

South Carolina Palmetto Autism
Study Committee Report
January 5, 2024

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I. EXECUTIVE SUMMARY

Pursuant to fiscal year (FY) 2023 Proviso 117.184, the Palmetto Autism Study Committee (Committee) convened in January 2023 and met throughout the year to study the state of autism diagnosis and treatment in South Carolina. Autism spectrum disorder (ASD) is a developmental disorder that impairs a child's social skills to varying degrees, including how they interact and communicate with others. During this time period, the Centers for Disease Control and Prevention (CDC) updated the prevalence of autism in children from 1 in 44 to 1 in 36, further demonstrating the need to increase access to services across the state. The South Carolina Department of Health and Human Services (SCDHHS) has noted that 1 in 31 children enrolled in South Carolina's Healthy Connections Medicaid have a diagnosis of ASD. Approximately 70% of individuals with ASD also have a co-existing dual diagnosis (DD) of a psychiatric condition, further compounding the challenges of meeting the needs of this patient population.

Findings: The Committee, comprised of parents, service providers, legislators and agency representatives, identified the following categorical findings:

- 1) **Workforce Shortages are Substantial:** Significant shortages of ASD and ASD/DD providers engaged in diagnosis or treatment existed pre-pandemic. This has translated into long waiting lists to access provider services, delaying diagnosis or treatment. Early intervention is key to optimal outcomes for individuals with ASD or ASD/DD.
- 2) **Medicaid Reimbursement Levels Are Too Low:** An underlying theme of workforce shortages is Medicaid reimbursement rates. Multiple provider groups involved in diagnosis and treatment indicate Medicaid reimbursement is inadequate to support provider costs and retain providers.

(Note: SCDHHS has implemented rate increases for ASD services and requested funding to increase reimbursement rates for the state's Developmental Evaluation Centers (DECs) and to cover additional ASD service codes in its state fiscal year (SFY) 2025 budget request.

- 3) **South Carolina Lacks ASD and ASD/DD-Capable Infrastructure:** The state lacks the needed infrastructure, namely specialized inpatient and residential care facilities, that can meet the needs of individuals with ASD or ASD/DD. Inadequate reimbursement from Medicaid for these services must be addressed to ensure sustainability long term.
- 4) **Medicaid Enrollment and Eligibility Processes Need to Be Simplified:** Enrollment and eligibility processes, particularly with respect to Katie Beckett/Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA) applications,

are cumbersome and prolonged. (Note: SCDHHS has convened a stakeholder group to work on this.)

Recommendations: The following Committee recommendations are largely organized by each stakeholder group to expedite a call to action and make this report more user-friendly for finding specific information. Specific recommendations for each of the following can be found in Section III of this report:

A. Legislative Recommendations

Community-based Residential Habilitation Settings:

Invest state funding for the development of specialized, community-based residential habilitation settings; These settings should address the complex behavioral needs of children and youth with ASD or ASD/DD and provide interventions to adjust to a group care setting, as well as facilitate the ultimate goal of transitioning to a longer-term, community-based environment.

Workforce Initiatives:

Invest state funding to develop workforce initiatives that increase the number of developmental and behavioral health providers providing services to individuals with ASD and ASD/DD; The lack of sufficient workforce is a substantial limitation for diagnosis and treatment. Workforce initiative funding is needed to develop training Extension for Community Care Outcomes (ECHO) programs to increase ASD and ASD/DD capacity of existing providers, incentivize recruitment of providers, fund training fellowships and compensate community providers for the extra time needed to provide services to this patient population. This would require a multi-year investment to build the state's workforce.

Inpatient Medical Facilities:

Establish enhanced reimbursement rates for specialized acute inpatient psychiatric and psychiatric residential treatment facilities with capacity to treat individuals with ASD or ASD/DD

B. State Agency Recommendations

Specific recommendations for the following state agencies can be found in Section III of this report: SCDHHS, SC Department of Disabilities and Special Needs (SCDDSN), SC Department of Mental Health (SCDMH) and SC Department of Education (SCDOE). These recommendations can be broadly described as recommendations to:

- 1) Improve provider reimbursement for services;
- 2) Increase provider capacity for existing workforce through training, reimbursement methodologies and additional resources;

- 3) Facilitate development of a coordinated network of providers for diagnosis and psychiatric care; and
- 4) Streamline and enhance administrative processes.

C. A Further Recommendation

Consider the development of a statewide autism resource center that can centralize and administer resources for providers, compile resources for families, coordinate training programs and other functions, as needed.

II. INTRODUCTION AND BACKGROUND INFORMATION

A. Enabling Legislation and Proviso Objectives

The Committee was created pursuant to Proviso 117.184 in the FY 2022-2023 appropriations act, H 5150. Proviso language and objectives are stated below:

Proviso 117.184. (GP: Palmetto Autism Study Committee)

- (A) For Fiscal Year 2022-2023, there shall be established the Palmetto Autism Study Committee to be housed in the South Carolina Department of Health and Human Services. The study committee shall address, but not be limited to, the following issues:
- 1) The best ways to ensure the timely evaluation diagnosis and treatment of autism for individuals aged eighteen and under and their families;
 - 2) The need for and viability of the development of statewide autism centers of excellence that engage in the training of practitioners and advanced treatment practices and research related to autism;
 - 3) Reviewing and evaluating the accessibility to initial autism evaluations and Medicaid eligibility to identify any barriers to diagnosis and enrollment; and
 - 4) Methods by which financial assistance can be provided to families in order to obtain needed autism services.
- (B) The study committee shall be composed of members appointed as follows:
- 1) Two appointees by the Governor, one of which may be a parent of an autistic child;
 - 2) Three appointees by the Chairman of the House Ways and Means Committee, one of which may be a House member, one of which may be a practitioner and one of which may be a parent of an autistic child;
 - 3) Three appointees by the Chairman of the Senate Finance Committee, one of which may be a Senate member, one of which may be a practitioner and one of which may be a parent of an autistic child;
 - 4) The director of the Department of Health and Human Services or his designee; and
 - 5) The director of the Department of Disabilities and Special Needs or his designee.

No member of the study committee shall be entitled to any compensation or reimbursement, and no three members of the study committee shall reside in the same public health region of the State.

(C) Any administrative services or support for the study committee shall be provided by the Department of Health and Human Services.

(D) No later than January 15, 2023, the study committee shall provide the Governor, the Chairman of the House Ways and Means Committee and the Chairman of the Senate Finance Committee with a report on its findings and recommendations on the issues contained in this provision.

NOTE: Due to a delay in Committee appointees being named, the timeframe for the Committee to meet was changed to include calendar year 2023 with reporting to the Governor, Chairman of Ways & Means and the Chairman of Senate Finance due by Jan. 15, 2024. The committee began meeting in January 2023, meeting as noted below:

B: Palmetto Autism Study Committee: 2023 Meeting Schedule and Focus Areas

Meeting Month: Focus Area	Meeting Month: Focus Area	Meeting Month: Focus Area
January 2023: Organizational meeting	May 2023: Workforce	September 2023: Medicaid eligibility and reimbursement
February 2023: Diagnosis and evaluation	June 2023: Workforce and Autism Center of Excellence	October 2023: No meeting, draft report writing
March 2023: Treatment	July 2023: (No meeting)	November 2023: Finalize report recommendations
April 2023: Dually diagnosed (autism and co-existing mental health condition)	August 2023: Autism Center of Excellence, residential needs, other family needs	December 2023: Report submission

C. Autism Defined and Prevalence

Autism Defined

Per the American Academy of Pediatrics, ASD is a “developmental disability that affects a child’s social skills, including how they interact and communicate with others. The term spectrum refers to the wide range of symptoms and degree to which children may be affected.” Additional information about autism from the American Academy of Pediatrics can be found at the following link: <https://www.aap.org/en/patient-care/autism/>.

Autism Prevalence:

The CDC, Autism and Developmental Disabilities Monitoring Network (ADDM) released updated surveillance data on autism in March 2023, noting that autism rates **have increased to 1 in 36 children** per surveillance data in ADDM Network Sites in 2020. There are 16 ADDM network sites across the United States in the current phase of funding (2023–2026). More information about this finding can be found at the following link: https://www.cdc.gov/mmwr/volumes/72/ss/ss7202a1.htm?s_cid=ss7202a1_w.

Looking at a comparative population of children aged 8 years old with a primary diagnosis of autism, the prevalence in the Healthy Connections Medicaid program has also increased. As of November 2023, 1 in 31 children enrolled in Healthy Connections Medicaid have a primary diagnosis of autism using FY 2022 diagnosis data (Figure 1). Out of the over 14,000 Healthy Connections Medicaid members with a primary diagnosis of autism, 66% are under the age of 18, and out of those under the age of 18, 48% are enrolled in a managed care organization (MCO) (Figure 2).

Figure 1. SC Medicaid Autism Prevalence in Children

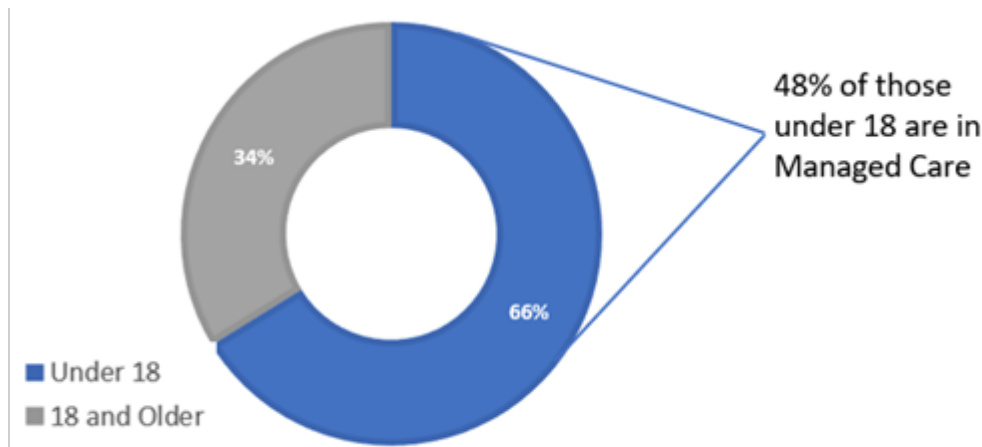
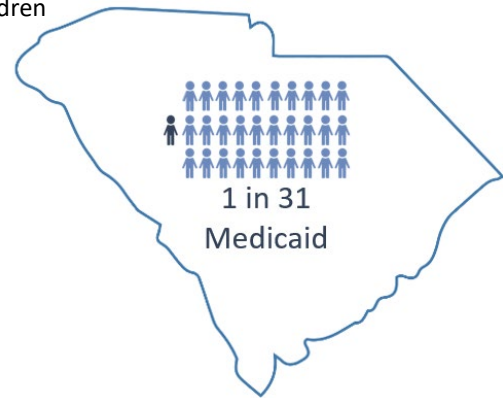


Figure 2. Percent of the SC Medicaid Population with Autism by Age and Managed Care Enrollment.

D. Glossary of Terms and Acronyms

Term/Acronym	Definition
ABA	Applied Behavior Analysis: ABA is a type of therapy frequently applied to children with autism and/or other developmental disabilities that focuses on imparting skills in specific domains of functioning such as social skills, communication, academic skills, motor dexterity, hygiene and grooming and more. (Source: <i>Psychology Today</i>)
Acute Inpatient Psychiatric Hospital	A hospital that provides psychiatric services, as described in 42 CFR Subpart E §482.60 - §482.62, to individuals in an inpatient hospital section; This includes short-term psychiatric hospitals (average length of stay 25 days or less) and long-term psychiatric hospitals (average length of stay greater than 25 days).
ADOS-2	Autism Diagnosis Observation Schedule – Second Edition: A standardized diagnostic test for autism spectrum disorder across ages, developmental levels and language skills; A completed ADOS is required by many insurers to confirm a diagnosis of ASD.
ASD	Autism Spectrum Disorder: A developmental disability that affects a child’s social skills, including how they interact and communicate with others; The term spectrum refers to the wide range of symptoms and degree to which children may be affected. (Source: <i>American Academy of Pediatrics</i>)
BabyNet	Administered by SCDHHS, BabyNet is South Carolina’s early intervention system for infants and toddlers under three years of age with developmental delays or who have conditions associated with developmental delays. (Source: SCDHHS)
BCBA	Board Certified Behavior Analyst: A graduate-level professional in behavior analysis who is able to practice independently and provide supervision for BCaBAs and RBTs (Source: Behavior Analyst Certification Board)
BCaBA	Board Certified Assistant Behavior Analyst: An undergraduate-level professional in behavior analysis who practices under the supervision of a BCBA (Source: Behavior Analyst Certification Board)

DBP	Developmental behavioral pediatrician: A pediatrician with an additional three years of fellowship training in developmental pediatrics and pediatric behavioral medicine; The American Board of Pediatrics offers a separate subspecialty certification for DBP physicians.
DD	Dual Diagnosis: For the purposes of this report, DD refers to individuals who have ASD and a co-existing diagnosis of a psychiatric health condition. Approximately 70% of individuals with ASD have a co-existing psychiatric condition and approximately 41% of individuals with ASD have 2 or more co-existing psychiatric conditions.
DEC	Developmental Evaluation Center: South Carolina has three DEC, one each in Charleston (MUSC Children’s Hospital), Columbia (Prisma Health Children’s Hospital-Midlands), and Greenville (Prisma Health Children’s Hospital-Upstate). The DEC are statutorily recognized in SC 44-21-80. Although the DEC are recognized as “agents of the state” in SC 44-21-80, they are funded solely through clinical service reimbursement at this time.
ECHO	Extension for Community Healthcare Outcomes: ECHO programs are generally tele-mentoring programs that bring together healthcare providers and subject matter experts using videoconference technology. From the American Academy of Pediatrics, ECHO follows these four principles: <ul style="list-style-type: none"> • Subscribes to the disease management model of care that aims to improve quality, reduce variety and standardize best practices; • Fosters multidisciplinary partnerships that increase access to care and reduce healthcare costs; • Engages health care providers to participate in case-based learning under guided practice to provide specialized care to their own patients; and • Utilizes technology to promote face-to-face mentorship and sharing of knowledge and experience by experts and peers without the need for cost-intensive supervision, in-person trainings and travel.
ECHO Autism	An empirically supported model for increasing the capacity of the community to provide care for patients with autism through initial in-person training and follow-up telehealth consultation with experts at an academic medical center.

HCBS Waivers	Within broad federal guidelines, states can develop home and community-based services waivers (HCBS Waivers) to meet the needs of people who prefer to get long-term care services and supports in their home or community, rather than in an institutional setting.
ICF	An intermediate care facility (ICF) is a long term care facility that provides nursing and supportive care to residents on a non-continuous skilled nursing care basis, under a physician’s direction. ICFs are designed to provide custodial care for those who are unable to care for themselves because of mental disability or declining health.
PRTF	Psychiatric Residential Treatment Facility: Licensed, inpatient psychiatric treatment facilities available for those under 21 years of age who meet admissions criteria and are prior approved by the beneficiary’s Medicaid managed care organization (MCO), or SCDHHS for those who have fee for service Medicaid; PRTFs are licensed and monitored by SCDHEC and SCDHHS establishes payment rates. (Source: SCDDSN)
RBT	Registered Behavior Technician: A (high school-level) paraprofessional in behavior analysis who practices under the close, ongoing supervision of a BCBA or a BCaBA (Source: Behavioral Analyst Certification Board)
RITA-T	Rapid Interactive Screening Test for Autism in Toddlers: A reliable level-two screening test for autism in toddlers ages 18-36 months; RITA-T screens take approximately 5-10 minutes to administer and score.
STAT	Screening Tool for Autism in Toddlers and Young Children: A level-two screening tool for children ages 24-36 months designed for use by community providers with the appropriate training; STAT screenings generally take about 20 minutes to complete.
TEFRA	Tax Equity and Fiscal Responsibility Act of 1982: Also known as “ Katie Beckett ,” TEFRA is an eligibility category for Medicaid for children aged 18 or younger who live at home and meet the Supplemental Security Income (SSI) definition of disability, have gross monthly income below \$2,427 and countable resources below \$2,000 and who meet an institutional level of care. (Source: SCDHHS)

E. Medicaid Eligibility

Effective July 1, 2017, the South Carolina Title XIX State Plan (Medicaid State Plan) began covering ASD services for medically eligible individuals up to age 21 years old. These services

may be provided in the member’s home, in their community, in their school or in a PRTF. For more information on eligibility and how to receive ASD services, visit <https://www.scdhhs.gov/resources/programs-and-initiatives/autism-spectrum-disorder-services>.

Home and community-based waiver programs provide services for individuals with ASD or ASD/DD. The Community Supports waiver and Intellectual Disability/Related Disabilities waiver serve individuals with a diagnosis of intellectual or related disability that require an Intermediate Care Facility for individuals with intellectual disabilities level-of-care. Many adults with ASD or ASD/DD are supported in home and community-based waivers.

F. State Agencies Involved with Autism: Role(s)

State Agency	Autism Related Services & Functions
SCDHHS	Medicaid eligibility and enrollment, Medicaid reimbursement for services, BabyNet, home and community-based waiver program renewal and funding
SCDDSN	Autism division services that include eligibility evaluations, advocacy and awareness activities, resource identification, and case management/collaboration with community organizations and partners; SCDDSN has regional autism eligibility offices located at SCDDSN Regional Centers.
SCDOE	School psychologist testing for autism, delivery of individualized education plan (IEP) services, school-based mental health counselors
SCDMH	School-based mental health counselors, limited psychiatric management services for individuals with ASD/DD
SCDHEC	Licensure of PRTFs
MUSC	Operation of the Charleston DEC
USC	Operation of the Columbia DEC and the Carolina Autism and Neurodevelopmental Research Center, a research and resource center for families

III. AUTISM STUDY COMMITTEE: LEGISLATIVE RECOMMENDATIONS

A. Community-based Residential Habilitation Settings

Invest state funding for the development of specialized, community-based residential habilitation settings; These settings will address complex behavioral needs of individuals with ASD or ASD/DD, providing interventions to adjust to a group care setting and to facilitate the ultimate goal of transitioning to a longer-term, community-based environment. While initially focusing on children and youth, this should ultimately include children, youth and adult populations.

B. Workforce Initiatives

Invest state funding to develop workforce initiatives that increase the number of developmental and behavioral health providers providing services to individuals with ASD and ASD/DD; The lack of workforce is a substantial limitation for diagnosis and treatment. Workforce initiative funding is needed to develop training ECHO programs to increase ASD and ASD/DD capacity of existing providers, incentivize recruitment of providers, fund training fellowships and compensate community providers for the extra time needed to provide services to this population of patients. This would require a multi-year investment to build the state's workforce.

C. Inpatient Medical Facilities

Establish enhanced reimbursement rates for specialized acute inpatient psychiatric and psychiatric residential treatment facilities with capacity to treat individuals with ASD or ASD/DD; Support establishing specialized units within facilities to address the need for short-term stabilization.

IV. AUTISM STUDY COMMITTEE: STATE AGENCY RECOMMENDATIONS

A. SCDHHS:

i. Workforce Initiatives: Improve provider reimbursement for services

- Increase reimbursement for existing providers: Increase reimbursement for providers involved in diagnosis and treatment services for Medicaid members with suspected or diagnosed ASD or ASD/DD; Reimbursement rate increases are needed for diagnosis and treatment providers at all levels. [Note: SCDHHS has increased reimbursement rates for some of these provider groups during the committee's meeting time and additional work is planned to address reimbursement rates.]

ii. Workforce Initiatives: Increase provider capacity for existing workforce

1. Create statewide network of DEC-affiliated autism specialists:
Create a statewide network of DEC-affiliated autism specialists

that includes community-based pediatricians who can provide level-two autism screens, RITA-T or STAT; This will increase the number of children ages 0-3 who can receive a presumptive diagnosis of autism and receive needed services through BabyNet. It will also help expedite the diagnostic process for patients being referred to a DEC for evaluation.

2. **Compensate primary care providers for ASD screening and care management:** Develop ASD/behavioral health management service add-on billing codes for primary care providers to ensure they are adequately compensated for the extra time required to perform level-two screening or care management for patients already diagnosed with ASD or ASD/DD.
3. **Psychiatric access network for ASD/DD:** Work with medical schools, health systems, SCDMH, the South Carolina Telehealth Alliance and private providers to increase the number of psychiatrists who have skill in treating individuals with ASD/DD, building a network of psychiatrists who are available for in-person or telehealth.
4. **ECHO training program development:** Work with the DECs and other stakeholders to build and fund ECHO training programs to increase provider capacity across the state (i.e., community pediatricians, psychiatrists and other provider types).
5. **Family flexibility on waiver programs:** Work to update waiver programs serving families of individuals with ASD or ASD/DD to give families further services and supports; Addition of caregiver coaching service will be focused on families with waiver participants that are aged 14-24 with ASD or ASD/DD; Review and update of staff qualification requirements and service definitions for behavior support services; Update policies to cover services that allow for family members to be paid caregivers for self-directed services; This change would allow participants or their representatives to have decision-making authority for certain services and take direct responsibility for managing services with assistance of available supports through the ability to recruit, hire, train and supervise individuals who render their services.
6. **Incentivize provider training programs:** Work with the medical schools and universities to increase the number of training programs for DBP, psychologists and psychiatrists, using Medicaid Graduate Medical Education or other funding sources and incentives.
7. **Keep DEC telehealth services:** Maintain the DECs' ability to provide appropriate non-testing services via telehealth as a means to provide services to rural areas.

- iii. **Workforce Initiatives: Streamline and enhance administrative processes**
 - 1. **Simplify TEFRA application process:** Shorten the Katie Beckett/TEFRA application process. [Note: SCDHHS has convened a multi-stakeholder group to work on ways to streamline this process.]
 - 2. **Increase eligibility/enrollment capacity:** Identify additional community partners who can be trained to assist families with eligibility and enrollment functions.

- iv. **Inpatient Medical Facilities: Facilitate development of a coordinated network of providers for diagnosis and for psychiatric care**
 - **Develop Reimbursement methodology for specialized acute inpatient psychiatric services and PRTFs:** Develop sustainable reimbursement methodologies for levels of service envisioned at the inpatient psychiatric hospitals and PRTFs for individuals with ASD or ASD/DD.

B. SCDDSN:

- i. **Community-based Residential Habilitation Settings: Increase provider capacity**
 - 1. **Continue to Develop Specialized community-based residential habilitation settings:** Continue development of youth residential habilitation services that can accommodate individuals with ASD or ASD/DD.
 - 2. **Develop Short-term intensive residential services:** Develop a short-term residential service for youth that is intended to reunite those children with their families/caregivers; The service should include a comprehensive functional behavioral assessment, a plan based on the assessment and rigorous implementation of the plan. This service would include a minimum number of hours of parent/caregiver training while the child is in services that will include learning to implement the techniques and skills in the plan, practicing those skills under the supervision of trained staff and providing additional support to the child, family and school upon his/her return home. Students in this environment would receive education services from the school district in which the setting is located. [Note: SCDDSN has visited the Great Lakes Center for Autism Treatment and Research in Portage, MI and has engaged in discussions with the New England Center for Children in Southborough, MA in an attempt to identify a model for services in South Carolina. This is an ongoing process.]

- ii. **Workforce Initiatives: Streamline and enhance administrative processes**
 - 1. **Include medical input in case management:** Strengthen case management requirements to ensure care plans are shared with primary care provider(s) to include updates from primary care provider recommendations; Add a requirement for SCDDSN care plan reviewers to assess for this in care plan reviews/approvals.
 - 2. **Align SCDDSN eligibility:** Continue to implement changes to align SCDDSN ASD eligibility criteria with that of Medicaid requirements for ASD services.

C. SCDOE:

- i. **Workforce Initiatives: Increase provider capacity for existing workforce through training, reimbursement methodologies and providing resources**
 - 1. **Develop training videos for school-based counselors:** Work with SCDHHS, SCDMH and the DECs to develop virtual training resources for school-based counselors to support the needs of students with ASD or ASD/DD; Ensure SCDOE works with SCDHHS through current school-based contract to implement training. Assess capacity for South Carolina School Behavioral Health Academy to leverage platform for e-learning.
 - 2. **Increase resources for school psychologists:** Work with the DECs to provide training resources for school psychologists.
 - 3. **Increase school psychologist compensation:** Increase salaries to retain and recruit school psychologists.
- ii. **Workforce Initiatives: Streamline and enhance administrative processes**
 - **Support additional assessment and diagnosis:** Support completion of updates to Standards for Evaluation and Eligibility Determination (SEED) document in the regulatory process as related to diagnostic criteria for ASD.

D. SCDMH:

- i. **Workforce Initiatives: Facilitate development of a coordinated network of providers for diagnosis and for psychiatric care**
 - 1. **Increase ASD/DD capacity of SCDMH providers:** Increase capacity of pediatric psychiatrists at community mental health centers to manage co-existing psychiatric disorders of individuals with ASD.
- ii. **Workforce Initiatives: Increase provider capacity for existing workforce through training, reimbursement methodologies, and providing resources**

- **Require school-based counselor training:** Require all school-based mental health counselors to have additional training on management of individuals with ASD or ASD/DD.

V. AUTISM STUDY COMMITTEE: ADDITIONAL RECOMMENDATION

Autism Resource Center

In lieu of an autism center of excellence, develop and fund an autism resource center to continually develop and manage training programs for ASD and ASD/DD providers, compile resources for families and potentially administer provider incentive programs.

APPENDIX: COMMITTEE MEMBERSHIP

Chair: Ms. Maggie Cash, Executive Director, SC Children's Hospital Collaborative
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Vice Chair: Ms. Marcella Ridley, Co-Founder, Executive Director, Winston's Wish Foundation
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South Carolina Senate: Senator Brad Hutto
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SCDHHS: Director Robert Kerr
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The Committee thanks the following individuals for their participation and valuable contributions to the discussion and resulting recommendations.

Developmental-Behavioral Providers:

Jane Charles, MD -DBP physician; Michelle Macias, MD - DBP physician at MUSC; Shawna McAfferty, MD- DBP Fellow at MUSC; Karen Ratliff Schaub, MD - DBP physician at Prisma Health; Anne Kinsman, PhD - Psychologist at Prisma Health; Laura Carpenter, PhD - Psychologist at MUSC; Emily Lowell, PhD - Psychologist at Prisma Health; and Hannah Reckart, PhD - Psychologist