CSAC FAMILY REPRESENTATIVE RECOMMENDATIONS

FOR THE CHILD & FAMILY BEHAVIORAL HEALTH WORK PLAN 2021-2025

CONTENTS

EXECUTIVE SUMMARY

The Children’s System Advisory Council (CSAC) reviewed the Policy Vision developed by the Oregon Health Authority (OHA) Child and Family Behavioral Health Program. Family representatives tasked themselves with developing recommendations for the implementation of the Policy Vision. To ensure dialogue involved a wide ranging and diverse population of family members, the work group enlarged from seven (7) to twenty-five (25). This expanded group met virtually six times between June 17, 2021, and September 7, 2021. Individuals in the work group exchanged ideas with their communities between meetings to edit and add to the draft language from the meetings.

RECOMMENDATIONS

Initially the group developed guidance with several general approach recommendations, which include:

- Regular full-time staffing of CSAC to ensure meaningful engagement of families in policy and programs guidance,
- Consistent and transparent policy and program consultation with CSAC
- Availability of children’s services through age 25,

- "No wrong door" entry and services across child serving systems, including current siloes of intellectual/developmental disabilities, mental health, public health, physical health and addiction, and
- Assessments, treatment and services that are holistic, wellness oriented, trauma-informed and family/youth driven in approach.

From this general guidance, the group formulated forty-nine (49) recommendations. These include improving the continuum of care and how both OHA and CSAC support reaching those outcomes.

The specific recommendations to improve the continuum of care included needing:

- Prevention: Flexible payments to families to pay for respite, information and assistance about specialized parenting and for navigation of the child-serving systems
- Early Intervention: Development and dissemination of fact sheets describing expected child emotional and physical development, expansion of insurance-neutral access to Family Support Specialists, advertisement of the Reach Out Oregon Warmline availability for parents/caregivers
- Care Coordination: Agency-neutral and insurance-neutral care coordinators
- Family Support: Community-based insurance-neutral Family Support Specialist before/during/and after engagement in behavioral health services
- Outpatient Services: Offer community and home-based services as an alternative to hospital crisis-based services, expand clinical and peer delivered services to reduce gaps between services, shorten wait times for services, coordinate multiple services into one plan (school, child welfare, juvenile justice, developmental disabilities, mental health, substance abuse) and ensure plans are family/youth-driven rather than agency-determined
- Residential Treatment: Coordinate community-based and residential treatment goals to facilitate trauma focused continuum of care with regular visits by parents/caregivers and siblings, use medication and restraints only when approved by parents/guardians with timely notification and plan discharges with parents/guardians and community-based services

The recommendations for OHA to support effective services implementation in communities included increasing:

- Advocacy for more "upstream and prevention" programs.
- Availability of "step-up and step-down" services between residential and community-based services.
- Promotion of "one stop/no wrong door" child-serving system treatment plans.
- Insurance-neutral services.

- Technical assistance and rule/contract enforcement to achieve “holistic oriented, trauma-informed and family/youth-driven services.

Additionally, the group recommended that CSAC increase its effectiveness by:

- Increasing outreach to broaden community participation and
- Requesting the assignment of a full-time staff to support inclusive meaningful family engagement in program planning and evaluation guidance to C&FBH

ACKNOWLEDGMENTS

The report was developed through many family voices brought by the following work group members and staffed by Frances Purdy, OHA Family Partnership Specialist:

Lisa Butler
Jeni Canady
Carol Dickey
Beth Edens
Laura Farmer
Sherrie Grieef
Jennie Hendrick
Carrie Leavitt
Roberta Lincoln
Kari Melda
Laura Rose Misaras
Lisa Moody
Shala Mosley
Kristie Nelson
Nelva Ojeda
Maxwell Olwa
Alisha Overstreet
Ardo Rage
Jules Rice
Sharyn Smith
Kara Sump
Mercedes Thorington
Karun Virtue
Roxanne Wilson
Kathy Zurfluh

CSAC FAMILY REPRESENTATIVE REPORT

BACKGROUND

The Oregon Health Authority (OHA) Child and Family Behavioral Health Program drafted a Policy Vision as a framework for the development of a work plan for 2021-2025. The public and the Children’s System Advisory Council was invited to provide comment and recommendation as guidance for formulating the work plan to address the behavioral health needs of children/youth (birth to 25) and their families.

This report represents the advice provided from twenty-five (25) family members as community representatives, including seven (7) CSAC Family Representatives. They met six (6) times from June 17, 2021, through September 2, 2021. Between meetings

they reviewed drafts of discussions and recommendation and met with the community members they represented. From the discussions and individual feedback between meetings, are the final four types of recommendations:

- Seven (7) general recommendations for guidance about approach for the work plan.
- Thirty-two (32) specific recommendations for the continuum of care, prevention to treatment services.
- Twelve (12) recommendations for OHA.
- Five (5) recommendations for the Children's System Advisory Council.

GENERAL APPROACH RECOMMENDATIONS

1. SERVICE AVAILABILITY

Have all behavioral health services for children available through age 25. This will increase consistency in treatment planning, be less confusing for families and expand the availability of family support services through the youth's transitional age to adulthood. Young people (18-25) would then have a choice to be involved with children's services, instead of adult services for some or all their services.

2. HOLISTIC, FAMILY/YOUTH-DRIVEN ASSESSMENTS AND SERVICES

Set a standard that assessments and treatment/service plans (including crisis plans) are holistic, and family/youth-driven in approach.

Incorporate the wellbeing of the entire family (adults and siblings). Holistic approach means a "treatment plan" that includes all services of choice, natural support, utilizing services from multiple organizations and culturally, linguistically, and developmentally appropriate approach. The plans need to address behaviors as well as underlying and multiple causes (e.g., developmental disabilities, health, cognitive diversity). Treatment of only one cause is abusive and therefore funding needs to be blended to have all programs and services work together.

3. INCREASE TRANSPARENCY ABOUT POLICY AND PROGRAMS

Increase transparency about policy and programs (development and evaluation) by consulting regularly with family and youth members as part of CSAC and liaison with other organizations, including outreach on issues specific to "where families are meeting/located". CSAC would benefit from having outreach plans to consult with and have input from all families (focused on populations, locations, topics/issues). This plan would have mechanisms for outreach, engagement and participation regarding implementing policy analysis and recommendations for services.

Recommend that permanent staff be appointed as support for the work of CSAC in family engagement (individuals and organizations) and outreach in order to guide the policy and development, implementation, maintenance and evaluation of programs in OHA and overall child-serving systems through its liaison with the System of Care Advisory Council.

4. FULLY IMPLEMENT "TRAUMA-INFORMED CARE"

Train, coach, or guide providers to fully implement "trauma-informed care" so blaming, shaming and disrespectful treatment of families does not continue, and meaningful engagement is routine at all tasks and levels (direct service, workforce support and administration).

5. DEVELOP A "NO WRONG DOOR" ENTRY ACROSS PROGRAMS

Develop a "no wrong door" entry across programs, including programs for intellectual/developmental disabilities (I/DD) and substance use disorder (SUD) so families do not have to completely repeat their history (e.g., My Chart, a recording of history, a CD/paper/email/portal controlled and shared by the family instead of having to do another comprehensive intake interview). The goal is to develop a toolkit and mechanism to assist parents to record and update history pertinent to developing integrated health/behavioral health treatment/service plans.

6. FAMILY ENGAGEMENT

Families want to be engaged in developing and modifying treatment and service plans. Families need to have sufficient notice to be able to review treatment/service plans, including diagnosis, medications, treatment goals and discharge/transition plans.

7. HEALTH EQUITY

Develop a mechanism for proactively providing "holistic oriented" services in the appropriate language with concurrent respect for culture/values of the family.

PREVENTION

1. RESPITE

Families can access respite or payments for specialized recreation/time out through the Reach Out Oregon Warmline, community-based family support, mobile response as well as outpatient services (insurance-neutral, not just Medicaid).

2. COMMUNITY CONNECTORS

Parents and Family Support Specialists are available as “community connectors” to reach out to families “where they are” (e.g., markets, churches, schools, businesses) to provide information about positive mental health, connection to the Oregon Warmline and in the child-serving system.

3. EARLY SYMPTOM RECOGNITION

Educate health/education providers about early symptom recognition rather than repeat “the child will grow out of it”/“it is how you parent” myths. Honor and respect the family’s expertise when they first identify “a problem” or otherwise want assistance.

4. PARENTING TRAINING

Provide advanced Collaborative Problem Solving or other parenting training tailored for children and youth with aggressive behaviors.

EARLY INTERVENTION

5. PUBLIC AWARENESS CAMPAIGNS

Add extensive publicity to let parents know about the Oregon Warmline and use/value of Family Support Specialists and how to access them.

6. FAMILY-CENTERED ONE-PAGERS

Support the drafting or compiling of “one-pagers” summarizing expected topics, such as emotional/physical child development and how to build resiliency. Distribute these widely or similarly to the First Five Campaign (e.g., physician offices, daycare, schools, shopping centers, faith organizations, cultural centers). Families need to be involved in creating these “one-pagers.”

7. PEER-DELIVERED SERVICES

Provide in-home and community-based access to peer-delivered services before a child is diagnosed with a behavioral health crisis and when a family first identifies a need.

8. INSURANCE-NEUTRAL FUNDING

Develop a mechanism for flexible insurance-neutral funding available through the Oregon Warmline (community-based Family Support Specialist) or mobile response to pay for respite, specialized recreational activities, skills training, adjunctive therapies, and assistive devices or home modifications.

CARE COORDINATION

9. AGENCY-NEUTRAL CARE COORDINATORS

Parents need to be offered an agency-neutral "care coordinator" who:

- Is identified in addition to a Family Support Specialist,
- Is not a gatekeeper, and
- Takes directions from and represents only the voice of family.

The "care coordinator" needs to be accessible whenever there is a need to coordinate two or more treatment/service plans, including special education, complex health, neurological/developmental diversity and behavioral health needs.

10. INSURANCE-NEUTRAL FAMILY SUPPORT SPECIALISTS

Community-based insurance-neutral Family Support Specialists need to be available alongside each care coordinator to ensure meaningful parent/caregiver engagement and decision-making based on the family's culture and values.

FAMILY SUPPORT

11. FAMILY SUPPORT SPECIALIST AVAILABILITY

Family Support Specialists are available in preparation for services, during implementation of a treatment plan to support the family across systems, and after the family has terminated from formal services.

12. FAMILY SUPPORT SPECIALISTS AT EVERY CLINICAL SERVICE

Family Support Specialists are available as a complement to every clinical service, including mobile response, school-based and residential services.

13. FAMILY SUPPORT SPECIALISTS FOR PARENTING SUPPORT

Family Support Specialists are available for parenting support even when child/youth is not actively in treatment.

14. COMMUNITY-BASED FAMILY SUPPORT SPECIALISTS

Family Support Specialists are based in the community they serve.

15. INFORMATION AND TRAINING

Family Support Specialists need have access to a database of local services and unpaid/volunteer resources and have regular coaching to maintain a family/youth-driven approach.

16. LEARNING COLLABORATIVES

Need to have “learning collaboratives” with other community-based Family Support Specialists about:

- Available resources,
- Rights of families/youth,
- Listening and maintaining a family-driven approach,
- Understanding insurance/agency responsibilities to their members,
- Clinical services best practices,
- Cross-system use of services, and
- Systems transformation.

OUTPATIENT SERVICES

17. ASSISTANCE IN NON-EMERGENCY SETTINGS

Assistance is provided to families without needing to go to a crisis center or hospital emergency room.

18. PRIORITIZE SERVICES TO PREVENT JUSTICE INVOLVEMENT

Increased services for children under 12 with aggressive behaviors are prioritized to prevent juvenile justice involvement.

19. TIMELY INCREASE OF SERVICES TO CHILDREN AT RISK

Increase services for children when they are at risk of being:

- A safety risk to themselves or others,
- Suspended from day care, or
- Given a “reduced school day” or “suspended” in K-12 and post K-12 school.

20. COORDINATED TRANSITION OF SERVICES

There is need to coordinate services to fill the gap between pre-school and K, such as developing coordinated “treatment or service plan” plans.

21. INSURANCE-NEUTRAL FAMILY SUPPORT SPECIALIST

Prior to the child/youth entering treatment services, provide insurance-neutral availability of Family Support Specialist to:

- Offer support, self-care skills, “specialized parenting skills” with parents,

- Coach the use of parallel “self-care/emotional regulation” with their children,
- Identify resources, connection with other parents, and
- Prepare parents for communicating with potential providers.

22. EXPAND SCHOOL-BASED SERVICES

Expand Medicaid billing or insurance-neutral services for Family Support Specialists in schools and expand school-based mental health.

23. INTEGRATED TREAMENT PLANS

Treatment plans need to integrate school Individual Educational Plans, accommodation 504 plan or individual service plans (medications/physical/behavioral health needs).

24. CONNECT SCHOOL- AND COMMUNITY-BASED SERVICES

Increase connection between school-based and community-based behavioral health services.

25. REDUCE BARRIERS TO CARE

Eliminate the need to have new assessments and plans each time a family adds/changes agency and allow skills training without having to agree to “verbal or individual” therapy.

26. EARLY INTERVENTION AND MENTAL HEALTH TREATMENT

Increase mental health treatment to include SUD treatment with group treatment that doesn’t mix “heavy and light users” so that early intervention and mental health treatment can be combined.

RESIDENTIAL

27. FAMILY/YOUTH AGREEMENT

Families need to have the option to identify treatment outcomes and agree to treatment “skills” and goals before admission, during the course of the residential program and integrated in outpatient treatment, when it is agreed to by the family/youth.

28. FAMILY/YOUTH EMPOWERMENT

Discharges should not be forced onto the family until step-down or outpatient services are fully engaged. Families need to be able to object to residential plans when the plan does not fit the cultural and other needs of the child and family.

29. FAMILY VISITS

Parents and siblings can visit regularly and overnight accommodations are available for the family, whenever necessary.

30. USE OF MEDICATIONS AND RESTRAINTS

Use of medications and restraints need to be in the family-driven treatment plan and agreed to prior to placement or before use.

31. SELF-REGULATION SKILLS

Residential treatment needs to teach self-regulation skills while the child is in residential, and coach outpatient providers and support family members how to sustain their use.

32. TRAUMA-FOCUSED SERVICES

Residential services need to be trauma-focused rather than just trauma-informed.

ROLE OF OHA

1. PREVENTION

Advocate for “upstream programs” and prevention services in early childhood and before there is need for treatment services.

2. FAMILY AND YOUTH SUPPORT SPECIALIST SERVICES

Ensure that Family and Youth Support Specialists services are meaningfully offered in all formal services.

3. STEP-UP AND STEP-DOWN SERVICES

Increase the availability of “step-up and step-down” services between outpatient and residential service in all communities.

4. AGENCY-NEUTRAL PARENT ADVOCATE

Fund or promote the funding of a designated agency-neutral “attorney-like” Parent Advocate (similar to Disability Rights Oregon) to review and monitor resolution of complaints about behavioral health services and support the family through the process to prevent retaliation so there are advocates that are not beholden to any agency

5. INTEGRATED TREATMENT AND SERVICE PLANS

Address the need to integrate behavioral health, K Plan, and other I/DD service plans into one coordinated treatment and service plan.

6. REMOVE PAYMENT BARRIERS

Develop payment mechanism to allow children/youth to access services when private insurance, self-pay or co-pay is a barrier or not available.

7. PROVIDER EDUCATION

Develop an accountability metric and monitor/develop/provide implementation education for the providers about stigma reduction, trauma-informed care, family/youth-driven care and meaningful family engagement in agency policymaking.

8. CROSS-SYSTEMS EDUCATION

Develop an accountability metric and provide learning collaboratives for:

- Cross-training (education, behavioral health, I/DD),
- Cross-systems treatment/service plan (goals),
- Honoring families as experts of their family's needs, experiences, and requests for services,
- Stigma,
- Family/youth--driven approach,
- Implementing CLAS standards,
- Transitional care to/from residential and outpatient/wraparound/in-home services/mobile response/crisis response.

9. ENFORCEMENT

Enforce coordinated care organization (CCO) and other service agency responsibilities and contracts related to "duty of care" and "coordinated treatment plans" for the entire continuum of care so that families don't have gaps in services or are placed on unofficial waiting lists.

10. OREGON ADMINISTRATIVE RULES (OARS)

Review OARs to address outcomes of services rather than just process.

11. PEDIATRICIAN SUPPORT

Continue to support ongoing training to primary care providers and pediatricians about the need for early identification and referral for behavioral health concerns and use of

Family Support Specialists for parental stress reduction, support and system information/navigation.

12. PROMOTE "ONE STOP" FOR SERVICES AND RESOURCES

Promote the concept of a community-based "one stop no-wrong door" for basic needs, housing, referrals, respite, resource information, parenting support and benefit sign-up (like relief nurseries and community-based family support/Oregon Warmline).

CSAC

1. ADVOCACY

Advocate for "upstream programs" and prevention services in early childhood and before a need for treatment services is identified.

2. STAFFING

Recommend a permanent full-time staff to be appointed to:

- Support the work of CSAC in meaningful family engagement (individuals and organizations) and outreach and
- Provide information and analysis to guide the integrated (youth, family and providers) policy and program development, implementation, maintenance, and evaluation of programs in OHA and overall child-serving systems through the System of Care Advisory Council.

3. PARENT ENGAGEMENT

CSAC should invite parents to share their lived experience to drive the work of CSAC by utilizing and incorporating the experiences in the topic for discussion to inform policymaking rather than put the parents on display.

4. POLICY AND PROGRAM DISCUSSION

Develop and implement process for meaningful family/youth/provider discussions about OHA policy and programs. Inform members about the data, background information about systems (funding, interagency/department, best practices, evaluation process). The process could include mentoring, information sharing through staff or another member, or a group/committee.

5. OUTREACH TO OTHER ORGANIZATIONS

Develop outreach to and input to the agenda from family/youth organizations and other policymaking groups (i.e., Oregon Consumer Advisory Council, Addiction and Mental Health Programs Advisory Council, and System of Care Advisory Council).

The Children's System Advisory Council accepted these recommendations on October 22, 2021.