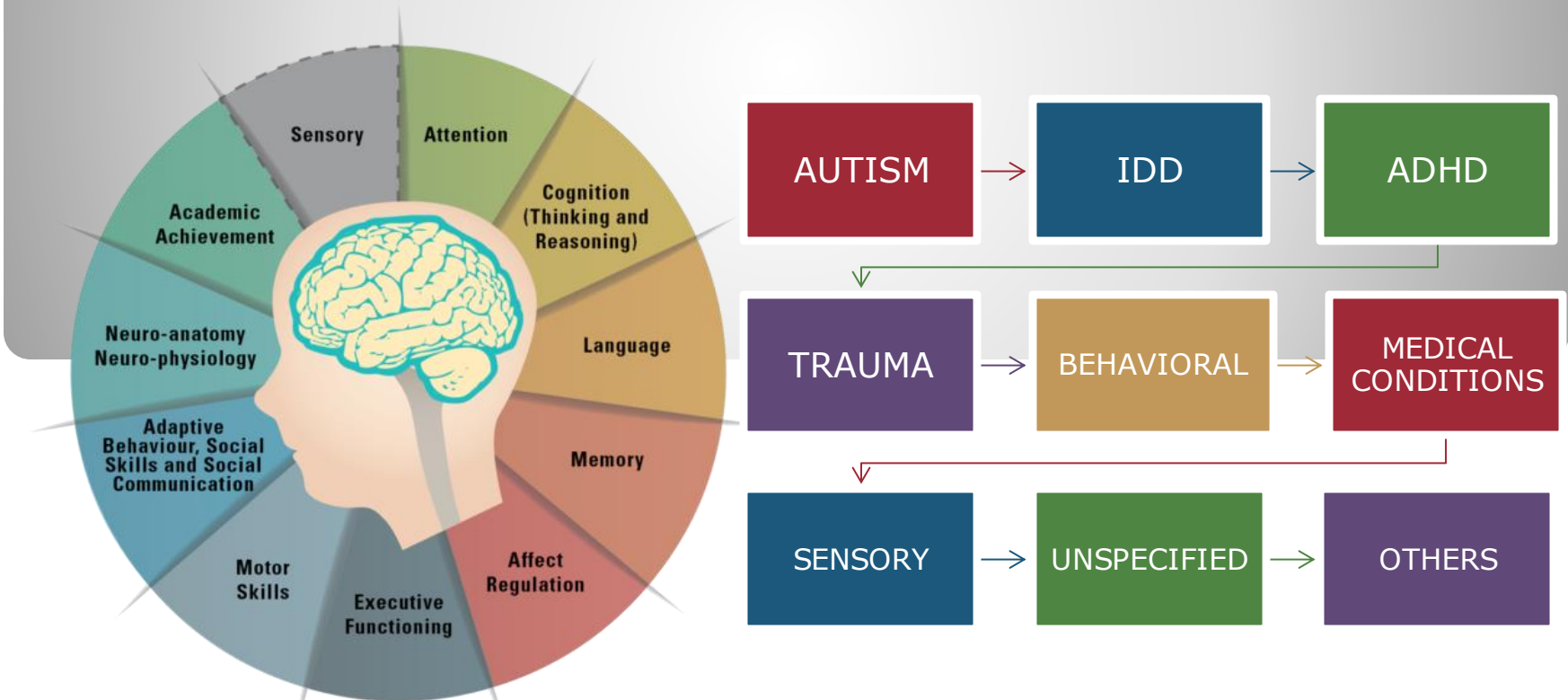
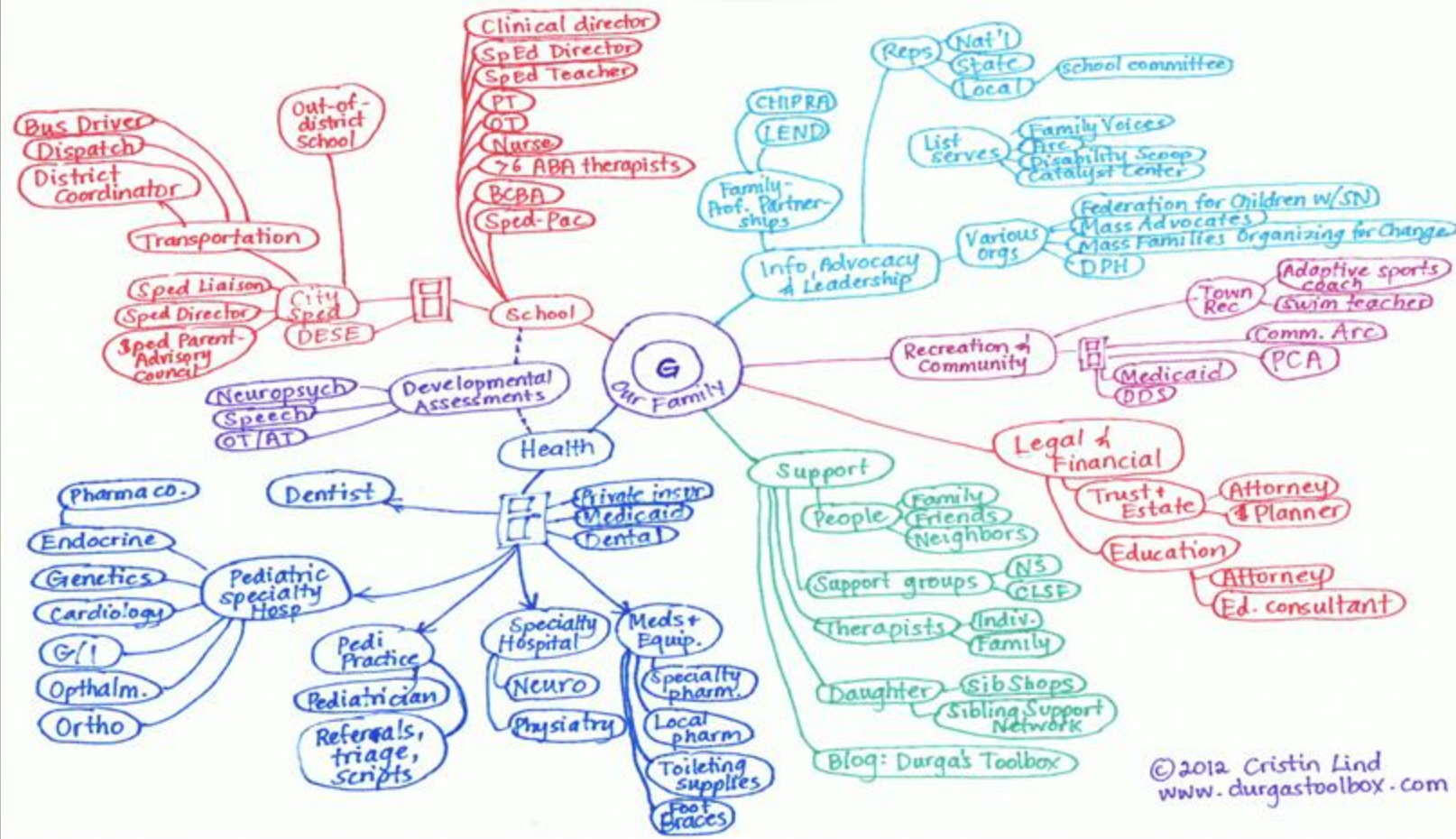


# BARRIERS TO CARE FOR CHILDREN AND FAMILIES LIVING WITH NEURODEVELOPMENTAL DISORDERS



**Clifford Beers**  
Community Care Center  
A Clifford Beers Community Health Partner



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Care Mapping: A How-To Guide for Patients and Families (childrenshospital.org)

# Systems Families Need to Navigate

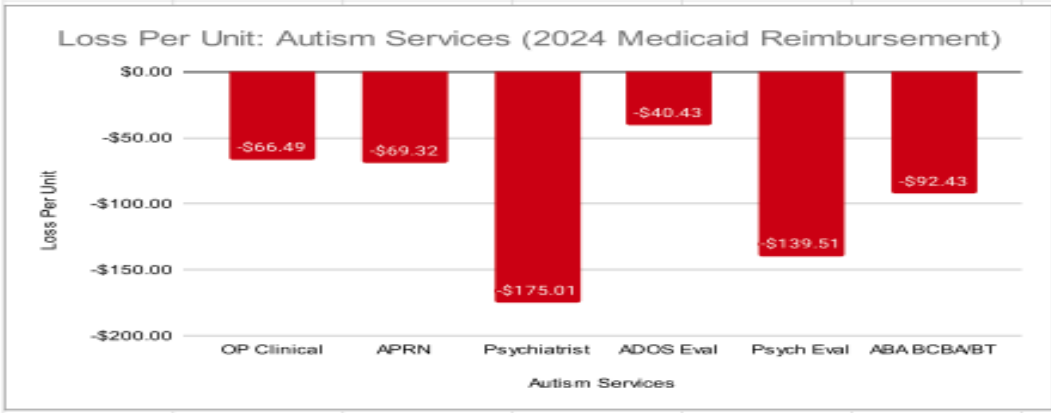
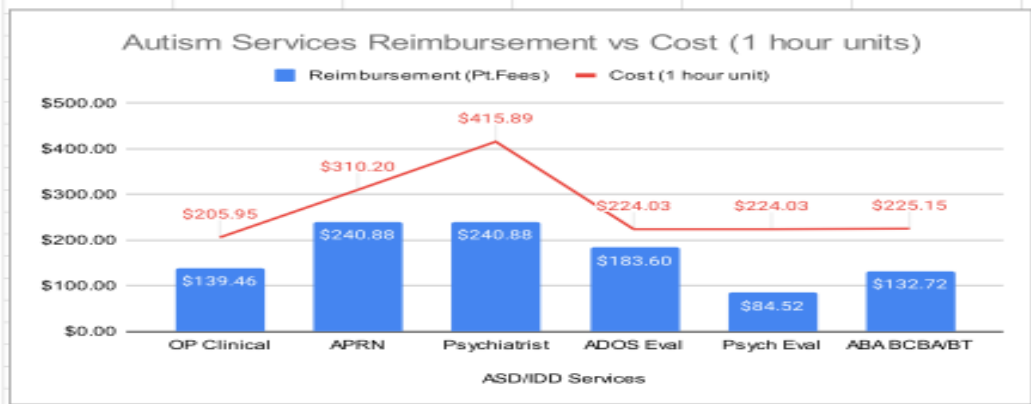
- **Challenge 1:** Current services are reliant on diagnosis-based, medical model of care which is inadequate for the diverse needs of individuals and families. Diagnosis can take a long time, and children may miss important service milestones due to lack of diagnosis.
- **Proposal:** Incorporate needs-based services focusing on individual requirements, rather than just diagnosis.
- **Key Components:**
  - **Family-Focused:** Active involvement of families in decision-making, support, and resources.
  - **Community Engagement:** Inclusion and understanding through community involvement, fostering sustainability.
- **Policy Implications:** Legislators urged to expand access to services through implementing funding streams prioritizing family-focused, needs based approaches.

- **Challenge 2:** Neurodevelopmental disorders and associated behavioral issues affect the entire family, yet the lack of specialized treatments and payment structures hinder whole family access to care.
- **Proposal:** Creation of family care/consultation/training codes to address the holistic needs of families impacted by neurodevelopmental disorders.
- **Key Components:**
  - **Specialized Family Support:** Develop codes for family care, consultation, and training to provide tailored support addressing the impact of neurodevelopmental disorders on families.
  - **Holistic Progress Monitoring:** Ensure interventions address the needs of the whole family, facilitating progress generalization to home and community settings.
- **Policy Implications:** Legislators are urged to introduce family care/consultation/training codes to enhance support for families affected by neurodevelopmental disorders, promoting sustainable outcomes.

- **Challenge 3:** Essential care coordination services, such as helping with paperwork applications, finding programs, school contacts, recreational activities and medical needs are not available. Lack of care coordination burdens the families and clinicians and hindering comprehensive care provision.
- **Proposal:** Inclusion of reimbursement rates for wraparound care coordination to address diverse needs effectively within the system of care.
- **Key Components:**
  - **Intensive care Coordination:** Establish reimbursement rates for wraparound care coordination to cover essential services like DDS applications, program finding, and school contact.
  - **Relieving Clinician Burden:** Alleviate clinician workload by enabling dedicated professionals to focus on wraparound care coordination, ensuring comprehensive support for individuals with neurodevelopmental disorders.
- **Policy Implications:** Legislators urged to introduce reimbursement rates for wraparound care coordination to alleviate family and clinician burden and ensure comprehensive care provision for individuals with neurodevelopmental disorders.



- **Challenge 4:** Inadequate Medicaid and Commercial reimbursement rates in CT hinder access to services for individuals with neurodevelopmental disorders, leading to fragmented systems and potential negative outcomes.
- **Proposal:** Improved reimbursement rates to facilitate smoother navigation of services and mitigate adverse effects on affected individuals.
- **Key Components:**
  - **Enhanced Reimbursement Rates:** Increase Medicaid and Commercial reimbursement rates to adequately cover the costs of comprehensive care for neurodevelopmental disorders.
  - **Integrated Service Navigation:** Streamline service navigation processes to ensure seamless access to necessary supports and interventions.
- **Policy Implications:** Legislators urged to prioritize revising reimbursement rates as soon as possible to align with the actual needs of individuals with neurodevelopmental disorders, promoting better outcomes and system coherence. Increase available codes for more holistic services.



- **Challenge 5:** Connecticut DSS Medicaid standards for Behavior Technicians exceeds what is required by all commercial insurance carriers, leading to recruitment challenges, workforce limitations, and reduced access to care for children on Medicaid.
- **Proposal:** Align Connecticut DSS Medicaid standards with requirements established by commercial insurance carriers to ensure workforce parity and equitable access to care for children with Medicaid.
- **Key Components:**
  - **Alignment with CT commercial insurance carriers:** Adjust Medicaid standards to align with commercial insurance requirements, ensuring consistency and reducing workforce recruitment barriers.
  - **Ensuring Equitable Access:** Ensure children with Medicaid receive adequate services by addressing workforce limitations and disparities compared to those with commercial insurance.
- **Policy Implications:** Legislators urged to align Connecticut DSS Medicaid standards with commercial insurance requirements to promote workforce parity and equitable access to care for children with Medicaid.



- **Challenge 6:** Connecticut faces a workforce shortage of practitioners trained in ASD and Neurodevelopmental Disorder care, resulting in long wait times for diagnosis, treatment, and disproportionate access to providers across regions. Additionally, there is a lack of training programs at various education levels.
- **Proposal:** Expansion of training programs and incentives to attract and retain practitioners in ASD and Neurodevelopmental Disorder care, addressing workforce shortages and improving access to services.
- **Key Components:**
  - **Expansion of Training Programs:** Develop and expand training programs at community colleges, undergraduate, and graduate levels to meet the growing demand for practitioners in ASD and Neurodevelopmental Disorder care.
  - **Incentives for Practitioners:** Offer incentives such as loan forgiveness programs, scholarships, and professional development opportunities to attract and retain practitioners in these specialized fields.
- **Policy Implications:** Legislators urged to prioritize funding and policies supporting the expansion of training programs and incentives for practitioners in ASD and Neurodevelopmental Disorder care to address workforce shortages and improve access to services.

- **Challenge 7:** Inclusive employment initiatives in Connecticut are limited, particularly for individuals with ASD who possess academic and intellectual capabilities but require social and communication supports. Restrictive access requirements by CT State agencies create high barriers to entry, limiting workforce inclusion.
- **Proposal:** Expansion of inclusive employment initiatives and the removal of restrictive access requirements to promote workforce inclusion for individuals with ASD and similar neurodevelopmental profiles.
- **Key Components:**
  - **Expansion of Inclusive Initiatives:** Develop and implement comprehensive inclusive employment initiatives tailored to the needs of individuals with ASD, providing necessary supports for social and communication challenges.
  - **Elimination of Access Barriers:** Remove restrictive access requirements imposed by CT State agencies to reduce barriers to entry for individuals with neurodevelopmental disorders, facilitating greater workforce inclusion.
- **Policy Implications:** Legislators urged to enact policies promoting the expansion of inclusive employment initiatives and the elimination of access barriers to facilitate greater workforce inclusion for individuals with ASD and similar neurodevelopmental profiles.

- **Challenge 8:** Severe behavioral crises in individuals with ASD present limited care options due to geographic constraints, staff expertise, bed availability, and community awareness gaps. Overreliance on Emergency Departments (EDs) exacerbates the issue. Additionally, there is a lack of specialized inpatient and outpatient services in Connecticut.
- **Proposal:** Development of specialized crisis care facilities, increased availability of inpatient beds for individuals with ASD across age groups, and expansion of outpatient and in-home services to address the needs of individuals with ASD in crisis situations.
- **Key Components:**
  - **Specialized Crisis Care Facilities:** Establish specialized facilities equipped to handle severe behavioral crises in individuals with ASD, ensuring appropriate care and support.
  - **Expansion of Inpatient Beds:** Increase the availability of inpatient beds for individuals with ASD, both under and over the age of 18, to meet the demand for specialized care.
  - **Enhanced Outpatient and In-Home Services:** Expand outpatient and in-home services to provide ongoing support and intervention for individuals with ASD, reducing the need for crisis care admissions.
- **Policy Implications:** Legislators urged to allocate resources and implement policies supporting the development of specialized crisis care facilities, increased availability of inpatient beds, and expansion of outpatient and in-home services for individuals with ASD in Connecticut.

- **Challenge 9:** Discrepancies among Connecticut State agencies regarding age requirements for access/discharge from services create confusion, complicated transitions, and disproportionately impact families with fewer advantages. Federal law mandates educational supports for individuals identified with ASD up to age 22, exacerbating the issue.
- **Proposal:** Standardize age access/discharge requirements across all Connecticut State agencies serving individuals and families affected by ASD, aligning with the federal mandate of services up to age 22.
- **Key Components:**
  - **Standardized Age Requirements:** Establish age 22 as the standard access/discharge age across all State agencies providing services for individuals with ASD, ensuring consistency and minimizing confusion during transitions.
  - **Alignment with Federal Law:** Ensure State agency policies align with federal mandates, particularly regarding the provision of educational supports for individuals with ASD up to age 22.
- **Policy Implications:** Legislators urged to enact policies standardizing age access/discharge requirements for ASD services across all State agencies, promoting consistency and equitable access for all individuals and families affected by ASD.

- **Challenge 10:** Disadvantaged families experience later diagnosis of ASD compared to advantaged families, impacting long-term outcomes. This health disparity is particularly pronounced in Black and Brown communities and regions with limited service delivery opportunities, creating significant service delivery deserts across Connecticut. Even where services exist, barriers such as transportation, employment, family needs, and language further limit access.
- **Proposal:** Implement strategies to reduce disparities in early diagnosis and access to ASD services, including targeted outreach, increased service availability and rates, and addressing barriers to access.
- **Key Components:**
  - **Targeted Outreach and Education:** Implement targeted outreach programs to raise awareness of ASD and available services, particularly in underserved communities.
  - **Expansion of Service Availability:** Increase the availability of ASD services in regions with limited access, addressing service delivery deserts and improving geographic equity.
  - **Addressing Access Barriers:** Develop solutions to address transportation, employment, family needs, and language barriers that hinder access to ASD services.
- **Policy Implications:** Legislators urged to allocate resources and implement policies supporting targeted outreach, expansion of service availability, and addressing access barriers to reduce disparities in early diagnosis and access to ASD services in Connecticut.

- **Challenge 11:** Limited availability of group homes licensed by Connecticut Department of Developmental Services (DDS) for children with Autism Spectrum Disorder/Intellectual and Developmental Disabilities (ASD/IDD) and behavioral challenges, exacerbated by closures and restrictions on admissions to Community Living Arrangements (CLAs).
- **Proposal:** Expand capacity and access to group homes for youth with ASD/IDD and behavioral health challenges to address the shortage of suitable placements.
- **Key Components:**
  - **Addressing Closure Impact:** Address the imminent closure of a group home, necessitating relocation of three boys, by finding appropriate alternative placements to ensure continuity of care.
  - **Mitigating Waitlist Concerns:** Alleviate the waitlist for placements at Adelbrook, a provider for girls with ASD/IDD, by expediting adult placement processes for individuals turning 22 years old, thus freeing up spaces for new admissions.
  - **Parent Advocacy Engagement:** Utilize the willingness of a parent affected by the group home closure to share their story as a means to raise awareness and advocate for solutions.
- **Policy Implications:** Advocate for increased funding and resources to support the establishment and operation of group homes tailored to meet the specific needs of boys with ASD/IDD and behavioral health challenges, ensuring equitable access to residential care options across genders.



- **#1: Incorporate needs-based services crucial for holistic support, family involvement, and community sustainability in neurodevelopmental disorder care.**
- **#2: Create specialized codes for family support essential for addressing the holistic impact of neurodevelopmental disorders, facilitating progress generalization, and promoting sustainable outcomes for affected families.**
- **#3: Integrate reimbursement rates for wraparound care coordination essential for alleviating clinician burden, facilitating comprehensive care provision, and meeting the diverse needs of individuals with neurodevelopmental disorders.**
- **#4: Improve reimbursement rates is crucial for addressing fragmented systems, facilitating service access, and mitigating potential negative outcomes for children with neurodevelopmental disorders in CT.**

# **A CALL TO ACTION**

- **#5: Align Medicaid standards with national requirements crucial for addressing workforce disparities, promoting equitable access to care, and ensuring children with Medicaid receive adequate services comparable to those with commercial insurance.**
- **#6: Expand training programs and offering incentives crucial for addressing workforce shortages in ASD and Neurodevelopmental Disorder care, reducing wait times, and improving access to services across Connecticut.**
- **#7: Expand inclusive employment initiatives and eliminating access barriers crucial for promoting workforce inclusion, empowering individuals with ASD, and fostering a more diverse and inclusive workforce in Connecticut.**
- **#8: Enhance crisis care options and access to services vital for addressing the needs of individuals with ASD during severe behavioral crises, reducing reliance on EDs, and ensuring comprehensive care across age groups in Connecticut.**

# **A CALL TO ACTION**

- **#9: Standardize age access/discharge requirements crucial for minimizing confusion, streamlining transitions, and ensuring equitable access to services for individuals and families affected by ASD in Connecticut, aligning with federal mandates.**
- **#10: Address racial health disparities in early diagnosis and access to ASD services critical for improving long-term outcomes, reducing inequities, and ensuring all individuals and families affected by ASD in Connecticut receive timely and appropriate support.**
- **#11: The shortage of group homes for youth, especially boys with ASD, IDD and behavioral health challenges in Connecticut underscores the urgent need for policy action to expand capacity, address closures, and prioritize equitable access to suitable placements.**

# **A CALL TO ACTION**