focus on inclusion and respect of diverse youth and families, representative of the communities in which services and supports are provided.

> *"I'm fine with not getting services if they're not there…I'm not fine with not being included."*
>
> *"If I were able to be treated in a good manner and not like I was a toddler."*

Pillar IV: Community based

Services and supports are community based so that appropriate care options are accessible, flexible, and available at home or close by.

Core Objectives:

- Local design
- Equity in local communities
- Connection to community
- Full local array of services
- Local cross-system approaches
- Local champions
- Local accountability
- Early local response
- Coordinated local supports

Coordination

1. Identify process for "no wrong door" to services for youth and families.

Policy and Funding

1. Identify barriers and create solutions in access, including eligibility, intake, and referral processes at the local level.

> *"We're in the dark. I don't know what the system has and I'm not sure it knows either. It's like it's top secret."*
>
> *"A case worker who can help coordinate care/access care. Listen to what my needs are."*

SOCAC's Ongoing Commitment

Fulfilling the Council's vision requires concentrated, intentional effort and must be a partnership with youth, families, providers and state agencies. The Council is committed to the strategies and tasks laid out in its strategic plan, and to supporting efforts at both the state and local level that align with SOC principles and values. The Council is especially committed to meaningful engagement with diverse youth and families to build a system that is just, accessible, and redresses and repairs harmful practices and policies that have resulted in inequities among historically oppressed and marginalized communities.

Oregon's system for children, youth and young adults is in crisis, with longstanding issues exacerbated by the COVID-19 pandemic. Fully embracing the System of Care approach offers hope for a future with an integrated system. Change can be difficult and uncomfortable, but the system will continue to crumble unless efforts to build innovative practices, equity and improved access are embraced and acted upon. Now is the time to have the hard conversations, to address ineffective and racist policies and practices, and explore ways to redirect existing funding. We must do this together, as efficiently and effectively as possible, to reimagine and revitalize a system that serves and supports families and provides opportunities for a brighter future for our young people.

Appendix A: The Family Experience within Oregon System of Care
OREGON FAMILY SUPPORT NETWORK – JULY 2021

From the first writings on System of Care (Stroul & Friedman, 1986) to the most recent (Stroul, Blau, & Larsen, 2021) family- and youth-driven services have been at the forefront of the discussion. Research across disciplines has shown that when families are included and relationships are collaborative, outcomes overall are better (Waid & Kelly, 2019, Toros, DiNitto, Tiko, 2018, SAMHSA, 2017). Families want to be involved and still, more often than not, they find themselves in the margins of their children's care and services. The feelings of blame, shame, and disenfranchisement underscored by Knitzer (1982) nearly four decades ago, remain a part of virtually every family's experience. The invitation from the Governor's System of Care Advisory Council for families and youth to be integrally involved in the development of a strategic plan, signals a tangible commitment to foundational values and true collaboration. It gives form to the possibility that the child- and youth-serving systems will revitalize to become systems which serve and not demand, support and not diminish, include and not marginalize.

Between June 21 and July 22, 2021, Oregon Family Support Network held six sessions with 86 primary caregivers of children with exceptional needs.[4] In addition to working within the four pillars and goals as provided in a draft document, participants were asked, "What would change for you and your family if services and supports were based on your needs?" Some of the responses were stark, "I wouldn't feel so wrecked." "I would be able to care for my children." "My husband and I would be able to leave the house at the same time. We would be able to do things together again." Many participants focused instead on all that stands in the way of an effective system. "We need to be treated like people…Respected, ya know?" "I feel like I'm always fighting. If services were available when we need them, it wouldn't feel like that." "We need a system that takes a holistic approach to care. […] Remember, it looks different for every family."

Beyond underscoring what is already known about deficits and gaps across the service array, several themes emerged in these sessions which characterized the experience as it is felt by parents and as it affects the wellbeing of families. Three were central, both in the frequency with which they were expressed, and the extent to which people are

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[4] A majority of individuals who participated (72%) identified as white, ten participants (12%) identified as Hispanic or Latino, and eight (9%) as Black or African American. Three (4%) participants identified as American Indian or Alaska Native, two (2%) as Asian, and five (6%) as other. All but six were female (93%). Forty-nine (57%) participants were insured through OHP. There was a broad geographical distribution. Participants' children were involved with a spectrum of services and supports across the following systems: Special Education, Behavioral Health, Intellectual and Developmental Disabilities, Child Welfare, Medical, Juvenile Justice.

affected.

- System incapacity as a barrier to the attainment of basic human needs
- The missing context of family
- Child- and youth-serving systems as a source of trauma and abuse

Each of these themes has been equally prominent in weekly listening sessions with the Director of OHA's Behavioral Health Unit and in ongoing conversations with families serving on the Children's System Advisory Council Workgroup addressing the Behavioral Health Unit's Policy Vision.[5] They are similarly noted by peer support workers and recognized in the outreach and advocacy efforts of organizations we contacted to collaborate in this process.

The information is not new. It has been long held within every aspect and entity which comprises the System. It is often pigeonholed within the context of an isolated complaint or the telling of a single story. The texture and substance of the lived experience is not captured within existing data collection procedures. It is therefore excluded from systematic review and is not available to inform policy, systems redesign, or service-level improvement efforts.

The issues expressed within these themes contribute to families' distress. They stand in the way of wellness and wellbeing and perpetuate unnecessary hardship. Families feel trapped, unacknowledged, marginalized, blamed, and battered.

This is not a single story. This *is* the experience of families with children who have exceptional needs. The issues are not idiosyncratic, they are endemic.

System Incapacity as a Barrier to the Attainment of Basic Human Needs

"We feel helpless." "They might as well put me in a cage, because I can't leave the house." "I wouldn't have to fight so hard if I had more support and backup." "They should consider Maslow's hierarchy in planning […] I'm not asking for things I want; it is something my son needs." "I was told my son was not disabled enough." "How are we supposed to function?" "We need a system that understands what we need – that has empathy."

Families characterized the system's incapacity as 1) not knowing where to go and not having access to a centralized source of information, 2) being dismissed by providers when symptoms are first noticed, 3) denial of service based on insurance status, eligibility, or acuity restrictions which seem overly exclusive and sometimes arbitrary, 4) lag time from identified need to service (or supply) availability, 5) services based on

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[5] Each group is unique. Over a six-month period approximately 40 individuals have provided input into the CSAC effort, three or four have also contributed to the weekly listening sessions. There was no overlap with the 86 individuals who participated in this process.

availability and not need, 6) lack of access to alternative or promising practices, 7) repeated intake processes, 8) lack of communication within and between systems, 9) lack of transparency between providers/agencies and families, and 10) absence of transition services and supports.

While this list is not exhaustive, it is representative of the scope of the insufficiency endured by families every day. Far from the *no wrong door* ideal, it feels like a rigged game of hide and seek which never ends. Families spoke of the deleterious effects of being without necessary services and supports over time. The act of being subject to repetitious intake processes followed by long delays, limited access, or outright denial is tormenting.

To be able to provide for one's children is a responsibility felt by every parent. Similarly, every parent can relate to the sensation of not having enough (e.g., time, patience, endurance). It is another order of magnitude entirely to be unable to secure services and supports which are essential for success in the activities of daily living, which are integral to development, and basic to play, socialization, learning, relationships, and safety.

As the child's symptoms increase in complexity or severity and the need for professional services compounds, the System's deficiencies are evermore threatening. The potential consequences may be terrorizing. They are indisputably life-altering. Many families spoke to the lack of preventive or supportive services early on as contributing to the need for crisis services later. For some of the parents who participated, crisis was the gateway to any service. For others it was DHS involvement.

The frequency with which such catastrophe might have been avoided in any individual circumstance is not knowable. It is, however, the experience of every family so involved that, when crises emerge or a DHS investigation is initiated, the System does not step up to claim responsibility for its shortcomings. Instead, families are chastised and penalized for theirs.

To be unable to access services within the child- and youth-serving systems is much like entering a grocery store after the food has run out. The impact is profound. The experience denies flourishing. It impedes self-agency, compromises individual health, and strains relationships. It stands in the way of daily rituals and routine, radically altering family dynamics.

The Missing Context of Family

"My husband is living in an apartment with our daughter and I'm at home with our son so we can all be safe." "They don't understand how this affects my other child." "Now DHS is involved. [The worker] is telling me my other children aren't safe […] I don't know what to do." "I can't spend any time with my other two children." "It was my son who got

the diagnosis, but our whole family was changed." "My daughter can't even have friends over to our place." "Our children have to be in crisis before we can get care and by that time, everyone's in crisis." "I'm a single mom. I have two kids and my younger son hardly gets any time with me. They don't get that this affects us all."

Families feel that they are not met as whole but are instead seen as an extension of their children's diagnoses. Subthemes in this area included 1) schools, providers, and agencies making assumptions about families, 2) providers' not asking about or considering family relationships, wellness, wellbeing, and overall functioning, 3) ignoring belief systems and unique cultures within which the family lives, 4) overlooking the needs of siblings, 5) lack of a holistic perspective, 6) lack of support for parent self-care and respite services, 7) lack of acknowledging individual and collective strengths as well as challenges, 8) families blamed and siblings labeled or marginalized by association, and 9) stigma affecting the entire family.

Having a child with special needs is a life-changing event which most families do not plan and cannot anticipate. It overwhelms the whole of life, shifting plans, challenging beliefs, and eroding any trace of certainty about what will be. Every member of a family experiences the onset and escalation of a child's behavioral, emotional, and physical symptoms. Individual perceptions accrue to the collective. Symptoms which may begin gradually – almost imperceptibly – land with a heaviness that reverberates through the family and beyond, to the community which surrounds it.

Parents described feeling increasingly isolated as the availability of natural supports declined. Having a child with complex needs, changes relationships and challenges friendships. The escalating demand for specialized care and more intensive services limits families' opportunities to socialize or to otherwise participate in activities outside of the home. Respite services are scarce, and some parents felt providers were not adequately trained or appropriately prepared. The apparent inverse relationship between need and access gives rise, over time, to overwhelm and dis-ease. Parents serve as front-line managers, seeking solutions, coordinating care, answering calls, and responding to crises. It is like living in a downward spiral which eventually closes in, obliterating ordinary, and squeezing out vitality until the family exists in a perpetual state of depletion.

The situation is compounded by a pervasive lack of acknowledgement or understanding of the child's needs. Noting that they are frequently called to their children's schools, parents expressed that repeated suspension or exclusion is used as a proxy for specialized and legally mandated support services. It is with remarkable frequency that professionals within the helping systems downplay symptoms or minimize parents' observations rather than attending to their concerns. Within the behavioral health system, providers often approach families mechanistically. Diagnostic labels which allow access to treatment also promote reductive assumptions about children and their

families. Prescriptive advice based on faulty judgments adds to distress.

Just as parents feel isolated, marginalized, and unheard, siblings feel left out and confused. They may experience separation from peers as the parents of friends come to fear behavior and anticipate threats to safety. All of the interactions, (mis)perceptions, punitive measures, acts of ignorance, and incuriosity are brought back to the family home. The capacity to manage even the most basic tasks diminishes as physical, emotional, and sometimes financial resources are spent attempting to provide what is not otherwise available.

The need for safety and survival overtakes all else. Some parents described sleeping in shifts in order to attend to a child's physical or safety needs. Others chose to live separately. A few people described being denied help for siblings who did not meet specific diagnostic criteria. The more typical aspects of family life, like playfulness, ease, reciprocity, intimacy, and understanding, are lost to urgency and overwhelm.

All families experience together. We celebrate milestones, grieve losses, and live in the joys, hardships, pleasures, and pains that move with the passage of time. For families of children with complex needs, loss is a slope and grief a constant. Although they may find new ways of celebration, redefine milestones, and learn to see joy in a different frame, the distress, once experienced as moderate frustration or fatigue, becomes a way of life. Services and supports which overlook the needs of the family, overlook the importance of the family as a place to thrive.

The Child- and Youth Serving Systems as a Source of Trauma and Abuse

"It's like we're not even human." "Service workers should get a mandatory training on trauma and the realities of parent caregivers." "The therapist just assumed I was an addict." "Schools are some of the hardest systems to work within. They always tell you you're doing it wrong." "We need a system with true empathy and understanding, not one that hurts us." "I'm afraid to speak up, because I know what they can do, then I'll never get what I need." "My child was shamed because of how he behaved." "They don't ask us, they tell us." "No one listens to me, but they tell me everything I'm not doing right." "When we don't agree with them, they say we are difficult parents, and they pass that information along to the next providers." "We're afraid of retaliation."

Families feel ignored, over-ruled, bullied, and belittled by the child-serving systems. Subthemes within this category included, 1) child's behavioral symptoms being met with blame or suspicion, sometimes before they were evaluated, 2) disregard for parents' observations and interactions with their children, 3) providers using power, threat, and intimidation to force compliance, 4) parents excluded from treatment planning, 5) parents and children blamed for unintended treatment outcomes (e.g., didn't try hard enough), 6) children discharged from treatment without transition planning (e.g., access to lower level of care, access to psychiatric services and medications), 7) parents

rebuked for calling crisis services for "parenting/discipline problems", 8) referral processes in which providers/agencies pass misinformation (disparaging information) about parents and families, 9) pathologizing parents' distress, 10) retaliating against complaints.

System induced distress or "trauma" is a part of every family's experience. This is the theme to which parents spoke most frequently and with the greatest passion. The effects extend to all other aspects of their being. Parents feel helpless. They are dependent upon systems within which bias and inequity are attendant costs of care. Some families described outright maltreatment while others spoke of apathy and aggression so deeply internalized that they have become routine.

Families spoke of the clear distress which results from the System's incapacity to provide needed services. Beyond that, however, they described a form of relational maltreatment. There is a compassion gap in which parents are excluded, set apart from meaningful interaction or participation in their children's care. This is felt to an even greater extent by those who identify as BIPOC or who live outside of a typical family structure (e.g., non-DHS placement with relatives). Caregivers' preferences are disregarded, their experiences subordinated to clinical impressions, and their unique strengths ignored. Some providers seem to neglect collaboration willfully. Others lack the professional experience and expertise to effectively serve children with complex needs.

Parents reported that from their earliest interactions with the child- and youth-serving systems, they are "known" through assumption and judgment. Their individual identities are lost to a form of systemic infantilization within which they are regarded as unknowing, incapable, and unqualified. Their compliance is expected. Some who said they had expressed differences or raised concerns about care described having been treated punitively – made to endure the retribution of unwritten policies (e.g., denial of service, longer wait to access service). These tacit rules, assumed as organizational norms, serve as the basis for the endorsement and support of untoward behavior as complaints are raised up the administrative ladder. With few options and no recourse, families are rendered evermore powerless. Their wellbeing is diminished, and their children's outcomes may be jeopardized.

The lack of collaboration and unambiguous subordination of the family voice within our systems of care come at a significant cost – human and financial. The situation is wholly, immediately, and freely avoidable. The fact that there is no organization, agency, provider, or entity associated with the child and youth-serving systems that would say they are not trauma informed, makes the emergence of this theme even more remarkable. That the *caring systems* impose and perpetuate trauma within the families they serve is as glaring as it is dreadful.

For every family who gave voice to this process, there are dozens more. As the parents

and caregivers of children with exceptional needs, all have experienced a knowing of the inexpressible. Each has been gifted with the subtle, sometimes fleeting rewards of challenge. None has made it through without scars. In the gathering of this information, two fears were expressed by families, 1) that details would be identifiable enough to result in retaliation, and 2) that nothing would be done in response. Ironically, the former is impossible, as there was so much similarity and overlap that no single story is distinguishable. The latter is a measure of the way they have always known it.

None of what was revealed was new. The information has been attenuated within the structure of a single story or an isolated complaint. Families tell stories to inform and inspire change. They file complaints because they cannot do more to affect the systems on which they must depend. Families want to be seen, heard, acknowledged, and included in their children's care. They want to collaborate in the shaping of a family- and youth-driven System of Care which is fully integrated, culturally responsive, and community-based. They want a system which is responsive to the needs of the children it exists to serve – the children they love.

Families who participated in this process did so generously, graciously, and in a spirit of hope that things can be better. To them, we extend our sincere thanks and appreciation. The challenge may always be in knowing the best way to affect the most optimal outcomes within a System of shifting but ever-present constraints. With the drafting of this first strategic plan, there is an opportunity for systems and families to collaborate in meaningful change. No System can eliminate the anguish of caring for children with exceptional needs. They can, however, work *with* families as co-advocates in the shaping of a compassionate, needs-driven System of Care.

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