

Issue Brief

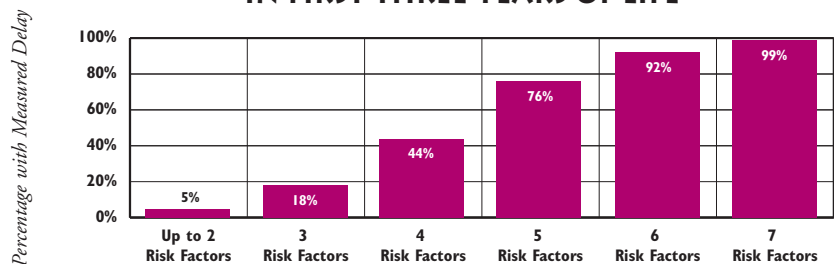
YOUNG CHILDREN WITH DEVELOPMENTAL DELAYS & DISABILITIES

Approximately 15% of children in the U.S. have developmental disabilities. Children from low-income families and boys are more likely to have a disability. The percentage of children recognized with developmental disabilities has increased over the past decade. The increase is attributed both to improved survival rates for children born preterm, with birth defects, or genetic disorders; and to increased awareness and diagnosis of certain conditions, including autism and attention deficit hyperactivity disorder.<sup>1</sup>

Developmental delays are identified when a child does not reach developmental milestones at the same time as other child his or her age.<sup>2</sup> Some children with developmental delays are eventually diagnosed with a disability while others catch up to their peers when therapy or intervention is provided. States provide services to young children with developmental delays in order to address emerging problems before they become intractable. Because young children’s development is complex, variable and skills are interrelated, it is often difficult to identify or determine whether there is an underlying disability. In Rhode Island, children from birth through age eight are eligible for special education services if they have an identified developmental delay without an identified disability.<sup>3</sup>

Children who are most at risk for developmental problems are those that have experienced multiple risk factors during early childhood including poverty, domestic violence, a biomedical risk condition, child maltreatment, or having a single parent, a parent with a mental health problem, and/or a teenage parent. Young children with more than five risk factors have a 90% or greater chance of delayed development.<sup>4,5</sup>

CHANCE OF DEVELOPMENTAL DELAY BY RISK LEVEL IN FIRST THREE YEARS OF LIFE



Source: Center on the Developing Child at Harvard University & Barth, R. P., Scarborough, A., Lloyd, E. C., Losby, J. Casanueva, C., & Mann, T. (2008). *Developmental status and early intervention service needs of maltreated children*. Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation.



## HEALTH AND DEVELOPMENTAL SCREENINGS

◆ Across the U.S., fewer than half of children with developmental problems are identified before starting public school. When developmental delays and disabilities are not recognized and addressed in early childhood, children miss opportunities to receive services that can prevent problems from worsening or help them catch up with their peers.<sup>6</sup> Early childhood screening is the first step in identifying children who may have a delay or disability that could benefit from intervention. Regular screening during the early stages of life, followed by evaluation and diagnostic assessment for children who appear to have special needs, helps children gain early access to needed services in order to prevent the occurrence of more severe problems.<sup>7</sup>

### NEWBORN SCREENINGS

◆ Newborns are screened before being discharged from the hospital to identify medical conditions that should be treated early to prevent serious problems from developing. A heel prick blood test can identify phenylketonuria (PKU), hypothyroidism, and other conditions such as sickle cell disease shortly after birth.<sup>8</sup> Newborns also receive a hearing screening in the hospital. Hearing loss is one of the most common identified disabilities for infants in the U.S. at 2 to 3 per 1,000 infants. Children with hearing loss who receive treatment early have better outcomes.<sup>9</sup>

### PEDIATRIC SCREENINGS

◆ Pediatricians play an important role in the early identification of developmental delays and disabilities. The American Academy of Pediatrics (AAP) recommends that physicians use a standardized developmental screening tool at the 9, 18 and 30 month well child visits and an autism screening tool at the 18 and 24 month visits for all children, not just those suspected of having developmental problems. Researchers have found that when physicians do not use a standardized screening tool, they sometimes miss developmental problems and are inconsistent in referring children with possible delays.<sup>10,11,12</sup>

◆ Guidelines for preventive pediatric health care in early childhood include vision screenings at ages three, four and five and hearing screenings at ages four and five to identify potential impairments. All children are screened for elevated blood lead levels at ages one and two to assess exposure to the toxic substance that can significantly impact health, cognitive and behavioral outcomes.<sup>13</sup>

◆ The AAP's Task Force on Mental Health recommends pediatricians use a valid instrument to screen for social-emotional or mental health problems in young children who have abnormal developmental or autism screenings. In addition, they recommend pediatricians screen for maternal depression in infancy and collect a history of trauma exposure and family psychosocial history at each well child visit.<sup>14</sup>

◆ Children with Medicaid health coverage receive comprehensive and preventative health services under the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) guidelines. This includes screening for developmental delays and autism according to a pediatric periodicity schedule.<sup>15</sup> As of September 2013, approximately 48% of Rhode Island children under age three were enrolled in Medicaid.<sup>16</sup>

### SCHOOL AND EARLY CHILDHOOD PROGRAM SCREENINGS

◆ In Rhode Island, all public school districts provide free annual hearing, vision, and developmental screenings for all children ages three to five through the Child Outreach program. Districts attempt to screen all preschool-age children living in the community.<sup>17</sup> In addition, many early learning and home visiting programs conduct developmental screenings, including Early Head Start and Head Start.<sup>18</sup>

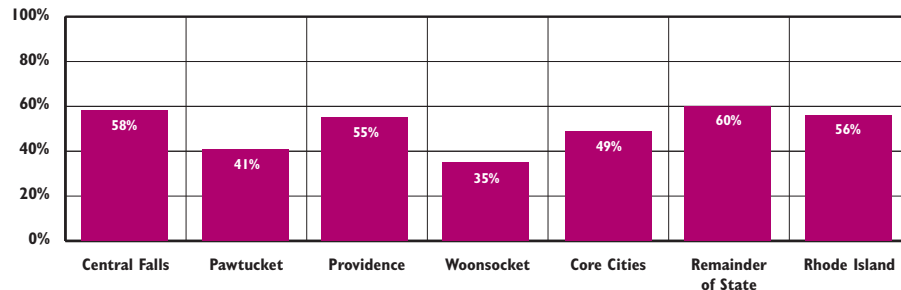
### FOLLOW-UP

◆ Regardless of who conducts developmental screening, when potential developmental problems are identified, referrals for further evaluation are needed to determine whether the child has a developmental delay. Those with delays need medical evaluation to look for causes of their challenges and access to educational interventions, including those provided by Early Intervention and preschool special education.<sup>19</sup>

## DEVELOPMENTAL SCREENING DATA

- ◆ In 2009, a national survey of pediatricians found that 48% reported always or almost always using at least one standardized screening tool at well child visits, up from 23% in 2002.<sup>20</sup>
- ◆ As reported by parents in a 2011-2012 survey, 28% of low-income children under age six in Rhode Island received a developmental screening by a health care provider, below the U.S. average of 30%.<sup>21</sup>
- ◆ In 2012-2013 in Rhode Island, 56% of children ages three to five received a developmental screening through the Child Outreach program. Children in the four core cities were less likely to receive a developmental screening (49%) than children in the remainder of the state (60%).<sup>22</sup>

### CHILD OUTREACH SCREENING RATES FOR CHILDREN AGES 3 TO 5, RHODE ISLAND, 2012-2013



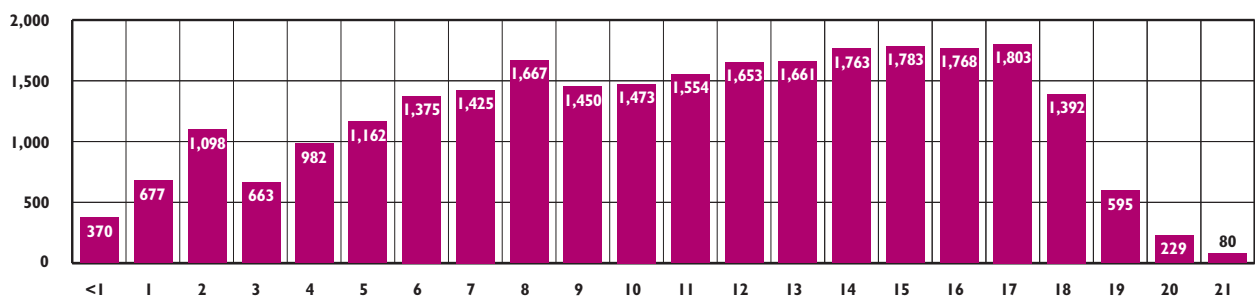
Source: Rhode Island Department of Education, 2012-2013 school year.

- ◆ The Rhode Island Department of Health is expanding the KIDSNET database to coordinate developmental screening data across the state, including screenings by physicians, school districts and some early care and education and home visiting programs. KIDSNET developmental screening data will help policymakers and practitioners understand more about children who miss developmental screenings and where resources are needed to improve screening rates.<sup>23</sup>

## SPECIAL EDUCATION

- ◆ The *Individuals with Disabilities Education Act (IDEA)* requires states to provide educational services to children with developmental delays and disabilities through Early Intervention from birth through age two (Part C of *IDEA*) and school districts from age three to 21 (Part B of *IDEA*). Part C of *IDEA* also allows states to provide Early Intervention services to children who are at risk for developmental problems.<sup>24</sup>
- ◆ In Rhode Island, the number of children receiving special education services increases from birth to age two and drops at age three with the transition from Early Intervention to preschool special education. Enrollment in special education then increases from age three through age eight.<sup>25,26</sup>

### CHILDREN RECEIVING SPECIAL EDUCATION SERVICES BY AGE, RHODE ISLAND, JUNE 2013



Source: Rhode Island Executive Office of Health and Human Services and Rhode Island Department of Education, June 30, 2013 enrollment.

## EARLY INTERVENTION FOR INFANTS & TODDLERS

◆ Early Intervention was established in 1986 as Part C of the *Individuals with Disabilities Education Act* in recognition of the “urgent and substantial need” to enhance the development of infants and toddlers with disabilities, reduce educational costs by intervening earlier, and enhance the capacity of families to meet their child’s needs. Early Intervention provides services and supports to eligible infants and toddlers from birth through age two and their families.<sup>27</sup>

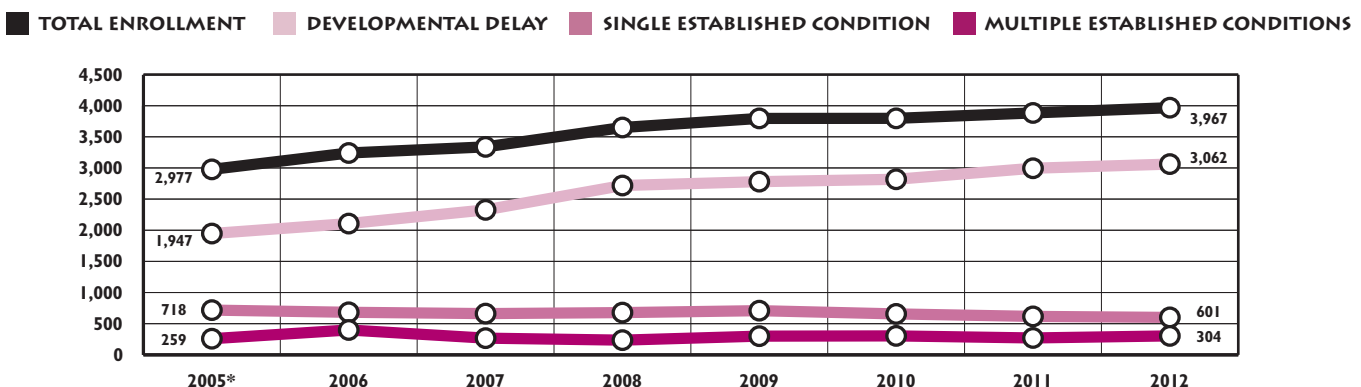
◆ States must serve all children who qualify, including those with developmental delays and those with a diagnosed condition that has a high probability of resulting in developmental delay. States have an option of providing services to infants and toddlers who are at risk of experiencing a substantial developmental delay without services.<sup>28</sup> As of 2012, there are six states that include “at-risk” children in their eligibility definition (Hawaii, Illinois, Massachusetts, New Hampshire, New Mexico, and West Virginia).<sup>29</sup>

◆ In Rhode Island, children are eligible for Early Intervention if they have a “single established condition” bearing relatively well-known expectancy for developmental delay or if they have a delay in one or more areas of development (cognitive, physical, communication, social-emotional and adaptive). Historically, Rhode Island has also served children through a “multiple established conditions” category that includes children with a history of biological issues and/or early life experiences that indicate a high probability for atypical or delayed development.<sup>30</sup> As of November 2013, Rhode Island will eliminate the category of “multiple established conditions” for Early Intervention but will broaden the category of “developmental delay” to include informed clinical opinion that significant circumstances exist “that are impacting the child and/or family functioning to the degree that without intervention would result in developmental delay.”<sup>31</sup>

## EARLY INTERVENTION REFERRAL & ENROLLMENT

◆ In 2012 in Rhode Island, 3,208 children were referred to Early Intervention for an evaluation. Forty-one percent of referrals were from health care providers or hospitals and 36% were from parents or guardians. The remaining referrals were from a variety of agencies including child care programs, Early Head Start, WIC, First Connections, the Family Care Community Partnership, and the Department of Children, Youth and Families. Of the 3,208 children referred to Early Intervention, 66% were found eligible, 17% were found not eligible, 17% did not complete an evaluation, and 1% were still in process.<sup>32</sup>

### CHILDREN ENROLLED IN EARLY INTERVENTION, RHODE ISLAND, 2005-2012



Source: Rhode Island Department of Human Services and Rhode Island Executive Office of Health and Human Services, 2005-2012.

\*In 2005 there was no eligibility information available for 53 children enrolled in Early Intervention.

◆ Enrollment in the Rhode Island Early Intervention program has increased 33% since 2005, from 2,977 children in 2004 to 3,967 in 2012, driven by growth in the number of children with developmental delays.<sup>33</sup>

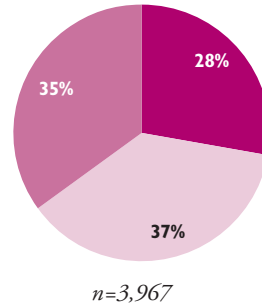
## CHILDREN ENROLLED IN EARLY INTERVENTION, RHODE ISLAND, 2012

CITY/TOWN	# ENROLLED	% ENROLLED
Barrington	41	11%
Bristol	74	15%
Burrillville	56	12%
Central Falls	129	13%
Charlestown	29	16%
Coventry	101	11%
Cranston	250	11%
Cumberland	123	13%
East Greenwich	40	13%
East Providence	157	10%
Exeter	16	10%
Foster	11	10%
Glocester	24	10%
Hopkinton	22	9%
Jamestown	7	8%
Johnston	73	9%
Lincoln	58	10%
Little Compton	3	4%
Middletown	69	14%
Narragansett	23	8%
New Shoreham	2	10%
Newport	107	13%
North Kingstown	103	14%
North Providence	89	10%
North Smithfield	28	10%
Pawtucket	328	11%
Portsmouth	41	10%
Providence	895	12%
Richmond	9	4%
Scituate	28	15%
Smithfield	44	11%
South Kingstown	75	12%
Tiverton	53	13%
Warren	42	14%
Warwick	297	13%
West Greenwich	15	8%
West Warwick	133	13%
Westerly	75	10%
Woonsocket	297	16%
<i>Four Core Cities</i>	<i>1,649</i>	<i>12%</i>
<i>Remainder of State</i>	<i>2,318</i>	<i>11%</i>
<i>Rhode Island</i>	<i>3,967</i>	<i>12%</i>

## EARLY INTERVENTION ENROLLMENT, RHODE ISLAND 2012

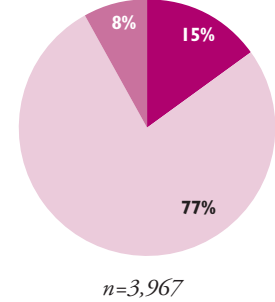
### By Age

28% Birth – 11 months  
37% 12 – 23 months  
35% 24 – 35 months



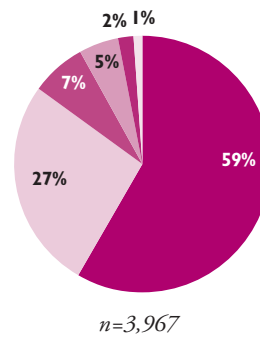
### By Eligibility

15% Single Established Condition  
77% Significant Developmental Delay  
8% Multiple Established Conditions



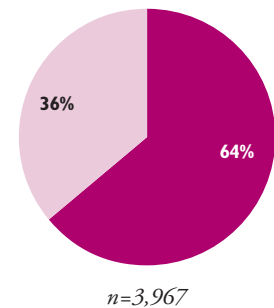
### By Race

59% White  
27% Hispanic  
7% Black  
5% More than one race  
2% Asian  
1% Other race



### By Gender

64% Male  
36% Female



Source: Rhode Island Executive Office of Health and Human Services, 2012

## PERCENT OF POPULATION SERVED

◆ In 2012 in Rhode Island, 3,967 children received Early Intervention services, 12% of the 33,788 Rhode Island children under age three.<sup>34</sup>

◆ Children in the four core cities participated in Early Intervention at a slightly higher rate (12%) than children in the remainder of the state (11%).<sup>35</sup>

◆ As of June 30, 2013, there were 2,153 children enrolled in Early Intervention, 6% of the 33,788 children under three.<sup>36</sup>

◆ In June 2012, 18% of the PK-12 students in Rhode Island were receiving special education services (20% in the core cities).<sup>37</sup>

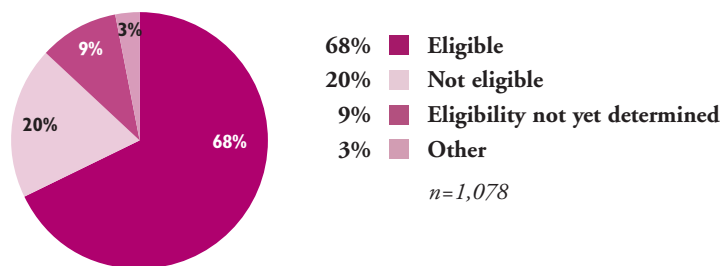
## EARLY INTERVENTION SERVICES

- ◆ Each child enrolled in Early Intervention has an Individualized Family Service Plan (IFSP) that is developed by Early Intervention staff and the family. The plan is developed based on information gathered from evaluations and assessments and outlines the child's strengths and needs as well as the family's concerns and priorities. The IFSP specifies the strategies and supports to be used to help the child and family meet the desired outcomes outlined.<sup>38</sup>
- ◆ There are 11 certified Early Intervention provider agencies in Rhode Island.<sup>39</sup> Early Intervention services are provided by a variety of professionals, including physical therapists, speech and language pathologists, occupational therapists, mental health therapists, nurses, early childhood educators, and social workers.<sup>40</sup>
- ◆ In Rhode Island in 2012, 87% of children enrolled in Early Intervention receive services in their home, while 4% receive services in a community-based setting (e.g., child care program) and 9% receive services in another setting (e.g., office visit).<sup>41</sup>
- ◆ Of the 1,985 children discharged from Early Intervention in 2012, 20% had met all goals in their IFSP and no longer required services, 55% had reached age three, 12% were lost/unreachable, 8% were withdrawn by a parent, and 4% moved out of state.<sup>42</sup>

## TRANSITION AT AGE THREE

- ◆ Early Intervention providers are required to ensure a smooth transition for children from Early Intervention to the local school district and/or appropriate community services and supports. The transition process begins when a child turns 28 months of age. Some children transition to preschool special education, while others are referred to community-based early learning programs and other services.<sup>43</sup>

**CHILDREN DISCHARGED FROM EARLY INTERVENTION AT AGE THREE  
BY ELIGIBILITY FOR PRESCHOOL SPECIAL EDUCATION, RHODE ISLAND, 2012**



Source: Executive Office of Health and Human Services, 2012.

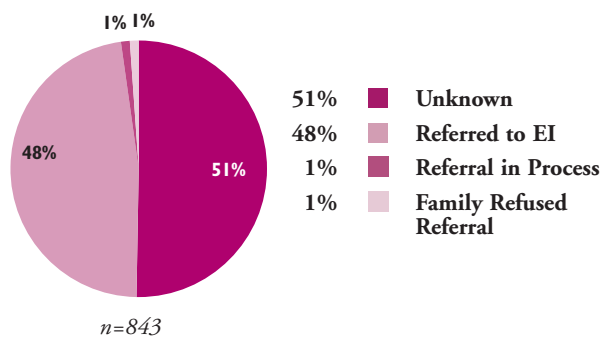
## EARLY INTERVENTION FINANCING

- ◆ Rhode Island law mandates that health insurance companies cover up to \$5,000 of Early Intervention services for each participating child per year. The state covers costs that exceed the maximum and all costs for families that do not have insurance. Of the 3,967 children enrolled in Early Intervention in 2012, 56% had Medicaid health coverage, 40% had private health insurance, and 4% were uninsured. Rhode Island receives an annual IDEA Part C federal grant of approximately \$2 million. In Rhode Island in State Fiscal Year 2013, the average cost per child for Early Intervention services was approximately \$3,500 per year.<sup>44,45</sup>

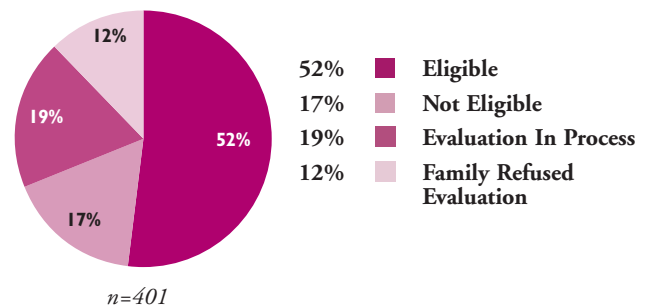
## EARLY INTERVENTION AND INFANTS & TODDLERS IN THE CHILD WELFARE SYSTEM

- ◆ Infants and toddlers who have been maltreated are six times more likely to have a developmental delay than the general population. The federal *Child Abuse and Prevention Treatment Act (CAPTA)* requires states to refer children under age three who have been involved in a substantiated case of child abuse or neglect to Early Intervention.<sup>46</sup>
- ◆ All children who have been subjects of child welfare investigations are at high developmental risk, not just those children with a substantiated finding of child maltreatment.<sup>47</sup>
- ◆ Very young children who have experienced maltreatment often experience other risk factors as well. A national study of maltreated infants and toddlers found that more than half have at least five risk factors associated with developmental delays, including minority status (58%), single caregiver (48%), poverty (46%), domestic violence (40%), caregiver substance abuse (39%), caregiver mental health problem (30%), low caregiver education (29%), biomedical risk condition (22%), teenage caregiver (19%), or four or more children in home (14%).<sup>48</sup>

**MALTREATED CHILDREN BY EARLY INTERVENTION REFERRAL STATUS, RHODE ISLAND, 2012**



**MALTREATED CHILDREN REFERRED TO EARLY INTERVENTION BY ELIGIBILITY STATUS, RHODE ISLAND, 2012**



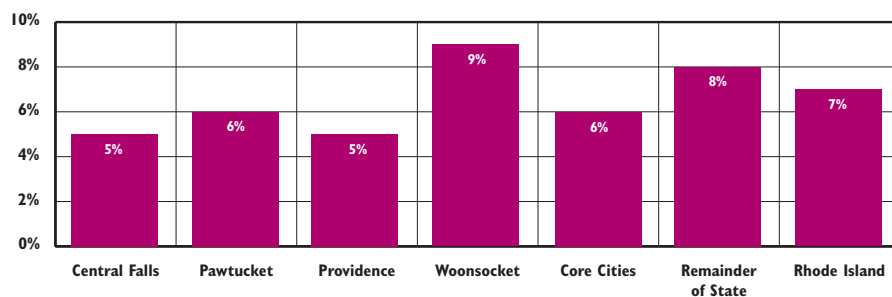
Source: Rhode Island Executive Office of Health and Human Services and Rhode Island Department of Children, Youth and Families, 2012.

- ◆ In 2012 in Rhode Island, there were 843 infants and toddlers under age three with an indicated investigation of child abuse or neglect. Of these, 401 (48%) were referred to Early Intervention for an eligibility evaluation, seven had families that declined the referral, and eight were in process at year's end. Half (52%) of the 401 children referred to Early Intervention were found eligible and 17% were found not eligible. Nineteen percent were in process at the end of the year and 12% had families that declined participation.<sup>49</sup>
- ◆ In Rhode Island, some families with young children who are involved with child welfare are referred to the First Connections home visiting program administered by the Rhode Island Department of Health as a first step to help families get connected with appropriate child development services.
- ◆ Early Intervention is a voluntary service so families that have custody of their child can refuse evaluations and/or services. Researchers find that many Early Intervention providers need training and support to effectively provide services to maltreated children and their families (birth and foster).<sup>50</sup>
- ◆ In Rhode Island, the Department of Children, Youth and Families, Early Intervention, and the First Connections home visiting program have formed a task force to improve the referral process and coordination of services to ensure federal *CAPTA* requirements are met.

## PRESCHOOL SPECIAL EDUCATION

- ◆ Under *IDEA*, children with developmental delays and disabilities are eligible for special education through their local school district beginning at age three. Preschool special education is an important component of the early care and education system.<sup>51</sup>
- ◆ Preschool special education is provided by all school districts in Rhode Island for children ages three, four, and five who have a developmental delay or disability and who are not old enough for kindergarten. Eligible children must be provided with a free and appropriate public education in the least restrictive environment in accordance with their individual needs.<sup>52</sup>
- ◆ Children with a specific disability or developmental delay in the areas of cognition, communication, social/emotional development, physical development, and/or adaptive functioning are eligible for preschool special education.<sup>53</sup>
- ◆ Transition from Early Intervention (Part C of *IDEA*) to special education services provided by schools (Part B, Section 619 of *IDEA*) is not automatic because the federal law established two distinctly different programs with different eligibility criteria. A program change at 36 months of age can be problematic for families because many developmental delays and disabilities are identified when children are older toddlers and eligible for Early Intervention, but then families and children must transition to preschool special education or have special education services end by age three if a child is not eligible under Part B.<sup>54</sup> Another difference between the two programs is the location where services are provided – preschool special education services are usually provided in school-based settings and Early Intervention services are usually provided in the child’s home.
- ◆ The majority of Early Intervention and preschool special education comes from very different sources. Early Intervention is largely supported by Medicaid and private health insurance funding and preschool special education is comprised of state and local district education funds, supplemented with small IDEA Section 619 grants. Funding for both Early Intervention and preschool special education is often inadequate to pay for services and programs at a level that ensures effective service delivery. Federal funding for early childhood special education has not kept pace with the increase in the number of children served.<sup>55</sup>

**CHILDREN ENROLLED IN PRESCHOOL SPECIAL EDUCATION,  
CORE CITIES & RHODE ISLAND, JUNE 2013**



Source: Rhode Island Department of Education, June 2013.

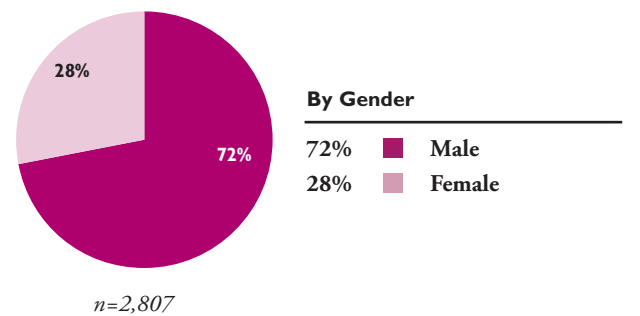
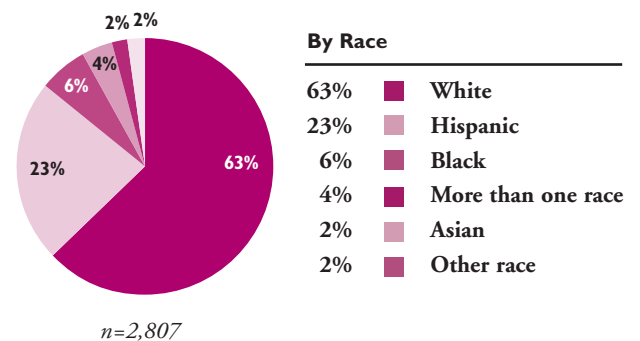
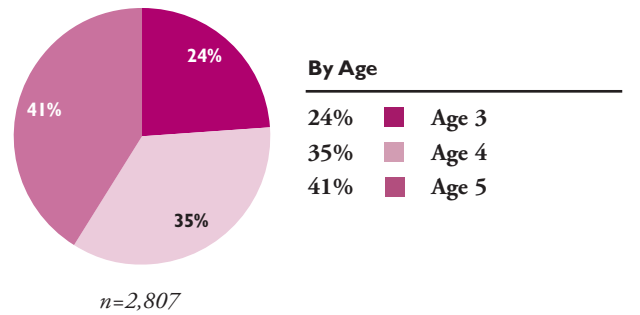
- ◆ As of June 2013, there were 2,565 children enrolled in preschool special education in Rhode Island, 7% of preschool-age children in the state. Children in the four core cities, where the majority of children living in poverty reside, are less likely to be enrolled in preschool special education (6%) than children in the remainder of the state (8%).<sup>56</sup>
- ◆ Of the 2,565 children enrolled in preschool special education in Rhode Island in June 2013, 53% were eligible due to a speech or language impairment, 36% were eligible due to a developmental delay, 6% had an autism spectrum disorder (some children who are later diagnosed with autism are served under the developmental delay category in preschool), and 5% had another diagnosed disability.<sup>57</sup>



### CHILDREN ENROLLED IN PRESCHOOL SPECIAL EDUCATION, RHODE ISLAND, JUNE 2013

DISTRICT	TOTAL ENROLLED	% ENROLLED
Barrington	34	11%
Bristol Warren	58	7%
Burrillville	40	9%
Central Falls	49	5%
Chariho	67	10%
Coventry	89	10%
Cranston	118	5%
Cumberland	75	8%
East Greenwich	33	11%
East Providence	130	8%
Exeter-West Greenwich	32	10%
Foster	11	11%
Glocester	22	10%
Jamestown	5	7%
Johnston	79	10%
Lincoln	68	12%
Little Compton	4	6%
Middletown	42	8%
Narragansett	29	12%
New Shoreham	5	14%
Newport	77	9%
North Kingstown	65	10%
North Providence	94	10%
North Smithfield	32	12%
Pawtucket	200	6%
Portsmouth	36	10%
Providence	441	5%
Scituate	22	13%
Smithfield	31	8%
South Kingstown	57	9%
Tiverton	25	7%
Warwick	161	7%
West Warwick	103	9%
Westerly	50	7%
Woonsocket	178	9%
<i>Charter Schools</i>	<i>0</i>	<i>NA</i>
<i>RI School for the Deaf</i>	<i>3</i>	<i>NA</i>
<i>Four Core Cities</i>	<i>868</i>	<i>6%</i>
<i>Remainder of State</i>	<i>1,694</i>	<i>8%</i>
<i>Rhode Island</i>	<i>2,565</i>	<i>7%</i>

### SPECIAL EDUCATION ENROLLMENT FOR CHILDREN AGES 3 TO 5, RHODE ISLAND, JUNE 2013



Source: Rhode Island Department of Education, June 2013.

### PERCENT OF POPULATION SERVED

◆ As of June 2013, there were 2,565 children ages three to five enrolled in preschool special education in Rhode Island, 7% of all preschool-age children in the state.<sup>58</sup>

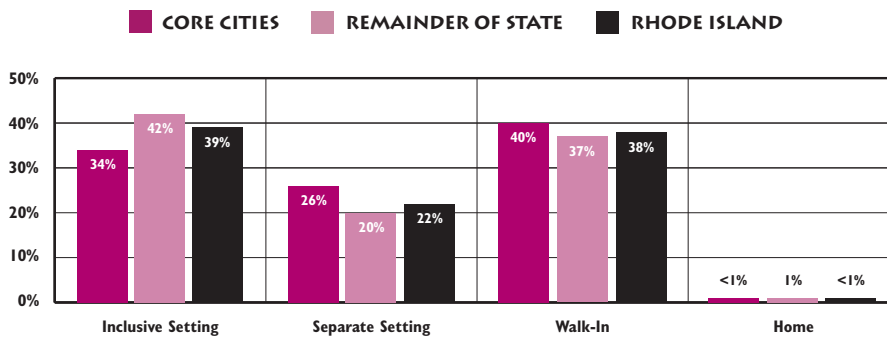
◆ Children in the four core cities, where the majority of children in poverty reside, are less likely to be enrolled in preschool special education (6%) than children in the remainder of the state (8%).<sup>59</sup>

◆ In June 2012, 18% of the PK-12 students in Rhode Island were receiving special education services (20% in the core cities).<sup>60</sup>

## PRESCHOOL SPECIAL EDUCATION SERVICES

- ◆ Children found eligible for preschool special education are provided with an Individualized Education Program (IEP) laying out goals, outlining specific steps for achieving the goals and providing services for the student based on their individual needs. Services described in the IEP must be provided in the least restrictive environment, i.e., to the extent appropriate, the child should receive special education services in a setting that is integrated with other children without disabilities.<sup>61</sup>
- ◆ Inclusion in high-quality early learning programs can benefit children with and without disabilities. Nationally, 51% of children ages three to five with disabilities are enrolled in an inclusive setting along with typically developing peers, while 35% receive services in specialized or self-contained settings.<sup>62</sup>

### PRESCHOOL SPECIAL EDUCATION BY SETTING, RHODE ISLAND, JUNE 2013



Source: Rhode Island Department of Education, June 2013.

- ◆ As of June 2013 in Rhode Island, 39% of preschool-age children received the majority of their special education services in an inclusive early childhood program along with their typically developing peers (in public schools, Head Start, child care, or preschool), while 22% were enrolled in a separate special education class, school or residential facility; 38% received services through walk-in visits to a service provider, and less than 1% received services at home.<sup>63</sup>
- ◆ Children in the four core cities are less likely to receive special education services in an inclusive early childhood setting and more likely to receive services in a separate setting or through walk-in visits than children in the remainder of the state.<sup>64</sup>

## HEAD START & CHILDREN WITH SPECIAL NEEDS

- ◆ Head Start programs are required to allocate at least 10% of their spaces for children with special needs and to screen all enrolled children to identify those who may have developmental delays and disabilities.<sup>65</sup>
- ◆ In 2012-2013 in Rhode Island, 25% of the 522 children enrolled in Early Head Start (children under age three) had an identified delay or disability and were receiving services from Early Intervention and 12% of the 2,432 Head Start (children ages three to five) children had an identified delay or disability and were receiving services from their school district.<sup>66</sup>
- ◆ Nationally, about half of the children with special needs are identified prior to the Head Start year and half are identified during the program year.<sup>67</sup>



## EARLY CHILDHOOD MENTAL HEALTH

- ◆ The development of sound mental health begins at birth and continues through early childhood as children's experiences with parents, caregivers, relatives, teachers and peers shape emotional and social development. Very young children are able to experience intense joy as well as profound sadness, grief, hopelessness, anger and rage.<sup>68</sup> Nationally, between 10% and 14% of children ages birth through five experience social-emotional problems that interfere with functioning.<sup>69</sup>
- ◆ Adverse experiences in early childhood, particularly for children with a genetic predisposition, predict the development of later mental health problems, including major depression. Early exposure to child abuse or neglect, extreme poverty, neighborhood and domestic violence, and parental mental illness causes trauma to the developing brain.<sup>70</sup>
- ◆ A young child's emotional well-being is directly tied to the quality of relationships and the emotional well-being of the people who care for him or her. Effective interventions for young children often focus on meeting the needs of the people caring for the child, including addressing adult mental health problems, parenting issues, and basic family needs.<sup>71</sup> Unfortunately, there is a nationwide shortage of effective, evidence-based parenting programs and social-emotional interventions for families of young children.<sup>72</sup> Early Intervention can provide services to address emerging mental health problems in young children.<sup>73</sup>
- ◆ Early childhood caregivers and educators are often the first to recognize mental health problems in young children when they enter a group or classroom setting. Interventions designed to improve the overall quality of early childhood programs as well as on-site mental health consultation can help improve outcomes for young children and reduce the number of children expelled from programs due to behavior problems.<sup>74</sup>



## YOUNG CHILDREN WITH AUTISM SPECTRUM DISORDERS

- ◆ Autism Spectrum Disorders (ASDs) are a group of neurodevelopment disorders with strong genetic underpinnings that affect an individual's ability to communicate, process and respond to sensory information, and form social relationships.<sup>75</sup>
- ◆ Most children with ASDs are diagnosed between ages four and seven. However researchers note that many children exhibit symptoms as early as their first year of life. Parents of children later diagnosed with ASD report that they first became concerned about their child between 15 and 18 months of age.<sup>76,77</sup>
- ◆ Pediatricians play a critical role in identifying children with autism and connecting families with services. Pediatricians ask parents questions at well-child visits to detect "red flag" indicators that require immediate evaluation for ASDs: 1) no babbling, pointing or other gesture by 12 months; 2) no single words by 16 months; 3) no two-word spontaneous phrases by 24 months; and 4) loss of language or social skills at any age. Standardized autism screening tools should be administered at ages 18 and 24 months or at any point when the parent or doctor is concerned. When a child is suspected of having an ASD, physicians are advised to simultaneously and immediately refer the family for a comprehensive evaluation and to services available through Early Intervention or preschool special education.<sup>78</sup>
- ◆ In Rhode Island, commercial insurance providers must provide coverage for the diagnosis and treatment of ASDs for children up to age 15, including behavioral therapies that have been proven effective. There is an annual cap of \$32,000, and small group coverage and direct pay health plans are exempt.
- ◆ Early intervention and treatment is important for children with ASDs. Although most children diagnosed with an ASD still have the diagnosis at age nine, many improve and some are eventually able to function relatively normally. Better outcomes for children with ASDs are associated with early identification, early enrollment in appropriate intervention programs, and inclusion in high-quality early learning programs along with typically developing peers.<sup>79</sup>



## YOUNG CHILDREN WITH SPECIAL HEALTH CARE NEEDS

◆ Children with special health care needs are those who have a chronic disease or disability that requires educational services, health care, and/or related services of a type or amount beyond that required generally by children. Special health care needs can be physical, developmental, behavioral, or emotional.<sup>80</sup> It is estimated that 15% of children in the U.S. and 17% of children in Rhode Island have at least one special health care need.<sup>81</sup> Nationally, 57% of children with special health care needs have two or more special health needs, while 29% report having three or more.<sup>82</sup>

### HEALTH COVERAGE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

◆ Adequate and affordable health insurance coverage for primary and specialty care, behavioral health, and oral health is important for all children, particularly for those with developmental delays and disabilities. Children with disabilities may require medical services, equipment, assistive technology or home modifications that may result in serious financial burdens on families. Many families experience financial hardships due to lack of insurance or underinsurance.<sup>83,84</sup>

◆ **SSI:** Children with a severe disability who are in low-income families are eligible for the Supplemental Security Income (SSI) disability benefit which provides monthly cash payments to families to help pay costs incurred in caring for a child with special needs. Children enrolled in SSI also receive Medical Assistance benefits.<sup>85</sup> In Rhode Island as of December 31, 2012, there were 5,350 children and under age 21 receiving Medical Assistance benefits through SSI.<sup>86</sup>

◆ **Katie Beckett:** Under federal Medicaid rules, states may disregard family income and provide coverage to children who have serious disabling conditions in order to provide care at home instead of in an institution.<sup>87</sup> In Rhode Island and in many other states this eligibility is called the Katie Beckett provision. As of December 31, 2012, there were 1,053 Rhode Island children enrolled in Medical Assistance through the Katie Beckett provision, a decline of 41% from the peak enrollment of 1,770 in 2007.<sup>88,89</sup>

◆ **Out-of-Home Placement:** Children and youth who are in the child welfare system are more likely to have special needs, including serious health problems. As of December 31, 2012, there were 1,883 children in Rhode Island were enrolled in Medical Assistance through the child welfare system.<sup>90</sup>

◆ **Adoption Subsidies:** Children who have special needs and who are adopted through the Rhode Island Department of Children, Youth, and Families may qualify for Medicaid. As of December 31, 2012, there were 2,251 children were enrolled in Medical Assistance because of special needs adoptions.<sup>91</sup>

### MEDICAL HOMES

◆ All children should have access to a medical home that provides ongoing, comprehensive, coordinated, family-centered care in the child's primary health care environment. In particular, families of young children with special health care needs require help navigating the complex health care delivery system.<sup>92</sup> Access to a medical home is associated with, fewer hospital admissions, fewer emergency department visits, shorter hospital stays, and reduced school absence.<sup>93</sup>

◆ A national study found that 53% of U.S. children and 49% of Rhode Island children with special health care needs do not have access to a comprehensive medical home, including 1) a usual place for sick/well child care, 2) a personal doctor or nurse, 3) no difficulty obtaining needed referrals, 4) help with care coordination, and 5) family-centered care. Although 98% of families in Rhode Island reported having access to a personal doctor or nurse, more than one-quarter of families experienced problems with specialty care referrals, care coordination, and family-centered care.<sup>94</sup>



## MEDICAID SERVICES FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

- ◆ ***CEDARR Family Centers:*** Rhode Island has a unique network of Comprehensive Evaluation Diagnosis Assessment Referral Re-evaluation (CEDARR) Family Centers, which provide information and support to families of children under the age of 21 with special needs who are enrolled in Medicaid. CEDARR Family Centers are designed to provide families with information on their child's disability or condition, how to address their child's needs, service and treatment options, connection with other families and additional community based resources. In 2012 in Rhode Island, there were 446 children ages birth to five who received CEDARR services, 15% of all children served by CEDARR Family Centers.<sup>95</sup>
- ◆ CEDARR Family Centers also provide ***CEDARR Direct Services***, which aim to improve the health and well-being of children with special health care needs and their families. These Direct Services vary in scope, intensity and duration and the need for any of these services is determined through a collaborative assessment process between the child's family and staff at the CEDARR Family Center.
  - \* ***Home Based Therapeutic Services (HBTS):*** An array of intensive treatment services provided in a child's home and in the community (as appropriate) by trained paraprofessionals under the direct supervision of an independently licensed health care professional. All services are provided in accordance with an approved Individualized Treatment Plan which contains measurable goals and objectives. Parents are required to participate in a majority of the treatment sessions (greater than 50%) so that skills and techniques acquired through treatment may be continued when HBTS has ended. HBTS treatment services are designed to enhance a child's ability to participate in their family and community by helping to improve communication, behavioral, psychosocial, and developmental skills.
  - \* ***Personal Assistance Services and Supports (PASS):*** PASS treatment services focus on daily life skills such as self-care, safety awareness and social interaction. Treatment is provided by a direct support worker in the child's home or appropriate community setting. Parents choose who is hired to work with their child and how services are delivered. Parents are included in the development and implementation of the PASS Treatment Plan, as well as the training and supervision of the direct service worker who will work with their child.
  - \* ***Respite Care:*** Respite services allow caregivers of children with special health care needs some time off from caregiving. Eligible children must require supports equal to those supports provided in an institutional setting, such as a nursing home or Intermediate Care Facility for the Mentally Retarded (ICF/MR). Families must complete and submit an application in order to determine if a child meets level of care criteria. Eligible families are responsible to locate, train, and supervise the respite worker.
  - \* ***Kids Connect:*** Delivers specialized treatment and support to children in licensed child care centers. These services are designed to help children with special health care needs participate in all aspects of the child care program alongside typically developing peers. The goals of Kids Connect services are to improve a child's communication and social skills, behavioral, and/or cognitive development. Families are responsible for paying the costs of child care and Medicaid pays for the additional Kids Connect supports. In 2012 in Rhode Island, there were 231 children who received Kids Connect services through 12 certified Kids Connect providers.<sup>96</sup>

Source: Rhode Island Executive Office of Health and Human Services.



## RECOMMENDATIONS

### HEALTH INSURANCE & MEDICAL HOMES

- ◆ Continue to ensure access for all children to affordable, comprehensive health coverage. Find and enroll all eligible children in RItE Care. Preserve current Medicaid benefits and use Essential Health Benefit provisions in the Affordable Care Act to ensure parity of benefits in commercial insurance.
- ◆ Ensure that all children with developmental delays and disabilities have a high-quality medical home that can help them navigate complex health and education systems in order to obtain needed services.

### SCREENINGS

- ◆ Ensure all families with young children have regular opportunities to receive recommended health, developmental, and autism screenings through their medical home, school district's Child Outreach program, early learning program, and/or home visiting program.
- ◆ Use the EPSDT provision to ensure all low-income children insured through Medicaid receive recommended developmental and autism screenings and necessary treatment.
- ◆ Use the KIDSNET database to help locate young children for developmental screenings, to coordinate and share developmental screening data, and to target resources so fewer children miss screenings.
- ◆ Improve information and referral networks to ensure that children who screen positive for potential developmental problems are referred for comprehensive evaluation and services.

### EARLY INTERVENTION & PRESCHOOL SPECIAL EDUCATION

- ◆ Increase efforts to enroll eligible children in Early Intervention and preschool special education so more children get the help they need before entering kindergarten.
- ◆ Make sure that children with multiple risk factors for developmental delays can continue to qualify for Early Intervention services in Rhode Island.
- ◆ Expand Rhode Island's definition of eligibility for Early Intervention to specifically include at-risk infants and toddlers.
- ◆ Address remaining barriers to fully implement the federal mandate requiring states to refer all children under age three with substantiated cases of child maltreatment to Early Intervention.
- ◆ Address geographic inequities in access to preschool special education, particularly in the core cities where poverty is concentrated, by improving the transition process from Early Intervention, reviewing the referral and eligibility determination process for each district, and using data to drive improvements in access.
- ◆ Expand access to inclusive early care and education settings for young children with developmental delays, disabilities and behavior challenges. Enhance supports available to community-based early care and education programs including support to provide a high-quality general education program, on-site mental health consultation, and help improving facilities to better accommodate children with disabilities.
- ◆ Use the state education funding formula, Title I resources, and Head Start and other community partnerships to expand access to high-quality inclusive preschool, particularly in the core cities.
- ◆ Identify ways the Kids Connect program can ensure that low-income children with moderate to severe special needs are enrolled in high-quality early care and education programs and that supportive services are effective.
- ◆ Expand professional development for the Early Intervention and preschool special education workforce. Additional resources are needed to help early childhood professionals better identify and respond to ASDs, social-emotional and mental health problems in young children, strengthen parent-child relationships and address toxic stress factors of poverty, substance abuse, domestic violence, maternal depression, and child maltreatment.

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Rhode Island KIDS COUNT is a children's policy organization that provides information on child well-being, stimulates dialogue on children's issues, and promotes accountability and action.

Primary funding for Rhode Island KIDS COUNT is provided by The Rhode Island Foundation, United Way of Rhode Island, The Annie E. Casey Foundation, Prince Charitable Trusts, Alliance for Early Success, Robert Wood Johnson Foundation, DentaQuest Foundation, Jessie B. Cox Charitable Trust, Hasbro Children's Fund, CVS Caremark, Neighborhood Health Plan of Rhode Island, UnitedHealthcare, Blue Cross & Blue Shield of Rhode Island, America's Promise Alliance, First Focus, and other corporate, foundation and individual sponsors.

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## ACKNOWLEDGEMENTS

Ruth Gallucci, Holly Ayotte, Patricia Strauss, Ken Gu, David Sienko, RI Department of Education; Brenda DuHamel, Christine Robin Payne, Paul Choquette, RI Executive Office of Health and Human Services; Deb Garneau, Blythe Berger, Kristine Campagna, RI Department of Health; Joseph Carr, Fran Rittner, DCYF; Karen Beese, Larry Pucciarelli, RI Department of Human Services; Pamela High, MD, Mary Fournier, Hasbro Children's Hospital; Susan Dickstein, Aimee Mitchell, RI Association for Infant Mental Health; Khadija Lewis Khan, Beautiful Beginnings; Alexandra Arnold, Children's Friend; Maureen Whelan, Amy Grattan, Sherlock Center on Disabilities at Rhode Island College; Andrea Riquetti-Salvatore, John Kelly, Meeting Street; Darlene Magaw, Ben Lessing; Family Resources Community Action; Joanne Quinn, The Autism Project of RI; Deborah Masland, Tina Spears, Tara Townsend, RI Parent Information Network.

We are very grateful to CVS Caremark for their support of this Issue Brief.

We also thank the Hasbro Children's Fund for their ongoing support of the Issue Brief Series.