IMPROVING THE LIVES OF CHILDREN, YOUTH, AND YOUNG ADULTS WITH COMPLEX NEEDS AND THEIR FAMILIES

A report from the Blueprint Workgroup

pennsylvania
DEPARTMENT OF HUMAN SERVICES

TABLE OF CONTENTS

Acknowledgements 3

Blueprint Workgroup Members 4

Executive Summary 6

Recommendations 1 – 3: Prioritizing Prevention and Strengthening System Response 13

Recommendations 4 – 5: Information Sharing and Resource Navigation 17

Recommendations 6 – 9: Guidance and Supporting County Multi-System Planning Efforts 19

Recommendations 10 – 13: Administrative Efficiencies and Supporting Our Systems 23

Recommendations 14 – 16: Understanding System Capacity and Direct Service Solutions 28

Recommendations 17 – 18: Strengthen Trauma Comprehension and Application 31

Appendix A: Background, Analysis, and Findings 33

Appendix B: ASERT Final Report 47

Appendix C: DAPIM Model 59

Appendix D: Parking Lot Concepts 61

Appendix E: Blueprint Workgroup Charter and Organizational Chart 65

Acknowledgements

The creation of this document is the culmination of months of intensive discussion, hard work, honest reflection, and challenging conversations. It is the embodiment of the determination and spirit of the families and professionals who continuously strive to provide a better life for all children, youth, and young adults. A very special thank you is owed to the families and professionals who participated as members of the Blueprint Workgroup and who continually give of themselves to improve the lives of their children and those they support.

I am especially grateful to Russ Cripps and Colleen Cox from the Child Welfare Resource Center, Kaitlin Koffer and Molly Sadowsky from the ASERT Collaborative, and the DHS Team: Michael Hershey, Roseann Perry, Jenn Newman, Courtney Malecki, Emily Burger, and the many members of the DHS Complex Needs Planning Team. None of this would have been possible without their leadership, knowledge, support, and dedication.

Thank you.

Jonathan McVey
Complex Needs Planning
Office of the Secretary
Pennsylvania Department of Human Services

Blueprint Workgroup Members

Paulette Benegasi, Director, Mental Health/Intellectual Disability, Mercer County
Sandie Beren, Deputy Administrator, Montgomery County Office of Children and Youth
Emily Burger, MS, NCC, Special Populations Clinical Support, PA DHS – Office of Developmental Programs
Lauren DellaCava, Clinical Director, Community Behavioral Health, Philadelphia
Laura DeRiggi, Senior Director, Clinical Consultant Philadelphia Dept. of Behavioral Health and ID Services
Danielle DiMatteo, Director, Delaware County Juvenile Probation
Dr. Meghan Eberle, Vice President Clinical Services, Carelon Health of Pennsylvania
Judy Erb, Administrator, Mental Health/Intellectual Disability, Lancaster County
Leesa Gehman, M.Ed., Deputy Administrator, Northampton County Developmental Programs
Jalissa Gresham, Interim Assistant Program Director, United Methodist Home
Ashley Horvath, Lead Care Manager, Magellan Behavioral Health of Pennsylvania
Marlene Jennings, Program Planner, Early Intervention, Lancaster County
Ashley Johnson, Foster Parent
Shayla Jones, Youth Quality Improvement Specialist, Univ. of Pittsburgh, Child Welfare Resource Center.
Crystal Karenchak, Family Policy and Engagement Consultant, PA System of Care
Ruth Ann Koss, CASSP Coordinator, Children's Mental Health, Allegheny County
Nancy Kukovich, CEO, Adelphoi
Bethany Leas, Director, Outpatient Services, University of Pittsburgh Medical Center
Lisa Lowrie, DSW, LSW, Director of Advocacy and Consumer Relations, The Bradley Center
Herta Madder, MA, MBA CASSP Coordinator - Retired Beaver County Behavioral Health
Stefania Maiale, Adoptive Mother
Courtney Malecki, Director of Planning, Policy and Program Development, PA DHS – Office of Mental Health and Substance Abuse Services, Bureau of Children's Behavioral Health
Athena Mandros, Children and Families Business Development, Merakey
Cindy Matthews, Administrative Entity, Early Intervention, Wayne County
Dr. Kathryn McCans, Chief – Division of Pediatric Emergency Medicine, Penn State Health, Hershey Medical Center.
Beth-Ann McConnell, Interagency Coordinator, Intermediate Unit 15- Capital Area
Shari Montgomery, Intellectual Disabilities Program Director – Armstrong Indiana Behavioral and Developmental Health Program
Crystal Natan, Executive Director, Lancaster County Children and Youth Agency
Dr. Geoff Neimark, Chief Medical Officer, Community Care Behavioral Health Organization
Jennifer Newman, HSA, Cross-Systems Specialist, Office of Children, Youth, and Families
Lisa Parker, Bureau Director, PA DHS – Office of Child Development and Early Learning
Lloyd Peffer, CASSP Coordinator, Tioga County DHS
Roseann Perry, Regional Special Projects Manager, PA DHS – Office of Children, Youth, and Families
Shawn Quigley, Chief Operating Officer, Melmark
Leah M. Raker, Director, Centre County Children, Youth Services
Amy Reed, Coordinator, Early Intervention, Cumberland County
Lana Rees, Executive Director, Erie County Children, Youth and Families
Shelly Rivello, Clinical Coordinator, Behavioral Health Alliance of Rural PA
Roni Russell, PaTTAN Consultant, Pennsylvania Department of Education
Chrissy Sandacz, Manager – Care Management, PeformCare
Erica Scanlon, CASSP Coordinator, Children's Mental Health, Lancaster County

Erin Seifrit-Townsend, Deputy Administrator of Children's Mental Health, Montgomery County Department of Health and Human Services, Office of Mental Health/Developmental Disabilities/Early Intervention
Kristin Smeins, Home and School Visitor, Garnett Valley School District
Adaminah Solita Tankersly, Family Coordinator, CASSP, Philadelphia County
Deborah Tate, Assistant Administrator, Intellectual Disability/Early Intervention Centre County
Bob Tomassini, Executive Director, Juvenile Court Judges' Commission
Kevin Webber, Program Supervisor, Intermediate Unit 5 – Northwest Tri-County
Jaime Yingling, Program Specialist, Intellectual Developmental Disability, Cumberland County
Jen Zingales, Coordinator of Special Education/Early Intervention Services, Colonial Intermediate Unit 20

Executive Summary

A growing number of Pennsylvania's children, youth, and young adults with complex needs and their families often experience significant barriers to treatment, supports, and services. The current child serving systems struggle to support young people who have the most complex needs. In this report, stakeholders have come together to discuss those barriers and to identify recommendations that will improve outcomes for these youth and their families.

Consider the following three stories as an illustration of what youth with complex needs, their families, and the systems supporting them often experience. Although the stories do not capture many of the complexities, or unique circumstances, it is important to start here because these scenarios happen every day, in many different ways, across all of our child-serving systems.

> One young woman experienced significant trauma and hurt long before she reached the system. Adopted and then abandoned, bounced from placement to placement her pain manifested more and more often as aggression and anger. She landed squarely in the system with people all around her who cared and were trying to help, but they didn't know what to do next. Her team recognized she was talented and bright with her own goals. With the right support and guidance, the team talked with her about what she wanted and what her vision for her future would look like. Through that process, she chose a provider to live with, services she would use and a path in her education. She worked to catch up academically and to work towards her dreams. Because her team listened, saw her strengths, and looked for who she was beyond the heartache and pain, she now has stability and a path toward a future she controls, feels safe within, and that is her own.
>
> A young man enters a residential treatment facility because his needs have reached the point where his community-based services and family can no longer safely support him in his home. His needs are significant and cross multiple domains: behavioral, developmental, and medical. The young man's team works diligently with him, and his family is continuously supportive and engaged. As this young man grows, the team sees some positive progress. However, this young man continues to need supports beyond what his family can provide to live a full and safe life in the community. He nears adulthood and the team begins preparing and planning for the next chapter of his life. Again, despite wanting to, his family still cannot bring him home safely. The team searches for assistance and contacts many other professionals and systems, but there are delays in planning, difficulties with funding and misunderstandings between each system. All systems are engaged, but the young man is still in the same place as no provider is able to step forward to support him. Frequent and targeted outreach is completed as the days, weeks, and months pass. Eventually a provider is engaged, but additional resources are required to meet him as his level of need. The process is slow and challenging for all, but most of all for the young man and his family. There is a new home on the horizon, but there are many steps and potential missteps along the way. To the young man and his family, the journey feels like it will never end.

Planning for the future will be an evolving and ongoing process as his needs change throughout his life.

Consider another young man who was abandoned as a young child and then placed with relatives who abused him. Lacking in support and understanding, his behaviors escalated, and he became a ward of the state. Placement after placement failed him until the team connected with his true need - healing and stability. His team worked together to plan for supports in the community, developing a crisis plan and school plan, partnering with intensive services and engaging in frequent multi-system and multi-disciplinary meetings. Even when things were rough, he said he knew it would be okay because he had so many people that cared about him. His team saw his unmet needs, not just the services, but the everyday life needs that are important to everyone. The team came together and worked alongside this young man to build a life he wants to live. He has held jobs, made friends, and started to plan for his future. The process took time away from important developmental years and milestones, and he was nearly an adult by the time enough stability, treatment, and communication occurred to support him in creating this life. We wonder what trauma could have been spared if we had intervened earlier, recognized his deep needs earlier, and helped him to work towards healing sooner.

The work of supporting these three young people is by no means at an end; however, they have the support they need and deserve and are on a positive trajectory toward an everyday life. Two of these stories show us that, with the inclusion of the youth and teaming of all involved systems, it is possible. The other story shows us that even with an engaged and supportive family and a team wrapped around the young man, systems still struggle to effectively and timely support young people. All of these stories illustrate the resilience of youth with complex needs and their families.

There are other youth with complex needs and families in Pennsylvania, right now and in the future, with similar stories of hope and challenges. All of these children and families deserve assistance in navigating these challenges, and we must ease barriers and avoid delays to care and supports whenever possible. Understanding that each youth with complex needs and their families are unique, there are several characteristics that differentiate the population we seek to help through this report. The following are the most often-encountered characteristics of youth (ages 0-21) with complex needs:[1]

- Complex trauma including abuse, neglect, developmental and institutional trauma;
- Multiple and complex diagnoses across the developmental, physical, and mental health domains;
- Potential diagnostic overshadowing due to an intellectual disability and/or autism diagnosis;
- Complex communication needs;
- Inconsistent presentation of behaviors and symptoms across settings;

[1] Not all of these characteristics are required; there is wide variability in the combinations, experiences, and level of acuity of these youth. Additionally, some youth may have very few of these characteristics, but because of complex social dynamics in their lives, are considered to be a youth with complex needs.

- Lack of diagnostic clarity;
- Disrupted education;
- Limited, strained, or no natural supports;
- Multiple system involvement including justice systems; and,
- An extensive history of out-of-home care.

The following national statistics further illustrate some of the complexity of the needs of youth with disabilities, their increasing vulnerabilities, and the prevalence of these youth in our communities. Youth with disabilities are significantly more likely to experience abuse, live in institutional care and not live with kin during a child welfare placement. Research shows that youth with developmental disabilities are more likely to have co-occurring mental health needs. On top of all of that, all of these youth have experienced some form of trauma in their life. As with the stories above, these statistics do not provide a complete picture of need or prevalence.[2]

- 1 in 6 U.S. children aged 2–8 years (17.4%) had a diagnosed mental, behavioral, or developmental disorder.[3]
- Among children living below 100% of the federal poverty level, more than 1 in 5 (22%) had a mental, behavioral, or developmental disorder.[3]
- Depression and anxiety have increased over time: ever having been diagnosed with either anxiety or depression among children aged 6-17 years increased from 5.4% in 2003 to 8% in 2007 and to 8.4% in 2011-2012.[4]
- An estimated 33.6% of individuals with intellectual disabilities have co-occurring mental health conditions.[5]
- Children diagnosed with an intellectual disability were 3.7 times more likely to be neglected, 3.8 times as likely to be emotionally abused, 3.8 times as likely to be physically abused, and 4.0 times as likely to be sexually abused.[6]
- Youth aged 17+ with disabilities experience higher rates of placement instability and longer stays in placement than peers without disabilities.[7]

---

[2] Efforts are underway in Pennsylvania to use data to better understand the scope of need for youth with complex needs and their families.

[3] Cree RA, Bitsko RH, Robinson LR, Holbrook JR, Danielson ML, Smith DS, Kaminski JW, Kenney MK, Peacock G. Health care, family, and community factors associated with mental, behavioral, and developmental disorders and poverty among children aged 2–8 years — United States, 2016. MMWR, 2018;67(5):1377-1383.

[4] Bitsko RH, Holbrook JR, Ghandour RM, Blumberg SJ, Visser SN, Perou R, Walkup J. Epidemiology and impact of healthcare provider diagnosed anxiety and depression among US children. Journal of Developmental and Behavioral Pediatrics. Published online before print April 24, 2018

[5] Prevalence of co-occurring psychiatric disorder in adults and adolescents with intellectual disability: A systematic review and meta-analysis. Mario G. Mazza, Aurora Rosetti, Giovanna Crespi, Massimo Clerici.

[6] Sullivan, P.M. and Knutson, J.F. (2000), ''Maltreatment and disabilities: a population-based epidemiological study'', Child Abuse and Neglect, Vol. 24 No. 10, pp. 1257-73.

[7] Hill, K. (2012). Permanency and placement planning for older youth with disabilities in out-of-home placement. Children and Youth Services Review, 34, 1418–1424.

- Youth with disabilities were 2.47 times more likely to live in an institution and 2.22 times more likely to live in community-based group homes.[8]

In Pennsylvania, a good foundation of services and supports exists across all child-serving systems. However, that foundation is primarily designed around the broader population, youth who have less acute and fewer multi-system needs. As a result, well-intended systems can still miss the wants and needs of youth with complex needs and their families – meaning they are not consistently supported on a positive, personalized trajectory.

In recognition of this problem, the Pennsylvania Department of Human Services (DHS) partnered with the Autism Services, Education, Resources and Training Collaborative[9] (ASERT) to conduct a series of focus groups and surveys. Youth, families, and the child-serving systems supporting them were engaged to better understand current and future needs. These convenings highlighted common challenges these youth, families, and child-serving systems experience. Five key themes emerged across these groups:

1. Communication
2. Services and programs
3. Resource Navigation
4. Staffing / Workforce
5. Trauma-informed supports

Overarching all of the themes above is family engagement. With this new understanding, DHS partnered with the University of Pittsburgh's Child Welfare Resource Center[10] to establish and sponsor a blueprint workgroup with families with lived experience, and a multi-system and multi-disciplinary membership.[11] The workgroup kicked-off in July 2023 to develop recommendations that will improve outcomes for youth with complex needs and their families.

The workgroup met until November 2023 and using the DAPIM framework,[12] identified the recommendations starting on page 12. The foundation for the workgroup's discussion and the recommendations were the five themes from the focus groups and surveys, and the "desired future state" objective provided below:

[8] Slayter, Elspeth, 2016. "Youth with disabilities in the United States Child Welfare System," Children and Youth Services Review, Elsevier, vol. 64(C), pages 155-165.
[9] PAAutism.org
[10] University of Pittsburgh: Pennsylvania Child Welfare Resource Center
[11] Despite efforts to recruit young adults with lived experience, none were able to participate in the Blueprint Workgroup. The Department and the Blueprint Workgroup agreed to delay the release of this report to again seek the valuable input of these young adults; however, few were able to review. Any further work on this topic must include significant efforts to gain the voice of youth with lived experience.
[12] See Appendix C – DAPIM Model

Desired Future State

In Pennsylvania, we believe all youth with complex needs and their families[13] will have the opportunity to access timely supports and services that are individualized, trauma-informed, holistic, respectful of race and culture, family- and youth- driven, and available in their own communities. This will be evidenced by:

- A focus on youth and family engagement while honoring their voice and choice;
- Establishing and maintaining a well-supported and qualified workforce;
- Collaboration and shared understanding across systems to support planning and shared goals;
- Systems that prioritize early identification, proactive intervention, and service options that support family stability, safety, and the youth's healthy development and meaningful relationships which support life-long connections;
- Teams that engage in ongoing and integrated planning that supports the everyday needs of a family and youth (housing, education, transportation, scheduling, access to medical care, etc.); and,
- Service delivery that is coordinated, accessible, timely and includes support throughout the process.

Using the desired future state, the information gathered through the focus groups and surveys, the blueprint workgroup's own assessments, identification of strengths and gaps, and root cause analyses, the blueprint workgroup identified 18 recommendations which help achieve the desired future state.[14] Each numbered recommendation is connected to one or more of the five themes mentioned previously and a supporting rationale is provided. The recommendations are not listed in priority order, rather they are grouped together based on interdependencies or common threads as reflected in the table of contents.

The recommendations address a wide variety of challenges and barriers encountered by youth with complex needs, their families, and the systems supporting them. Some recommendations involve the provision of direct services, such as establishing a multi-disciplinary team of professionals for treatment and stability in the community or developing a unified and proactive approach to transitions for youth. Other recommendations reflect the need for administrative efficiencies, like improving information sharing, establishing greater uniformity in processes and forms among all insurers and health care payors, or finding a better balance in provider credentialing. Still other recommendations focus on building system capacity[15] through uniformity in trauma training, developing trainings and tools to help teams build a complete picture of the child and family, and, very importantly, the need to build and retain a qualified workforce.

All of the recommendations are intended to push the conversation forward in specific critical areas. Due to the time limited nature of the workgroup, the recommendations require further development before implementation can be achieved.[16] For example, the suggested amendments to Act 212 for Early Intervention screening and

[13] "Family" is defined by the individual.

[14] For more detailed information on the background of this effort, please see Appendix A – Background, Analysis, and Findings; and Appendix B – ASERT Final Report.

[15] The Department of Human Services is also launching the first annual Pediatric Capacity Building Institute in January 2024 to increase clinical and administrative capacity for all child-serving systems supporting youth with complex needs and their families. For more information please visit: Complex Behavioral Health Blueprint (pa.gov)

[16] For a brief list of ideas and discussion points that, due to the time limited nature of the workgroup, were not fully conceived and merit future discussion, please see Appendix D – Parking Lot Concepts.

tracking are not intended to provide exact statutory language. The blueprint workgroup recognizes that the categories in the recommendation are conceptual and that there are other potential categories and language that may be preferable. Ultimately, the blueprint workgroup seeks to ensure children with complex needs are identified as early as possible so they and their parents or caregivers can access the services and supports they need through childhood.

The blueprint workgroup also identified four recommendations that deserve separate attention because of their importance to this work:

1. Broadly, there are many young people with complex needs who are receiving interventions but are at a point in their life when they have already faced extreme challenges and adversity, have experienced significant trauma and loss, and are developing in a world without friends or family. By growing up in such an environment, imprints are being made all along the way, the challenges and adversity they were already going to experience because of their disabilities, or the circumstances of their birth are exponentially magnified and new ones are added. Many times, families, practitioners, planning team members ask themselves, what more could we have done? What could we have done differently?

   A broad systematic restructuring is needed with a commitment to implement diverse and holistic prevention activities. States, such as California and Washington, have undertaken massive initiatives to transform their systems of care for youth:

   - A statement from California's Vision for Prevention: "California is committed to the reformation of the child welfare system by shifting the mindset from a child protection and foster care system to a child and family well-being system."[17]

   A multi-year task force should be established to design and implement this restructuring to ensure all child-serving systems of care become prevention focused first and foremost.

2. Persons in state leadership roles (Governor's Office, General Assembly, regulators and/or funders) who seek to implement any of these recommendations should solicit input[18] from youth and families with lived experience. **"Nothing about us, without us."**

3. A multi-disciplinary steering team of state and system leaders, as well as youth and families, should be formed to carry these recommendations forward. Due to the breadth of this work and the time limitation on the blueprint workgroup, these recommendations require further development. Many members of the workgroup expressed a strong desire to continue developing these ideas and carrying them forward to fruition. Additionally, this steering team should leverage the knowledge and expertise of other statewide partners, such as the various associations and advocacy groups, who did not directly participate in the Blueprint Workgroup.

[17] California's Vision for Prevention

[18] In soliciting input from those with lived experience, it is critical to ensure those individuals are supported throughout that process. Safe spaces that meet their developmental, emotional, safety, and accessibility needs are required.

4. Broadly, there are two groups of youth and families in need: those who require help right now and those who will. The blueprint workgroup's recommendations will help both groups, however, the recommendations will also take time to implement. As such, the workgroup recognized the growing number of youth with complex needs who may not be in the most appropriate location for treatment and urges state, local, and system leaders to find solutions which can be implemented right now.

Ultimately, children, youth, and young adults with complex needs and their families deserve solutions that are creative, flexible, and consistently reflect the needs of the whole child and family – the following recommendations can help us achieve that.

Recommendations 1 – 3: Prioritizing Prevention and Strengthening System Response			
	Themes	**Rationale**	**Recommendation**
1.	Services & Programs, Resource Navigation	Not all children and youth with complex needs are identified at an early age and as a result, without appropriate interventions, services, and family engagement, their needs and behaviors increase requiring greater services and supports from other systems as they get older. Children who are engaged in Early Intervention services consistently experience better outcomes over the course of their life. The first opportunity to identify these children is through screening and tracking a child's development. Act 212 (Early Intervention) established six categories of children who are at particularly high-risk of requiring early intervention services, those categories include: low birth weight, neonatal intensive care, prenatal substance exposure, referral by county children and youth agency, lead exposure, or experiencing homelessness. These categories mean the child automatically qualifies for regularly occurring developmental screenings and tracking until age three. Participation is voluntary, parents or caregivers may decline at any time. Regardless of whether a	Amend Act 212 (Early Intervention) to add new categories for screening and tracking up to age 3. The following five categories[19] should be added to Act 212 for screening and tracking: 1. Children with a parent or caregiver with mental illness or SMI; 2. Children with a parent or caregiver with intellectual disabilities and/or ASD; 3. Children who live in extreme poverty; 4. Children with a parent or caregiver currently incarcerated; and, 5. Children born to individuals who had previous involvement with a county children and youth agency within the past two, three, or four years. Notably, the first four categories are all considered Adverse Childhood Experiences (ACEs) for which there is significant data showing positive outcomes when interventions are implemented. Additionally, although prenatal substance exposure (including alcohol), is a critical category that is already in use, it should be re-examined to consider a broader range of scenarios. Some examples may include: where the mother was not using substances during pregnancy, but relapses following child birth or where the father has a history of substance use.

[19] These five eligibility categories were identified without the intent of excluding other potential categories, such as Intimate Partner Violence or Domestic Violence. It should also be noted that each one of these categories can be interpreted and defined in many different ways. Lastly, there are additional methods that should be strengthened to supplement the EI screenings and tracking required in Act 212. For example, providing training to pediatricians to conduct brief screenings like ages and stages during standard well-child visits birth to three.

Recommendations 1 – 3: Prioritizing Prevention and Strengthening System Response			
	Themes	**Rationale**	**Recommendation**
		child is determined eligible for Early Intervention services as a result of these screenings and tracking, the child and family are also referred to other supports and services as they are identified. There is growing interest in expanding EI tracking categories. Children experiencing homelessness was added in 2017 and legislation has been introduced in recent years to add post-partum depression as a category. The six categories in use now should be expanded upon to ensure no children and families slip through the cracks and do not get the help they need as early as possible. The earlier a high-risk child is identified, the more likely the child will experience greater positive outcomes and require less costly supports and services later in life. Although expanding screening and tracking categories is a good start, more is needed to ensure these children do not fall through the cracks. A strong family engagement and education component is needed combined with a bridge between early childhood services and school age services. Even if these children qualify for developmental screenings and tracking, without their families engaged and without a strong bridge between systems, these children may still fall through the cracks.	In implementing these, family engagement and education is critical. Assessments should be respectful of the family culture and conducted in a thoughtful and empathetic manner. Related to family engagement and education, services like Home Visiting and Nurse Family Partnership should be examined with the goal of increasing system capacity and expanding availability to every new parent or caregiver, including access to virtual home visitation. Lastly, it is important that we also increase and strengthen the connection between Early Intervention services and school-age services – this is a critical transition period which can make a world of difference. A warm hand-off is needed between these systems – an individual who can manage this transition and ensure the holistic approach of Early Intervention is not lost.

Recommendations 1 – 3: Prioritizing Prevention and Strengthening System Response

	Themes	Rationale	Recommendation
2.	Services & Programs, Resource Navigation	Traditional funding structures and processes were identified as a root cause of challenges related to service provision, access to services, and navigation of resources. Youth with complex needs and their families have needs that require many different types of services and support – as a result, they have to interact with many different systems and entities. Each of those systems have their own goals, rules, and processes for eligibility, service provisions, admission/discharge criteria, target ages, etc. As a result, instead of youth and families getting services to meet their unique needs, the systems try to "fit" them into each of their boxes because that is what the funding stream dictates. The current structures are designed for the general population or youth and families with low to moderate acuity. They are not flexible enough and do not allow for a more holistic approach that youth with complex needs and their families actually need.	Establish a single, dedicated funding stream outside of the human services block grant that addresses all of the developmental, physical, and mental/behavioral health requirements of youth with complex needs. By placing these domains within the same funding stream, there is greater flexibility to create programs that better meet the needs of these youth. A fully holistic approach becomes more feasible because everything will be funded and coordinated under the same funding stream. This also creates the opportunity to establish new and innovative approaches which may not be currently available or at least not available with consistency across the Commonwealth. Until this can happen, develop written guidance to all child serving systems that will aid county agencies and funders to develop programming which crosses multiple systems. Additionally, fiscal experts are needed to provide direct technical assistance to local planning entities as requested for specific youth with complex needs. (See Recommendation 14 - Needs/Gap Analysis, Recommendation 11 - Insurer Processes, Recommendation 4 – Statewide Clearinghouse, Recommendation 6 – Integrated Child/Family Team, Recommendation 7 – Integrated Family Peer Specialist, and Recommendation 13 – Billing During Teaming)

Recommendations 1 – 3: Prioritizing Prevention and Strengthening System Response			
	Themes	**Rationale**	**Recommendation**
3.	Services & Programs, Resource Navigation	Children with complex needs and families often encounter multiple providers in the community and many more through inpatient or residential treatment. Each professional provides their own assessment of the child and family, and each doctor or psychologist typically provides diagnoses or recommendations. As a result, children frequently carry multiple and sometimes conflicting diagnoses and there are no clear recommendations for the next steps. Additionally, the quality of evaluations, the reasoning for diagnoses, treatments, and recommendations may vary. Evaluations represent a snapshot in time for that child and family and there is no mechanism to revisit and revise or eliminate diagnoses that are not accurate. Standards for each profession vary by license, setting, and service, which can lead to confusing and unclear next steps. When inaccurate diagnoses remain or unclear recommendations follow the child, the child and family are at greater risk of receiving inappropriate services or not being eligible for services that are needed. There is a risk of polypharmacy at a young age and long-term impacts to the child and youth.	Form a time-limited workgroup to complete a root cause analysis on unclear and conflicting diagnoses and recommendations. Review the current standards across professions and payors to find areas of consistency and differences, and develop best practice standards for assessments, evaluations, and recommendations. Develop a guide for planning team members to use when reviewing these types of records to foster greater understanding of the content. Establish a process through which children and families can request re-evaluation or question evaluation outcomes without retribution. Provide a mechanism to provide second opinions when requested that is consistent and can be implemented across settings. (See Recommendation 14 - Needs/Gap Analysis, Recommendation 4 – Statewide Clearinghouse, Recommendation 17 – Healing Centered State, Recommendation 6 - Integrated Child/Family Team, Recommendations 11 - Insurance Processes)

Recommendations 4 – 5: Information Sharing and Resource Navigation

	Themes	Rationale	Recommendation
4.	Resource Navigation	Finding and accessing services and supports can be very challenging for a variety of reasons. For example, many child-serving systems are structured differently between state and local levels, these different structures result in different mechanisms to find and access services. Many systems have some iteration of how to access resources, but they also have serious limitations such as compatibility with other systems, ease of navigation, or are not always up to date. As a result, it is very challenging for professionals and families to identify what resources are available near them and to access them.	Develop a statewide, comprehensive and holistic clearinghouse of information on supports, services, and program availability in Pennsylvania. This clearinghouse should compile resources from all systems[20] into a "one-stop-shop." The platform should be accessible, easy to navigate for families and professionals, and should support referrals by professionals to services and supports specific to the needs of the youth being supported. PA Navigate[21] is scheduled to launch in January 2024. PA Navigate is currently structured around social determinants of health (transportation, food insecurity, housing, homelessness, financial strain, clothing, utilities, etc.). A logical next step for PA Navigate is to expand that platform to support the service and support domains identified in the paragraph above.
5.	Communication, Services & Programs, Resource Navigation, Family Engagement	Information critical to support planning efforts is often missed or delayed when concerns about confidentiality prevent systems and planning team members from sharing information. For example, some agencies/entities/providers will not accept another entity's release form. Families are required to sign releases of information repeatedly as new systems, practitioners, and team members join the treatment and planning efforts. This is burdensome,	A time-limited, specialized workgroup with subject matter experts from across systems, including legal counsel, is needed to examine current laws, policies, practices, and tools (including infrastructure) across systems and identify opportunities to support more effective and efficient information sharing across all child serving systems.

[20] References refer to "all systems" includes, but is not limited to medical, developmental, educational, child welfare, early intervention, juvenile justice, mental health, drug and alcohol.

[21] Please visit FindHelp.org to view the platform used by PA Navigate. Please visit PA NAVIGATE - HealthShare Exchange to read a description about PA Navigate.

Recommendations 4 – 5: Information Sharing and Resource Navigation			
	Themes	**Rationale**	**Recommendation**
		frustrating, and time consuming to all parties. Meanwhile the youth is awaiting their next steps. Systems and planning teams need to be able to quickly and completely share information among themselves to make informed decisions with the family.	Potential solutions may include providing template memorandums of understanding or template releases of information, which should include the ability for families to exclude specific parties as they choose. For example, the Centers for Disease Control and Prevention provided a template Memorandum of Understanding[22] to states participating in the Autism and Developmental Disabilities Monitoring Grant program. The template designates state development disability agencies "as an authorized representative of Data Provider for the purposes of collecting information from early intervention or education records." (See Recommendation 14 - Needs/Gap Analysis, Recommendation 8 - Comprehensive Tool, and Recommendation 9 - Transitions)

[22] Memorandum of Understanding between the State Agency under the Individuals with Disabilities Act (IDEA) and the State Autism Developmental Disabilities Monitoring Program (State ADDM) (cdc.gov)

Recommendations 6 – 9: Guidance and Supporting County Multi-System Planning Efforts

	Themes	Rationale	Recommendation
6.	Communication, Resource Navigation, Family Engagement	A significant challenge for effective planning, when multiple systems are involved, is the lack of a consistent central figure or structure at the local level. This results in a variety of issues, which include, but are not limited to key partners/resources missing from the table, key information/background missing from the discussion, information being dispersed across multiple people/systems instead of centralized within the team, lack of accountability, confusion around goals, lack of effective transition planning (as described in Recommendation 9), significant family stress related to not knowing who to talk to, etc. Additionally, although there are many highly skilled individuals across various counties and in some cases successful multi-system structures that some counties have built, it isn't consistent across the state and in some cases those successful areas could still use additional support and training.	Develop guidance to counties with funding to support an Integrated Child and Family Team. The guidance should provide a template which encourages counties to utilize evidence-based teaming models to be selected at a county's discretion. Regardless of the teaming model selected, team membership should include the youth and family, a family peer specialist, all child and family serving system partners, and be multi-disciplinary. The guidance should leverage existing structures/principles (for example Child and Adolescent Service System Program (CASSP)[23] / Systems of Care (SOC)[24]; identify best practices from across the state; provide training, tools, and templates for facilitating multi-system planning meetings. Within this structure a single person/s should be identified to organize, schedule, and facilitate planning meetings. This individual/s is also responsible for maintaining the complete biopsychosocial profile of the youth and their family. (See Recommendation 8 – Comprehensive Tool, Recommendation 5 – Information Sharing, Recommendation 2 – Single Dedicated Funding, Recommendation 5 – Information Sharing, and Recommendation 13 – Billing During Teaming)
7.	Communication, Resource Navigation, Family Engagement	Families are expected to navigate extremely complex systems and communicate clearly and effectively when they are also trying to manage their own emotions, particularly coming out of crisis situations.	Catalogue and assess the types of peer supports that currently exist, identifying their role, the context and system they work within, and what types of supports and training they are provided.

[23] Child and Adolescent Service System Program (pa.gov)
[24] Systems of Care (pa.gov)

Recommendations 6 – 9: Guidance and Supporting County Multi-System Planning Efforts

	Themes	Rationale	Recommendation
		Families struggle with having the right support to assist them when they enter system(s). Two key features of that struggle relate to emotional support and navigation. Overlapping both is the importance of clear and effective communication. Having someone who has lived experience, who knows the systems and can help families engage effectively while avoiding re-traumatization is critical. There are peer and family-peer support services currently available, however, not all are available statewide, some exist in pockets, some are more robust than others, and it is unclear whether these peer supports are available across systems to meet the needs of youth with complex needs and their families. Systems need to more broadly recognize the value of peer supports and expand resources and availability of peer support positions across the Commonwealth	Using the information from the catalogue, develop an Integrated Family Peer Specialist role to participate in the Integrated Child and Family Team (see Recommendation 6 – Integrated Child and Family Team and Recommendation 14 - Needs/Gap Analysis) to support the youth and family as they engage with that team. Consistent funding to support this role must be identified and broadly supported by all systems.
8.	Communication, Trauma-Informed Care	Children and families often must tell their stories over and over. This leads to re-traumatization and a feeling of distrust or disconnect from supports. Children and families often give up when they feel like no one knows them or understands their history. Additionally, because of having so many different systems and supports involved, contextual or historical information is frequently lost, behaviors and symptoms are misinterpreted, or inaccurate information is carried forward with no ability to confirm/correct or fully	Establish a small, time-limited work group of providers, counties, those with lived experience, and DHS staff to review available tools and assessments that chronicle a child and family's life. This should include reviewing tools like the biographical timeline, wellness recovery action plan, child profile, Early Intervention assessment, Life Course, and functional behavioral assessment.

Recommendations 6 – 9: Guidance and Supporting County Multi-System Planning Efforts

	Themes	Rationale	Recommendation
		understand what happened. Without a thorough understanding of the child and family, we cannot support them effectively and say a child "failed" when in fact, we were missing the reason the issue was occurring or we were not addressing the root cause.	The workgroup's goal is to select or develop a process and tool that can synthesize critical contextual/historical information and be used and understood across all child-serving systems and professions. This process and tool can then be used by families to tell their story without re-traumatization and ensure a full and complete picture of the youth and the family is presented consistently to new providers or team members. This workgroup would also offer recommendations around training and support for each of these tools so that a team can choose the best tool to meet the needs of the child/family. Create a consortium of specialists across the state and across systems who are fully trained and can support the use of this tool and process in the Integrated Child and Family Team. (See Recommendation 6 - Integrated Child/Family Team, Recommendation 5 – Information Sharing, Recommendation 17 – Healing Centered State, Recommendation 9 - Transitions)
9.	Services & Programs	Transitions are consistently a time of challenges and high risks for youth and their families. This can include seemingly small transitions like graduating from a service to much larger changes such as transitioning back to their home from a residential treatment facility or group home, returning home from a juvenile justice facility, from EI to school age services, or from child serving systems to adult serving systems. Planning Team members and providers are often challenged to think about transitions as more than a move	Develop a unified and proactive approach to transitions across systems which addresses the unique needs of each child and family and considers existing regulatory requirements. Support the idea that transition is not just the move from one placement or system to another but rather any change or transition in the child and family's life – a change in therapist, change in teacher, etc. Proactive transition planning should be integral to a youth and family's long-term goals and address the immediate changes and plan for the future. Transition planning is an evolving process, the plan

Recommendations 6 – 9: Guidance and Supporting County Multi-System Planning Efforts

	Themes	Rationale	Recommendation
		from a physical location to another location rather than globally like the change from one therapist to the next, or from one teacher to another teacher. Each of these impacts the child and family, and they often find themselves in crisis afterward because the transition was not carefully thought out and prepared for and the needs of the child and family were not addressed adequately. Youth with complex needs and their families often need clearer and more supportive transition plans due to their level of need, which may not always be recognized by the larger team. Without thoughtful transition planning, we risk destabilizing a child and family further and may restart a cycle toward crisis before supports and services can be fully implemented in the home (or other settings). Every youth is unique, and their transition plan must recognize that uniqueness. Although some transition plan templates or approaches exist, they are typically limited to a particular system and do not necessarily account for the level of complexity some youth present.	should be a living document and be re-evaluated regularly with input from the child and family. Planning should establish expectations in preparation for transition, ensuring a complete understanding of the supports, interventions, and tools to be used – including family supports, managing communication, transfer of information and teaming ahead of these transitional times. Transition planning should also prepare the team for ongoing support after the transition and continuously work to identify challenges as they arise, such as during emergencies, and identify solutions for those new challenges. Establish strong and open communication between the child, family, and team to ensure supports can be fully implemented. Transition planning should also be reviewed after each transition for lessons learned and ways to prepare for transitions in the future. (See Recommendation 5 – Information Sharing and Recommendation 7 - Integrated Child/Family Peer Specialist)

Recommendations 10 – 13: Administrative Efficiencies and Supporting Our Systems			
	Themes	**Rationale**	**Recommendation**
10.	Staffing/Workforce, Trauma Informed, Services & Programs	Human service fields across service sectors are struggling to maintain a well-qualified workforce across all systems. Challenges with recruitment and staff retention impact all levels of services from case management to direct delivery. Vacancies are at an all-time high. Colleges and universities have also seen a sharp decline in the number of students enrolling in programs related to human service fields. When entities can fill a vacancy, the ability to maintain the entry level staff remains a challenge. The extensive turnover does not solely exist with entry level positions, entities are also losing long-term experienced staff. This has, at times, resulted in staff being promoted before they're ready for greater responsibility, further exacerbating staffing challenges. The ability to recruit and retain staff is impacted by the lack of a livable wage, discrepancies between wages and the cost of higher education, and inconsistencies in wages across geographic areas and between public and private agencies. Additionally, the danger of the work, the nature of the job, and the impacts of vicarious trauma	Create strong incentives to build a qualified workforce willing to enter and remain in human service fields. Consider programs that assist those who are interested in the human services field to commit to that area of study such as: • Collaboration with high schools and colleges to create innovative programming that includes opportunities for workforce training and apprenticeships, with credit. • Develop programs similar to Child Welfare Education[25] and Leadership and Child Welfare Education for Baccalaureates[26] to support broader cross-system efforts to attract candidates into the human services field. • Collaborate with colleges and universities to develop targeted and rigorous courses of study in the human services field. • Fund loan forgiveness options for child and family service providers and/or human services providers. • Identify flexibilities for employment qualifications without compromising on quality such as military service, related fields of work, and lived experience. • Create opportunities across practices and positions which support licensing and career advancement tracks. Many disciplines require advanced training or supervision that is costly and difficult to acquire. For example, social work and counseling require supervisory hours for licensing, if an employer can provide those supervisory hours in the context of the job, then employees can stay with the organization and obtain licensure. This could also look like providing an avenue for

[25] Child Welfare Education for Leadership (CWEL) | School of Social Work | University of Pittsburgh
[26] Child Welfare Education for Baccalaureates | School of Social Work | University of Pittsburgh

Recommendations 10 – 13: Administrative Efficiencies and Supporting Our Systems			
	Themes	**Rationale**	**Recommendation**

		on staff all compound the ability to retain staff. Formal education and job-related training are insufficient in preparing the workforce and equipping staff with the skills and knowledge necessary.	frontline personnel to advance such as moving from a direct support professional to a more advanced position by supporting tuition reimbursement or incentives. Supporting employee career pathways and advancement helps everyone and will increase recruitment and retention rates.
			
			Support staff already employed in the human services field through:
			• Standardized livable wages across the state that are equitable from county to county.
			• Provide retention incentives for all levels of staff such as:
			  o Tuition assistance or comparable salary adjustments for staff pursuing higher education and/or necessary credentials; or
			  o Longevity increases for staff who remain with their employer for certain periods of time.
			• Strengthen and expand upon existing benefit options for hourly and low-income workers.
			• Develop standards and career benchmarks that can promote competency and career advancement.
			• Provide staff with support and resources for self-care and work/life balance.
			
			Work with current child serving systems to develop and implement support and training opportunities for better supervision and retention of staff. Encourage the use of models of positive support, such as Sanctuary, Reflective Supervision, or Person-Centered Thinking across the board.

11.	Resource Navigation, Services & Programs	A root cause for many challenges faced by children and families is the variability with insurance coverage, navigating complex insurance mechanisms – especially	Establish a time-limited workgroup to identify challenging areas of interactions with and between insurers/healthcare payors and potential solutions to support easier and more efficient navigation of these already

Recommendations 10 – 13: Administrative Efficiencies and Supporting Our Systems			
	Themes	**Rationale**	**Recommendation**
		between insurers and healthcare payors, lack of consistency between insurers (forms, nomenclature, processes, etc.), and geographic disparities (partially a function of some system structures). The variation of responses from insurance companies results in lag times for service provision, often resulting in decompensation, thus requiring higher levels of service. This is seen in both child and adult-serving systems. While it is recognized that parent companies for insurances guide much of this, exploring this area to see what can be streamlined may provide opportunities for simplifying interactions with insurance.	complex systems. A structure is needed that supports greater consistency and alignment among insurers/healthcare payors. This recommendation applies to all insurers/healthcare payors and the relationships between those insurers: private insurers, Medicaid managed care organizations, between physical and behavioral health, between managed care entities within the same system, etc. Some examples of challenging areas to address include forms, approval/denial processes, processes in general, collaboration between insurers/healthcare payors, sharing data between insurers/healthcare payors, and nomenclature. One potential solution could be the creation of a universal form used by all insurers/healthcare payors to streamline the approval/denial process across systems. (See Recommendation 13 – Billing During Teaming, Recommendation 14 - Needs/Gap Analysis, Recommendation 12 - Provider Credentialing)
12.	Resource Navigation, Communication, Services & Programs	An important benchmark for high-quality healthcare is "credentialing," which is the process of assessing the academic qualifications and clinical practice history of a healthcare provider. This helps ensure providers have the	A better balance is needed between the burden on providers to prove their qualifications and the interests of insurers/healthcare payors to ensure funding is going toward high-quality healthcare. A time-limited workgroup of subject matter experts and stakeholders is needed to catalogue what requirements and practices are currently in place and identify potential solutions which help to balance these interests. Below are two potential solutions:

Recommendations 10 – 13: Administrative Efficiencies and Supporting Our Systems			
	Themes	**Rationale**	**Recommendation**
		appropriate qualifications, training, licensure, and ability to practice medicine.[27] In Pennsylvania, in accordance with state and federal laws, insurers/healthcare payors establish their own parameters for the types of credentials they require for a provider to enroll in their network. Notably, many, if not all, insurers in Pennsylvania are subsidiaries of larger, national companies that determine the credentialing practices and rules for their subsidiary. In addition to the variety of credentialing requirements providers must meet, the processes themselves vary from insurer to insurer. This variability is problematic because it results in providers spending a significant amount of time and resources complying with each insurer's requirements and processes, it also results in significant duplication. Rapid changes in personnel exacerbate this issue resulting in additional time away from the important work providers were trained to do.	• Establish uniform credentialing requirements across insurance companies; or, • Centralize the credentialing process for all providers and insurers. A "one-stop-shop" for providers and insurers to go for credentialing purposes. Notably, there are number of other states that have already established a centralized credentialing system and process.[28]
13.	Services & Programs,	Currently, certain practitioners cannot bill for time with a child and family if they see them concurrently with other practitioners. This results in a child and family having to	Federal and state rules and policies should be closely examined to identify and apply funding flexibilities to appropriately fund practitioner time spent

[27] Credentialing - StatPearls - NCBI Bookshelf (nih.gov)
[28] Ohio, North Carolina, Nevada (starting implementation), Mississippi, Georgia.

Recommendations 10 – 13: Administrative Efficiencies and Supporting Our Systems		
Themes	**Rationale**	**Recommendation**
Resource Navigation, Staffing/Workforce, Communication	share their story multiple times – something that can retraumatize all parties. This has a negative effect on the mutual understanding of the practitioners and systems interacting with the child and family. For children with complex needs and multi-system involvement, the negative impacts are compounded because of the number of practitioners with whom they interact. The teaming and planning efforts required for these children are extensive and it is reasonable to expect, especially during the staffing shortage, to compensate these practitioners when they participate in teaming efforts. Some examples of these teaming and planning scenarios include: the earlier recommendation regarding forming an Integrated Child and Family Team at the county, Family Based Mental Health Services, Intensive Interagency Meetings, Complex Needs Planning Meetings.	during intensive teaming and planning efforts specifically for youth with complex needs. Potential solutions may be teaming or bundled rates. Early Intervention uses teaming codes allowing different disciplines to meet with the child and family and to bill under that code. The Early Intervention model should be considered when examining this recommendation. (See Recommendation 11 Insurance Processes)

Recommendations 14 – 16: Understanding System Capacity and Direct Service Solutions

	Themes	Rationale	Recommendation
14.	Services & Programs	It is currently unclear what the true need for and availability of services and supports is at the local and statewide levels. We know there is disparity between rural/urban, large/small counties, etc. This is particularly true for youth with specialized treatment needs. Planners at all levels need better information to make data driven decisions regarding the services and supports needed by youth with complex needs and their families.	Conduct a comprehensive needs and gaps analysis across all relevant child serving systems. The analysis should address: • Whether there are particularly successful services or models and where they are available; • Whether and where demand may outstrip the availability of services and supports; • Whether there is a need for additional levels of care, step downs, or adjusting existing levels of care for a better bridge between facility-based care and community-based care / return to home (e.g. a setting for young adults which supports independent living, but also incorporates intensive behavior supports; • Whether there are evidence-based practices missing or which need to be expanded upon; and, • Whether and where specialty programming is needed and for what specialties (genetic disorders, fire setting, PICA, etc.). This analysis should also move beyond quantitative analysis, it should also include qualitative analysis to determine what services, supports, and models are most effective. In addition to helping local and state level planners make informed decisions, this analysis can also be used to inform the implementation of many of the recommendations contained in this report. (See Recommendation 5 – Statewide Clearinghouse, Recommendation – 2 Single Dedicated Funding)

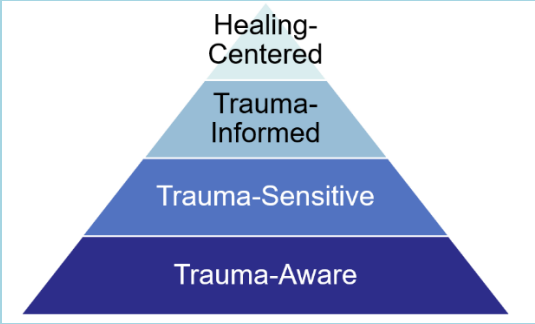
Recommendations 14 – 16: Understanding System Capacity and Direct Service Solutions

	Themes	Rationale	Recommendation
15.	Services & Programs	The continuum of care and transitions from facility-based care and back to the community, or moving from the child to adult system, is a consistent challenge for many youth with complex needs. Family-based services are not always equipped to respond to the myriad or acuity of the challenges these young people face. A program is needed to provide intensive supports around recovery, coordination, medication management, behavior support, and crisis support, in addition to other supports as needed. This intensive level of service can be successful in preventing re-institutionalization, loss of placement, support children and families in maintaining in the community setting and help bridge transitions to the adult system.	Create a multi-disciplinary team of professionals (e.g. a treatment service like a Dual Diagnosis Treatment Team) who are well equipped to treat and coordinate services and supports for youth with intensive multi-system needs. At a minimum this team would include a medical professional (nurse or similar), a mental health professional, behavior support, and a care coordination component. This multi-disciplinary team could be used to support individuals with complex needs. (See Recommendation 14 - Needs/Gap Analysis, Recommendation 6 - Integrated/Child Family Team)
16.	Services & Programs	Children with complex needs and their families often present to services during a crisis. They have often tried other services or have cycled through emergency rooms and inpatient hospitalizations with little time in between. They could be reintegrating into the family setting from another out of home setting and that transition can present unique needs and considerations. Family-based mental health services (FBMHS) are designed for children who are at significant risk of out of home placement. This presumes that the child has either had or is imminently at risk of no longer living in a family setting. Because of this, families with younger children may not be able to access the service and those with older children (generally, 11 years and older) may already have a long history of struggles. Because of the particular model that	Increase the flexibility and scope of Family Based Mental Health Services by: Reviewing the medical necessity criteria for FBMHS and exploring if the "at risk of out of home placement" is a required criteria or if there is a more flexible interpretation that can be applied for younger children who would benefit from this service. Consider developing tiers within FBMHS: one that is for the traditional FBMHS structure, one for a more advanced acuity and one for specialized needs such as significant trauma, problematic sexual behaviors, developmental disabilities, psychosis, etc. Explore ways to work with broader groups more consistently across the state, such as younger children or those with ID/ASD. Provide additional adjunct services within a tiered system of FBMHS to better support the family such as the addition of IBHS/ABA type supports or more robust crisis planning.

Recommendations 14 – 16: Understanding System Capacity and Direct Service Solutions			
	Themes	**Rationale**	**Recommendation**
		FBMHS uses (Eco System Structural Family Therapy) patience is needed to build relationships with a strong emphasis on gathering history, etc. Accomplishing those things takes time and may not meet the immediate needs of the family. This model also does not address behavioral interventions and parent or caregiver training around those which can be necessary when working with children with complex needs. Additionally, FBMHS does not typically provide supports for younger children (below 10) or those with ID/ASD, each of which present unique challenges to the structure of FBMHS. There also is no tract for children and families with significantly complex needs such as trauma or sexually problematic behaviors and families may be reluctant to use the service if they feel their needs are too complex for the service.[29]	The comprehensive needs and gaps analysis in recommendation 14 will inform the implementation of this recommendation. With that said it may be easier and more expedient to adjust this service as described in the meantime. (See Recommendation 14 - Needs/Gap Analysis, Recommendation – 11 - Insurance Process, Recommendation 13 – Billing During Teaming)

[29] There are FBMHS providers who do serve younger children or children with specialized needs; however, it is not consistent or widespread.

Recommendations 17 – 18: Strengthen Trauma Comprehension and Application

	Themes	Rationale	Recommendation
17.	Trauma-Informed, Services & Programs, Staffing/Workforce, Communication	Nearly all children and families that we support have experienced some level of trauma, many have experienced extreme trauma over the years. It is important that children and families are treated with a positive regard that is respectful of their lived experience. A healing-centered environment at all levels recognizes that some behaviors and outcomes that have been seen as negative are actually symptoms of underlying and unhealed trauma and must be addressed to assist the child and family in moving forward. Currently, there are many interpretations of trauma informed care across all system partners. As children and families move through these systems, they may receive trauma informed care that has been implemented with varying levels of fidelity. This inconsistency makes it difficult for children and families to find a path toward healing and engage with supports and services.	Develop uniform standards to make Pennsylvania a healing-centered state. This should include shared language, cultural competence, definitions, and technical support to ensure fidelity. Entities across all levels of service systems should commit to providing basic and advanced trauma training as well as developing internal assessment training standards and supervision consistent with trauma informed care. Additionally, recent statewide efforts, such as HEAL PA,[30] have resulted in significant forward movement with trauma-informed care in Pennsylvania. There continues to be many different groups working on trauma-informed care, and continued leadership at the highest levels is needed to bring these groups together to ensure consistency and resources are brought to bear. (See Recommendation 5 – Information Sharing, Recommendation 6 - Integrated Child/Family Team, Recommendation 18 – Judiciary Trauma Training & Application) 

[30] HEAL PA

Recommendations 17 – 18: Strengthen Trauma Comprehension and Application			
	Themes	**Rationale**	**Recommendation**
18.	Trauma Informed Communication	County judges operate differently from county to county. This applies to the use of trauma-informed language and application. Allegheny County is an example of a family court system that has applied trauma-informed strategies and could provide input to other counties.	Training should be made available for judges in both juvenile justice and child welfare systems regarding trauma and how to apply trauma-informed strategies consistently county to county. This training should include continuous opportunities for review, monitoring, and coaching to ensure fidelity. The culture of the particular workforce being trained should be accounted for with respect to content and trainer – consider whether the audience is comprised of juvenile justice professionals or child welfare professionals. (See Recommendation 17 – Healing Centered State)

Appendix A: Background, Analysis, and Findings

Background

The Pennsylvania Department of Human Services (DHS) recognized a need to understand and improve service delivery to children, youth, and young adults with complex needs and their families. Prior to making any changes, it was crucial to gather information from those families and children, as well as child and family serving systems across Pennsylvania, to learn what is and is not working. A series of surveys were sent and focus groups conducted from December 2022-May 2023 with families and youth, residential providers, behavioral health managed care organizations (BHMCO), county agencies, education system representatives, behavioral health primary contractors, and hospital systems. The surveys and focus groups were managed by ASERT (Autism Services, Education, Resources and Training)

Commissioned by DHS, ASERT is a partnership of medical centers, centers of autism research and services, universities, and other providers involved in the treatment and care of individuals of all ages with autism and their families. ASERT was developed to bring together resources locally, regionally, and statewide. Their mission is to innovate, collaborate, and lead to improve access to quality services, data, and information; to provide support, training, and education in best practices; and to facilitate the connection between individuals with autism, developmental disabilities, and special populations, families and key stakeholders at local, state, and national levels.

ASERT utilized two methods to gather data; surveys and focus groups. Data was collected around eight areas to inform this work moving forward:

- Identification of children, youth, and young adults with complex needs and the changes in this population over time;
- Barriers in service planning and provision;
- Service array;
- Education;
- Transition and discharge planning;
- Family and youth engagement;
- Social and diagnostic history; and,
- Successful strategies and opportunities for improvement.

DHS identified representatives from each of the participating child and family serving systems, as well as connections to family and child advocacy groups across PA to which ASERT sent invitations to online discussion boards and surveys. Surveys were sent to child and family organizations like Youth Advisory Board and National Alliance on Mental Illness (NAMI), then sent directly to youth and families. Hospital systems received surveys and inclusion in the focus groups through the Hospital Association of Pennsylvania (HAP). There were 97 people who participated in focus groups, 45 hospital staff respondents, and 138 family/youth

respondents. From this data collected, five themes emerged, which are communication, resource navigation, services and programs, trauma informed support, and staffing/workforce. Family engagement was included in all of the themes.

The full ASERT report can be found in **Appendix B**.

The Complex Needs Steering Committee identified what the ideal system would look. Through this process, the following Desired Future State was developed:

In Pennsylvania, we believe all youth with complex needs and their families* will have the opportunity to access timely supports and services that are individualized, trauma-informed, holistic, respectful of race and culture, family and youth driven, and available in their own communities.
This will be evidenced by:

- A focus on youth and family engagement while honoring their voice and choice.
- Establishing and maintaining a well-supported and qualified workforce.
- Collaboration and shared understanding across systems to support planning and shared goals.
- Systems which prioritize early identification, proactive intervention, and service options that support family stability, safety, and the youth's healthy development and meaningful relationships which support life-long connections.
- Teams engage in ongoing and integrated planning that supports the everyday needs of a family and youth (housing, education, transportation, scheduling, access to medical care, etc.).
- Service delivery is coordinated, accessible, timely and includes support throughout the process.

** Family is defined by the individual*

Once data collection was complete, DHS, in partnership with the University of Pittsburgh Child Welfare Resource Center (CWRC), collaborated to facilitate discussion regarding children, youth, and young adults with complex needs and their families to improve all family and youth serving systems. To ensure family and youth, as well as the systems that serve them, had a role and voice in the process, DHS provided CWRC with a large workgroup of people dedicated to working through the five theme areas.

The kickoff was held at the CWRC in Mechanicsburg on July 19-20, 2023, with small workgroup meetings held weekly thereafter. Blueprint workgroup members were facilitated through a change management framework to identify strengths and barriers, identify root causes, and make recommendations for change. Blueprint workgroup members came together at the CWRC on October 19-20, 2023, to finalize recommendations.

Themes

As discussed in Section II, focus groups and surveys were used to gather data around the needs of children and families across the state. Through the focus groups and surveys, five themes emerged from all the child and family systems. They are:

- Communication
- Services and programs
- Resource navigation
- Staffing/workforce
- Trauma informed supports

A key consideration for all five themes is the importance of family engagement throughout all five themes. Using the data collected during small workgroup meetings, employing a crosswalk of common data across all four of the groups and focus group/survey data, strengths and barriers were identified. The data collected is directly from the field and shared in the language used by those providing it, either through direct quotes or paraphrased with their permission. This is broken down by theme below and include strengths and barriers identified:

Strengths & Barriers Analysis

Communication:

- **Strengths**:
  - Systems recognize the challenges and want to work to improve communication.
  - There are mutual goals across systems to more intentionally communicate and collaborate.
  - Pennsylvania is diverse with a variety of providers and local level associations and advocacy groups, offering opportunities to come together for information sharing.
  - Child and family serving system partners value families with lived experiences.
  - Technology innovations have been implemented that can support enhanced communication.
  - Resources and access to interpreters to assist with language barriers.
  - When team members are together at the table everyone does well communicating issues and what has been tried. The passion for helping the child is there, and there is a willingness to ask and answer hard questions.
  - CASSP system when working as designed. There are other meetings similar to this that work when there is not a CASSP coordinator.
  - County team getting alerts from the Managed Care Organizations (MCO) when there is a child that is experiencing a 24 hr. Emergency Room (ER) stay.
  - Complex case conferences, and other regularly scheduled venues that bring systems together.
  - Draft OCYF regulations have been expanded to include the family and youth voice.

- **Barriers**:
  - Meeting procedures – Roles & Responsibilities
    - Not all systems are invited to the table at times and/or only those currently involved with the family. Impact on decision making and associated costs.
    - Lack of identifying roles and responsibilities of those at the table. Why are they there and what can they do? Builds trust.
    - Scripted information on what they do, but not how they can help that particular family.
    - Prioritization of stakeholders and system partners varies resulting in a certain lack of urgency.
    - Correspondence and presence in meetings don't always lead with positives. Focus on what you can bring to the table rather than what you cannot offer.
    - Definition of complex case is different between systems. Education vs. Child Welfare vs. Mental Health, etc. View on diagnosis can vary and lead to a different approach to services.
  - Confidentiality and Privacy Restrictions
    - Systems & Departments limited in what they can share with each other. Sometimes it is a perceived inability to share. Negativity can enter the collaboration.
    - Lack of sharing can lead to key information missing which may impact the services being recommended.
    - Age of consent varies from system to system.
  - Centralized Resources/Hub for Information
    - Need for an integrated plan, prioritizing needs and goals shared between systems.
    - Lack of a centralized location where cross-system and cross-county information can be stored and accessed (i.e., electronic records). System/organization databases are isolated.
    - Confusion on who regional system leadership is and how to contact them.
    - State initiatives that conflict and/or confuse professionals and families. (i.e., Trauma-informed approach).
    - Lack of a message board or listserv to reach out to system partners to share success and needs.
  - Family/Youth Engagement
    - We start with the professional's schedules, not the families.
    - Assumptions that families understand something if they are not asking about it.
    - Lack of information about the family (i.e., primary language, impairments, processing ability) leads to poor communication.
    - Lack of preparation for families prior to meetings.
    - Families/Youth feel excluded from service planning and don't feel they have a voice in services being offered.
    - Lack of purposeful and intentional check-ins with families to get feedback on how services are going for them and prioritization of services.
    - Need to consider when there are too many services in place for families.

Services and programs:

- **Strengths**:
  - There is a desire to implement successful and creative programming and supports
  - Systems share the goal to collaborate and learn about other systems' services and programs.
  - There are some very successful high-quality services and programs available in some counties for children and families (e.g., early intervention, IBHS, emotional support school placement, trauma therapy).
  - Funding to support children with complex needs exists, we just need to develop strategies to use it more effectively.
  - Pennsylvania has a robust early childhood service array.
  - Pennsylvania's five (5) children's hospitals. Some states do not have one (1) children's hospital.
  - Expansion of beds with in some 24-hour levels of care of note the beds for youth with Autism and Intellectual Diagnosis
  - The Tips program at Hershey where Primary Care physicians (PCP) can consult with a psychiatrist to triage the PCP's med management of the child until a psych appointment is available.
  - Evidence based child welfare practices like multi systemic therapy (MST) and Functional Family Parenting (FFP)
  - School based behavioral health and prevention programming.
  - Federal shift in funding (Family First) leading to increase and more services related to prevention.

- **Barriers**:
  - Service and Program availability
    - Limitation of appropriate placements and services.
    - Long waiting lists often result in decompensation and a need for higher levels of care.
    - Limited service and program availability in locations geographically close to families.
    - A lot of youth with behavioral health problems because of home challenges. If caretakers' mental health needs are addressed, it would impact challenges for youth.
    - Frequent denials or refusal of services based on the need being "too acute."
  - Transition to Adult Serving Systems
    - Moving from child to adult serving systems is a big challenge for families and older youth.
    - Many programs, including evidence-based programs, don't cross over to adult system.
    - Needs of transition-age youth are complex and include the need for housing complicated by the grey area of 18–21-year-olds caught between child and adult serving systems.
  - Funding
    - Lack of Funding flexibility to use practice to show progress and allow for new funding opportunities.
    - Funding needs to follow individual and unique family needs instead of fitting families into limited EBPs.
    - Base-funding increase needed.

        - Private insurance not funding crisis services.
        - Need an integrated funding model to create a stabilization home/group home that assessments can be done and not necessarily fit into a Medicaid treatment service.
        - Lack of direction from State agencies about moving forward to support a child/family and making the funding work. Need for state agency action to have an impact on this work.
        - Who is ultimately responsible for ensuring that the child gets what they need, funding available, waive whatever needs to be waived to secure funding?
        - Is there a better way to work with counties to share funding/programs that require large populations. Ex. EBPs that cycle through children quickly and may need a large number of children serviced to secure staff/resources.
    - Rules & Regulations
        - Different parts of DHS licensing the same entity/provider.
        - Lack of cross-system education and training.
        - Various interpretations of regulations cause inconsistencies in service provision, delivery, and access.
    - Assessments
        - Assessments are not conducted from a holistic approach, considering the lifespan of the child and family. Child is "patient" and family dynamics are not always incorporated into the assessment and service provision. "Medical Model"
        - Lack of focus on attachment and ability to establish relationships. Need to identify root causes for children and families.
        - Missed diagnosis and how one system partner will translate the information.
    - Education
        - Servicing students' MH needs in the Least Restrictive Environment (LRE) is often limited to the availability and/or strength of a Community School-Based Behavioral Health (CSBBH) Model in schools; some schools have partnered with agencies to support this level of care, while other districts used finite ESSER Funds to develop the model, and now it's likely to be pulled from many students accessing this supports found within it.
        - Others have relied heavily on other referral-based services such as School Assistance Program (SAP), and possibly outpatient care available in school to help students in need of MH (or other counseling). But as with many things, it is largely a siloed practice.
        - Education around the strengths/limitations regarding med management should be more robust so that educators have a better sense of their efficacy for students accessing that as part of a treatment plan.

Resource Navigation:

- **Strengths**:
    - The system can be effective with transparency and a willingness to be open, seeing families and youth holistically.
    - Pennsylvania's Department of Human Services-wide Child Welfare Information System and its potential to integrate with all systems.
    - Openness of PA Department of Human Services (DHS) in acknowledging insurance challenges.

- Influx of capacity building institutes and potential to enhance cross-system awareness and training.
- Insurance companies are making progress in connecting social, behavioral, and physical health services.

- **Barriers**:
  - *By professionals:*
    - Regulatory requirements, including documentation, place unnecessary burdens on staff's efforts to navigate various systems. System regulations are, at times, in conflict with one another, ex. School-based Mental Health and Education.
    - Lack of consistency in staff qualifications and need for training support.
    - Need for professionals and families to know about resources early on (preventative).
    - Evaluators/psychiatrists do not know the actual availability or timeline of the recommended service. There is often not someone who helps the family with the set-up/finding of these services and the family is left confused. No designated person to assist, similar to someone in a CASSP Coordinator role.
    - Education System – Schools are cautious in suggesting a community-based service. If it is recommended but not approved, the school may be liable to pay for the service. This can create frustration when it is a home-based service and can lead to trust and relationship challenges with the family.
    - Schools without a model that employs something like a dedicated social worker or MH liaison often struggle to bridge support across settings such as the educational environment and the community. School counselors do not have the time to provide 1:1 counseling as if often believed by the public. Often, classroom teachers do not possess adequate knowledge of systems beyond their role as educators. This is a limiting factor when we consider that educators are second only to families with time spent working with youth.
  - *By families:*
    - Need to build capacity of families early, first couple of years of parenting. Build community support and self-advocacy, natural support.
    - Families are unable to find providers who are trained and also covered by their insurance in a location that is geographically close.
    - Lack of explanation to families (what the services are, trajectory of services, why are they being referred to, etc.). IBHS vs. ABA services, combinations, etc. Informed decision-making. Services on Autism side and IDD side, families are confused about what system to access services. Complicated further by child vs. Adult serving systems. Lack of explanation around recovery and resiliency.
    - Families get lost in the system with no awareness of what is available, what is needed to access services, or how to get them in a timely manner. Identification of what resources exist and how to access them is key. Often don't understand the relationship between family and youth systems and services, as well as the role of insurance, and vice versa, system providers understanding the family needs and how it corresponds to available services and if those services are covered by insurance.

- Burden falls on families expected to repeatedly inform the school, providers, agencies and insurance about the past and current circumstances. Different points of entry to systems, this also means their story must be told multiple times.
- Multiple waiver supports in the family and no ability bring them altogether. Need someone who can understand and be broker for family in helping navigate and pull together.
- Overwhelming and Complex - Lack of information shared and also not explained in a way that a family can understand. Treatment plans are being worded too clinical and the need for them to be more family friendly.
- Resources exist, but not comprehensive and/or accessible as needed. (Ex. 211 – but does not have everything) No longer hard copies, online only. It can also be inaccurate and leads to frustration for family and workers. Need for a resource list that can be shared with providers/facilities that are located at a distance.
- Aftercare planning considerations and sharing across Counties. Central repository. Ex. Interagency coordinating council (IU 3-5) OCDEL requirement. Ex. Finding Your Way in PA. Initial intention of PA 211. If a database and repository is developed it needs to be clear about where resources are available and keep information up to date and have a warm hand off is in place.
- Complex needs children from adoption disruptions – there is limited support provided during the foster to adopt process. Following finalizing the adoption there is only a few months of support if that and then post permanency support most often can only be found through the Statewide Adoption and Permanency Network.

- *Insurance Impact:*
  - Lack of awareness in navigating complex insurance processes for both families and providers with limited experience. This can create silos.
  - Insurance can be a barrier due to multiple entities, geographic parameters, etc.
  - MA providers not allowed in network- third-party will not provide appropriate documentation to allow MA to pay.
  - HIPP- Health Insurance Premium Payment Program- have private and qualify for MA- struggles with billing when families "flip to HIPPP"- agencies passing the buck to one another, can rise to state needing to sort it out. Once involved with HIPP, getting back to managed care is nearly impossible.
  - Level of clinician that can bill MA for private insurance will vary. Multiple occasions of insurance willing to pay for certain services on increased services and provider not willing to do so.
  - Private insurance doesn't provide letters to confirm that a service is not covered. School and insurance play tag and there are many barriers in getting services.

Staffing/Workforce:

- **Strengths**:
  - There are dedicated practitioners striving to provide services across the state and improve the experiences for children, youth and families.
  - There are innovative efforts being made to retain and recruit staff amid the current staffing crisis.

- System partners are reassessing the qualifications of the workforce as a result of staffing shortages. Ex. Minimum requirements and how regulations impact hiring.
- Peer support in certain areas of the system allows those with lived experience to enter the workforce.
- The younger workforce encourages leaving work at work, setting better boundaries for the workday, leaving on time

- **Barriers**:

  - Lack of qualified staff results in a reluctance to take more complex cases. Turn away children due to a lack of confidence in staff's ability to manage complex youth.
  - Regulation and licensing barriers to who can provide behavioral health services and what is prohibited within that service.
  - Misconceptions around regulations and impact on staffing.
  - Care teams need more EBP trainings (not just clinicians)
  - Some young people with complex needs understand how to have staff investigated. This can then impact on other staff needing to step in to work that youth. This can lead to a youth being denied in future settings due to the history of this behavior. Complex and multilayered....one decision can have ripple effect.
  - Barriers around clinical training, workshops on actual cases, critical thinking, and clinical support on the front end of CPSL issues.
  - Impact of regulations requiring certain number of hours, topic areas. Can be up for interpretation by organization leadership. Qualifications required for what we need staff to do, BA level degree and all they do is paperwork.
  - Promotions to supervisor earlier than possibly ready due to a lack of staff, retention challenges. Situations where staff can't grow as supervisors and/or clinicians due to still carrying caseloads, managing non-supervisory work. Individuals are apprehensive, possibly do not have developed skills (ex. soft skills), and do not always have understanding for the system and families.
  - Providers have relatively low pay compared to other careers with a lack of pathways to licensure and career advancement that others in the helping field may have.
  - Salaries can't compete with other sectors.
  - Staff have debt and are unable to repay student loans in certain areas of the child/family serving system.
  - Work is dangerous, stressful, low paying.
  - Front-line work is not a career anymore. Diminishing number of students entering high ed. in general, but specifically education programs. Decrease in number of students entering human service academic programs and the field. Similar for graduate programs.
  - Professionalism is not clearly defined, resulting in a breakdown of facilitation of interventions. Profession is not valued or promoted. Need to professionalize areas of this field. Certifications in areas. Curriculum-based track towards a certification that leads to recognition, higher pay. Residential program positions are not viewed through a professional lens. They are not given the same respect or compensation as those with the "title" or "licensure,", yet they are the staff who are with the youth more than the other staff and have the greatest opportunity to impact the youth.

- Psychiatrists, even those trained in PA, are often leaving PA to work in other states. Many reporting costs of liability insurance in PA is too expensive to practice in our state.
- Lack of training focused specifically on Family Engagement, holistically looking at family dynamics and roles. Professionals not engaging in true engagement due to fear and/or capacity challenges.
- *Supervision:*
  - Lack of strong clinical supervision.
  - Need for reflective supervision to support workers, supporting families.
  - Self-care needs to be prioritized for staff, especially direct service staff, to understand their own baggage/ privilege/ trauma and how it impacts their work with families.
  - Need enhanced recruitment efforts for diverse staff.
  - Lack of shadowing and coaching of new staff. Sometimes what they learn in an academic setting doesn't translate to skills needed in the workforce.

Trauma informed supports:

- **Strengths**:
  - There are training courses available across the state to support this need.
  - There is a desire to implement creative programming and support using a trauma-informed approach.
  - Pennsylvania's plan to become trauma informed, Heal PA
  - The education system acknowledges trauma through social/emotional learning awareness. CASEL – Collaborative for Academic Social Emotional Learning. PA uses model and PA Career Ready Skills Continuum
  - Getting better at providing behavioral health support prenatally when moms are experiencing trauma, reduce cortisol levels.
  - By looking through a trauma-informed lens we are diving deeper into also looking through cultural lenses and understanding things from a point of view never acknowledged before- increased cultural humility- this leads to empowerment of the families/youth we work with.

- **Barriers**:
  - Supports and the protected time dedicated to that. Move from theoretical approach to implementation and modeling.
  - Different definitions and perspectives around trauma informed. Not accepted by all providers/staff- both in MH/SUD and outside other professional fields. There is not enough consideration of trauma history in the planning and provision of care for children and youth with complex needs. There is a lack of holistic approach to providing care. Families and children who present with complex needs often have extensive trauma histories that affect behavior, mental health, and other issues. Lack of connecting the 'dots' over the lifeline that can help understand all the adversities that a child/family may go through resulting in possible misdiagnosis and lack of appropriate treatment interventions.

- Educators have embraced this concept, but many have fallen short of applying its tenets to their school policies and classroom management styles. Public embrace of "Zero Tolerance" does not allow for a truly trauma-informed approach to thrive. "Consequences" must be dealt with for restitution to occur. Neither of these practices is trauma-sensitive, and it compounds issues for many of our youth experiencing some sort of MH concerns along the continuum of need.
- Impact on Staffing theme area: Kids with trauma are more likely to try to sever attachments which can lead to accusations and reporting. Staff who are not well trained are more likely to take this very personally and leave. It's like a cycle that cannot be broken until the root cause is addressed.
- Translating the trauma and its impact on children, youth and families is a skill that requires more cultivation. For example, no one understands the concept of 'disenfranchised grief' when children are removed from their homes and put into placement resulting in a fractured spirit, becoming identified by a diagnosis or by system status, and not ever grieving the losses associated with placement.
- Little to no support for staff in dealing with vicarious trauma or compassion fatigue Sometimes we don't acknowledge the need to take care of ourselves and give permission to colleagues to say they are not okay.
- So focused on the maladaptive or abnormal behavior, we forget what is going well, what works for families and youth, what is important for critical development for children/youth (negative things follow children for life at times)
- Lack of acknowledgement further exploration into the intersection of culture and trauma.
- Particularly for kids with complex needs, attachment is really lacking in a lot of service provision. Limitations placed on time for therapy to address trauma. Bare minimum being provided even if it is in the scope of service to extend time.

Key Findings

Once the groups identified the barriers, they were prioritized based on the areas which, if improved, would lead to the desired future state for services to children and families with complex needs (See Section III). Root cause analysis was completed with all four groups around the prioritized barriers. It should be noted, many of the root causes identified crossed over multiple theme areas with impacts intersecting between systems. These findings are highlighted below:

- Legislation impacting child and family serving systems is interpreted rigidly by system partners, resulting in the development of regulations that limit flexibility in funding.
- There is a lack of knowledge by system partners on what other systems can offer children and families, and what limitations or opportunities may exist. This may be interpreted by system partners as a reciprocal lack of cooperation and resistance.
- A family's choice in determining which system partner is engaged in the planning process is an often-overlooked barrier to working collaboratively across systems. Stigmas related to system involvement may limit the desire for family to engage with professionals.
- Expertise in navigating and supporting families in Pennsylvania's child and family serving system is underutilized. System partners value the philosophy and principles of the Child and Adolescent Service System Program (CASSP); however, they acknowledge many counties across the commonwealth are no longer resourcing the CASSP Coordinator position or have varied interpretation of the position and related duties.

- System partners define and approach children with “complex needs” differently, often driven by a diagnosis impacting service and program provisions.
- Interpretation of confidentiality laws by professionals serving children and families create communication barriers. Confidentiality laws are often not connected at the federal level (Ex. HIPPA, FERPA are not aligned with state laws). Litigious society results in a conservative approach by professionals when sharing information to support families. Engagement and communication with families around age consent laws and their impact on service delivery are areas needing particular attention.
- Cross-system, integrated plans to prioritize the needs and goals of families are underutilized. There is no centralized hub of information and/or ability for system partner’s case management systems to interact with one another. The use of data and targeted reports to identify trends and needs within the community is not occurring consistently across counties.
- Inconsistencies in types of programs available and/or willingness to fund programs from one county to the next exist, and the staffing crisis has impacted the innovation of new programming.
- Early, preventative measures to identify children and families with complex needs exist; however, those programs identifying needs can feel siloed from the child and family serving systems with an inability to navigate the most appropriate referrals for families. (ex. Early Intervention (EI) programs)
- Bridge and step-down programming exists across the Commonwealth but is not universally accessible or successful.
- There are decision-making complexities with providers determining if they have the capacity and/or space to accept children with complex needs. Children with aggressive and high-risk behaviors may be involved in confrontations with front-line staff, potentially leading to staff placed on leave while internal and CPS (Child Protective Services) investigations occur. This interaction can lead to a lack of staffing needed to support an appropriate staff/child ratio and a provider’s willingness to accept children with particular behaviors due to concerns for staff/child safety and minimizing risk. This situation can result in children being labeled as high risk, which negatively impacts their ability to be serviced in the most appropriate setting. These concerns are shared by the juvenile justice system partners and can result in children being detained in secure settings with subsequent charges being filed.
- There is a perceived lack of flexibility regarding the DSM-V meeting a family's diagnostic needs. Family and child experiences are considered and made to fit into DSM-V categories to initiate services and program eligibility. The impact of diagnosis can follow a child throughout their lifetime and impact them well into adulthood. (Ex. Military enrollment). More accountability is needed around differentiating trauma and the need for additional diagnosis to pull down funding. Outreach to the PA Psychiatric Leadership Council would be beneficial in further addressing these challenges.
- There is a perception that funding does not follow the child/family to best meet their needs, but rather the child/family needs to follow the funding to determine what program/services will best meet their needs.
- The Medicaid program does not allow for an integrated funding model to create stabilization settings for youth while comprehensive assessments are conducted as necessary to access treatment services.
- Servicing students with mental health needs is limited to availability of Community School-Based Behavioral Health models in schools. The level of funding and resources to support this service can vary throughout the community.
- Family and youth voice is often overlooked in the planning process. There is a system-wide lack of preparation of families prior to meetings, assumptions are made on the child/family’s knowledge and planning meetings often start with the coordination of professional's schedules rather than ensuring family availability first.

- While system partners value those with lived experience, there is a need to implement system-wide strategies to incorporate peer support into services and programing to help families better understand and navigate complex systems.
- There is an unspoken culture within treatment facilities that seems to support a hesitancy in complex discharge planning.
- Medicaid funding is acknowledged as the largest amount of funding supporting youth with complex needs; however, there is a lack of flexibility in funding due to the "medical model" approach, focusing on the child as the "patient" and limitations in treating treat the family through a holistic approach.
- Communication gaps exist between state and local system partners and providers regarding 3800 regulations. Feedback was solicited from county and providers; however, there has been a lack of follow-up communication around potential regulation changes.
- Quality, holistic assessments of children/families are not occurring consistently among all providers. There is a perception that assessments are completed to validate pre-conceived recommendations rather than allowing for quality assessments to inform recommendations.
- Managed Care Organizations (MCOs) do not have a standard denial process across MCOs, and they often do not honor one another's decisions. Gaps in services and extended stays in treatment settings exist when waiting through denial and appeal processes.
- Challenges exist when navigating MCOs and getting services in place for families. Non-participant agreements can take multiple weeks to get finalized and waiting lists are often identified after the agreement is in place. System partners often meet with providers who may not work with non-participant agreements and/or recommendations for a child may expire during the wait.
- There are communication gaps between The Health Insurance Premium Payment (HIPP) program and MCOs. MCOs can see when the insurance changes to the HIPP program, but they are limited in the support they can provide families moving forward.
- Challenges exist for juvenile justice partners in balancing restorative justice, keeping the community safe, while acknowledging trauma and working from a trauma-informed lens. Similar challenges exist in educational settings with zero-tolerance policies and related consequences to balance the learning environment for all students while addressing the needs and impact of trauma on students.
- The academic status of youth residing in residential settings can be challenging to identify. Academic progress with respect to credits earned towards successfully advancing academically can be impeded during transitions from inpatient and residential education settings to community-based settings.
- Many child and family-serving system partners struggle to recruit qualified front-line staff. The lack of qualified staff has a direct impact on some service providers' ability to service children with complex needs, citing a limited number of competent and qualified staff to meet the needs of the child.

System partners acknowledge that supervisors are an integral component to addressing the staffing crisis in Pennsylvania, however because of their expertise and the ongoing challenges in retaining direct-service staff, many supervisors are carrying caseloads and lack the ability to provide clinical coaching-focused strategies to develop staff skills and support retention.

Appendix B: ASERT Final Report

FINAL REPORT: IMPROVING THE STATEWIDE SYSTEM OF CARE FOR CHILDREN, YOUTH, AND YOUNG ADULTS WITH COMPLEX NEEDS

ASERT bringing autism resources together. PAautism.org

JUNE 2023

Table of Contents

Executive Summary 49
Introduction and Background 50
Methodology and Study Design 50
Data Collection 50
Participant Recruitment 51
Participant Demographics 51
Conduct of Focus Groups 52
Analysis and Report Generation 52
Limitations 52
Findings 52
Theme 1: Communication 53
Theme 2: Availability of services and programs 54
Theme 3: Awareness and navigation of resources 55
Theme 4: Staffing 56
Theme 5: Trauma-informed supports 57
Conclusions 57
References 58

Executive Summary

This project assessed the current state of health and health-related services and programs in Pennsylvania and identified barriers in supporting children, youth, and young adults with complex needs and their families. Convenings of behavioral health managed care organizations (BHMCO), behavioral health primary contractors, county agencies, and education system representatives and surveys of hospital system staff and families and youth highlighted common challenges these groups experience. Five key themes emerged across these groups:

1. **Communication**
2. **Availability of services and programs**
3. **Awareness and navigation of resources**
4. **Staffing**
5. **Trauma-informed supports**

These themes and the barriers identified within them are interrelated. As DHS moves to the next phase of strategic planning for supporting this population, it may be helpful to consider these relationships and prioritize addressing these barriers.

Introduction and Background

The Autism Services, Education, Resources, & Training Collaborative (ASERT) Eastern Region was commissioned by the Pennsylvania Department of Human Services (DHS) to conduct an assessment to better understand current and future needs of children, youth, and young adults with complex needs, and the systems supporting them.

To support this project, focus groups and surveys were conducted with residential providers, behavioral health managed care organizations (BHMCO), behavioral health primary contractors, county agencies, education system representatives, hospital systems, and families and youth. The feedback collected through these focus groups and surveys will be used to inform DHS in future systems planning.

Methodology and Study Design

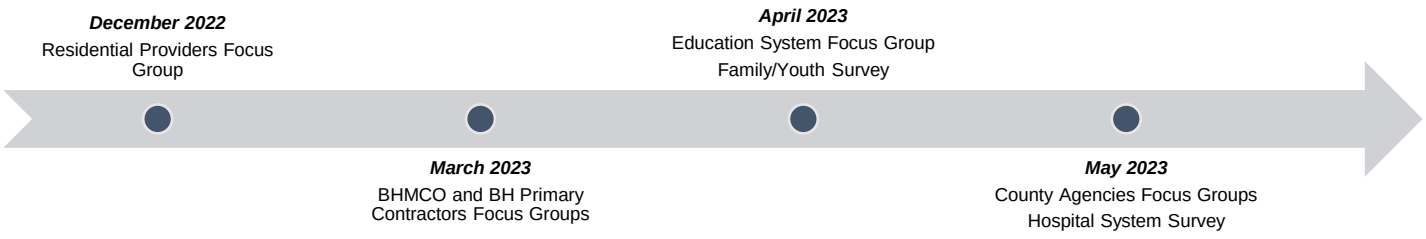
Focus groups and surveys were intentionally selected as the methodology for this project. Focus groups offer a broader and more open-ended forum for participants to describe their experiences and reactions to the topic of discussion compared to other qualitative and quantitative research methods. Qualitative research by nature, "is interactive: context dependent; holistic; flexible; evolving; inductive and descriptive. It has as its foci, perspectives, meanings, uniqueness, and subjective lived experiences. Its aim is to provide understanding" (Trudeau-Hern & Daneshpour, 2012). Focus groups are particularly useful because the moderator(s) can ask follow-up questions and probe for additional answers; this is not possible in a survey or questionnaire. There also may be topics or issues that were unknown when the initial guide questions were developed but can be probed to aid in future planning.

Surveys were intentionally selected as the methodology for emergency department personnel and family and youth for different reasons: for family and youth, the survey provided an anonymous, private way to communicate sensitive information (e.g., suicidal ideation, justice system interaction); for emergency department staff, the survey offered a more efficient method to collect information from a hard-to-reach population (DeVon et al., 2013). Focus groups would have been challenging to convene for hospital system personnel due to competing clinical priorities and limited schedule availability. Surveys were thus an appropriate alternative to collect feedback from these important stakeholder groups.

Data Collection

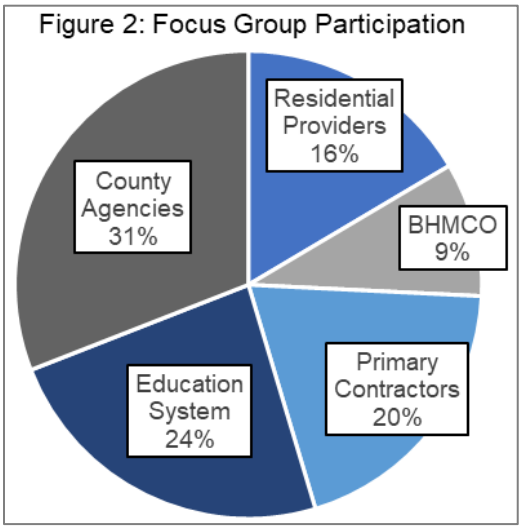
ASERT facilitated focus groups between December 2022 and May 2023 (*see Figure 1 below)* using an online discussion board through the online qualitative software, iTracks. Each iTracks online discussion board remained open for two days with each day's questions posted from the focus group moderator's guide. Participants then had the flexibility to respond to the day's (or previous day's) questions, the posts of their fellow participants, and probes or follow-ups from the moderator(s) at any time of day or night. The online discussion board forum allowed

Figure 1: Focus Group and Survey Timeline



for beneficial aspects of the focus group methodology (follow-up, probing, interaction among the group, etc.) while also accommodating for differing locations across the state, diverse schedules, and competing priorities.

Questions posed in the focus groups covered a variety of domains, including identifying children, youth, and young adults with complex needs and the changes in this population over time, barriers in service planning and provision, service array, education, transition and discharge planning, family and youth engagement, social and diagnostic history, and successful strategies and opportunities for improvement.



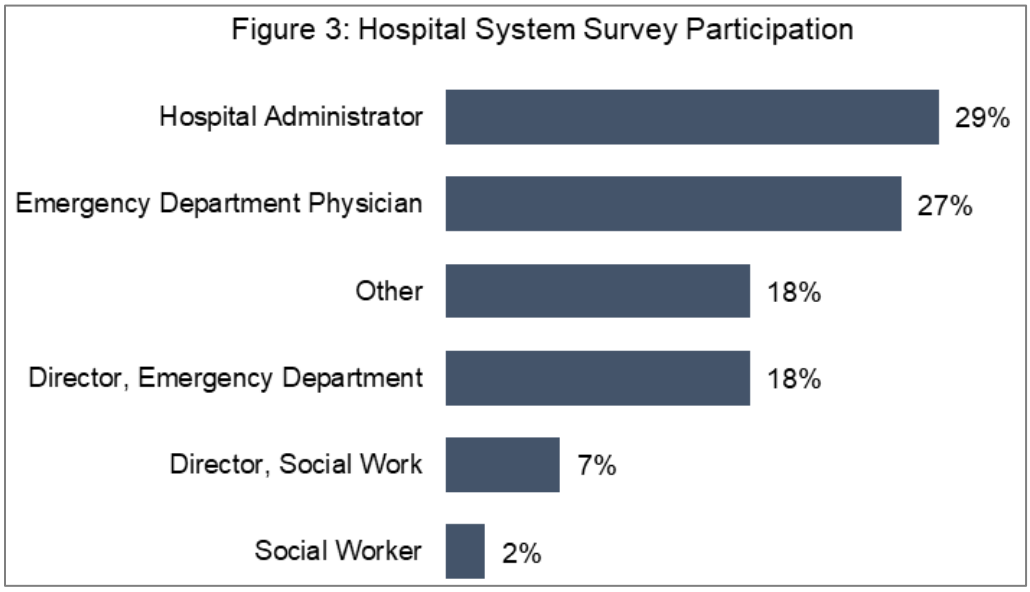
In April and May 2023, using snowball sampling methods, surveys were shared via Qualtrics links with family and youth as well as with hospital systems that serve children, youth, and young adults with complex needs. Surveys were designed with both open- and closed-ended questions to allow participants to provide detailed feedback about their experiences.

Participant Recruitment

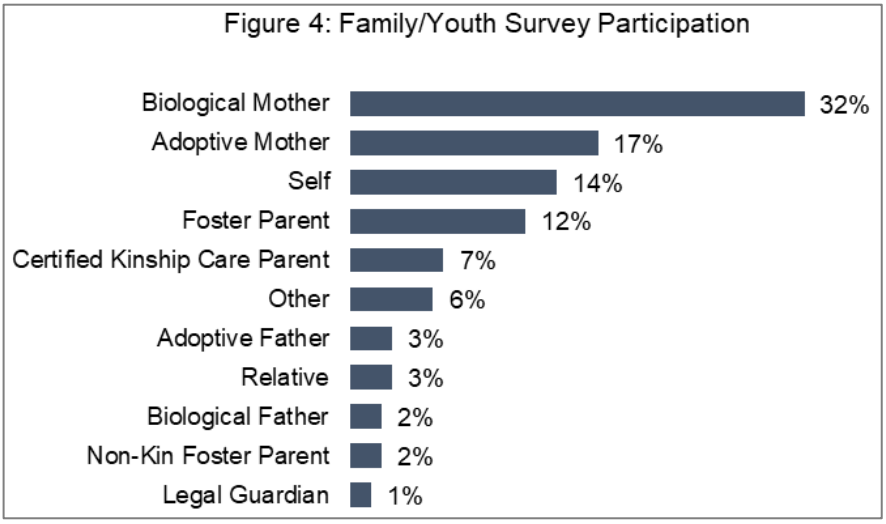
DHS identified appropriate representatives from each of the participating systems for the focus groups and ASERT invited them to participate in the online discussion boards via email link. For the youth and family survey, survey links were distributed to organizations serving this population (e.g., NAMI, YAB, Youth Move) and then sent directly to family and youth. The hospital system survey was shared with the Hospital Association of Pennsylvania (HAP) and then distributed directly to appropriate hospital system staff.

Participant Demographics

Overall, 97 people participated in six focus groups: 16 residential providers, 9 BHMCO representatives, 19 primary contractors, 23 education system representatives, and 30 county agency representatives. The county agency group was divided into two focus groups to account for its larger size (*See Figure 2*). Among the survey respondents, 45 represented hospital system staff and 138 participated as family or youth. Of the hospital system participants, 29% were administrators, 27% were Emergency Department physicians, and 18% were Emergency Department directors (*See Figure 3*). Within the "Other" category, participants identified as Operations Managers, Case and Care Management Directors, Clinical Directors, and Behavioral Health Directors. Another 10% of participants reported as Directors of Social Work or Social Workers. Of the 138



family and youth participants, 118 (86%) were family members and 20 (14%) identified as youth with complex needs (*See Figure 4*). About half of the respondents identified as biological or adoptive mothers while nearly 20% responded as foster or certified kinship care parents. The remaining 17% of participants represented adoptive and biological fathers, other relatives, non-kin foster parents, and legal guardians.



Conduct of Focus Groups

In accordance with standard focus group methodology and practice, moderators' guides were developed in collaboration with DHS to facilitate the flow of two-day online discussion boards with each participating group.

ASERT moderators posted a series of questions on the first day of the discussion boards, and participants logged on and responded to questions at times that were convenient for them. Participants were also permitted to comment on other participants' responses, allowing for a collaborative discussion. Participants were asked to log on at least three times per day during the two-day period to respond to any follow-up questions from moderators or fellow participants. DHS observed the discussions and periodically sent prompting follow-up questions to ASERT moderators to post on their behalf.

Analysis and Report Generation

The questions and responses from the moderators and focus group participants automatically generated a transcript that was used as the basis to report findings and to provide recommendations. Transcripts were read, summarized, and key themes were identified. Themes were documented after each focus group and evaluated together to inform the findings and recommendations presented in this report.

Limitations

Focus groups are a useful tool for qualitative research. However, focus group methodology has several limitations. It is important to note that the focus group findings are not generalizable to the entire target population nor are they quantitative in nature. The focus group was comprised of a targeted sample of people and does not represent an entire population. Similarly, the hospital system and family and youth surveys were distributed to a targeted sample of stakeholders belonging to these groups. Therefore, while quantitative, their responses are also not generalizable to the entire population of interest.

Findings

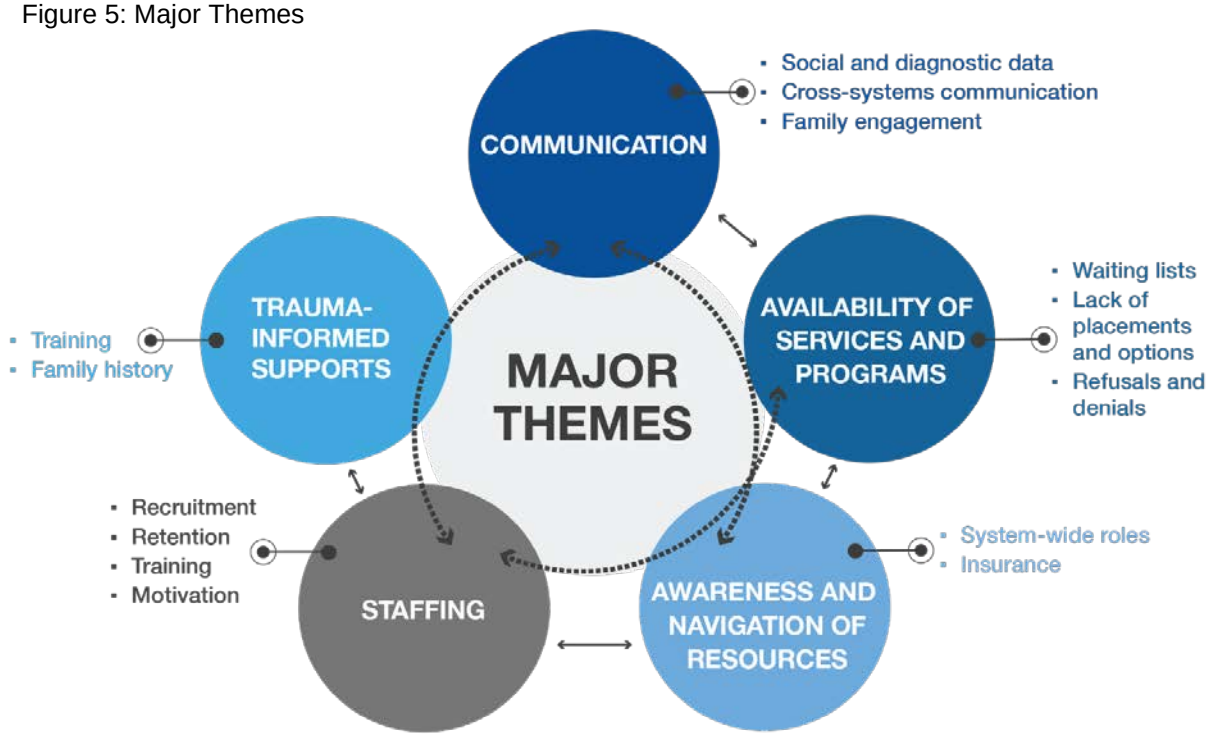
Five major themes were conceptualized across all stakeholder groups: communication, availability of services and programs, awareness and navigation of resources, staffing, and trauma-informed supports. These thematic concepts dominated discussions and were most frequently mentioned as barriers and facilitators of service planning and provision for this population.

It is also notable that many participants described existing strengths of their respective systems and of the impact of the collaborative efforts across systems to best serve children, youth, and young adults with complex needs and their families. Some strengths included:

- Staff dedicated to improving the experiences of system-involved children, youth, and young adults with complex needs and their families
- Mutual goals across systems to more intentionally collaborate, communicate, and learn about other services and programs
- Ability Desire to implement and some successful examples of creative programming and supports (e.g., peer support programs)
- Innovative efforts to retain and motivate staff amid staffing crises
- Some successful high-quality services and programs provided to children and families (e.g., ongoing therapy, early intervention, IBHS, emotional support school placements, trauma therapy)

While these strengths were mentioned in each of the groups, due to the nature of the question prompts most of the discussion and feedback was focused on the system-wide barriers that prevent them from achieving the most success. Additionally, participants recognized that the COVID-19 pandemic exacerbated existing barriers that impede system efforts to support children, youth, and young adults with complex needs which serve as a backdrop and consideration to understand the context of these findings.

Figure 5: Major Themes



Theme 1: Communication

Participants consistently noted a **lack of communication and coordination across systems** serving children, youth, and young adults with complex needs. These silos were particularly prominent throughout the initial information gathering stages and the transition and discharge processes. Participants reported that as children enter different systems or move across them, critical information is often missing or incomplete. They suggested

that improving the quality of clinical, diagnostic, social, family, and trauma histories, including the ways in which the information is shared across systems, would allow them to better serve this population.

> *"We do not always have a clear diagnosis picture for these children. Each system (MH, ID, CYFS, medical, educational, probation, etc.) have their own criteria for what they need to make them eligible for services within their program. This makes it very hard. Their needs are different for each system, and we are siloed." – **County Representative***

In addition to the siloes across systems, participants frequently reported barriers in communicating and engaging with families. For example, in discussing service planning, participants noted occasional disagreement about placements and levels of services across support teams and families. Focus group participants further noted that training opportunities for families to support their child with complex needs are limited.

> *"Additionally, there are times when teams will disagree with the level of supports and services that a student requires. Our IEP teams are required to make the recommendations that are most appropriate for the child based on the evaluations. At times a parent will have a differing opinion. For example, if the District recommends that a child requires an Autistic Support program, but a parent wants their child included in general education, we would need to continue to make the appropriate recommendation." – **School District Representative***

Families of children, youth, and young adults with complex needs echoed this sentiment of disengagement, and emphasized **feeling excluded from the service planning and provision processes**. About a quarter of family respondents (23%) disagreed or strongly disagreed that they had a voice in their child's treatment planning and the services received; similarly, among youth respondents, 23% felt they did not have a voice in their own treatment planning and the services they received.

Theme 2: Availability of services and programs

Participants noted the dearth of available services and programs as one of the most significant barriers in adequately supporting children, youth, and young adults with complex needs. They cited a **lack of appropriate placements and services, long waiting lists,** and **limited service and program availability** in locations that are geographically close to families. Similarly, across all groups, participants mentioned frequent denials or refusals of services based on individuals being "too acute."

> *"In terms of appropriate out of home placements, we see children who are recommended for RTF sitting on waitlists or being denied due to being too acute or not acute enough. We see the same with inpatient hospitalizations. We see kids who have ID or MH diagnosis unable to find an appropriate foster care placement because they are too young, too old, or their needs are too intense resulting in them being in a group home or congregate setting until a foster home can be located." –**County Representative***

Many participants reported that they had observed or identified children who should have received other services or programming that could have prevented the need for higher levels of care or crisis placements. Specifically, they noted that residential treatment and inpatient facilities tend to become the default when other options are not available. However, participants consistently reported an overall lack of availability in both residential and community-based settings and a lack of beds available in both inpatient and RTF settings.

> *"We had a child wait over a year for ABA services and in the meantime received FBMH services but unfortunately ended up going to residential treatment. FBMH model of addressing relationships is*

*not always effective when the behaviors are not driven by relational deficits but require an ABA approach. The wait is so long to access ABA treatment that the behaviors continue to increase and the family require higher levels of care. Quicker access to the treatment, respite, parent support groups, increase the family connections within the community are all services/supports that aid better outcomes if accessed in a timely manner. a lot of our services are reactive and not preventive- the problem must manifest itself to enact services. If services can be accessed in a timely manner, have the proper training, be more creative with supports being delivered- combining FBMH and BC on cases when necessary, increase PA consults when barriers and challenges are being met, increase parent peer supports to provide insight and feedback from lived experiences." – **County Representative***

A majority (76%) of hospital system representatives reported that they have observed increases in the number of children, youth, and young adults using Emergency Department (ED) services within the past year. Almost all (91%) attributed these increases to limited resources and supports for children with complex needs. Further, they shared that they do not believe the ED is the most appropriate environment to provide services to this population.

"The ED should never be where these patients are treated. The ED is triage not ongoing care." – ***Hospital Administrator***

"It is worse than incarceration when they are in the ED." – ***Emergency Department Physician***

Families and youth reiterated challenges associated with long waiting times for services, lack of service availability entirely, and a lack of service options tailored to their needs. Nearly half (48%) of family respondents reported that they strongly disagreed or disagreed that the services provided to their child met their child's needs when they needed them. Similarly, half (47%) of the family respondents felt they did not receive services in a timely manner because there was no provider availability either among the providers in their area or staffing within an agency.

Theme 3: Awareness and navigation of resources

Family and youth respondents reported that they experience significant challenges navigating the systems they encounter. Almost half (41%) of family respondents shared that they did not have a clear understanding of the services and supports available for their child; 47% did not have a clear understanding of what the available services and supports could offer their child. Similar responses were observed among youth respondents: over one-third (36%) did not have a clear understanding of the available services and 40% did not have a clear understanding of what those services could offer. When asked to share specific challenges related to services, families and youth offered the following:

"Finding what services might be available to help our adult child is a continued challenge." – ***Biological Mother***

"We had been unable to reach our case manager and had trouble finding people to guide us in the process of finding services. My mom had to do a lot of that work on her own." – ***Young Adult***

In addition to siloes across systems, focus group participants reported a general lack of awareness and understanding about the function of the other systems that also serve children, youth, and young adults with complex needs. While some participants reported that cross-systems meetings have been effective at times,

others mentioned that they were not aware of regional partnerships that they could use to pool resources to support youth with complex needs. There was an identified need for better cross-system planning to facilitate early identification, appropriate provider training, and consistent follow-up.

> *"The system CAN be effective if all parties are open and transparent about all of the needs. At times families do not fully disclose all of their needs so we only know what we know and can assist with what we know. Involving the physical healthcare system could be improved. We always take a look at the person as a whole, not just as in need of one particular system or service. Getting everyone to the meeting is a struggle but the most beneficial and successful meetings happen when everyone is on the same page and supporting the family where they are at in their treatment process. I think holding teams meeting earlier is always a way to improve the system." – **County Representative***

Participants also reported a general **lack of awareness in navigating complex insurance processes**. Some noted that having multiple types of insurance introduces unique challenges for both families and providers. The lack of coordination between private insurance and Medicaid especially has at times prevented families from accessing services. Providers experience challenges submitting claims due to limited training, which then creates barriers for them to receive compensation for the services they provided.

> *"Many private insurances don't include the same levels of care within their benefit packages or have much more limited provider options. I have also learned that private MCO speak a different language regarding some levels of care." – **Behavioral Health Primary Contractor***

Theme 4: Staffing

Participants reported significant staffing challenges as barriers in supporting children, youth, and young adults with complex needs. They emphasized **provider availability and qualifications, burnout, recruitment and retention, training, and motivation** as primary areas of concern. Participants occasionally noted that while there is intent to meet the needs of this population, staffing challenges prevent them from doing so.

> *"Currently I see that educators are working extremely hard to meet these children's needs. However. these efforts often fall short due to overloaded schedules, lack of staffing, appropriate training opportunities, etc." – **IU Representative***

Further, challenges related to staffing have exacerbated shortages in services and programming.

> *"We certainly have shifted programming due to staffing. This can primarily be seen in the reduction of census. There is a delicate daily balancing of filling open beds while at the same time keeping in mind the staffing expertise and staffing levels in each treatment location. Ultimately decisions are made regarding reduction of census in each treatment location and/or closing a treatment unit." – **Residential Provider***

Families shared their frustrations in being able to find appropriately trained providers and caregivers for their children and emphasized that they experience challenges finding providers whose services are covered under their insurance. Approximately one-third (36%) of family respondents reported that their child did not receive timely access to services and supports due to staff not being available at a provider agency.

In addition to a lack of provider availability, many participants noted challenges related to workforce recruitment and retention. They attributed these issues to the intensity of the job, relatively low wages compared to other

roles, limited training opportunities, and a lack of opportunities for career advancement and pathways to licensure.

Theme 5: Trauma-informed supports

Across all groups, participants cited the importance of **considering trauma history in the planning and provision of care** for children, youth, and young adults with complex needs to ensure a holistic approach. Although trauma was included in the definition provided, many participants suggested that it would be helpful to have more specific information about type of trauma, including family- and community-related trauma.

> "*I would like to see under the history of trauma, a mention that not only do the youth/young adults we serve having a history of trauma, but this history of trauma is often best categorized as complex and chronic trauma. Additionally, there should be some emphasis placed on historical trauma that has occurred within the youth/young adult's support system. I also believe that noting any community trauma or violence is impactful for their treatment." – **Residential Provider***

Participants also noted an **increase in children and families with extensive trauma histories**, increases in behaviors and their intensity, and increases in mental health diagnoses like anxiety and depression. Some attributed these increases to the trauma caused by the pandemic.

> *"Yes - I think the collective and complex trauma associated with the COVID pandemic and the opioid epidemic continue to have a detrimental impact on the children we serve. We have seen an increase in critical incidents relating to suicidal ideation, emergency room referrals for psychiatric reasons and suicide attempts. In regard to suicide attempts, we are seeing attempts at younger ages, and the lethality of attempts in our adolescent population has seemed to have increased. We're also seeing a higher prevalence of anxiety, and they are often treated as behavioral problems until recognized as severe anxiety or symptoms of trauma exposure." – **Residential Provider***

Additionally, participants expressed the need for staff to receive more trauma-informed training to better understand the social and diagnostic pictures of the youth they support. County agency participants also reported that due to turnover, many providers lack the experience and knowledge to help the youth they serve with the challenges they face.

> *"We need a more holistic approach which includes qualified professionals who understand how to provide trauma informed care to both the child and their family." – **County Representative***

Conclusions

To understand how to best support children, youth, and young adults with complex needs, it is critical to periodically evaluate the systems that serve them and their families. Through focus groups and surveys, barriers across these systems were identified. Based on a reported lack of communication, limitations in service and program availability, resource awareness constraints, staffing issues, and a dearth of trauma-informed supports, DHS may wish to focus on these areas to improve the overall system of care.

The relationships between the themes presented in this report are noteworthy and may also inform future program and system planning. Challenges related to communication and coordination across systems may lead to a lack of awareness about system-wide roles and available service and program options. Relatedly, staffing concerns may impact service and program availability and the ways in which systems communicate with each other and engage with families. The availability of trauma-informed supports and related training opportunities

may affect recruitment and retention of qualified staff as well as family and youth perspectives on the availability of appropriate services and programs.

These findings are consistent with feedback DHS has previously collected from a variety of stakeholders regarding children, youth, and young adults with complex needs. The challenges that currently exist across the Pennsylvania system of care have been further exacerbated by the public health emergency. Challenges related to staffing, funding, service availability, and cross-system understanding have been previously identified. Their perceived importance by all stakeholder groups in this assessment suggests these areas could be prioritized and addressed to better serve this population.

References

DeVon, H. A., Patmon, F. L., Rosenfeld, A. G., Fennessy, M. M., & Francis, D. (2013). Implementing Clinical Research in the High Acuity Setting of the Emergency Department. *Journal of Emergency Nursing*, *39*(1), 6-12. https://doi.org/https://doi.org/10.1016/j.jen.2012.08.012

Trudeau-Hern, S., & Daneshpour, M. (2012). Cancer's Impact on Spousal Caregiver Health: A Qualitative Analysis in Grounded Theory. *Contemporary Family Therapy*, *34*. https://doi.org/10.1007/s10591-012-9211-9

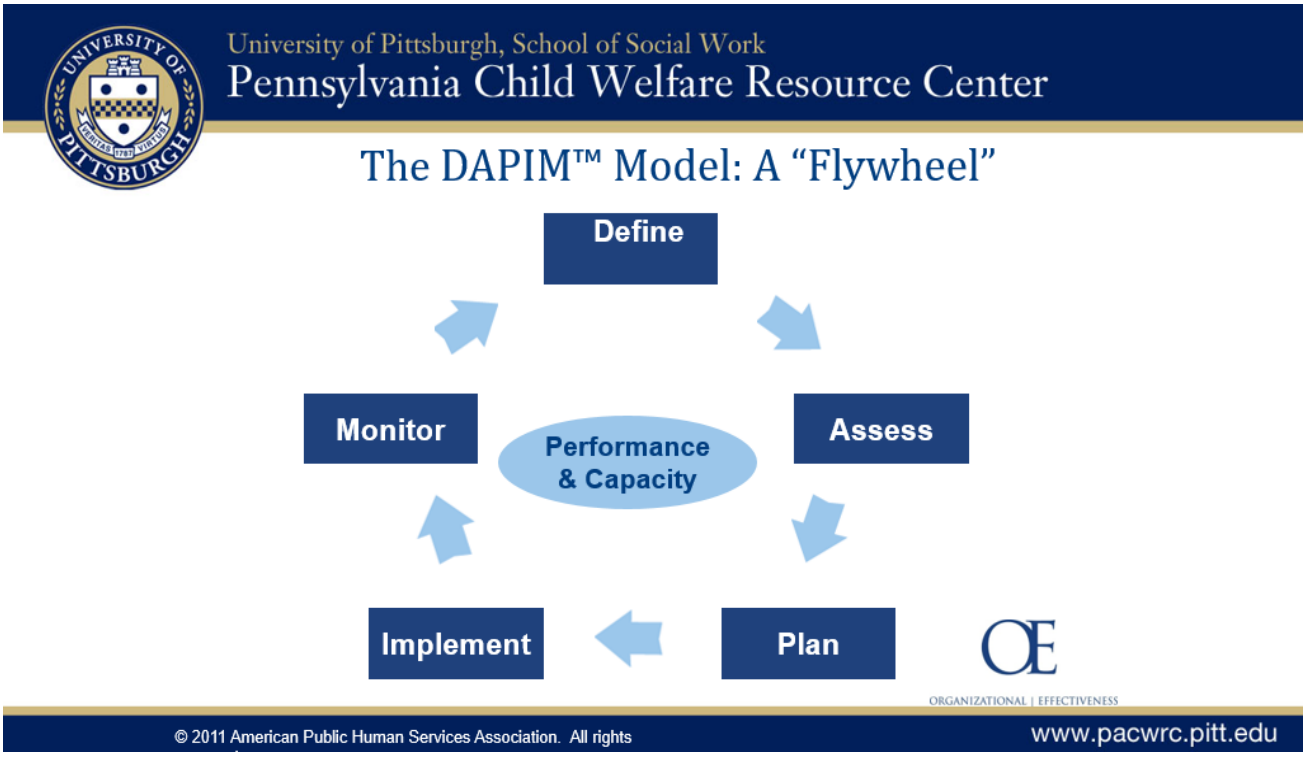
Appendix C: DAPIM Model

Blueprint for Youth with Complex Needs

A Continuous Improvement Approach

The Pennsylvania Department of Human Services (DHS), in partnership with the University of Pittsburgh - Child Welfare Resource Center (CWRC) collaborated to facilitate the Blueprint for Youth with Complex Needs Workgroup through a systemic continuous improvement approach, utilizing the American Public Human Services Association's (APHSA) DAPIM™ model.

APHSA has found that to close the gap between where we are today and achieving the results and vision we desire, we must follow a step-by-step process. It was this DAPIM process that the Complex Needs workgroup stepped through to identify system partner strengths and gaps and establish recommendations to ensure Pennsylvania's youth with complex needs and their families have access to timely supports and individualized services.



Step One: **Define** priority improvements in operational terms. Development of a Desired Future State (DFS), i.e. when child and family serving systems are working at an optimal level, supporting youth and families with timely and individualized services.

Step Two: **Assess** observable, measurable strengths, and gaps. Prioritize gaps and identify root causes.

Step Three: **Plan** and develop recommendations and remedies for priority gaps. Identify quick wins, mid-term, and longer-term improvements.

Step Four: **Implement** action plans while managing communication and capacity.

Step Five: **Monitor** progress, impact, and lessons learned for accountability and on-going adjustments.

Appendix D: Parking Lot Concepts

The Blueprint Workgroup recognized that the concerns and issues that face youth, families, and systems are multi-faceted and require more than we could offer within the time constraints of the workgroup. The workgroup developed a "parking lot" to capture ideas and potential solutions that were not completely developed. The list below captures those ideas and potential solutions for future consideration.

	Parking Lot Items
1	Explore opportunities for improvements with school-based access to mental health services, including more comprehensive service availability. There are some federal level changes in development now that may offer opportunities to strengthen services in Pennsylvania. Other states are pushing on this front as well, for example, Vermont is now allowing schools to bill Medicaid for services in school.
2	Youth with complex needs often require providers with specialized knowledge and training. Not all counties have access to providers with every specialty, it is important to develop a mechanism to share resources across counties so children and families can get what they need, when they need it. Given the specialty needs of youth with complex needs, unique approaches like regionalization of specialty services or broad access to specialist via telehealth services, including being able to consult with the onsite team may be beneficial. PA TiPS (Telephonic Psychiatric Consultation Service Program (TiPS) (pa.gov) may be a resource for youth with Medicaid, but there needs to be consideration for those with private insurance as well.
3	There is a pending state legislative bill that would prevent juvenile probation involvement for a child until age 13, which could increase the burden on other systems. New York recently implemented something similar; see House Bill 1831. It was noted that it may be challenging for this Bill to get through the Senate.
4	Other systems are developing satellite-based outpatient licenses to allow for more flexibility in providing services in the home and community environment. This could be something to explore with children's services particularly when children are located in a non-clinical setting such as a licensed group home. We would need to carefully consider how to implement this in many respects, but particularly to ensure that the setting does not become a clinical setting, but rather that the services are auxiliary in nature and have a plan to transition to a different setting.
5	Consider the accountability of team members to create environments that are conducive/favorable to change, creative, constructive, and solution focused. Notably, this also has workforce implications. Family and professional perceptions are important, and everyone involved has a responsibility to be part of the solution.

	Parking Lot Items
6	Liability is a challenge in a variety of service arenas. Some providers cannot afford the liability insurance necessary to serve certain high-risk populations. The liability issue(s) can include a need for workers compensation, litigation, and other support, particularly around CPSL. Consider offering a pool of funding to support workers comp, litigation, etc. regarding CPSL. Additionally, there needs to be a consensus on handling of incidents and reports and creation of acceptable protocols where minimal facts interviewing can help determine risk. Supporting providers in their ability to afford the insurance needed. Impact on providers' ability to accept referrals, meet staffing needs. Some insurance companies are not insuring some providers. This affects foster care and other providers, like RTF.
7	Develop statewide systems services training to support better cross-systems understanding and provide more comprehensive supports for the child and family. It promotes that the children are "our children" and not just that of one system or another. Promoting knowledge and connection among systems via learning opportunities could be a rich opportunity to connect. Several models exist for this in pocket and could be explored (DHS training systems, ASERT training etc.). These opportunities could be live and archived so they are accessible to all in the human services system. Incorporate planning with pediatric CBI as possible to engage those efforts as well.
8	Develop a mechanism for "after action reviews" of efforts to support youth/families with complex needs. This would be done in conjunction with the team and family to consider lessons learned and ways to improve experiences moving forward. Several models exist within the various systems already (e.g. Act 35 - child fatality and near fatality reviews), but it is likely a new one would need to be developed for this group and a way to manage that information that makes it applicable not only to the particular youth and family, but also benefits the broader system.
9	Children and families who are part of the adoption system experience challenges as they adjust to their new family structure. Ongoing education, resources and support are needed for both adoptive families, including siblings, as well as the adopted child. The current system does not consistently provide these opportunities and it is believed with the appropriate on-going supports such as case management, in home visitors, educational opportunities and support networks the number of failed adoptions would decrease. Providing support to everyone in the family could assist with understanding how to build the new family structure, potential challenges that might arise and specialized topics at all stages of family development.
10	Explore giving people with lived experience preference on the Civil Service just like they do for military veterans. This could improve our ability to support people through the lens of lived experience and provide more comprehensive supports informed by real life experience. There are pockets of this occurring across the state at the local level.

	Parking Lot Items
11	The safety of staff and youth supported are often an important subject of discussion. Things like accusations or reports of inappropriate treatment add trauma to an already challenging time. Can we improve safety supports using technology, training, and ongoing support for staff for how to get through false accusations, and how to get back to a healthy relationship with a youth? For example, videos could be reviewed and used as learning tools for staff.
12	How can we support providers better to take youth with these challenging behaviors? Is there a way, from a data perspective, to understand which diagnoses are resulting in the primary behaviors and/or challenges increasing incidents with staff, resulting in investigations, and so on. This, along with insurance considerations (mentioned in #6), may decrease providers refusing services due to challenging behaviors. Is there a connection to rate setting/differential rates for the level of service needed, high acuity needs, to encourage and support providers in taking youth with challenging behaviors, complex MH needs, Support staff/child ratio, education, etc.
13	More transparency is needed about those who accept Pennsylvania's Health Insurance Premium Payment program (HIPP). A close examination to ensure greater transparency is needed. Some counties/providers don't accept HIPP leaving families without resources they need. It is important to see how this is benefiting families and children and their access to services and support.

Appendix E: Blueprint Workgroup Charter and Organizational Chart

Charter: Blueprint Complex Case Planning 2023

Rationale:

The Pennsylvania Department of Human Services (DHS), in partnership with Child Welfare Resource Center (CWRC) are collaborating to facilitate discussion regarding children, youth, and young adults with complex needs and their families to improve all family and youth serving systems.

A Desired Future State was developed to guide the work and move it forward:

In Pennsylvania we believe all youth with complex needs and their families* will have the opportunity to access timely supports and services that are individualized, trauma-informed, holistic, respectful of race and culture, family and youth driven, and available in their own communities.

This will be evidenced by:

- A focus on youth and family engagement while honoring their voice and choice.
- Establishing and maintaining a well-supported and qualified workforce.
- Collaboration and shared understanding across systems to support planning and shared goals.
- Systems which prioritize early identification, proactive intervention, and service options that support family stability, safety, and the youth's healthy development and meaningful relationships which support life-long connections.
- Teams engage in ongoing and integrated planning that supports the everyday needs of a family and youth (housing, education, transportation, scheduling, access to medical care, etc.).
- Service delivery is coordinated, accessible, timely and includes support throughout the process.

* Family is defined by the individual.

The goal is to facilitate discussion with the Blueprint workgroups in identifying strengths and gaps in the system of care for youth with complex needs, identify root cause issues with gaps, and develop recommendations around strengthening those gap areas to reduce silos and streamline services to youth with complex needs.

Four groups have been identified to collaborate and include representatives from all child and family serving systems as well as families and youth with lived experience. Focus groups conducted with these systems identified five key areas for development recommendations. These are communication, services and programs, resource navigation, staffing/workforce, and trauma informed supports. Family engagement is a crucial part of the success of this work and will be highlighted in each of the five key areas.

Draft recommendations will be presented to the State Leadership (Governor's Office, Secretary of Education, Secretary of Human Services, Legislators, County Administration) by the end of November

2023.

Facilitators - University of Pittsburgh, School of Social Work, Child Welfare Resource Center (CWRC), Organization Effectiveness (OE) Staff:
Russ Cripps- Southeast (SE) OE Regional Team Supervisor, CWRC
Colleen Cox, SE OE Practice Improvement Specialist, CWRC

DHS Steering Team:
Jonathan McVey, Complex Needs Planning, Office of the Secretary, PA DHS

Roseann Perry, Regional Special Projects Manager, OCYF, PA DHS

Jennifer Newman, Human Services Analyst, OCYF, PA DHS

Emily Burger, Special Populations Clinical Support, ODP, PA DHS

Courtney Malecki, Children's MH Program Rep, OMHSAS, PA DHS

Michael Hershey, Project Manager, Office of the Secretary, PA DHS

DHS Complex Needs Planning Team:

Office	Name	Title
OCDEL	Andrea Algatt	Executive Assistant
OCYF	Roseann Perry	Regional Special Projects Manager
OCYF	Jennifer (Jenn) Newman	Human Services Analyst
OCYF	Gerry Lynn Butler	Human Services Supervisor
ODP	Nina Wall	Bureau Director Supports for Autism & Special Populations
ODP	Emily Burger	Special Populations Clinical Support
ODP	Heidi Arva	Clinical Consultant
OMAP	Katrina Becker	Manager, Special Needs/Complaints, Grievances and Fair Hearings
OMAP	Julie Escobar	Human Services Program Specialist Supervisor
OMHSAS	Scott Talley	Bureau Director Children's Behavioral Health Services
OMHSAS	Courtney Malecki	Division Director
OMHSAS	Crystal Doyle	Human Services Program Representative
Policy	Jameekia Barnett	Executive Policy Specialist
Sec. Office	Jonathan McVey	Special Assistant – Complex Needs Planning

Blueprint Workgroups:
Please see attached organizational chart.

Boundaries:
Using several change management strategies, CWRC staff will host meetings with the Blueprint Workgroups and Steering teams to help identify strengths and gaps in meeting the needs of youth with complex needs. The role of Organizational Effectiveness (OE) staff is to schedule and facilitate these meetings at the request of the Steering Team. Initial meetings will be held in person with the rest being scheduled virtually.

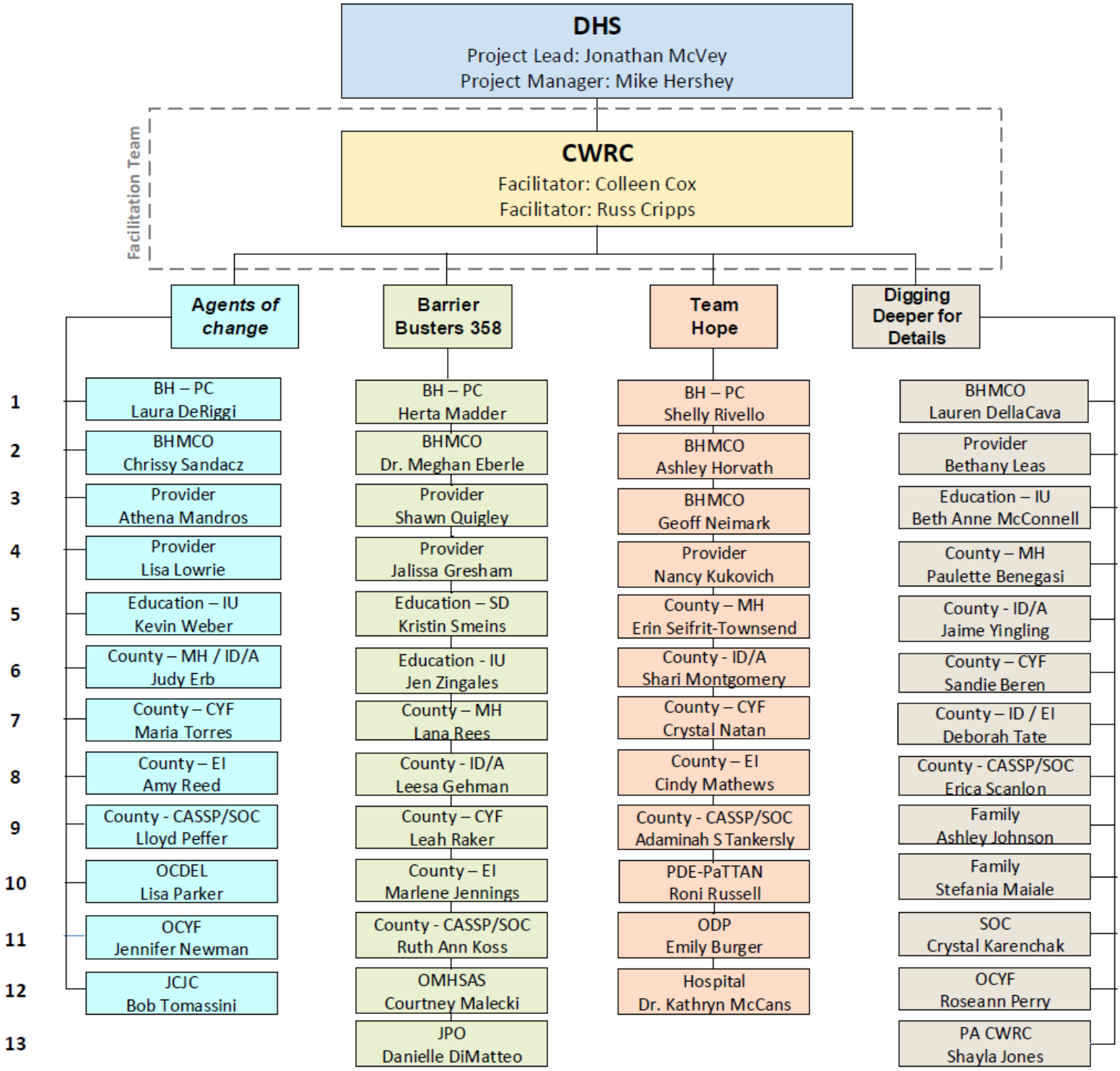
Non-negotiables:
- Workgroups to remain solution-focused and stay within the scope of this charter and defined expectations.
- Everyone will respect the opinions and ideas of others.
- Everyone will be open-minded, ready to learn, and willing to be inclusive of others' experience and expertise.
- Steering and Blueprint workgroups will be mindful of proprietary and intellectual properties of programs and organizations as part of the development of recommendations.
- All workgroups and subgroups will respect sensitive discussions, adhering to privacy and confidentiality expectations.

Goals:
For the group to:
- Provide an open forum for all participants to share their ideas and solutions in a collaborative manner.
- Using the information collected in the focus groups and the collective knowledge of the Blueprint workgroup, develop recommendations to improve the system of care for youth with complex needs across the state, and
- to bring families and youth with lived experience, service providers, and agencies together as a team to support better access to services for children and families with a focus on continuous quality improvement.

Completion Date:
The Steering and Blueprint Workgroups will be identified by April 21, 2023, with meetings to begin July 19, 2023. An initial draft of recommendations will be completed and ready for submission to the State Leadership (Governor's Office, Secretary of Education, Secretary of Human Services, Legislators, County Administration) by the end of December 2023.

Impact:
The work is designed to improve services to those youth with complex needs, bringing agencies and providers together to eradicate the silos and work collaboratively as a team to serve the children and families in need.

Commitments:
Members will be expected to prioritize meeting attendance and intersession work as needed to meet the deadline. The project will start with an in person kick off on July 19 and 20, 2023 and continue through mid- October with the groups identified. Virtual meetings will occur every other week for 2 hours. It is anticipated that groups will be assigned intersession work between meetings. A second in person wrap up is scheduled for October 19 and 20, 2023 to review and finalize recommendations to be submitted.

Communication:
There will be fluid communication from the Blueprint workgroup to the Steering Team, with key messages developed at every meeting. Information will be shared both in-person at meetings, as necessary and through email updates. Key messages after every meeting may be used to solicit feedback from external stakeholders, such as associations, advocacy organizations, and other state agencies. This will not be done without approval from the groups. Finalized recommendations will be presented to the State Leadership at the conclusion of this chartered work.

Small Workgroups Organizational Chart