

DEPARTMENT OF HEALTH

SECRETARIAT FOR SURVEILLANCE

AND PROTECTION OF PUBLIC HEALTH

- DIVISION OF EPIDEMIOLOGY AND RESEARCH -

AUTISM SPECTRUM DISORDER EARLY IDENTIFICATION AND DIAGNOSIS: SUMMARY OF IMPLEMENTED STRATEGIES 2015-2022

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DEPARTAMENTO DE

SALUD

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Introduction

This document summarizes the strategies and activities implemented to increase the number of children at risk of autism spectrum disorder (ASD) that receive their first diagnostic evaluation at 36 months or earlier during the period FY2015-FY2022 under the leadership of the Puerto Rico Title V Children with Special Healthcare Needs (CSHCN) Program Director and the Centers for Disease Control and Prevention (CDC)'s Learn the Signs. Act Early (LTSAE) Ambassador.

The CSHCN program director, as Chair of the Autism Steering Committee (ASC) created by Law #220 of 2012, "Law for the Well-being, Integration and Development of People with Autism" (Ley BIDA, Spanish acronym), and the LTSAE ambassador worked with the ASC, to align priorities and assure that common goals were addressed.

Background

CSHCN Program 2016-2020 Needs Assessment

A body of stakeholders was convened on May 12, 2014, to present and discuss the needs identified by the focus groups convened by the CSHCN program. The top six (6) CSHCN population needs identified by the stakeholders, data collected from other state partners along with quantitative data were considered for the selection of the CSHCN Program priorities. Key criteria used for the prioritization process included: alignment with Title V mission and scope, federal requirements, state and local capacity, and ability to make a measurable impact in the short- and long-term. Increasing the number of children at risk of autism spectrum disorder (ASD) that receive their first diagnostic evaluation at 36 months or earlier was selected as a new state priority in 2015.

Rationale for selection: Many children with autism miss out on early behavioral interventions and other benefits because health professionals are reluctant to diagnose autism early out of fear of labeling young children. Reliable diagnosis has been documented during infancy and toddlerhood, and evidence suggests that the earlier the onset of intervention, the greater likelihood of an improved developmental trajectory. In 2011, it was estimated in PR there were 2,890 children with ASD ages birth to three years old, the majority without a diagnosis. Given that a reliable diagnosis of ASD is possible by 24 months, and that about 90% of parents whose children are later diagnosed with ASD express documented concerns before age 2, the gap between best practice guidelines and community implementation is tangible.

CSHCN Program 2016-2020 Action Plan

- **New state CSHCN priority:** Decrease the age when children at risk of ASD receive their first diagnostic evaluation.
- **Measure:** Percentage of children with ASD that are diagnosed at age 3 years or earlier.

CSHCN Program 2021-2025 Needs Assessment

Early screening, diagnosis, and treatment for children with Autism Spectrum Disorder (ASD) continues as a priority from the previous 5YR Action Plan. Growing evidence points to the importance of early screening, diagnosis, and treatment for children with ASD. Evidence-based intervention can significantly improve the development and quality of life of children with ASD. The 2019 Maternal and Child Health-Jurisdictional Survey (MCH-JS) showed that 11.2% of children with ASD, 3 to 17 years of age, were identified or diagnosed before three years of age. Efforts must continue to improve ASD early identification.

CSHCN Program 2021-2025 Action Plan

- **Continued state CSHCN priority:** Decrease the age when children at risk of ASD receive their first diagnostic evaluation.
- **Measure:** Percentage of children with ASD that are diagnosed at age 3 years or earlier.

Strategies implemented

FY 2014-2015

1. **Capacity building for the early identification of ASD: Increase access to ASD evaluations through the CSHCN Program Regional Pediatric Centers and Autism Centers**
 - July 2015: The administration of the Puerto Rico Autism Center (PR-Autism Center) was transferred from the Institute for Developmental Disabilities (IDD) to the CSHCN Program to provide a unified collaborative and administrative structure designed to ensure the successful execution of plans and strategies that support the implementation of the CSHCN 5YR Action Plan. This included prioritizing ASD screening and diagnostic services for children aged 3-years-old or less.

- September 2015: A collaborative agreement with the Medical Science Campus, University of Puerto Rico to use the PR-Autism Center clinical facilities to train medical students was signed.

2. Developing and implementing protocols to support early ASD identification.

- January 2015: Two protocols were completed: 1- “*Standard Protocol for the Early Identification of Autism Spectrum Disorder: Surveillance and Screening 0 – 66 months of age*” and 2- “*Standard Protocol for the Diagnosis of Autism Spectrum Disorder*”, based on the American Academy of Pediatrics (AAP) recommended practices and the AAP algorithm.
- July 2015 and October 2015: Meetings were held with the Puerto Rico-Health Insurance Administration (PR-HIA) to discuss and agree upon the provisions of the “*Standard Protocol for the Early Identification of Autism Spectrum Disorder: Surveillance and Screening 0 – 66 months of age*” and the “*Standard Protocol for the Diagnosis of Autism Spectrum Disorder*”.

3. Education and training to health care providers and other staff that provide services to children.

- February 2015 (5, 17, 19 and 24) and March 2015 (10, 12, 19 and 24): Trainings on the ASQ-3, ASQ-SE-2 developmental screening tools and the M-CHAT-R/F were provided to the Puerto Rico Family Department’s regional supervisors that approve the Child Care’s licenses.

FY 2015-2016

1. Capacity building for the early identification of ASD: Increase access to ASD evaluations through the CSHCN Program Pediatric and Autism Centers.

- December 2015: A Collaborative Agreement between the Department of Health (CSHCN Program), the Ponce Autonomous Municipality and the Ponce Autism Center (CEPA, Spanish acronym) was signed. The agreement provided for ASD screening and diagnostic services for children aged 3-year-old or less to be provided at the CEPA by CSHCN Program contracted staff.
- January 2016: The PR-Autism Center and CEPA are providing ASD diagnostic evaluations for children younger than 3 years old at risk for ASD island wide. The PR Autism Center provides services to families from the north-east-central municipalities of the island, and CEPA to families from the south-west municipalities.

2. Developing and implementing protocols to support early ASD identification.

- February 2016: A “*Developmental Screening Certification Form*” was developed to promote developmental screening, including screening for ASD. Pediatricians, primary care physicians or any other health provider that performs a developmental or ASD screening to a child between 0 to 66 months can register on the certification form the screening tool used, date and results.
- September 2016: The “*Standard Protocol for the Early Identification of Autism Spectrum Disorder: Surveillance and Screening 0 – 66 months of age*” and the “*Standard Protocol for the Diagnosis of Autism Spectrum Disorder*” were revised, approved, and signed by the Secretary of Health.
- September 2016: The “*Guide for the Early Identification of ASD*” was developed. The guide includes information on the importance of early identification of ASD, the algorithm for early identification, developmental milestones for the first five years, instruments for developmental and ASD screening, the DSM-5, interviewing families, instruments that help establish an ASD diagnosis, the comprehensive medical evaluation, differential diagnosis, other conditions associated or commonly comorbid with ASD, and how to share the diagnosis with families.
- September 2016: The “*Guide for the Early Identification of ASD*” was made available on-line at www.apnpr.org. The link was shared with the BIDA Law Steering Committee, pediatric neurologists, pediatricians, psychologists, the Early Head Start and Head Start, the Administration of Child Care and Development, the Institute for Youth Development, the Multi-sectorial Council for Early Childhood, private schools for students with ASD, corporations that provide diagnostic and related services to the Department of Health and Department of Education, United Way, Health Professions Boards, and pertinent Department of Health Divisions and Programs.

3. Education and training to health care providers and other staff that provide services to children.

- January 2016 (26 and 30), February 2016 (2, 7, 8, 9, 10 15 and 23) and March 2, 2016: Trainings on the revised versions of the “*Standard Protocol for the Early Identification of Autism Spectrum Disorder: Surveillance and Screening 0 – 66 months of age*”, and the “*Standard Protocol for the Diagnosis of Autism Spectrum Disorder*” were provided to pertinent staff of the seven (7) Regional Early Intervention Program offices, the eleven (11) Special Education Services Centers, the seven (7) Regional CSHCN Centers, and the two (2) CSHCN Autism Centers.

The “*Guide for the Early Identification of ASD*” was also distributed during the trainings.

4. Increasing ASD awareness and its early signs among families with children.

- February 2016: A booklet named “*Pasaporte a la Salud*” (Passport to Health) was developed with the purpose of informing families about children’s growth and development from birth to five years of age, and the warning signs for developmental delay and ASD. The booklet will be available at birthing hospitals and at the Demographic Registry offices to be distributed to mothers that recently gave birth.

5. Implementation of the PR-Autism Registry

- December 2015: With the support of the Office of Informatics and Technology Advances (OIAT) of the Department of Health, an electronic platform for the Autism Registry was developed and piloted in December 2015. The Autism Registry collects the following information: demographics, age when ASD signs were observed for the first time, ASD diagnosis, date of diagnosis and severity, diagnostic tools used, health professional that made the diagnosis, and comorbid conditions, among others.
- March 2016: Staff of the seven (7) CSHCN Regional Pediatric Centers (RPCs) and the two (2) Autism Centers, and the eleven (11) Puerto Rico Department of Education (PR-DE) Special Education Services Centers received training regarding the Autism Registry.
- April 2016: The Autism Registry was officially launched.
- April – May 2016: Information about the Autism Registry was disseminated on radio programs, written press and television programs.
- July 2016: There were 375 children with ASD between 11 months and 18 years of age in the Autism Registry.

FY 2016-2017

Strategies implemented:

1. Developing and implementing standard protocols to support early ASD identification.

- N/A

2. Education and training to health care providers and other staff that provide services to children.

- December 2016: Transdisciplinary competencies on ASD for health care providers, mental health providers, social providers and special education professionals were developed and approved by the ASC for the following disciplines: special education, speech and language pathology, speech and language therapy, occupational therapy, physical therapy, social work, medicine, odontology, nursing, psychology, rehabilitation counseling, and nutrition/dietician. The competencies include knowledge, skills and disposition for the following four areas: 1- general, 2- diagnosis and assessment, 3- services and intervention, support and working with the person with ASD, and 4- support and working with the family.
- August 2017: The transdisciplinary competencies for providers who work with children with ASD were shared with professional organizations, licensing boards, and the university programs that prepare such professionals.
- August 8, 2017: Orientation was provided on the “*Standard Protocol for Autism Spectrum Disorder Diagnosis*” and the Autism Registry to the psychologists of the largest corporation contracted by the Department of Education that carry out ASD diagnostic evaluations. The psychologists were also able to open their Autism Registry account.

3. Increasing ASD awareness and its early signs among families with children.

- January 2017-September 2017: The CDC booklet, “*Learn the Signs. Act Early*” in the Spanish version, was distributed to families when they registered their newborn at their local Demographic Registry Office. A letter welcoming the infant, and the “*Developmental Screening Certification Form*” were also distributed with the CDC booklet.

4. Implementation of the PR-Autism Registry

- November 2016: Brochures and flyers regarding the Autism Registry and the “*Standard Protocol for the Diagnosis of Autism Spectrum Disorder*” were distributed to the participants at the Annual Convention of the PR Association of Psychologists. During the convention, psychologists were able to open an Autism Registry account to register children diagnosed with ASD.
- March 2017: A brochure addressed to parents about the Autism Registry was created and distributed to the Regional CSHCN Centers, the Special Education

Services Centers, Early Intervention Programs, Early Head Start and Child Care Centers and Parent Training and Information Center.

- September 2017: There were 911 entries to the Registry. The 911 entries were primarily from the CSHCNP RPCs, the majority from the two (2) CSHCNP Autism Centers.

FY 2017-2018

1. Developing and implementing protocols to support early ASD identification.

- February 2018: The “*Standard Protocol for the Diagnosis of Autism Spectrum Disorder*” was revised to include *counseling psychology* as a discipline qualified to diagnose ASD.
- April 2018: The revised version of “*Standard Protocol for the Diagnosis of Autism Spectrum Disorder*” was approved and signed by the Secretary of Health.
- April 2018: The “*Guide for the Early Identification of ASD*” was updated according to the revised protocol.
- May 2018: The revised versions of the “*Standard Protocol for the Diagnosis of Autism Spectrum Disorder*” and the “*Guide for the Early Identification of ASD*” were published in the Parent Information Center’s (APNI) web page, www.apnipr.org.
- July 2018: A meeting was held with the Special Education Associate Secretary of the PR Department of Education (DOE) to present the “*Standard Protocol for the Early Identification of Autism Spectrum Disorder: Surveillance and Screening 0 – 66 months of age*”, the “*Standard Protocol for the Diagnosis of Autism Spectrum Disorder*” and the Autism Registry. The Associate Secretary agreed to amend the contracts of the corporations that provide ASD diagnostic services to the DOE to ensure compliance with the Department of Health’s ASD protocols and that any child who meets the criteria for a diagnosis of Autism is registered in the PR-Autism Registry.
- August 2018: Meetings were held with the PR-HIA to discuss and agree on the provisions of the revised version of the “*Standard Protocol for the Diagnosis of Autism Spectrum Disorder*”.

2. Education and training to health care providers and other staff that provide services to children.

- April 2018: Service coordinators at the seven (7) CSHCN program RPCs were trained on the administration of the M-CHAT-R/F screening tool.

3. Increasing ASD awareness and its early signs among families with children.

- October 2017: A digital version of the "*Passport to Health*" booklet was provided to the Puerto Rico Association of Primary Health Care Providers (ASPPR, Spanish acronym) to be printed and shared with families through the sixty-two (62) Federally Qualified Health Centers (FQHC's) in PR.
- October 2017-February 2018: The CDC booklet, "*Learn the Signs. Act Early*", Spanish version, continued to be distributed to families when they register their newborn at their local Demographic Registry Office. A letter welcoming the infant, and the "*Developmental Screening Certification Form*" were also being distributed with the CDC booklet.
- February 2018: The booklet "*Passport to Health*" was revised to include information on the procedures for the developmental surveillance of infants and toddlers born to mothers with laboratory evidence of possible ZIKA virus during pregnancy during their first three years of life.
- March 2018: 15,000 copies of the revised "*Passport to Health*" booklet were provided to the Demographic Registry regional offices to be distributed to families of newborns.
- May 2018: The CMS Zika Health Services Program assigned twenty-seven (27) Arbovirus Health Educators to sixty (60) WIC clinics throughout PR. They provided follow-up and support to families of infants and toddlers born to mothers with laboratory evidence of possible Zika infection during pregnancy and encouraged families to participate in the Surveillance and Service Coordination Services for Children born to mothers with Zika virus infection during pregnancy CSHCN Program. The program provided follow-up service for children through age 5 years. The Arbovirus Health Educators also provided support to families on the use of the Passport to Health, the "*Developmental Screening Certification Form*" and the implementation of the developmental and ASD monitoring with the Act Early materials and the Milestone Tracker App.

4. Implementation of the PR-Autism Registry.

- January 2018: A summary of the ASD diagnostic procedures was distributed to all participants at the PR Psychologist Association on January 26 and 27, 2018. During the convention psychologists who carry out ASD diagnostic evaluations were able to open an Autism Registry account.

FY 2018-2019

1. Developing and implementing protocols to support early ASD identification.

- April 2019: Secretary of Health Administrative Order Num. 405, requiring that examining boards include the corresponding ASD professional competencies as part of the mandatory continued education courses, was signed on April 8, 2019.
- May 2019: The competencies on ASD for teachers were presented to the Department of Education, which agreed to ensure that they were addressed through teachers and other key personnel training.
- September 26, 2019: Meetings were held with the PR-HIA to facilitate the approval of the temporary Autism Special Coverage to perform ASD diagnoses in a timely manner.

2. Education and training to health care providers and other staff that provide services to children.

- October 2018: A staff member of the Children with Special Health Care Needs Program (CSHCNP) was awarded the PR Act Early Ambassador Liaison to the CDC's Learn the Signs. Act Early initiative. The PR LTSAE Ambassador established the following goals: 1-Support developmental surveillance and screening services for infants and toddlers born to mothers with laboratory evidence of possible Zika infection during pregnancy at the CSHCN Program Regional Pediatric Centers, and 2- Systematically integrate LTSAE materials in programs that provide services to young children and their families, such as: Community Health Centers, WIC, EHS/HS, Child care centers and MCH Home visiting programs.
- October, November, December 2018: Training was provided to FQHCs staff on the importance of providing families information on developmental milestones and early identification of developmental delays to strengthen their participation in the surveillance of their child's development. The centers' nursing, pediatric, social work, psychology, community liaisons, service coordinators, and health education staff participated. The training also informed on the services provided by the CSHCN Program and the referral process for ASD diagnostic evaluations at the seven (7) RPCs and two (2) Autism Centers. The trainings were held on October 23, 2018 (North Region), November 15, 2018 (West Region), and December 11, 2018 (South Region).

- November 2018: A conference on the administration of the M-CHAT R/F was provided at the Pediatricians of the East Region Annual Conference. Early Identification of ASD materials were also distributed.
- February 2019: Early Identification of ASD materials were distributed at the PR Pediatric Society Conference.
- April 2019 (12 & 16): Training on the following screening and diagnostic instruments was provided to the ASD teams of the RPCs and Autism Centers: Communication Symbolic Behavioral Scales- Developmental Profile, Gilliam Autism Rating Scale, Autism Diagnostic Interview-Revised, and the Social Communication Questionnaire.

3. Increasing ASD awareness and its early signs among families with children.

- February 2019: The article “*Early Identification of Developmental Disorders and ASD*” was written and published in the PR Parent Information Center’s Newsletter, reaching 15,000 parents and professionals.

4. Implementation of the PR-Autism Registry.

- January -September 2019: The Department of Education distributed materials regarding the Autism Registry in public schools and required that corporations that complete ASD evaluations for special education eligibility follow the “*Standard Protocol for the Diagnosis of Autism Spectrum Disorder*” and register those students that are diagnosed with autism.

FY 2019-2020

1. Developing and implementing protocols that support early ASD identification.

- May 2020: As a result of policy changes and regulatory waivers from the Centers for Medicare & Medicaid Services (CMS) in response to the COVID-19 pandemic, the Puerto Rico Government revised the local tele-medicine regulations authorizing the tele-health modality for specific health care services. This allowed the CSHCN Program to offer services in a two-way remote modality: from provider’s home to family’s home. A remote services protocol was developed and implemented expeditiously in collaboration with RPCs’ and Autism centers’ directors/ administrators, supervisors, health care providers and service coordination providers.

2. Education and training to health care providers and other staff that provide services to children.

- January 2020 (15 & 29): A two-afternoon remote capacity building activity was held for health care providers who work with young children with ASD. The first afternoon covered the following topics: services provided by the CSHCN program, early signs of autism, the role of the family in the early identification of ASD, and the “*Standard Protocol for Early Identification of Autism Spectrum Disorder: 0-66 months*”. The topics for the second afternoon were: “*Standard Protocol for Autism Spectrum Disorder Diagnosis*”, differential diagnosis, comorbidities in ASD, the Autism Registry and special health coverage for ASD.
- March 5, 2020: Training and orientation activities about early ASD identification were carried out to stakeholders such as: health insurances’ case managers, pediatricians, the Planning Committee of the Preschool Development Grant-Birth to 5 of the Department of the Family, social workers, Child Care staff and Early Head Start and Head Start staff.

3. Increasing ASD awareness and its early signs among families with children.

- October 2019 - September 2020: 19,233 booklets of “*Pasaporte a la Salud*” were distributed to families when they register their newborn at their local Demographic Registry Office together with the “*Developmental Screening Certification Form*”.
- July 2020: The Head Start Collaboration Office agreed to reproduce 25,000 copies of the “*Passport to Health*” to facilitate developmental monitoring of all Early Head Start and Head Start participants.
- July-Aug 2020: Collaborated with APNI in the preparation of the proposal to the Association of University Centers on Disabilities and the CDC for the Act Early Response to COVID-19 project to strengthen the four steps of early identification of developmental delays and disabilities, and promote the distribution of existing relevant tools, materials and programs to improve resiliency among families with young children during COVID-19 response and mitigation efforts.
- September 2020: APNI was awarded the Act Early Response to COVID-19 project. The Puerto Rico Act Early Ambassador was the co-leader of this project.

4. Implementation of the PR-Autism Registry.

- October 2019-Sept 2020: APNI and the CSHCN program continued the promotion of the Autism Registry, distributing the Registry’s brochure to participants in their outreach and training activities.
- October 2019-Sept 2020: The Department of Health continued requiring that the corporations contracted by the Department of Education follow the “*Standard*

Protocol for Autism Spectrum Disorder Diagnosis” and register in the PR-DOH Autism Registry those students that are diagnosed with ASD.

FY 2020-2021

1. Capacity building for the early identification of ASD: Increase CSHCN program workforce.

- January 2021: At the end of CMS Zika Healthcare Services Program project period (01/17/2021), direct services staff were transferred to the CSHCN program to increase the RPCs capacity to address the early identification of ASD priority. Fifty-two (52) healthcare and family support providers, including care coordinators (9), family engagement and support advocates (7), nurses (5), psychologists (5), occupational therapists (5), speech and language pathologists (4), physical therapists (4), pediatricians (4), social workers (3), speech and language therapists (2), occupational therapy assistant (1), physical therapy assistant (1), nutrition specialist (1) and audiologist (1) were hired.
- January 2021: To address the waiting lists of referrals for ASD evaluation, the following strategies to increase the capacity for ASD evaluations were implemented at the Autism Centers:
 - For children whose ASD evaluation took longer than one day, the following days for ASD evaluations were coordinated through tele-health whenever possible.
 - Autism centers prioritize the ASD evaluations for children less than 36 months and refer 3-year-old children to the CSHCN program RPCs for ASD diagnostic evaluations.
 - Children who are less than 36 months of age in the waiting list for ASD evaluation were referred to Part C Early Intervention, so they are served while waiting for their ASD evaluation.

2. Developing and implementing protocols that support early ASD identification.

- October 2020: Quality improvement strategies were implemented at the Autism Centers for the tele-medicine and tele-health services, which included the collection of families and providers’ feedback tele-health services’ feedback, training to providers, and tuning the telehealth protocols for ASD.
- January 2021 (15 & 29): Training on the “*Standard Protocol for the Early Identification of Autism Spectrum Disorder: Surveillance and Screening 0 – 66*”

months of age”, and the “*Standard Protocol for the Diagnosis of Autism Spectrum Disorder*” as well as orientation about the processes to refer to the CSHCN Program, were provided to staff at all DOE Special Education Centers throughout the island.

- February 12, 2021: Workshops about evidence-based interventions for infants/toddlers with ASD in their natural environments as well as the PR-DOH Protocols for ASD Surveillance, Screening and Diagnosis were offered to Part C Early Intervention providers.

3. Education and training to health care providers and other staff that provide services to children.

- January 2021: A two-day virtual forum on ASD was provided to 410 providers: pediatricians, physicians, speech and language pathologists and therapists, psychologists, occupational therapists and OT assistants, physical therapists and PT assistants, social workers, nutritionists, audiologists, and rehabilitation counselors. A total of five continuing education credits were available for each of the mentioned disciplines that participated during both days. Topics included the early signs of autism, the role of the family in the early identification of ASD, the “*Standard Protocol for Early Identification of Autism Spectrum Disorder: 0-66 months*”, “*Standard Protocol for the Diagnosis of Autism Spectrum Disorder*”, differential diagnosis, comorbidities in ASD, the Autism Registry and special health coverage for ASD.
- January-September 2021: As part of continuous improvement, technical assistance regarding ASD screening and diagnosis to Regional Pediatric and Autism Centers’ staff was periodically provided.

4. Increasing ASD awareness and its early signs among families with children.

- October 2020: The following variables were added to the Autism Registry: report of laboratory evidence of possible or confirmed Zika virus infection during pregnancy; report of laboratory evidence of possible or confirmed SARS-CoV-2 infection during pregnancy; and report of any other virus infection during pregnancy.
- October 2020 - September 2021: The distribution of the “*Pasaporte a la Salud*” booklet together with the “*Developmental Screening Certification Form*” continued at the Demographic Registry Office. At least 15,000 packages were distributed.

- October 2020 – January 2021: Collaborations with APNI continued regarding the distribution of educational materials to families and providers. The “*Standard Protocol for Early Identification of Autism Spectrum Disorder: 0-66 months*”, the “*Standard Protocol for the Diagnosis of Autism Spectrum Disorder*”, and the “*Guide for the Early Identification of ASD*” continued to be published in APNI’s webpage to be downloaded by providers.

5. Implementation of the PR-Autism Registry

- April 2021: Staff from the Central Level held several meetings with the Office of Informatics and Advanced Technology (OIAT) of the PR-DOH to discuss improvements to the Autism Registry.
- August 2021: The electronic interface of the registry was updated making it easier for families and providers to navigate. Aggregated reports are now available for students and other professionals interested.

FY 2021-2022

1. Developing and implementing protocols that support the early ASD identification.

- N/A

2. Education and training to health care providers and other staff that provide services to children.

- October 2020 – September 2021: Trainings on the Early Identification of ASD: Surveillance, Screening and Diagnosis; Assessment Intervention Planning for Children and Adolescents with ASD; Guide to Evidence-Based Interventions for ASD; and awareness of ASD signs in families with children was provided to teachers, assistants, and caregivers that work at the Administration for the Comprehensive Care and Development of Children (ACUDEN, Spanish acronym), of the PR-Family Department.
- December 12, 2021: Workshops about the Early Signs of ASD were provided to Head Start and Early Head Start special need coordinators and education coordinators.
- December 2021: The “*Guide for Evidence-based Interventions for Children and Adolescents with ASD*” was released. This guide was developed by specialized ASD educators from the CSHCN Program and revised by the BIDA Law Steering Committee members.

- *December 2021*: The “*Guide for Evidence-based Interventions for Children and Adolescents with ASD*” was published on the PRDOH website and APNI’s website.

3. Increasing ASD awareness and its early signs among families with children.

- *October 2021- September 2022*: 15,000 LTSAE Development Indicators Booklets, as well as information for the promotion of the electronic application “Milestone Tracker App” were provided to the WIC Program.

4. Implementation of the PR-Autism Registry

- *October 2021 - September 2022*: Data linkages with the Demographic Registry were performed to identify and correct data errors.
- *October 2021 - September 2022*: The PR SET-NET used data from the Autism Registry to explore ASD among children born to mothers with/without laboratory evidence of Zika virus infection during pregnancy.

For more information about the Puerto Rico’s Autism and Developmental Disabilities Monitoring (ADDM) Network, visit https://www.salud.pr.gov/vigilancia_autismo.

For any questions, please email vigilancia_autismo@salud.pr.gov.

Resources





PASAPORTE A LA SALUD



Red para la Vigilancia de Autismo
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vigilancia_autismo@salud.pr.gov



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RECURSOS

Puede descargar las siguientes guías sobre autismo, desarrolladas por el Departamento de Salud, en la página web https://www.salud.pr.gov/centros_pediatricos o a través de los siguientes códigos QR.



- 1 Guía para la Identificación Temprana del Trastorno del Espectro del Autismo: Vigilancia, Cernimiento del Desarrollo y Diagnóstico



- 2 Guía para el Avalúo Dirigido a la planificación de intervenciones para niños y adolescentes con Trastorno del Espectro del Autismo



- 3 Guía de Intervenciones basadas en evidencia para niños y adolescentes con Trastorno del Espectro del Autismo

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787-765-2929, extensión 4587, o acceda
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