Massachusetts Child Fatality Review

Annual Report

Fiscal Year 2024

About the Child Fatality Review Program

The Massachusetts Child Fatality Review (CFR) program works to decrease the incidence of preventable child fatalities and near fatalities. The program comprises 11 local teams—one in each of the Commonwealth's judicial districts—and a state team with 16 seats. All CFR teams are multidisciplinary, comprised of state agency representatives, health experts, service providers and law enforcement. Following the death of a child under the age of 18, local teams conduct a review of that child's birth, death, medical, social service, and police records to better understand the circumstances surrounding the death. Following a review, the local teams submit findings, in the form of a problem statement or recommendation, to the state team. The state team reviews the findings, contextualizes them with epidemiological data, and consults experts to identify opportunities to improve programs, policies, regulations, and practice that address the findings. Those opportunities are shared in the form of recommendations in an annual report to the governor and legislature pursuant to M.G.L. Chapter 38 § 2A. For team membership, see Appendix B. State Team and Local Team Membership.

Preface

The loss of a child is devastating to a family and can have a profound impact on communities. Since 2001, the Massachusetts Child Fatality Review (CFR) program has worked to learn from these tragedies to protect the health and safety of children in the future.

This Fiscal Year 2024 (FY24) Annual Report of the state CFR team describes program findings and activities from July 1, 2023 through June 30, 2024 and is released in compliance with the program's authorizing statute (M.G.L. Chapter 38 § 2A). This report and the activities of the state team would not be possible without collaboration between the Office of the Chief Medical Examiner (OCME), the Office of the Child Advocate (OCA), and the Department of Public Health (DPH). Through this collaboration, the CFR program is developing more timely reports with deeper explorations of the causes and prevention of child fatalities.

This report is dedicated to the children with autism spectrum disorder who drowned while the report was being researched, and to caregivers everywhere. If our society is to thrive, our caregivers must be given the tools, resources, and services they need to raise healthy children who survive well into adulthood.

Need Help? Resources Are Available

If you or someone you know is struggling with the loss of a child, support is available:

988 Suicide & Crisis Lifeline
Call or text 988 for free, confidential support 24/7 for anyone in suicidal crisis or emotional distress.

The Massachusetts Center for Unexpected Infant and Child Death
Resources, counseling, and support to families dealing with the sudden and unexpected loss of an infant or child. Visit their website or contact them directly for assistance.

Acknowledgements

This report was prepared by Bekah Thomas and Meg Crowley of the Office of the Child Advocate and Dr. Samatha Riley and Johnny Rezendes at the Department of Public Health on behalf of the Office of the Chief Medical Examiner.

The state team is immensely grateful to the local teams who carry out the psychologically taxing review of individual child fatalities. Child fatality review is not an easy task; without exception, local teams conduct professional, thorough, and thoughtful reviews that are foundational to the state team's work.

Finally, the state team would like to thank the many partners who contributed their knowledge, expertise, and personal experience to this report, including:

Alyssa Kolbert	Cambridge Health Alliance	Laurie Gobeil	Department of Mental Health
Amy Weinstock	MA Autism Insurance Resource Center	Lee Robinson	MassHealth
Andrea Barruch	Apex Behavioral Consulting	Lisa Belmarsh	Department of Youth Services
Anna Sutton	William James College	Lisa Collins	The Flutie Foundation
Carolyn Kain	MA Autism Commission	Margie Gilberti	Department of Early Education and Care
Carrie Noseworthy	Parent & Community Advocate	Mary Kate Haswell	Department of Developmental Services
Christine Palladino-Downs	Office of the Child Advocate	Maura Sullivan	The Arc of Massachusetts
David Cochran	University of Massachusetts Memorial Medical Center	Melanie McLaughlin	The Federation for Children with Special Needs
Emily White	Department of Public Health, Early Intervention	Melanie Schanche	Department of Mental Health
Gene Saunders	Lifeworks First Responder Training	Michelle Harris	Department of Developmental Services
Jamie Camacho	Department of Elementary and Secondary Education	Mi-Haita James	Department of Mental Health
Jenn Chebator	Department of Children and Families	Miriam Aframe	University of Massachusetts Memorial Medical Center
Jimmy Donohoe	Autism Awareness for First Responders	Nandini Talwar	Department of Mental Health
Juan Rojas	Office of the Child Advocate	Sarah Abbott	William James College
Judith Ursitti	Profound Autism Alliance	Shari Krauss	The Autism Program, Boston Medical Center
Judy Crocker	Safe Routes to School Program	Stephanie Coburn	Department of Developmental Services
Kathy Sanders	Department of Mental Health	Susan Hachby	Department of Early Education and Care
Kerry Wilkins	Department of Mental Health	Terri Farrell	MA Autism Insurance Resource Center
Kevin Coughlin	Cambridge Health Alliance	Tiffany Bassi	Department of Early Education and Care
Kobie Stewart	Department of Youth Services	Tory Karlsen	Butterfly Effects ABA

Table of Contents

Executive Summary

Massachusetts continues to be a national leader in safeguarding the health and wellbeing of children, as evidenced by its low infant and child fatality rates. However, a **troubling increase in child fatalities began in 2020**, both nationally and in Massachusetts. This increase disrupts a two-decade decline in child fatality rates. In 2022, the overall child death rate in Massachusetts was 29.5 deaths per 100,000 population, which equates to 403 deaths of children aged zero to 17 years. While this figure remains substantially lower than the 648 child deaths recorded in 2000 and 501 in 2010, it is higher than the 390 children who died in 2020 and 397 in 2021. This is a concerning reversal of progress.

The leading causes of child deaths in 2022 were:

- congenital malformations,
- unintentional injuries,[1]
- short gestation/low birthweight
- cancer, and
- complications from pregnancy

Despite the low rate of infant and child fatalities in Massachusetts, substantial inequities exist. **Boys, children of color, and children and infants living in urban centers are all at higher risk of fatality**.[2] These inequities are not rooted in biological or genetic differences between races and ethnicities, nor are they inherent to other aspects of a child's or infant's race or ethnicity. Rather, they are linked to social determinants of health, including factors like socioeconomic status and access to health care.[3]

Findings from local CFR team reviews and media reports indicated that in addition to the inequities the state team had identified in prior years, children with Autism Spectrum Disorder (ASD) may also be at higher risk of fatality. Further research on the topic indicated that compared to their neurotypical peers, **children with ASD face a 160-fold increased risk of drowning**.[4] Drowning is the leading cause of death for children with ASD, and these drowning events frequently occur in the context of wandering or elopement, a behavior seen more frequently in children with ASD.[5]

Preventing wandering or elopement may decrease childhood death of children with ASD and reduce their increased risk of fatality. Methods for preventing wandering and drowning deaths for

---

[1] Injuries are bodily harm – fatal or nonfatal - that can be caused by fires, motor vehicle crashes, drowning, sharp objects, firearms, being struck by an object, tripping and falling, pedestrian and bicyclist injuries, and more. Injuries can be unintentional (sometimes called "accidental") or intentional, such as suicide and self-harm or homicide and assault related (Injury Surveillance Program (n.d.). Massachusetts Department of Public Health. https://www.mass.gov/injury-surveillance-program).

[2] The Office of the Chief Medical Examiner (2023). *Fiscal Year 2022 Child Fatality Review Annual Report*.

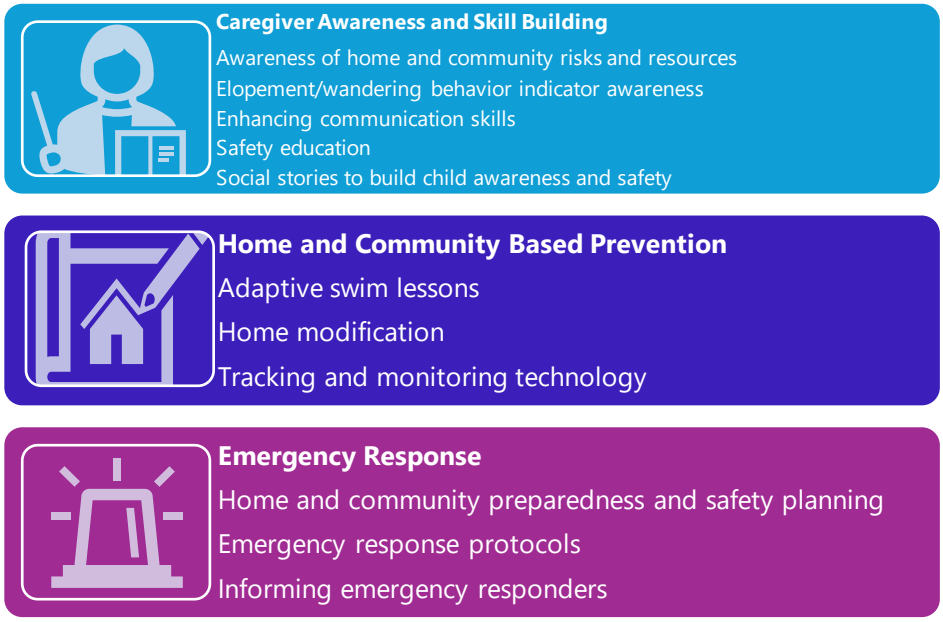
[3] Jang, C., & Lee, H. (2022). A Review of Racial Disparities in Infant Mortality in the US. *Children*, *2*, 257. https://doi.org/10.3390/children9020257, ACEs and PCEs of Massachusetts Residents (n.d.). Population Health Information Tool, Massachusetts Department of Public Health. https://www.mass.gov/info-details/positive-and-adverse-childhood-experiences-pces-aces

[4] Guan, J., & Li, G. (2017b). Characteristics of unintentional drowning deaths in children with autism spectrum disorder. *Injury Epidemiology*, *1*. https://doi.org/10.1186/s40621-017-0129-4

[5] McIlwain, L., & Fournier, W. (2012). Lethal Outcomes in Autism Spectrum Disorders (ASD) Wandering/Elopement. *National Autism Association*. /https://nationalautismassociation.org/wp-content/uploads/2012/01/Lethal-Outcomes-In-Autism-Spectrum-Disorders_2012.pdf

children with ASD include caregiver awareness, therapeutic interventions, home modifications, emergency preparedness, emergency response, education, and life skills. Caregivers access these methods through a complex array of educational policy, therapeutic and healthcare provider practices, insurance policies and social services. While there are many resources and services available to support wandering and drowning prevention in Massachusetts, they are time consuming to navigate, expensive to access, lack standardization, and are inconsistently available across the state. For caregivers who must provide 24/7 vigilance over their children with wandering behaviors, the ASD support system is insufficient.

Figure 1. Layers of Wandering Prevention



The recommendations in this report for legislators, agencies, community leaders, and caregivers aim to increase the ease of service navigation and improve access for families. Implementing these recommendations involves several state secretariates, including the Executive Office of Health and Human Services, The Executive Office of Labor and Workforce Development, The Executive Office of Education, and the Executive Office of Public Safety and Security. In particular, the Department of Early Education and Care (EEC), the Department of Developmental Services (DDS), the Department of Public Health (DPH), the Department of Higher Education, the Department of Elementary and Secondary Education (DESE) and the MA Autism Commission can play critical roles in creating systems that support caregivers and prevent drowning among children with ASD who have wandered. Some recommendations may require legislative or regulatory changes, infrastructure development, time and resources. And by improving the coordination, standardization, and accessibility of services for children with ASD, we can ultimately reduce fatality rates and improve the wellbeing for children with ASD and their families. To that end, this report also contains succinct fact sheets and resource lists for caregivers and providers (see Appendices D, G, and H).

Recommendations
Raising Caregiver Awareness
Collect ASD diagnosis as part of child fatality review criteria in all cases
Identify or create and promote a centralized hub of educational resources, material goods, service providers, and funding opportunities for caregivers and providers of children with ASD.
Develop and disseminate a standardized tool for asking caregivers about elopement risk with provider education about wandering behavior, associated risks, and prevention.
Conduct an elopement screening and provide caregiver education, including emergency preparedness, during provider interactions.
Home Modification Access
Establish a pilot program for home safety modifications.
Provide insurance coverage for prevention methods such as home modifications, elopement risk screenings, swim lessons, and tracking devices.
Educational and Therapeutic Support
Create a centralized intake for Applied Behavior Analysis (ABA) therapies.
License and regulate Applied Behavior Analysis (ABA) Centers.
Create a strategy for growing the workforce that supports children with ASD, including but not limited to: • Board Certified Behavior Analysts • Registered Behavior Technicians, and • Aquatics Professionals
Create strategies for meeting DESE's Comprehensive Health and Physical Education objective for children to have the "ability to apply strategies for staying safe…around water" that are adapted to the specific needs of children with ASD.
Identify and/or develop model curriculum for the personal safety standards and provide guidance for adapting the curriculum to students with special needs.
Increase funding for adaptive swim lessons.
Emergency Preparedness & Response
Conduct an assessment to determine the extent to which first responder training regarding children with autism has spread across the commonwealth, the availability of radio tracking devices and reverse 9-1-1, and create a strategy to improve access as necessary.
Develop and promote in-service training on public safety risks, including elopement of people with ASD for first responders.
Encourage parents to maintain a packet of information that is easy to access in a moment of crisis, and or proactively speak with local first responders. The packet should include information about the child's key interests, points of concern near the home, and consideration for how best to approach the child when they are located.
Create and promote a standardized practice in first responder agencies to identify and maintain information about children with ASD.
Care Coordination
Expand access to respite care for caregivers of children with ASD.

Introduction

This report presents the latest available data on child and infant deaths, covering the calendar year 2022. Massachusetts continues to experience low rates of infant and child fatalities compared to other U.S. states, highlighting the robust public health infrastructure of the Commonwealth. However, child fatality rates have increased both nationally and in Massachusetts since 2020, interrupting a two-decade decreasing trend.[6] In 2022, the overall child and infant (ages zero to 17 years) death rate was 29.5 deaths per 100,000 population[7] (n= 403 deaths). This is a slight increase from 2021 (29.1 per 100,000, n=397) and 2020 (28.1 per 100,000, n=390).

Fifty-six percent of all deaths among children (ages zero to 17 years) were infants (ages < one year). The infant fatality rate decreased in 2022 (325.3 per 100,000) compared to 2021 (331.0 per 100,000). Child (ages one to 17 years) death rates increased in 2022 (13.6 per 100,000) compared to 2021 (12.9 per 100,000).

Causes of Death

In 2022, for all ages between zero to 17 years, the top five causes of death were congenital malformations (n = 49), unintentional injuries (n = 37), short gestation/low birthweight (n = 29), cancer (n = 20), and pregnancy complications (n = 19). Nationally, the top three causes of death were pregnancy complications, unintentional injuries, and congenital malformations followed by homicide and suicide as the fourth and fifth leading causes of death for those between the ages zero to 17 years.[8]

Compared with the 2021 top causes of deaths in Massachusetts, in 2022 there was an increase in deaths due to pregnancy complications (15 deaths in 2021 and 19 deaths in 2022) and a slight increase in unintentional injuries (34 deaths in 2021 and 37 deaths in 2022). There was a decrease in deaths from cancer (31 deaths in 2021 and 20 deaths in 2022) and Sudden Unexpected Infant Deaths (26 deaths in 2021 and 17 deaths in 2022).

[6] Xu, Jiaquan et al. (2022). Mortality in the United States, 2021. (456), Kochanek, Kenneth D. et al. (2023). Mortality in the United States, 2022. (492).
[7] All rates per 100,000 population
[8] Centers for Disease Control and Prevention, National Center for Health Statistics. National Vital Statistics System, Mortality 2018-2022 on CDC WONDER Online Database, released in 2024. http://wonder.cdc.gov/ucd-icd10-expanded.html

Table 1. Leading Causes of Death by Age Group- in Massachusetts in 2022

Rank	Infants (<1 year)	1-4 Years	5-9 Years	10-14 Years	15-17 Years	1-17 years	0-17 Years (Total)
1	Congenital malformations (N=36)	Unintentional injuries (N=8)	Cancer (N=9)	Cancer (N=5); Unintentional injuries (N=5)	Unintentional injuries (N=18)	Unintentional injuries (N=37)	Congenital malformations (N=49)
2	Short gestation / low birth weight (N=29)	Congenital malformations (N=4); Other infections (N=4)	Congenital malformations (N=6); Unintentional injuries (N=6)	Epilepsy and recurrent seizures (N=4); Heart disease (N=4)	Suicide (N=13)	Cancer (N=20)	Unintentional injuries (N=37)
3	Pregnancy complications (N=19)	Ill-defined conditions-signs and symptoms (N=3); Injuries of undetermined intent (N=3)	COVID-19 (N=2); In situ neoplasms (N=2); Influenza & pneumonia (N=2)	COVID-19 (N=2); Obesity, unspecified (N=2)	Heart disease (N=6); Homicide (N=6)	Suicide (N=15)	Short gestation / low birth weight (N=29)
4	Sudden Unexpected Infant Death (SUID) (N=17)	COVID-19 (N=2); Cancer (N=2); Homicide (N=2); Influenza & pneumonia (N=2)	Diabetes (N=1); Heart disease (N=1)	Other infections (N=2); Suicide (N=2)	Cancer (N=4)	Congenital malformations (N=13)	Cancer (N=20)
5	Bacterial sepsis of newborn (N=11)	Acute bronchitis (N=1)	Injuries of undetermined intent (N=1); Interstitial pulmonary disease (N=1)	Cerebral Palsy (N=1); Chronic Sinusitis (N=1)	Chronic lower respiratory disease (N=2); Congenital malformations (N=2); Diabetes (N=2); Injuries of undetermined intent (N=2)	Heart disease (N=12)	Pregnancy complications (N=19)
Total by Age Group	**226**	**41**	**36**	**37**	**63**	**177**	**403**

Data Source: Registry of Vital Records and Statistics, Massachusetts Department of Public Health, 2022

* Please be advised that 2022 data are preliminary and subject to change. Raw preliminary data may be incomplete or inaccurate, have not been fully verified, and revisions are likely to occur following the production of these data. DPH strongly cautions you regarding the accuracy of statistical analyses based on preliminary data, particularly regarding small numbers of events.

Infants

The top five causes of death for infants (ages <1 year) were congenital malformations (n = 36), short gestation/low birthweight (n = 29), pregnancy complications (n=19), Sudden Unexpected Infant Death (SUID) (n = 17), and bacterial sepsis (n = 11). A notable difference between infant fatality trends from 2021 to 2022 is the increase in bacterial sepsis cases in infants (two cases in 2021 and 11 cases in 2022). Bacterial sepsis ranks among the top five causes of infant death in Massachusetts, whereas it was the seventh leading cause of infant death nationally in 2022. Compared to top causes of infant death nationally, Massachusetts has fewer infant unintentional injuries and infant homicides. Additionally, compared with the U.S., the state has a lower infant death rate (MA: 325 deaths per 100,000 births; U.S.: 566 deaths per 100,000 births).[9]

Ages One to Four

For one- to four-year-olds, the top causes of death were unintentional injuries (n = 8), congenital malformations (n = 4), other infections (n = 4), ill-defined conditions (n = 3), and injuries of undetermined intent (n = 3). Massachusetts aligns with national trends for this age group in the top two causes of death, where unintentional injury and congenital malformations were also the leading causes of death.[10] Massachusetts has fewer homicides in this age group compared to nationally, where it was the third leading cause of death.

Ages Five to Nine

For five- to nine-year-olds, the top causes were cancer (n = 9), congenital malformations (n = 6), unintentional injuries (n = 6), COVID-19 (n = 2), *in situ* neoplasms (n = 2) and influenza & pneumonia (n = 2). At the national level and in Massachusetts unintentional injuries, cancer, congenital malformations, and influenza & pneumonia are among the top five leading causes of death for this age group. Similar to other age groups, Massachusetts had fewer deaths involving homicide compared to nationally for five- to nine-year-olds.[11]

Ages Ten to Fourteen

For ten- to 14-year-olds, the top causes were cancer (n = 5), unintentional injuries (n = 5), epilepsy and recurrent seizures (n = 4), heart disease (n = 4), COVID-19 (n = 2), and obesity (n = 2). Unintentional injury and cancer were leading causes of child death for this group in Massachusetts and nationally, with fewer deaths involving homicides and suicides occurring in Massachusetts.[12]

Ages Fifteen to Seventeen

Among 15- to 17-year-olds, the top causes of death were unintentional injuries (n = 18), suicide (n = 13), heart disease (n = 6), homicide (n = 6), and cancer (n = 4). This age group is most similar to the national top causes of death for adolescents, with unintentional injuries, homicides, suicides, cancer, and heart disease all being leading causes.[13]

---

[9] Ibid.
[10] Ibid.
[11] Ibid.
[12] Ibid.
[13] Ibid.

Inequities

Geographic

In 2022, the infant death rate was highest in Hampden County with 500.9 deaths per 100,000 population followed by Essex with 463.0, Plymouth with 387.9, and Worcester County with 381.6. From 2021 to 2022 Essex, Middlesex, and Worcester counties saw an increase in the infant death rate while Bristol, Hampden, Norfolk, and Suffolk counties saw a decrease (See Table 2).

Table 2. Infant Deaths (ages <1 year) by Geographic Region in 2021 and 2022.

Region	2021		2022*	
	Deaths	Death Rate[14]	Deaths	Death Rate[14]
Berkshire	7	688.9	2	--
Bristol	27	472.3	19	332.4
Cape & Islands	7	382.9	6	328.2
Essex	21	243.1	40	463.0
Hampden	27	563.5	24	500.9
Middlesex	35	210.7	42	252.8
Norfolk	23	328.5	13	185.6
Northwestern	3	--	4	--
Plymouth	19	387.9	19	387.9
Suffolk	35	397.9	24	272.9
Worcester	26	300.7	33	381.6
Total	230	331.0	226	325.3

Data Source: Registry of Vital Records and Statistics, Massachusetts Department of Public Health, 2021-2022

Rates for counts of five or less have been suppressed and any rates for counts of 20 or less are unstable and should be interpreted with caution.[15]

In 2022, the child death rate (ages one to 17) was highest in Hampden County at 23.5 deaths per 100,000 population. Child death rates increased in Hampden, Plymouth, Suffolk, and Worcester counties and decreased in Essex, Middlesex, and Norfolk counties from 2021 to 2022 (See Table 3). The remaining counties had child death rates that were unstable due to small numbers in either 2021 or 2022.

[14] All rates are per 100,000 population.

[15] Rates calculated for small populations are often unstable because a small change in the number of cases can lead to large percentage changes in the rate.

Table 3. Child Deaths (ages 1-17) by Geographic Region in 2021 and 2022.

Region	2021		2022*	
	Deaths	Death Rate[14]	Deaths	Death Rate[14]
Berkshire	3	--	3	--
Bristol	14	12.5	14	12.5
Cape & Islands	4	--	5	13.5
Essex	28	17.5	17	10.6
Hampden	16	17.1	22	23.5
Middlesex	31	10.3	28	9.3
Norfolk	18	12.7	9	6.4
Northwestern	1	--	9	26.0
Plymouth	13	12.2	20	18.8
Suffolk	13	10.9	18	15.1
Worcester	26	15.3	32	18.8
Total	167	12.9	177	13.6

Data Source: Registry of Vital Records and Statistics, Massachusetts Department of Public Health, 2021-2022

Rates for counts of five or less have been suppressed and any rates for counts of 20 or less are unstable and should be interpreted with caution.

Birth Sex

In 2022, the death rate per 100,000 births for male infants was 367.2 and 278.0 for females. Between 2021 and 2022 the infant death rate decreased slightly for both males and female infants from 289.9 deaths per 100,000 births for females and from 370.0 deaths per 100,000 births for males in 2021 (see Table 4).

In 2022, the death rate per 100,000 population between the ages of 1-17 was 16.6 for males and 10.5 for females. From 2021-2022 females saw an increase in death rate per 100,000 between the ages of five- to nine-years-old while males saw an increase in deaths among all age groups besides infants and ten- to 14-years-old (see Table 4).

Table 4. Infant and Child Deaths by Sex and Age Cohort in 2021 and 2022.

Age (in years)	**Male**				**Female**			
	2021		2022*		2021		2022*	
	Deaths	Death Rate[13]	Deaths	Death Rate[14]	Deaths	Death Rate[13]	Deaths	Death Rate[14]
<1	132	370.0	131	367.2	98	289.9	94	278.0
1-4	21	14.3	29	19.7	11	7.8	12	8.6
5-9	14	7.4	17	9.0	12	6.6	19	10.5
10-14	30	15.3	19	9.7	20	10.6	18	9.6
15-17	35	27.0	45	34.7	24	19.0	18	14.3
1-17	100	15.1	110	16.6	67	10.5	67	10.5
Total	232	33.3	241	34.6	165	24.6	161	24.1

Data Source: Registry of Vital Records and Statistics, Massachusetts Department of Public Health, 2021-2022

Rates for counts of five or less have been suppressed and any rates for counts of 20 or less are unstable and should be interpreted with caution.

Race and Ethnicity

In 2022, the infant death rate per 100,000 population for Black, non-Hispanic/non-Latinx infants was 688.1, for Hispanic infants the rate was 393.4, and for White, non-Hispanic/non-Latinx infants the rate was 279.7. Between 2021 and 2022 the infant death rate increased for Hispanic and White, non-Hispanic/non-Latinx infants and decreased for Black, non-Hispanic/non-Latinx Infants. Despite the decrease in Black, non-Hispanic/non-Latinx infant mortality rate, it is still the highest among racial demographic groups.

Table 5. Infant Deaths (ages <1 year) by Race and Ethnicity in 2021 and 2022.

Race/Ethnicity	2021		2022*	
	Deaths	Death Rate[14]	Deaths	Death Rate[14]
American Indian/Alaska Native, non-Hispanic/non-Latinx	0	--	0	--
Asian, non-Hispanic/non-Latinx	14	289.3	7	144.6
Black, non-Hispanic/non-Latinx	52	941.6	38	688.1
Hispanic/Latinx	57	367.6	61	393.4
White, non-Hispanic/non-Latinx	94	255.3	103	279.7

Data Source: Registry of Vital Records and Statistics, Massachusetts Department of Public Health, 2021-2022

Rates for counts of five or less have been suppressed and any rates for counts of 20 or less are unstable and should be interpreted with caution.

In 2022, the child death rate (ages one to 17) per 100,000 for Black, non-Hispanic/non-Latinx children was 33.1, for Hispanic children the rate was 18.0, for Asian, non-Hispanic/non-Latinx children the rate was 11.7, and for White, non-Hispanic/non-Latinx children the rate was 10.6. Between 2021 and 2022 the child death rate increased for Black, non-Hispanic/non-Latinx and Hispanic children. The child death rate decreased for White, non-Hispanic/non-Latinx children and Asian, non-Hispanic/non-Latinx children.

Table 6. Child Deaths (ages 1-17 years) by Race and Ethnicity in 2021 and 2022.

Race/Ethnicity	2021		2022*	
	Deaths	Death Rate[14]	Deaths	Death Rate[14]
American Indian/Alaska Native, non-Hispanic/non-Latinx	1	--	1	--
Asian, non-Hispanic/non-Latinx	12	12.7	11	11.7
Black, non-Hispanic/non-Latinx	21	19.9	35	33.1
Hispanic/Latinx	38	15.5	44	18.0
White, non-Hispanic/non-Latinx	87	11.7	79	10.6

Data Source: Registry of Vital Records and Statistics, Massachusetts Department of Public Health, 2021-2022

Rates for counts of five or less have been suppressed and any rates for counts of 20 or less are unstable and should be interpreted with caution.

Other Characteristics

Geography, sex, race, and ethnicity alone do not reflect the only inequities seen in childhood fatalities. While exploring local team findings and discussing the leading causes of child fatalities, the state CFR team began considering developmental disability, and specifically if Autism Spectrum Disorder (ASD) is associated with an increased risk for fatality. A 2022 study confirmed that indeed, nationally, ASD is associated with an increased risk of fatality in children.[16] Further, a 2017 study of National Vital Statistics data from 2010 to 2016 reported that drowning was the leading cause of death for children with ASD.[17] While ASD is not a life-limiting diagnosis, specific behaviors sometimes seen in children with ASD can contribute to an increased risk of unintentional fatality.[18]

[16] Catalá-López, F., Hutton, B., & Page, M. (2022). Mortality in Persons with Autism Spectrum Disorder or Attention-Deficit/Hyperactivity Disorder. *Journal of American Medicine Pediatrics*. https://doi.org/10.1001/jamapediatrics.2021.6401; Guan, J., & Li, G. (2017). Characteristics of unintentional drowning deaths in children with autism spectrum disorder. *Injury Epidemiology*, *1*. https://doi.org/10.1186/s40621-017-0129-4

[17] Guan, J., & Li, G. (2017). Injury Mortality in Individuals With Autism. *American Journal of Public Health*, *5*, 791–793. https://doi.org/10.2105/ajph.2017.303696

[18] Emerging research suggests children with ASD face other disproportionate injury risks, particularly in the areas of suicidality and self-injurious behaviors (Weng et al). While the focus of this report is unintentional fatality, other mechanisms of injury are important to understanding the scope of mortality and injury risk children and persons with ASD face.

Autism Spectrum Disorder and Unintentional Fatality

A Growing Population

Autism Spectrum Disorder is a neurodevelopmental condition characterized by communication and interaction deficits and restrictive, repetitive patterns of behavior.[19] There is no singular test to determine if a person has ASD, and the severity of symptoms varies across individuals.[20]

Nationally, the Centers for Disease Control and Prevention estimates that in 2020, one in 36 eight year-olds had an ASD diagnosis.[21] The Massachusetts Department of Elementary and Secondary Education (DESE) reports that **the number of children with ASD enrolled in special education rose from 4,876 students in the 2002-2003 school year to 28,355 in the 2022-2023 school year.**[22] This is a nearly six-fold increase in the number of Massachusetts children with ASD receiving special education. The higher rates of children diagnosed with ASD is most likely due to increased awareness of ASD, and improved access to diagnostics.[23] The increase in Massachusetts mimics national trends, though Massachusetts has slightly higher rates of diagnosis than the national average.[24,25] This is likely because of our robust Early and Periodic Screening, Diagnosis, and Testing (EPSDT) requirements for Medicaid (also called MassHealth in

What is EPSDT?

Providers are required to follow federal EPSDT standards for patients under 21 receiving Medicaid. EPSDT stands for:

Early: Assessing and identifying problems early
Periodic: Checking children's health at periodic, age-appropriate intervals
Screening: Providing physical, mental, developmental, dental, hearing, vision, and other screening tests to detect potential problems
Diagnostic: Performing diagnostic tests to follow up when a risk is identified, and
Treatment: Control, correct or reduce health problems found.

[19] American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Arlington, VA: American Psychiatric Association; 2013.
[20] Researchers and advocates have begun to distinguish "profound autism" as a subcategory of persons with ASD who are non-verbal or minimally verbal or have an IQ under 50. This report does not distinguish between children with ASD and children with profound ASD, as research suggests that verbal children with ASD also wander at disproportionate rates compared to the general pediatric population (Rice et al, 2016). While some interventions mentioned here may seem more fitting to a child with or without a profound autism designation, it is important to acknowledge every child's experience of ASD differs and supports for their unique behavioral or cognitive abilities should be tailored to their needs.
[21] Maenner, M. J., Warren, Z., Williams, A. R., Amoakohene, E., Bakian, A. V., Bilder, D. A., Durkin, M. S., Fitzgerald, R. T., Furnier, S. M., Hughes, M. M., Ladd-Acosta, C. M., McArthur, D., Pas, E. T., Salinas, A., Vehorn, A., Williams, S., Esler, A., Grzybowski, A., Hall-Lande, J., … Shaw, K. A. (2023). Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. *MMWR. Surveillance Summaries*, *2*, 1–14. https://doi.org/10.15585/mmwr.ss7202a1
[22] Executive Office of Health and Human Services. (2023). Autism Commission 2023 Annual Report. https://www.mass.gov/doc/2023-annual-report-of-the-autism-commission/download
[23] Wright, J. (2017, March 3). *The Real Reasons Autism Rates Are Up in the U.S.* The Scientific American.
[24] Maenner, M. J., Warren, Z., Williams, A. R., Amoakohene, E., Bakian, A. V., Bilder, D. A., Durkin, M. S., Fitzgerald, R. T., Furnier, S. M., Hughes, M. M., Ladd-Acosta, C. M., McArthur, D., Pas, E. T., Salinas, A., Vehorn, A., Williams, S., Esler, A., Grzybowski, A., Hall-Lande, J., … Shaw, K. A. (2023). Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. *MMWR. Surveillance Summaries*, *2*, 1–14. https://doi.org/10.15585/mmwr.ss7202a1
[25] Zeidan, J., Fombonne, E., Scorah, J., Ibrahim, A., Durkin, M. S., Saxena, S., Yusuf, A., Shih, A., & Elsabbagh, M. (2022). Global prevalence of autism: A systematic review update. *Autism Research*, *5*, 778–790. https://doi.org/10.1002/aur.2696

Massachusetts), including the Children's Health Insurance Program (CHIP), and EPSDT uptake by most private insurers. EPSDT requires that children enrolled in MassHealth receive regular screenings at key developmental stages, including for ASD. Pediatric providers are increasingly detecting and diagnosing ASD and ASD-like behaviors.[26]

This report delves into the concerning behavior of wandering in children with ASD and associated risks for fatality, and the barriers to receiving services. While these barriers may present unique and complex challenges for families, it is important to remember and acknowledge the many benefits and joys that accompany raising and working with children with ASD.

Risky Behaviors & Affinity for Water

While ASD is not a life-limiting diagnosis, specific behaviors sometimes seen in children with ASD can contribute to an increased risk of unintentional fatality.[27] Wandering, also called elopement or bolting, is more common in children with ASD compared to their neurotypical counterparts after the age of four. One study found a nearly five times greater occurrence of wandering in four- to five-year-olds with ASD compared to their neurotypical peers.[28] One meta-analysis found one quarter to one-half of caregivers of individuals with ASD reported wandering in the preceding six months.[29]

Once a child with ASD leaves a supervised space, they are at risk for contact with dangerous environments, including bodies of water and busy roads. A 2012 study reported that 24% of children with ASD who wandered had a close call with water, and 65% with

What is Wandering?

Wandering occurs when a child leaves a supervised space unaccompanied, which can occur at home, school, programming, or a public area. Wandering behavior is common in children with ASD. Wandering occurs for many reasons, including:

- to access an item, place or person,
- to leave a stressful or overwhelming situation,
- curiosity and a desire to explore

Wandering behavior can be addressed by therapies, home and routine modification, and redirected in school or center-based education spaces (CDC, 2024).

[26] Executive Office of Health and Human Services. (2023). Autism Commission 2023 Annual Report. https://www.mass.gov/doc/2023-annual-report-of-the-autism-commission/download

[27] Emerging research suggests children with ASD face other disproportionate injury risks, particularly in the areas of suicidality and self-injurious behaviors (Pitter, 2023. Mayes et al, 2013). While the focus of this report is unintentional fatality, other mechanisms of injury are important to understanding the scope of mortality and injury risk children and persons with ASD face.

[28] Wiggins, L. D., DiGuiseppi, C., Schieve, L., Moody, E., Soke, G., Giarelli, E., & Levy, S. (2020). Wandering Among Preschool Children with and Without Autism Spectrum Disorder. *Journal of Developmental &; Behavioral Pediatrics*, *4*, 251–257. https://doi.org/10.1097/dbp.0000000000000780; Rice, C. E., Zablotsky, B., Avila, R. M., Colpe, L. J., Schieve, L. A., Pringle, B., & Blumberg, S. J. (2016). Reported Wandering Behavior among Children with Autism Spectrum Disorder and/or Intellectual Disability. *The Journal of Pediatrics*, 232-239.e2. https://doi.org/10.1016/j.jpeds.2016.03.047

[29] T-Pederson, C., Reisert, H., & Adesman, A. (2021a). Wandering behavior in children with autism spectrum disorder and other developmental disabilities. *Current Opinion in Pediatrics*, *4*, 464–470. https://doi.org/10.1097/mop.0000000000001038

motor vehicles.[30] These interactions can be fatal. A 2012 study of media-reported wandering cases of children with ASD from 2011 to 2016 found that 49% of fatal wandering events originated from the home and 71% of fatal outcomes were the result of drowning.[31] The same report found the age group with the greatest number of reported wandering events, and greatest number of fatal wandering events, was between the ages of five and nine.

Not only do children with ASD wander at greater proportion to the general pediatric population, but they also may have less awareness of environmental dangers that they encounter while unsupervised.[32] Researchers have observed an affinity for water in children with ASD, and many service providers and educators encourage water play for children with ASD as a stimulating and soothing activity. In a 2015 study of activity enjoyment, children with ASD had a much higher enjoyment score for water activities compared to their neurotypical peers.[33] While aquatic play can be a fruitful source of stimulation, relaxation and enrichment, it may also mean that in an instance of wandering, children with ASD may seek out or be drawn to water environments.

This report provides a detailed characterization of unintentional fatality prevention best practices, harm reduction strategies, programs available to caregivers and providers, and areas for improved coordination across the state for the reduction of child fatalities related to wandering in the context of ASD. Not all children with ASD exhibit wandering behavior, and not all children that wander have ASD.[34] However, this is a risky behavior that affects one quarter to one half of children with ASD—theoretically at least 7,000 to 14,000 Massachusetts children—and must be addressed to reduce the inequitable risk of fatality faced by children with ASD.

Prevention & Harm Reduction

Fatality prevention requires a multi-tiered approach, including understanding and addressing the root causes of wandering, creating barriers to wandering, and preparing for the riskiest scenarios. Layers of prevention work together to ensure that if one intervention fails, another is in place to reduce the harm to the child. The first step to prevention is recognizing the behavior and understanding the risk it causes.

Understanding why a child is exhibiting wandering behavior and addressing that root cause is a critical aspect of preventing the behavior. However, this usually takes time, effort, and access to

---

[30] Anderson, C., Law, J. K., Daniels, A., Rice, C., Mandell, D. S., Hagopian, L., & Law, P. A. (2012). Occurrence and Family Impact of Elopement in Children With Autism Spectrum Disorders. *Pediatrics*, *5*, 870–877. https://doi.org/10.1542/peds.2012-0762

[31] McIlwain, L., & Fournier, W. (2012). Lethal Outcomes In Autism Spectrum Disorders (ASD) Wandering/Elopement. *National Autism Association*. /https://nationalautismassociation.org/wp-content/uploads/2012/01/Lethal-Outcomes-In-Autism-Spectrum-Disorders_2012.pdf

[32] Pardej, S. K., & Mayes, S. D. (2024). Prevalence and Correlates of Poor Safety Awareness and Accidental Injury in ASD, ADHD, ASD + ADHD, and Neurotypical Youth Samples. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-024-06417-z

[33] Eversole, M., Collins, D. M., Karmarkar, A., Colton, L., Quinn, J. P., Karsbaek, R., Johnson, J. R., Callier, N. P., & Hilton, C. L. (2015). Leisure Activity Enjoyment of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *1*, 10–20. https://doi.org/10.1007/s10803-015-2529-z

[34] Children with other Intellectual and Developmental Disabilities (IDD) diagnoses may also exhibit wandering behavior (Rice et al, 2016). Additionally, children with diagnoses of Attention Deficit Hyperactivity Disorder (ADHD) and/or epilepsy may be at a higher risk of drowning (Pardej et al 2024, Franklin et al, 2017).

skilled professionals. While understanding and addressing the cause of the behavior, other prevention measures must be put in place.

Home modifications, such as locks, fencing, and window guards can prevent the child from leaving when installed and used appropriately. And still, tenacious children can sometimes find a way to leave their safe environment, even with those precautions in place. Once a wandering episode occurs, finding the child quickly reduces their chances of encountering a dangerous environment. If a child encounters water while eloping, water safety skills such as swimming or floating can increase the time that rescuers have to find them.

Figure 1. Layers of Wandering Prevention

These prevention strategies function best in tandem, and the interventions laid out must be considered in the context of the caregiver and child's unique circumstances and needs. Of note, caregivers must cope with the very real fear of knowing the risks associated with wandering. Caregivers of children of all abilities who have experienced wandering episodes may be stressed and fearful for their child's safety should it happen again. A 2018 study confirmed that parents of children with ASD who wander alter their behavior to keep their children safe, like limiting outings in public or not leaving their child under family or friend's supervision.[35] Coordinating a child's care, remaining constantly vigilant for wandering, and engaging in the routine tasks of caregiving can understandably lead to burnout. Minimizing the risk of wandering can be both tiring and isolating.

Further, these stressors and barriers to treatment are exacerbated for caregivers with language and socioeconomic inequities. A 2023 review found interactional factors, such as

[35] McLaughlin, L., Keim, S. A., & Adesman, A. (2018). Wandering by Children with Autism Spectrum Disorder: Key Clinical Factors and the Role of Schools and Pediatricians. *Journal of Developmental &; Behavioral Pediatrics*, *7*, 538–546. https://doi.org/10.1097/dbp.0000000000000591

language/communication barriers, a lack of trust in professionals, and limited training in cultural responsiveness, hindered support for diverse families of youth with ASD.[36] Ensuring access to services and support for language and socioeconomically diverse children with ASD and their caregivers is necessary to improve outcomes equitably.

Raising Caregiver Awareness

Caregivers to children with ASD must be informed of the increased likelihood of wandering and educated that this behavior may change over the course of the child's life. It is essential that caregivers understand how common wandering behavior is in children with an ASD diagnosis, and the outsized fatality risk that wandering poses for children with ASD.[37] A 2018 study found only a third of parents of children with ASD reported any formal counseling about elopement.[38]

While some providers conduct a risk assessment during diagnosis or subsequent appointments, standardized screening tools would ensure the risk of wandering and affinity for water is discussed with all caregivers of children with ASD or wandering behavior.[39]

Providers, from pediatricians to special education teachers to therapists, should be well-versed in and ready to ask about wandering behavior, associated risks, and prevention opportunities with caregivers, starting when the child is around two years old, regardless of an autism diagnosis. See Appendix E for ways providers can support families in accessing prevention tools and understanding risk.

Home Modifications

A 2017 study found that 52% of children with ASD who fatally wandered were initially at home, and other places children visit like school or other structured programming can provide constant supervision that is not possible at home.[40] It is essential to install physical barriers at home as soon as possible once wandering tendencies are identified or if parents are concerned about the danger of wandering depending on the environmental hazards nearby. These may be temporary, until longer-term treatments become effective, or permanent depending on a child's wandering behavior. In the general population, home modifications are shown to reduce injuries by as much

[36] Pham, A. V., & Charles, L. C. (2023). Racial Disparities in Autism Diagnosis, Assessment, and Intervention among Minoritized Youth: Sociocultural Issues, Factors, and Context. *Current Psychiatry Reports*, *5*, 201–211. https://doi.org/10.1007/s11920-023-01417-9

[37] Guan, J., & Li, G. (2017b). Characteristics of unintentional drowning deaths in children with autism spectrum disorder. *Injury Epidemiology*, *1*. https://doi.org/10.1186/s40621-017-0129-4

[38] McLaughlin, L., Keim, S. A., & Adesman, A. (2018). Wandering by Children with Autism Spectrum Disorder: Key Clinical Factors and the Role of Schools and Pediatricians. *Journal of Developmental &; Behavioral Pediatrics*, *7*, 538–546. https://doi.org/10.1097/dbp.0000000000000591

[39] Access to resources may also be enhanced by provider prescriptions, as wandering can be medically coded under ICD-10-CM code Z91.83.[39]

[40] McIlwain, L., & Fournier, W. (2017). *Mortality & risk in ASD wandering/elopement 2011–2016*. Retrieved September 16, 2021 from https://nationalautismassociation.org/wp-content/uploads/2017/04/NAAMortalityRiskASDElopement.pdf

as 26% within the home.[41] For people with ASD, home modifications are effective for preventing wandering behavior.[42]

Home modifications depend on the child's preferred routes of wandering, areas of high risk, and the family's needs. Some examples are listed below in Figure 2. Caregivers should be encouraged to use a combination of these barriers, depending on their home and their child's needs and behavior. Additionally, usage plays an important factor in the effectiveness of each modification. If a deadbolt is not locked, or if caregivers experience alarm fatigue[43], then these will not be effective in a wandering episode.[44]

Figure 2. Examples of Wandering Prevention Methods

Physical Barriers	Alarms	Visual Cues
Out of reach door locks Window locks Yard fencing Pool fencing Enclosed beds	Door alarms Window alarms Pool alarms	Stop sign stickers

The child's caregiver is usually responsible for seeking out and negotiating the installation of any home modifications. Caregivers bear the responsibility of navigating the multitude of home modification products on the market and weighing the safety risk of wandering against other risks such as efficient egress in the event of an emergency. Caregivers may also face financial barriers, particularly for expensive products like fencing and enclosed beds.[45] Finally, caregivers may not have the skills or tools needed to install the products, time to complete the task, or permissions to make modifications. Home modifications that alter the home, like window guards and additional door locks may be prohibited by the terms of a lease and expensive additions like fencing are at the discretion of a landlord.

[41] Keall, M. D., Pierse, N., Howden-Chapman, P., Cunningham, C., Cunningham, M., Guria, J., & Baker, M. G. (2015). Home modifications to reduce injuries from falls in the Home Injury Prevention Intervention (HIPI) study: a cluster-randomised controlled trial. *The Lancet*, *9964*, 231–238. https://doi.org/10.1016/s0140-6736(14)61006-0

[42] Anders, C., Law, J. K., Daniels, A., Rice, C., Mandell, D. S., Hagopian, L., & Law, P. A. (2012). Occurrence and Family Impact of Elopement in Children with Autism Spectrum Disorders. *Pediatrics*, *5*, 870–877. https://doi.org/10.1542/peds.2012-0762

[43] Alarm Fatigue occurs when people become desensitized to an alarm and often occurs when an alarm is placed on a door or window that is opened frequently. Alarm fatigue can lead to missed or ignored alerts, rendering alarms ineffective.

[44] Johnson, K. R., Hagadorn, J. I., & Sink, D. W. (2017). Alarm Safety and Alarm Fatigue. *Clinics in Perinatology*, *3*, 713–728. https://doi.org/10.1016/j.clp.2017.05.005

[45] Enclosed or safety beds are specially designed to prevent elopement in individuals with autism by providing a secure and enclosed sleeping environment. Despite being secure, safety beds are designed to be comfortable and non-restrictive. They allow for free movement within the bed while still preventing the individual from leaving it (Huang, 2023)

Several organizations provide free or low-cost home modification resources or funding. For example:

Table 7. Home Modification Resources

Organization	Coverage	Cost	Stipulations
National Autism Association's Big Red Safety Box	Two window or door alarms and stop sign decals, among other resources	Free, with possible shipping fee	Must be installed by caregiver
The Department of Developmental Services (DDS) Children's Autism Waiver Program	Most home modifications up to yard fencing	Free	Must be enrolled in Autism Waiver Program, which requires MassHealth Standard eligibility
The Department of Children & Families (DCF)	May be able to use State funds for door locks and window guards	Free	Must be a child consumer of DCF
The Massachusetts Rehabilitation Home Modification Loan Program (HMLP)[46]	$1,000 to 50,000 loans for home modification at 0% interest	Must be repaid, but with no interest	Homeowners only
The Flutie Foundation Joey's Fund | Hope Fund	Grants of up to $2,000 for door locks, alarms, and fencing	Free	Must apply for a grant, may provide professional installation
Some Applied Behavior Analysis (ABA) providers	Low-cost modifications like door locks	Free	Depends on the policies of the ABA provider

There is no statewide program that can support residents in identifying and addressing injury risks and preventing wandering from the home. The MassSAVE program helps homeowners identify and address energy efficiency and weatherization solutions and offers a promising model for providing subsidized home modifications. Through contractors, MassSAVE provides homeowners and landlords with no-cost home energy assessments. Homeowners are provided with simple energy-saving modifications during the assessment; they also receive education on energy saving practices and become eligible to receive certain no-cost energy-saving products, rebates towards the purchase of energy-efficient appliances, and loans towards more expensive energy-saving home modifications, like window replacements.[47]

A comparable program aimed at addressing in-home wandering risks could greatly reduce the risk of negative outcomes associated with wandering and ease the burden on caregivers. Such a program would engage trained specialists to conduct assessments for home modifications, coordinate and subsidize construction or installation services by third-party contractors, and follow up with residents to ensure that modifications were performed correctly. Various small-scale pilot programs that have provided home modifications for safety found a range of improvements in

[46] Massachusetts Rehabilitation (2024). Home Modification Loan Program. https://www.mass.gov/home-modification-loan-program-hmlp

[47] Mass SAVE Energy assessments and Audits. (n.d.) https://www.masssave.com/

health outcomes: improved sleep and mental health, fewer falls, and lower health care usage and costs.[48]

Another example program with a more targeted scope comes from the Aging Services Access Points (ASAPs) model, where home-based service providers like occupational and physical therapists can recommend home modifications to local or regional ASAPs. ASAPs are then able to offer free or discounted home modification service procurement and installation.[49] This model could inform the structure of a separate program for the provision of home modification products to households with a child with ASD through Autism Resource Centers, as recommended by in-home providers like registered behavior technicians (RBTs), Board Certified Behavior Analysts (BCBAs), and others. For more information about Autism Resource Centers, see the Service Coverage and Care Coordination section (page 32).

Educational & Therapeutic Support

Wandering behavior can be addressed by Applied Behavior Analysis (ABA) and other therapeutic treatments and reinforced at home, school, and other programming. Children under the age of three who have an ASD diagnosis or who have noted developmental deficits consistent with ASD can receive Early Intervention (EI) services, which are overseen by the Department of Public Health and free for all Massachusetts families. Children with ASD or ASD-like behaviors enrolled in EI are eligible for Early and Intensive Behavioral Intervention (EIBI) services, which is a form of Applied Behavior Analysis (ABA, see below for more information).[50] In FY23, 1,578 children under three years old received EIBI services through Early Intervention.

Applied Behavior Analysis (ABA) provides functional analysis to understand the underlying cause, also called the function, of specific behaviors, including wandering.[51] ABA is the primary evidence-based method for treating ASD and requires intensive assessment, program development, program implementation, and continued observation on behalf of Board Certified Behavior Analysts (BCBAs), registered behavior technicians (RBTs), the child's caregivers, and the child. ABA and alternative therapies can curb wandering by enhancing a child's ability to communicate. Expressing needs and wants, walking safely in unconfined spaces, waiting for desired objects or activities, and other skills targeted through therapy can reduce the root function of wandering or curtail the desire to wander before the behavior emerges.

From ages three to five, a child with ASD living in Massachusetts may qualify for Early Childhood Special Education (ECSE), a category of special education.[52] By law, ECSE must be free, developmentally appropriate, and available to any child with a disability that needs specially designed instruction to participate in age appropriate typical activities. This is the first point where

[48] Nadel, S. (2020). *American Council for an Energy-Efficient Economy*. Weatherization and Home Improvements: A Promising Path for Improving Health and Reducing Medical Costs for Older Adults
[49] Executive Office of Health & Human Services (n.d.) *Executive Office of Elder Affairs, Aging Services Network*
[50] Executive Office of Health & Human Services (n.d) *Early Intervention,* Autism Spectrum Disorder (ASD) Services: Early Intensive Behavioral Intervention (EIBI)
[51] Scheithauer, M., Call, N. A., Lomas Mevers, J., McCracken, C. E., & Scahill, L. (2020). A Feasibility Randomized Clinical Trial of a Structured Function-Based Intervention for Elopement in Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-020-04753-4
[52] *Early Childhood Special Education*. (2018). Massachusetts Department of Elementary and Secondary Education. https://www.doe.mass.edu/sped/ecse/

the child's caregivers and the schools may collaborate to develop an Individualized Education Program (IEP), if the child meets eligibility criteria.[53] After age five, children with ASD will transition to kindergarten and be re-evaluated for special education needs.

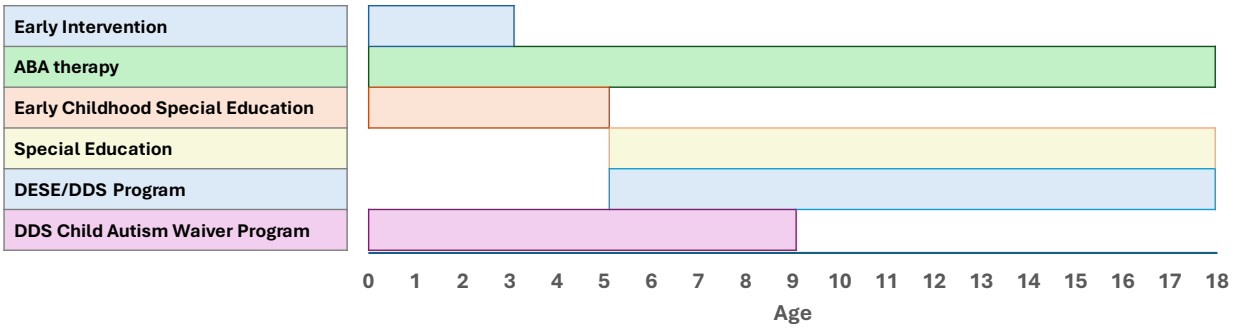
IEPs serve to ensure a child with a disability has the supports to make progress towards knowledge and skill acquisition, and nurture healthy social relationships. The child's IEP can address safety skills, including risk of wandering if the child exhibits this behavior. While wandering is not a behavior directly addressed on the IEP form, caregivers and educators who identify this behavior can advocate for wandering prevention as part of an annual goal, behavior intervention planning, accommodations (if the child will require greater supervision or changes to the physical environment), and/or safety planning.

Additionally, wandering can be included in an Individualized Healthcare Plan (IHCP, also called an IHP), which is developed with the school nurse. An IHCP provides a tailored approach to managing and supporting the specific health and medical needs of a child, including wandering. ICHPs can be standalone guidance or can be added as an appendix or as additional recommendations to an IEP. Including an IHCP in the IEP helps to ensure coordination between medical and educational supports, as well as provide legal assurance that the child's health needs will be managed alongside educational goals.

The IEP may only address elopement risk in the school setting and will not identify risks or set goals for the home and community, however. It is therefore important to ensure that IEP goals targeting wandering consider how to generalize that skill in other settings, and to also seek out supplemental therapies outside of the school setting, as needed.

ECSE and special education are both important avenues for learning and skill acquisition, but children with ASD may also require in-home or center-based services outside of the classroom. Caregivers may choose to or need to pursue other options or a combination of services including Developmental, Individual-based, Relationship (DIR, also called DIRFloortime) therapy, sensory integration therapy, cognitive behavioral therapy (CBT), occupational therapy, and speech therapy.[54]

Figure 3. Behavioral and educational services by age of eligibility for children ages 0 to 18.



[53] *Individualized Education Program Process Guide*. (2001). Massachusetts Department of Elementary and Secondary Education. https://www.doe.mass.edu/sped/iep/proguide.pdf

[54] *What is DIR?* (n.d.). DIRFloortime® (Floortime). https://www.icdl.com/dir, *Sensory Integration Therapy*. (2019, October 7). HealthyChildren.Org. https://www.healthychildren.org/English/health-issues/conditions/developmental-disabilities/Pages/Sensory-Integration-Therapy.aspx, *What is Cognitive Behavioral Therapy?* (2017). American Psychological Association. https://www.apa.org/ptsd-guideline/patients-and-families/cognitive-behavioral

ABA Provider Landscape

It is unknown how many center- and home-based ABA programs exist in Massachusetts, how many children with ASD are receiving ABA services, and how many are on waitlists to receive such services. MassHealth covered ABA treatment for 8,536 unique youth at 203 ABA organizations in the 2023 calendar year.[55] However, the number of children receiving ABA therapy through private insurance or out-of-pocket expenses is unknown. The Behavior Analyst Certification Board reported that 3,560 Board Certified Behavior Analysts were employed in Massachusetts in 2023, however, it is unknown how many children they treated, in what setting, and for how many hours.[56]

The number of ABA providers has expanded with the steadily increasing number of children diagnosed with ASD and seeking treatment in recent decades.[57] And while more ABA providers mean more children have access to ABA therapy, there has been a growing concern among some specialists, families, advocates, and self-advocates about the quality and safety mechanisms in place at ABA centers. **Currently, center-based ABA facilities are not licensed by the state of Massachusetts, unlike most other out-of-home child-serving facilities like childcare and residential schools.**[58] This means there are no standards set statewide for ABA centers, including safety protocols, Criminal Offender Record Information (CORI) background checks, and staffing ratios. While many centers do have such protocols in place, these are not required, not standardized, and not externally monitored. While Board Certified Behavior Analysts who develop treatment plans and work with children with ASD are licensed, the license applies to the individual provider only, and not to the other providers like behavioral therapists who work closely with the client, or the centers themselves. More state oversight would ensure the safety and wellbeing of children served by the centers, and standards of quality in the services provided. Currently, the Department of Early Education and Care (EEC) is assessing the regulations required for oversight and licensure of center-based ABA programs.[59] EEC is working in collaboration with MassHealth and the Executive Office of Health and Human Services (EOHHS) to assess options for oversight and licensure of center based ABA programs for children, including needed regulatory authority, governance, and staffing capacity.

Community & Water Safety

Children with ASD should not be limited from interacting with water, but rather these interactions should be enhanced with safety measures, including community safety education and early and adaptive swim lessons.[60] Educators and providers can help a child with ASD cultivate an

---

[55] Executive Office of Health and Human Services. (2023). Autism Commission 2023 Annual Report.
[56] Behavior Analyst Certification Board. (n.d.) https://www.bacb.com/services/o.php?page=101134
[57] Ibid.
[58] Announced October 2024, MassHealth addressed this concern by requiring all managed care entities providing Medicaid services to contract only with accredited ABA providers over the next three years (Autism Commission on Quality, 2024).
[59] Department of Early Education and Care. (n.d) https://www.mass.gov/orgs/department-of-early-education-and-care
[60] Alaniz, M. L., Rosenberg, S. S., Beard, N. R., & Rosario, E. R. (2017). The Effectiveness of Aquatic Group Therapy for Improving Water Safety and Social Interactions in Children with Autism Spectrum Disorder: A Pilot Program. *Journal of Autism and Developmental Disorders*, *12*, 4006–4017. https://doi.org/10.1007/s10803-017-3264-4; Mische Lawson, L., D'Adamo, J., Campbell, K., Hermreck, B., Holz, S., Moxley, J., Nance, K., Nolla, M., & Travis, A. (2019). A Qualitative Investigation of Swimming Experiences of Children With Autism Spectrum Disorders and Their Families. *Clinical Medicine Insights: Pediatrics*, 117955651987221. https://doi.org/10.1177/1179556519872214; Grosse, S. J. (2014).

understanding of potential dangers and safety in their environment. The Department of Elementary and Secondary Education's 2023 Comprehensive Health and Physical Education Framework upholds personal and community safety as two essential pillars of health education.[61] The framework names the following safety objectives:

- Apply strategies for staying safe in a variety of situations (e.g., on the playground, during physical education, around water, when using wheeled recreation, as a pedestrian, around cooking elements or fire, on the bus, when online, around weapons or in situations of gun violence) and determine when to report unsafe situations to an adult
- Recognize aspects of the environment (e.g., whether or not crosswalks are clearly marked, presence of sidewalks, access to healthy foods, access to green space, levels of violence in a community) that can positively or negatively impact safety

School districts have the discretion to determine how standards are implemented at the local level, including what curriculum and materials they will use, and how they will ensure that instruction is differentiated to ensure access for students with disabilities. At this time, there are no standardized curricula or materials related to community safety for general or special education in Massachusetts.

Children with ASD have varying abilities to conceptualize safety depending on their developmental age, so safety education will look different for every child. There are tools educators can use to adapt safety education for children with ASD.[62] For some, this may include similar accommodation to those listed on the child's IEP, such as extended time for lessons to ensure comprehension. For others, this may mean developing novel accessible lessons around safety. This can include using different tools, like video narratives, visual cue cards, and social stories, which describe a skill or concept in a supportive way that centers the child.[63] Many of these exist for water safety and can be tailored to the child's preferences, environment, and abilities.

Children with ASD may need accommodations to learn ways to navigate their environment safely. Some skills can be built around enhancing the emergency response to wandering. Behavior analysts can work with children with ASD to respond to a stranger who they may come across when lost, whether this is verbal communication or holding up an identification bracelet. Providers can also work on skills related to asking for help, which a child may need if they are lost. Other lessons on situational awareness and community safety are necessarily a focus of ABA or other therapies, which are behavior-, skill-, or relationship-oriented.

A promising example of the way to purvey safety education for children with ASD comes from the Safe Routes to School Program.[64] The majority of public schools in Massachusetts utilize the

---

Aquatic Safety for Individuals with Autism Spectrum Disorders. *International Journal of Aquatic Research and Education*, *3*. https://doi.org/10.25035/ijare.08.03.08

[61] Department of Elementary and Secondary Education. (2023). Comprehensive Health and Physical Education.

[62] Kay, S. (n.d.). *Teaching Children with Autism About Safety*. May Institute. Retrieved August 2, 2024, from https://www.mayinstitute.org/news/acl/asd-and-dd-child-focused/teaching-children-with-autism-about-safety/

[63] Social Stories are brief, individualized narratives designed to help individuals with (ASD) understand and navigate social situations. Social stories use simple, descriptive language and visual supports to outline social scenarios, promoting appropriate behavior and understanding of others' perspectives (Tobik, 2020).

[64] Massachusetts Department of Transportation (2024). Safe Routes to School Program. https://www.mass.gov/safe-routes-to-school

materials and lessons provided by Safe Routes to School for road safety and awareness education. Safe Routes to School provides information on crossing the street, remaining on the sidewalk, navigating a parking lot, and bike safety in age-appropriate, interactive lessons.[65] While the program does not provide specific lesson plans for children in special education or an IEP, their All Abilities Guide emphasizes the ways to adapt lessons for children of all abilities and backgrounds.

Safety objectives in DESE's Comprehensive Health and Physical Education include the "ability to apply strategies for staying safe…around water …" As such, all schools in Massachusetts should provide education on water safety, and those lessons should be adapted for children with ASD. Some special education schools, like the New England Center for Children, incorporate swim lessons into their curriculum, which can seamlessly tie together situational awareness education with the essential ability to swim.[66]

Adaptive Swimming Lessons

Adaptive swimming lessons should be thought of as the last line of defense against drowning. Once a child enters a body of water unsupervised, the risk of fatality substantially increases, even with the ability to swim. Currents, aquatic plants, waves, steep drop off, other hazards, and stamina can make this scenario fatal. Still, the ability to swim can prolong the window of time first responders have to find the child or allow a child to return to land.

Teaching children with ASD to swim can come with unique considerations. Swimming lessons often need to be adapted for a child with ASD. This may include one-on-one instruction to lower the visual and aural stimulus of a group class, extending the number of lessons to accommodate the child's learning pace, and preceding sessions to sensitize the child to the pool, swimsuit, instructor, and water. Adaptive swimming lessons require more space and specialized instructors compared to typical swim lessons. Adaptive swimming lessons also require greater financial and time investments and are almost always an out-of-pocket expense for families. They must also be consistent, and the child given ample opportunity to use their swimming skills, so that the skill is not lost once it is gained.

There is a shortage of adaptive lessons in general across the state. Access inequity, particularly for children in Western and Central Massachusetts, means that caregivers shoulder the extra burden of finding class availability, providing extended transport to and from lessons, and lack of choice if a class is not fitting their child's needs. Furthermore, without a centralized repository of available adaptive swim lessons, caregivers must find these on their own through individual searches or informal resource sharing with other parents, without cost comparisons and program characteristics. See Appendix H for a list of adaptive swim lessons by region.

Caregivers may reduce the financial burden of swimming lessons by applying for a grant of up to $2,000 through the Flutie Foundation. Swimming lessons may also be billed as a medical service if provided by a specialist such as an occupational therapist. Of note, non-profit organizations like Wonderfund provide financial assistance for swimming lessons for children receiving DCF services.

---

[65] Caregivers of children with ASD are also entitled to disability placards, which can make navigating parking safer. See more information for applying for a disability placard in Appendix D.

[66] *Special Education School Services*. (n.d.). The New England Center for Children. https://www.necc.org/education/school-services/

This is an example of supporting organizations providing unique wraparound services that can both broaden the interests and enrichment opportunities for children, as well as provide important life-saving skills. As child-serving agencies consider how the information in this report affects the children they serve, looking at funding and resourcing options to expand adaptive swim lesson access for children and their families could follow the model set forth by DCF, where broadening partnerships can expand access to wraparound services without increasing agency spending or workforce.

Emergency Preparedness & Response

Preparation and planning are key to any successful emergency response. The same goes for responding to the elopement of a child with autism. The following provides strategies that caregivers can proactively implement to prepare emergency responders for an elopement, and best practices for local emergency response teams.

Emergency Preparedness for Caregivers

Caregivers can take additional steps to reduce the harm of a wandering event should it occur. Two key steps in emergency preparedness include considering the use of tracking and monitoring devices and preparing for the involvement of first responders. These measures can enhance the safety and swift recovery of the child if wandering occurs.

Tracking & Monitoring Devices

Tracking and monitoring devices can alert a caregiver as soon as a child has wandered and expedite locating the child who has wandered. Several options for tracking and monitoring devices are available at different price points, with different functionality, battery life, and wearability. There are two primary methods of tracking and monitoring, one using radio signals and the other using Global Positioning System (GPS) technology, which is typically dependent on cellular coverage.

Radio signal tracking bracelets can be used to pinpoint a missing child. This technology does not require frequent charging, can be worn as a bracelet or anklet, can penetrate underground, in water and tunnels, and does not require a satellite signal. However, typically only first responders have the technology to pick up the radio signal. Therefore, this method must be coordinated through a participating agency. The uptake of radio tracking technology varies across municipalities, although all Sherriff's Departments in Massachusetts are equipped with the tracking technology.

Determining whether and which radio signal device a department uses can be a time-consuming endeavor for caregivers searching for a suitable tracking device for their child. These devices can be accessed for free for children enrolled in services with the Department of Developmental Services (DDS), or the non-profit organization the Flutie Foundation or may be subsidized through one's local law enforcement agency depending on their policies.

GPS devices provide monitoring abilities directly to the caregiver. These may not be as effective depending on service coverage and charging needs. These can be worn as a bracelet or anklet, sewn into the child's shoes or clothes, or carried in a backpack. GPS devices may also work both as a tracking mechanism and as a geo fence. In the case of a geofence, the caregiver sets a proximity requirement to the device (e.g. the boundary of their yard or apartment complex), and the caregiver receives an alert if the device leaves that proximity requirement. These are useful if a parent would

like to be proactively alerted, for example if the family may be visiting a crowded public space or there is a highly dangerous area like a busy road or the ocean near their home. For a non-exhaustive list of some tracking and monitoring devices currently available, see Table 8.

Table 8. Tracking and monitoring devices for locating a missing child with ASD. [67]

Product	Tracking/ monitoring	Characteristics	Cost	Financial Resources
SafetyNet Tracking Systems	Radio frequency, must alert first responders to initiate tracking, widely available across state	Worn as a non-removable bracelet or anklet, will work underground, in tunnels and underwater	$199.95, then $24.95/mo	DDS or the Flutie Foundation may cover all costs
Project Lifesaver	Radio frequency, requires law enforcement involvement for tracking and is not available everywhere. Check the availability near you here.	Worn as a non-removable bracelet or anklet, will work underground, in tunnels and underwater	$350, though may vary by law enforcement agency	Some subsidization may be available through local law enforcement agency.
Apple Air Tag	Bluetooth proximity monitoring to caregiver. Range of about 30 feet (but to any Apple product, not just the caregiver's).	Small tracking tile can be sewn into clothing, backpacks or shoes. Year-long battery life. Water-resistant up to one meter.	$29	--
Angel Sense	GPS live monitoring to caregiver, additional features for two-way speaker, geofencing, and setting alerts for unexpected locations	Wearable tracker or watch, must be charged every 16 to 24 hours. Water-resistant	$44.99/mo	--
Verizon Gizmo Watch	GPS monitoring and call to pre-approved contacts	Smartwatch. Up to 3.6 days battery life. Not waterproof.	$99.99	--
JioBit	GPS and Bluetooth live monitoring to caregiver via app, with geofencing & proximity alert features	Small tracking tile, can be pin-locked to clothing. Rechargeable with 20-day battery life. Water-resistant	$129.99	--
Amber Alert GPS	GPS monitoring to caregiver via app, with geofencing and two-way communication options.	Clip-on or wearable on lanyard. Rechargeable with 40-hour battery life. Not waterproof.	$135, then $35/mo	--
GPS Smart Sole	GPS monitoring to caregiver via app, with geofencing option	Removable shoe insert; can be cut down to size. 24-96 hour battery life. Not waterproof.	$359	--

Last updated: September 2024

[67] This resource list is meant as a reference of currently available products. The CFR Program and its affiliates do not endorse any of these products.

Caregivers considering a tracking device for their child should think about the nuances of these different devices for their child's individualized needs and the risks in their environment. A child's sensory sensitivities should also be considered, though DDS and most ABA providers have protocols to gradually build tolerance to a bracelet or anklet monitoring device. If a child does not tolerate a wearable device, other products exist to tag clothing and backpacks, or caregivers can utilize built-in tracking technology for tablets and other communication devices.

In 2015*, H.B. 956: An Act Concerning the Safety of Autistic and Alzheimer Individuals* was proposed to provide insurance coverage for radio tracking devices through MassHealth on a voluntary basis for families of children with disabilities and elderly persons with dementia. The legislation failed in part due to privacy concerns for tracking vulnerable populations. As the public's understanding of tracking technology--found in smartphones and tablets that many now use on a regular basis--has evolved, there may be less pushback for a similar bill now, especially given how lifesaving these devices can be. Other states like Florida have successfully covered tracking devices as durable medical equipment, specifically as assistive technology under the Community and Home-Based Services Medicaid waiver.[68]

Providing Information to First Responders

The final step caregivers can take to enhance first responders' speed and efficacy is to proactively provide information about the child to first responders near where they live, work, learn, play, or pray. This includes providing a photo and description of the child, their preferred methods of communication, interests, and any history of wandering. Caregivers can also note nearby environmental hazards of concern, including natural and seasonal bodies of water, public and private pools, railroad tracks, and dangerous intersections. This information can help first responders speedily identify the areas of highest concern first, identify the missing child easily, and safely interact with the child, who may be dysregulated. For examples of the forms used to provide this information to law enforcement, see Appendix D.

If a family is not comfortable interacting with first responders prior to an emergency, an alternative is the File of Life, which prompts caregivers to put all relevant information in one file or on a magnet to succinctly relay to first responders in an emergency. [69] File of Life information is stored by the caregiver, and the caregiver has the choice to share this information with first responders in an emergency. These physical files can be saved at home, in a car, at school, and anywhere else the child goes. It is important to update the file of life regularly, especially if there is a change in the child's behavior, physical health, or interests.

First Response Training & Best Practices

The next section addresses the ways first response agencies, including law enforcement, fire, and Emergency Medical Services (EMS), can adapt their practices to actively engage with families effectively.

[68] State of Florida. (2023) pp 1-14. iBudget Waiver Handbook.
[69] *File of Life*. (2022). File of Life. https://www.thefileoflife.org/

Response Preparation

In the emergency response to wandering, law enforcement, fire, and emergency medical services play a vital role in searching for a missing child. Before a child with ASD wanders, there are steps departments can take to ensure the most effective response. First, local law enforcement can partner with a radio signal tracking device organization to be able to quickly locate missing children wearing a tracking device. If the department has not implemented the radio tracking technology, they can collaborate with neighboring jurisdictions and the Sherriff's Department or familiarize themselves with the nearest department with tracking capability.

Second, police can proactively engage families to voluntarily provide information about a child before the child ever goes missing. Taking proactive steps to gather helpful information from caregivers and families before an incident can improve responses and increase responder and child safety. Many, but not all, local law enforcement departments advertise proactive programs for families to voluntarily provide relevant information about a child with ASD who may wander. This information can increase the efficacy of response, decrease the length of response, and keep children and officers safe during interactions. Additionally, this introduction allows local law enforcement agencies an opportunity to provide consistent information to caregivers about what relevant information to share during an emergency call, how to contact the law enforcement agency for a wandering event, and what to expect in the event of a response. See Appendix F for a template form and additional resources.

Finally, first responders should acknowledge that language and cultural barriers, personal history, and stigma may impede a caregiver's willingness to activate an emergency response. However, when a child is missing, it is imperative to not delay initiating an emergency response. First responders can increase community engagement, particularly with historically underserved and stigmatized communities, to improve outcomes for children who have wandered.

Response Best Practices

Once first responders are alerted to a missing child with ASD, there are specific and necessary actions that should be taken immediately. Knowing that drowning poses the greatest fatality risk to children with ASD, first responders should prioritize searching nearby bodies of water and station responders at them.[70] While most searches may begin within the home or nearby attractions, drowning has such a high associated risk for children with ASD that bodies of water must be the priority. These can be identified through satellite images on apps like Google Earth, and through conversations with caregivers.

Ideally, the child is known to law enforcement due to prior coordination with caregivers, and the child is trackable via a device. If not, then responding officers should get a detailed description and photo of the child and rely on caregivers to identify relevant interests. For example, if a child has an interest in trains, then nearby train tracks should be an important search area. Caregivers can also provide important information for keeping the child and responders safe if the child is dysregulated when found.

[70] National Autism Association. (2017). First Responder Toolkit: A Guide to Searching for Missing Persons on the Autism Spectrum.

Per M.G.L Chapter 6 § Section 116I, Massachusetts police cadets are required to receive training on working with people with ASD. This training is essential, but specific training on wandering response for children with ASD, as well as continuing education for established officers, can ensure the most effective and consistent responses across the state. In 2023, *Bill H.2351 An Act relative to police interactions with persons on the autism spectrum* would have required mandatory in-services on working with people with ASD for law enforcement agencies. This bill was not passed by the legislature.[71]

Other first responders, including firefighters and emergency medical technicians, can also benefit from additional in-service trainings on working with people, and specifically children, with ASD. Groups like the Autism Law Enforcement Coalition (ALEC) offer voluntary in-service trainings for interested emergency response departments.[72] These organizations support officers and retired officers with lived experience as parents of children with ASD in providing peer-to-peer, in-depth, and personal trainings on these best practices and other ways to remain safe and keep people with ASD safe in different emergency situations.

[71] H.2351, 193rd Sess. (2023). An Act relative to police interactions with persons on the autism spectrum
[72] Autism Law Enforcement Coalition (n.d.) https://lifeworksarc.org/service/alec-first-responder-training/

Service Coverage & Care Coordination

While there are many providers in Massachusetts and the service network is growing rapidly, caregivers are faced with navigating an uncoordinated and complex maze of options, waitlists, insurance coverage, and eligibility criteria. Coordinating these services and ensuring consistency across providers can be an arduous task that normally falls to the child's caregiver.

After a diagnosis, healthcare providers typically give caregivers a list of ABA options in their area. Caregivers then must navigate the available options based on the child's needs, insurance coverage, and location and choose center- or home-based services. Many ABA providers have waitlists due to workforce constraints, so caregivers are encouraged to contact multiple ABA centers and join various waitlists. Caregivers must then commit to both the financial burden of therapy, as well as the time and transportation costs. Once accepted into an ABA program, the child must complete an initial assessment, and work with providers to prioritize the skills to be addressed. Finally, the caregivers must coordinate between the child's service providers, including school, other therapies like occupational therapy, and other supporting caregivers to ensure consistent implementation of the treatment plan.

Accessing therapies and educational interventions depends on the caregiver's insurance and whether they meet certain eligibility criteria for additional waivers.

Legal Obligations for Coverage

In 2010, An Act Relative to Insurance Coverage for Autism (ARICA) required private insurers in Massachusetts to cover ABA services.

In 2015, the Autism Omnibus Act expanded public insurance coverage for ASD services, including ABA therapy. In FY2023, MassHealth reported spending $188.7 million for 9,328 children and transition-age youth with ASD ages zero to 20 for ABA therapy (Autism Commission 2023 Annual Report, 2023).

In 2023, 39,367 distinct youth under 21 years of age had an ASD diagnosis on a claim during the twelve calendar months. The total spending by MassHealth for 2023 for this population was $528,561,280.

Wraparound services like occupational and speech therapies can also be covered by insurance or accessed at no cost through public schools as appropriate and available. Developmental, Individual-based, Relationship therapy and alternative therapies to ABA can be covered if billed as therapy, though this option may be limited based on the licensure of the therapy provider. ABA is considered most widely accessible, in part because of the specialized rates of reimbursement for ABA. More information about insurance options for therapy and other services can be found at the Massachusetts Autism Insurance Resource Center.[73]

To support access to services and support caregivers with coordination, some options exist through DDS, the Department of Elementary & Secondary Education (DESE), and MassHealth, though their eligibility criteria are narrow.

[73] Massachusetts Insurance Resource Center (2018). Insurance Coverage for Autism Treatments in Massachusetts: Overview and FAQs

CommonHealth

Mass CommonHealth is a MassHealth supplemental program available to individuals with disabilities—including people with ASD—regardless of income or assets. Coverage is purchased via a sliding-scale monthly premium that is based on total household income and can be purchased in addition to private insurance if a person is ineligible for MassHealth.[74]

For people who have private insurance coverage through their employer, MassHealth CommonHealth will pay for any medically necessary Medicaid-covered services that the employer health plan does not cover, if the provider accepts MassHealth. The sole exception is ABA—the ABA provider does not have to be a MassHealth provider for co-pays to be covered. MassHealth CommonHealth enrollment also opens up access to MassHealth Children's Behavioral Health Initiative (CBHI), which pays for an enhanced continuum of home- and community-based behavioral health services for children under 21.

Children's Autism Waiver

The DDS Children's Autism Waiver Program can alleviate some of the burden of care coordination for caregivers. The Autism Waiver Program is available to children birth up to age ten with a confirmed ASD diagnosis whose family is eligible for MassHealth Standard and can engage in intensive in-home services. This program also provides related support services including family training, respite, and free home modification. After three years of intensive programming, children enrolled in the Autism Waiver Program are then eligible for step-down services, with associated funds, provided they remain eligible.[75]

By September 2025, the Autism Waiver Program must be running at capacity for 565 children and their families. An open enrollment period begins annually in October and applicants are randomly selected for eligibility screening and potential enrollment. While the Autism Waiver program is highly effective in assisting families with accessing intensive services, due to the limited number of spots and strict income eligibility criteria, this program is not a feasible option for many families in Massachusetts.

DESE/DDS Program

For children over six, the DESE/DDS program is available to coordinate wraparound in-home services with the goal of preventing out-of-home placement. Supports include coordinating in-home therapy and skills training and the support of a family navigator. A minimum of 55% of the family's budget must be spent on services, like in-home therapy, and up to 45% of funding can be used to purchase ancillary goods and services. This does not include home modification. The funding provided is based on the level of need based on a standardized assessment. [76] In FY24, the DESE/DDS Program served 845 students. Children who leave a residential school and return home

[74] Massachusetts Insurance Resource Center (2018). MassHealth CommonHealth Fact Sheet. https://massairc.org/factsheets/masshealth-commonhealth-fact-sheet/

[75] Department of Developmental Services. (n.d.) https://www.mass.gov/dds-childrens-autism-waiver-service-program-overview

[76] Department of Developmental Services. (n.d.) https://www.mass.gov/dese-dds-program

are prioritized for this program.[77] So, while this program is another important support in the social services network for children with ASD, the program's scope is children whose behaviors and needs put them at-risk for out-of-home placement.

Autism Support Centers

Caregivers are responsible for the process of coordinating care and transitioning services as a child grows up or their needs change. There are piecemeal systems to support caregivers in this process, but more centralized service coordination could help alleviate this burden.

DDS maintains seven Autism Support Centers accessible to all residents across the state to improve service access and educate and support caregivers and families of children with ASD. The Autism Support Centers also offer culturally competent and language-diverse options to improve access equity. The services they offer include:

- Information and Referral
- Family Clinics
- Support Groups
- Access to the latest information on autism
- Family Trainings
- Parent Networking and Mentoring, and
- Social/recreational events, among other activities

The Autism Support Centers are an invaluable resource for families and caregivers, though caregivers may not be aware they exist, and services vary by center. Some Autism Support Centers may directly provide home modification products and subsidization of radio tracking devices. All of the Support Centers are able to provide information about ABA and other nearby therapeutic options, referrals to providers, and familial support while navigating the care coordination process.

Model Programs for Care Coordination

The first and most substantial care coordination phase occurs after an initial ASD diagnosis, when caregivers face a multitude of decisions outlined above, including enrolling in therapies, applying for supplemental insurance, handling care reimbursement, and researching alternative or non-therapeutic services like swim lessons. Healthcare providers, Autism Resource Centers, and parent support groups can all help find and access services, but more centralized coordination would benefit all families in receiving consistent and high-quality support.

A few promising models exist for supporting caregivers in a time of overwhelming care coordination. First, the Massachusetts Child Psychiatry Access Program (MCPAP) connects primary care providers with behavioral health consultation teams to increase behavioral health care access in

[77] Residential schools may offer day or full-time programs for children with ASD. This report does not cover out-of-home placements in considering the services addressing wandering, as the focus of this report is preventing wandering from the home. Out-of-home placements have unique considerations in their ability to provide 24/7 supervision and other safeguards that are typically not possible for caregivers. However, residential school day programs or full-time placement are important resources to consider in the services available to children with ASD and their caregivers.

part through effective referrals and care coordination.[78] In translating this approach to ASD services, primary care providers and developmental health specialists could refer families directly to a centralized program structured like MCPAP after diagnosis. These teams could function in a similar manner as MCPAP to consult with the family or caregiver before referring them to the appropriate services in their network. This would also create an opportunity for consistent care connection for caregivers to receive information about CommonHealth insurance, Autism Resource Centers, DDS waiver programs, EIBI, and more.

A second model for care coordination comes from the William James College INTERFACE Referral Service, which coordinates mental health care for individuals experiencing suicidality in participating municipalities.[79] Individuals make a single short call, and the INTERFACE staff then call programs to assess availability and access, before providing this list back to the individual seeking care. Implementing a similar process for coordinating the initial care for a child with ASD would alleviate some of the difficulties caregivers face when negotiating long waitlists and differing insurance coverage.

These are not the only examples of care coordination. Other strong models include the Massachusetts Behavioral Health Helpline and Children's Trust by Find Help.[80] Implementing a centralized program for care coordination after diagnosis would alleviate the primary responsibility on Autism Support Centers and allow them to offer greater support at later phases of a child's ASD journey. This includes navigating the end of EIBI services and the transition to ABA services, special education, the possible transition to out-of-home placement, the transition from child and youth to adult services, and provision of home modification tools.

Conclusion & Recommendations

The rates of child fatalities are increasing while rates of infant mortality are decreasing in Massachusetts. The worrying trend in child fatalities after the age of one increasing must be carefully monitored, especially for areas of inequity including geographic location, age, sex, race and ethnicity, and for vulnerable populations like new arrival status and children with developmental disorders, like Autism Spectrum Disorder.

Autism Spectrum Disorder presents unique risks for fatality before the age of 18, especially in the context of wandering behavior and drowning. Understanding the risk for fatality for children with ASD, coupled with the increase in the number of children diagnosed with ASD in Massachusetts, means that the safety and fatality prevention for this vulnerable population should be continually assessed.

---

[78] Massachusetts Child Psychiatry Access Program (n.d.) Massachusetts Department of Mental Health. https://www.mcpap.com/

[79] INTERFACE Referral Service (n.d.) William James College. https://interface.williamjames.edu/

[80] Behavioral Health Help Line (BHHL) FAQ (n.d.) Massachusetts Department of Mental Health. https://www.mass.gov/info-details/behavioral-health-help-line-bhhl-faq
Children's Trust Massachusetts (n.d.) Find Help. https://childrenstrustma.findhelp.com/

By implementing comprehensive prevention strategies, improving awareness and education for caregivers and first responders, and enhancing service delivery across the state, Massachusetts can better protect and support our children with ASD. These efforts will require coordinated action and sustained commitment from all stakeholders, including state agencies, healthcare providers, educators, and families.

Understanding why a child is exhibiting wandering behavior and changing the root behavior will be the most effective strategies for keeping a child safe. However, this may not always be possible or realistic, and harm reduction tools like home modification can prevent the child from leaving, even if that is their desire. If a child does leave a safe area, being able to find them quickly and accurately will reduce their chances of encountering a dangerous environment. Finally, if a child wanders, is not found, and encounters water, being able to get out of the water or stay afloat will increase the time that rescuers have to find them.

While some agencies have developed and translated documents on wandering, water safety, and other ASD-specific risks that could be shared for greater access for vulnerable populations, information is not centralized, irregularly updated, not shared across agencies or organizations, and may have conflicting guidance.

Navigating all this information and processes while caring for a child with ASD can be exhausting as well as isolating. The state team believes that implementing the following recommendations will reduce caregiver burden, improve the quality of services provided in Massachusetts, and ultimately prevent child fatalities:

Recommendations
Raising Caregiver Awareness
Collect ASD diagnosis as part of child fatality review criteria in all cases
Identify or create and promote a centralized hub of educational resources, material goods, service providers, and funding opportunities for caregivers and providers of children with ASD.
Develop and disseminate a standardized tool for asking caregivers about elopement risk with provider education about wandering behavior, associated risks, and prevention.
Conduct an elopement screening and provide caregiver education, including emergency preparedness, during provider interactions.
Home Modification Access
Establish a pilot program for home safety modifications.
Provide insurance coverage for prevention methods such as home modifications, elopement screenings, swim lessons, and tracking devices.
Educational and Therapeutic Support
Create a centralized intake for Applied Behavior Analysis (ABA) therapies.
License and regulate Applied Behavior Analysis (ABA) Centers.
Create a strategy for growing the workforce that supports children with ASD, including but not limited to: • Board Certified Behavior Analysts • Registered Behavior Technicians, and • Aquatics Professionals

Create strategies for meeting DESE's Comprehensive Health and Physical Education objective for children to have the "ability to apply strategies for staying safe…around water" that are adapted to the specific needs of children with ASD.
Identify and/or develop model curriculum for the personal safety standards and provide guidance for adapting the curriculum to students with special needs.
Increase funding for adaptive swim lessons.
Emergency Preparedness & Response
Conduct an assessment to determine the extent to which first responder training regarding children with autism has spread across the commonwealth, the availability of radio tracking devices and reverse 9-1-1, and create a strategy to improve access as necessary.
Develop and promote in-service training on public safety risks, including elopement of people with ASD for first responders.
Encourage parents to maintain a packet of information that is easy to access in a moment of crisis, and or proactively speak with local first responders. The packet should include information about the child's key interests, points of concern near the home, and consideration for how best to approach the child when they are located.
Create and promote a standardized practice in first responder agencies to identify and maintain information about children with ASD.
Care Coordination
Expand access to respite care for caregivers of children with ASD.

This report's scope is narrow in addressing the increased risk of fatality that children with ASD face. There are countless agencies, organizations, committees, groups, and families that work tirelessly every day to nurture and provide for children with ASD, including but not limited to keeping them safe. Caring for and working with children with ASD can sometimes be stressful, in part because of the barriers to care that exist, but can also be joyful and rewarding. It is the aim of this report to help more children and their families remain safe and make the process of accessing care less burdensome.

The recommendations outlined in this report provide a roadmap for ensuring the safety and well-being of children with ASD in the Commonwealth of Massachusetts. These solutions delve into to the root of service access barriers that affect children with ASD and their families. Improving access to services, supporting caregivers, and standardizing practices across agencies will improve outcomes not only in drowning deaths, but for children with ASD at large.

References

1. Alaniz, M. L., Rosenberg, S. S., Beard, N. R., & Rosario, E. R. (2017). The Effectiveness of Aquatic Group Therapy for Improving Water Safety and Social Interactions in Children with Autism Spectrum Disorder: A Pilot Program. *Journal of Autism and Developmental Disorders*, *12*, 4006–4017. https://doi.org/10.1007/s10803-017-3264-4
2. Alec First Responder Training. (n.d.) LifeWorks Autism Resource Center. https://lifeworksarc.org/service/alec-first-responder-training/
3. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Arlington, VA: American Psychiatric Association; 2013.
4. Anderson, C., Law, J. K., Daniels, A., Rice, C., Mandell, D. S., Hagopian, L., & Law, P. A. (2012). Occurrence and Family Impact of Elopement in Children with Autism Spectrum Disorders. *Pediatrics*, *5*, 870–877. https://doi.org/10.1542/peds.2012-0762
5. Barnard-Brak, L., Richman, D. M., & Moreno, R. (2016). Predictors of Elopement Exhibited by School-Aged Children with Special Health Care Needs: Towards the Development of a Screening Instrument for Elopement. *The Journal of Primary Prevention*, *6*, 543–554. https://doi.org/10.1007/s10935-016-0449-0
6. Catalá-López, F., Hutton, B., & Page, M. (2022). Mortality in Persons with Autism Spectrum Disorder or Attention-Deficit/Hyperactivity Disorder. *Journal of American Medicine Pediatrics*. https://doi.org/10.1001/jamapediatrics.2021.6401
7. *Early Childhood Special Education*. (2018, March 20). Massachusetts Department of Elementary and Secondary Education. https://www.doe.mass.edu/sped/ecse/
8. Eversole, M., Collins, D. M., Karmarkar, A., Colton, L., Quinn, J. P., Karsbaek, R., Johnson, J. R., Callier, N. P., & Hilton, C. L. (2015). Leisure Activity Enjoyment of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *1*, 10–20. https://doi.org/10.1007/s10803-015-2529-z
9. Executive Office of Health and Human Services. (2023). Autism Commission 2023 Annual Report. https://www.mass.gov/doc/2023-annual-report-of-the-autism-commission/download
10. Executive Office of Health and Human Services. (2023). Autism Commission 2023 Annual Report. https://www.mass.gov/doc/2023-annual-report-of-the-autism-commission/download
11. *File of Life*. (2022). File of Life. https://www.thefileoflife.org/
12. Franklin, R. C., Pearn, J. H., & Peden, A. E. (2017). Drowning fatalities in childhood: the role of pre-existing medical conditions. *Archives of Disease in Childhood, 10*, 888–893. https://doi.org/10.1136/archdischild-2017-312684
13. Grosse, S. J. (2014). Aquatic Safety for Individuals with Autism Spectrum Disorders. *International Journal of Aquatic Research and Education*, *3*. https://doi.org/10.25035/ijare.08.03.08
14. Guan, J., & Li, G. (2017b). Characteristics of unintentional drowning deaths in children with autism spectrum disorder. *Injury Epidemiology*, *1*. https://doi.org/10.1186/s40621-017-0129-4
15. H.2351, 193rd Sess. (2023). An Act relative to police interactions with persons on the autism spectrum

16. Huang, P. (2024, May 30). *Keeping Autistic Children Safe While Sleeping | | CIRP*. Center for Injury Research and Prevention. https://injury.research.chop.edu/blog/posts/keeping-autistic-children-safe-while-sleeping
17. *Individualized Education Program Process Guide*. (2001). Massachusetts Department of Elementary and Secondary Education. https://www.doe.mass.edu/sped/iep/proguide.pdf
18. Injury Surveillance Program (n.d.). Massachusetts Department of Public Health. https://www.mass.gov/injury-surveillance-program).
19. Johnson, K. R., Hagadorn, J. I., & Sink, D. W. (2017). Alarm Safety and Alarm Fatigue. *Clinics in Perinatology*, *3*, 713–728. https://doi.org/10.1016/j.clp.2017.05.005
20. Kay, S. (n.d.). *Teaching Children with Autism About Safety*. May Institute. Retrieved August 2, 2024, from https://www.mayinstitute.org/news/acl/asd-and-dd-child-focused/teaching-children-with-autism-about-safety/
21. Keall, M. D., Pierse, N., Howden-Chapman, P., Cunningham, C., Cunningham, M., Guria, J., & Baker, M. G. (2015). Home modifications to reduce injuries from falls in the Home Injury Prevention Intervention (HIPI) study: a cluster-randomised controlled trial. *The Lancet*, *9964*, 231–238. https://doi.org/10.1016/s0140-6736(14)61006-0
22. Maenner, M. J., Warren, Z., Williams, A. R., Amoakohene, E., Bakian, A. V., Bilder, D. A., Durkin, M. S., Fitzgerald, R. T., Furnier, S. M., Hughes, M. M., Ladd-Acosta, C. M., McArthur, D., Pas, E. T., Salinas, A., Vehorn, A., Williams, S., Esler, A., Grzybowski, A., Hall-Lande, J., … Shaw, K. A. (2023). Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. *MMWR. Surveillance Summaries*, *2*, 1–14. https://doi.org/10.15585/mmwr.ss7202a1
23. Massachusetts Department of Transportation (2024). Safe Routes to School Program. https://www.mass.gov/safe-routes-to-school
24. Massachusetts Rehabilitation (2024). Home Modification Loan Program. https://www.mass.gov/home-modification-loan-program-hmlp
25. *MassHealth Announces Accreditation Requirement for Applied Behavior Analysis Providers*. (2024, October 1). Autism Commission on Quality.
26. *Mayes, S. D., Gorman, A. A., Hillwig-Garcia, J., & Syed, E. (2013). Suicide ideation and attempts in children with autism. Research in Autism Spectrum Disorders, 1, 109–119. https://doi.org/10.1016/j.rasd.2012.07.009*
27. McIlwain, L., & Fournier, W. (2012). Lethal Outcomes in Autism Spectrum Disorders (ASD) Wandering/Elopement. *National Autism Association*. https://nationalautismassociation.org/wp-content/uploads/2012/01/Lethal-Outcomes-In-Autism-Spectrum-Disorders_2012.pdf
28. McIlwain, L., & Fournier, W. (2017). Mortality & risk in ASD wandering/elopement 2011–2016. Retrieved September 16, 2021 from https://nationalautismassociation.org/wp-content/uploads/2017/04/NAAMortalityRiskASDElopement.pdf
29. McLaughlin, L., Keim, S. A., & Adesman, A. (2018). Wandering by Children with Autism Spectrum Disorder: Key Clinical Factors and the Role of Schools and Pediatricians. *Journal of Developmental &; Behavioral Pediatrics*, *7*, 538–546. https://doi.org/10.1097/dbp.0000000000000591

30. Mische Lawson, L., D'Adamo, J., Campbell, K., Hermreck, B., Holz, S., Moxley, J., Nance, K., Nolla, M., & Travis, A. (2019). A Qualitative Investigation of Swimming Experiences of Children With Autism Spectrum Disorders and Their Families. *Clinical Medicine Insights: Pediatrics*, 117955651987221. https://doi.org/10.1177/1179556519872214
31. Nadel, S. (2020). *American Council for an Energy-Efficient Economy.* Weatherization and Home Improvements: A Promising Path for Improving Health and Reducing Medical Costs for Older Adults
32. National Autism Association. (2017). First Responder Toolkit: A Guide to Searching for Missing Persons on the Autism Spectrum.
33. Pardej, S. K., & Mayes, S. D. (2024). Prevalence and Correlates of Poor Safety Awareness and Accidental Injury in ASD, ADHD, ASD + ADHD, and Neurotypical Youth Samples. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-024-06417-z
34. Pereira-Smith, S., Boan, A., Carpenter, L. A., Macias, M., & LaRosa, A. (2019). Preventing elopement in children with autism spectrum disorder. *Autism Research*, *7*, 1139–1146. https://doi.org/10.1002/aur.2114
35. Pham, A. V., & Charles, L. C. (2023). Racial Disparities in Autism Diagnosis, Assessment, and Intervention among Minoritized Youth: Sociocultural Issues, Factors, and Context. *Current Psychiatry Reports*, *5*, 201–211. https://doi.org/10.1007/s11920-023-01417-9
36. Pitter, Marron. (2023, October 12). *Psychology Professor to Study Effects of Injuries on Children with Autism Spectrum Disorder | UMass Lowell*. UMass Lowell. https://www.uml.edu/news/stories/2023/shen-asd-grant.aspx
37. Rice, C. E., Zablotsky, B., Avila, R. M., Colpe, L. J., Schieve, L. A., Pringle, B., & Blumberg, S. J. (2016). Reported Wandering Behavior among Children with Autism Spectrum Disorder and/or Intellectual Disability. *The Journal of Pediatrics*, 232-239.e2. https://doi.org/10.1016/j.jpeds.2016.03.047
38. Scheithauer, M., Call, N. A., Lomas Mevers, J., McCracken, C. E., & Scahill, L. (2020). A Feasibility Randomized Clinical Trial of a Structured Function-Based Intervention for Elopement in Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-020-04753-4
39. *Special Education School Services*. (n.d.). The New England Center for Children. https://www.necc.org/education/school-services/
40. *Tobik, A. (2020, January 15). Social Stories for Autistic Children. Autism Parenting Magazine; https://www.facebook.com/AutismParentingMagazine.* *https://www.autismparentingmagazine.com/social-stories-for-autistic-children/*
41. T-Pederson, C., Reisert, H., & Adesman, A. (2021a). Wandering behavior in children with autism spectrum disorder and other developmental disabilities. *Current Opinion in Pediatrics*, *4*, 464–470. https://doi.org/10.1097/mop.0000000000001038
42. *Wandering (Elopement).* (2024, May 14). Centers for Disease Control and Prevention, Child Development. https://www.cdc.gov/child-development/disability-safety/wandering.html
43. Wiggins, L. D., DiGuiseppi, C., Schieve, L., Moody, E., Soke, G., Giarelli, E., & Levy, S. (2020). Wandering Among Preschool Children with and Without Autism Spectrum Disorder. *Journal of Developmental &; Behavioral Pediatrics*, *4*, 251–257. https://doi.org/10.1097/dbp.0000000000000780

44. Wright, J. (2017, March 3). *The Real Reasons Autism Rates Are Up in the U.S.* The Scientific American. https://www.scientificamerican.com/article/the-real-reasons-autism-rates-are-up-in-the-u-s/
45. Zeidan, J., Fombonne, E., Scorah, J., Ibrahim, A., Durkin, M. S., Saxena, S., Yusuf, A., Shih, A., & Elsabbagh, M. (2022). Global prevalence of autism: A systematic review update. *Autism Research*, *5*, 778–790. https://doi.org/10.1002/aur.2696

Appendix A. FY24 CFR Program Activities

State CFR Team

The state team met a total of four times in FY24, including two joint in-person meetings with the local team leaders. The meetings focused on providing resources and workflow guidelines for the local teams, determining team priorities, and directing the development of the ASD & Unintentional Fatality research project. The joint in-person meetings allowed for collaboration and information exchange between state team members and local team leaders, and perspective-sharing on topics of interest.

Local CFR Teams

In FY24, eight of the 11 local teams met a total of 21 times and reviewed 84 fatalities. The Berkshires District Attorney's Office successfully held the first local CFR team meeting for their district in over three years. Both Worcester and Hampden local teams did not meet in FY24 but have engaged in technical assistance meetings to prepare for meetings in FY25. The Bristol local team did not meet in FY24. Local team meetings resulted in 40 prevention recommendations and five continuous quality improvement recommendations. The state Team is currently analyzing those recommendations with the support of subject matter experts to generate recommendations for the legislature and other audiences.

Technical assistance

In FY24 the CFR program hired two administrative roles. Johnny Rezendez joined in July 2023 as the CFR Epidemiologist, and Meg Crowley joined in December 2023 as the full-time CFR Coordinator. The CFR Epidemiologist supported both the local and state CFR teams in FY24 by providing epidemiological data relevant to specific regions and demographic groups and overall epidemiologic statistics for child fatalities in Massachusetts. The CFR Coordinator provided technical assistance to the local teams for application of the Local Team Guidelines, utilizing subject matter experts, meeting facilitation and organization, and relationship building through collaborative sessions open to all local team leadership. The CFR coordinator offered technical assistance to all teams, including the teams that were not meeting in FY23 and FY24. Of the teams that were not regularly meeting, the CFR Coordinator provided technical assistance to the Berkshires, Hampden, and Worcester local team leadership. The CFR Coordinator also organized the first of standing quarterly local team collaborative sessions, where local team leadership can share strategies and support one another's reviews.

Appendix B. FY24 Team Membership

State Team Membership

Dr. Mindy Hull
Chief Medical Examiner, Chair

Amanda Paull
Designee of the Attorney General

Dr. Eileen Costello
Designee of the Commissioner of the Department of Children and Families

Margie Gilberti
Designee of the Commissioner of the Department of Early Education and Care

Katharine Folger
Representative of the Massachusetts District Attorneys Association

Kelley Cunningham
Designee of the Commissioner of the Department of Public Health

Michelle Harris
Designee of the Commissioner of the Department of Developmental Services

Rachelle Engler Bennett
Designee of the Commissioner of the Department of Elementary and Secondary Education

Shari Krauss
Director of the Massachusetts Center for Unexpected Infant and Child Death

Karine Martirosyan
Designee of the Commissioner of the Department of Youth Services

Maria Mossaides
Director of the Office of the Child Advocate

Dr. Nandini Talwar
Designee of the Commissioner of the Department of Mental Health

Chief John Paciorek, Jr.
Designee of the Massachusetts Chiefs of Police Association

Dr. Celeste Wilson
Representative of the Massachusetts Chapter of the American Academy of Pediatrics with experience in child abuse and neglect

Alex Levie
Representative of the Massachusetts Health & Hospital Association

The team positions for Colonel of the State Police or designee and Chief Justice of the Juvenile Division of the Trial Court or designee are vacant. The CFR statute also allows for attendance to state team meetings by other individuals with information relevant to fatalities under review.

Local Team Leadership

Berkshires
Timothy Shugrue, District Attorney
Team Leader: Andrew Giarolo,
Assistant District Attorney

Bristol
Thomas Quinn, District Attorney
Team Leaders: Dennis Collins,
Assistant District Attorney

Cape and Islands
Robert J Galibois, District Attorney
Team Leader: Alissa Goldhaber,
Assistant District Attorney

Essex
Paul Tucker, District Attorney
Team Leader: Kate MacDougall,
Assistant District Attorney

Hampden
Anthony Gulluni, District Attorney
Team Leader: Eileen Sears,
Assistant District Attorney

Middlesex
Marian Ryan, District Attorney
Team Leader: Katharine Folger,
Assistant District Attorney

Norfolk
Michael Morrissey, District Attorney
Team Leader: Lisa Beatty,
Assistant District Attorney

Northwestern
David Sullivan, District Attorney
Team Leader: Lori Odierna,
Assistant District Attorney

Plymouth
Timothy Cruz, District Attorney
Team Leader: Shanan Buckingham,
Assistant District Attorney

Suffolk
Kevin Hayden, District Attorney
Team Leader: Audrey Mark,
Assistant District Attorney

Worcester
Joseph Early, District Attorney
Team Leader: Courtney Sans,
Assistant District Attorney

Appendix C. Previously Issued Recommendations

Year	Recommendations	Updates and Information
FY22	Develop guidance to support municipalities and communities in the establishment of community schools and expansion of availability of and resources for school-based health centers.	No updates at this time. In January 2021, DESE released Massachusetts Family, School, and Community Partnership Fundamentals 2.0. These guidelines are a strong first step to establish more community schools.
FY22	Expand programs that support the deployment of active and passive cooling technologies—including in residences, rental properties, and schools—with an emphasis on growing heat pump use in environmental justice communities.	No updates at this time. S893 An Act relative to access to air conditioning and relief from oppressive heat was proposed in the 2022-2023 legislative session and reported favorably in committee but ultimately was not passed.
FY22	Require the use of integrated pest management as standard practice by licensed pesticide applicators and subsidize the provision of such services to residents in environmental justice communities.	No updates at this time. H783 An Act relative to the pesticide board was proposed in the 2022-2023 legislative session and reported favorably in committee but ultimately was not passed.
FY22	Study the feasibility of a program that pairs home safety assessments with subsidized home modifications to mitigate injury risk among children.	No updates at this time. The Home Modification Loan Program, which began in 1999, provides 0% loans up to $50,000 for eligible homeowners, but does not offer grants or subsidies.
FY22	Create a statewide Fetal and Infant Mortality Review program to examine the circumstances surrounding individual fetal and infant deaths and to make recommendations that would prevent similar deaths in the future.	An act promoting access to midwifery care and out-of-hospital birth options was passed in August 2024 and includes the creation of a fetal and infant mortality review board within the Department of Public Health.
FY21	Massachusetts policymakers petition the FDA to reconsider the inclusion of corn masa in their fortification requirements, and work to create incentives for corn masa manufacturers to fortify their products, for food manufacturers to use fortified corn masa in their products, and for retailers to stock products that contain fortified corn masa.	No updates at this time. However, the Center for Science in the Public Interest released *Food Companies Thwarting Success of FDA Fortification Policy, Report Finds*, in February of 2023.
FY21	Massachusetts policymakers implement an ethical and equitable primary seat belt law, alongside updated, linguistically appropriate, culturally responsive, and accessible education campaigns about the importance of seat belt use geared	HB2340 (HD1956) An Act relative to primary enforcement of seatbelt violations was proposed in the 2022-2023 legislative session and an accompanied study order was filed in August 2024.

Year	Recommendations	Updates and Information
	towards audiences with the lowest seat belt use rates and highest unbelted crash rates, and improved access to car seats and installation services.	
FY20	The state team continues its support for legislation moving the responsibility for administrating the CFR program from OCME to OCA, with OCA and DPH representatives becoming designated co-chairs of the state team.	No updates at this time. HB 4391, An Act Relative to Child Fatality Review was proposed and initially incorporated as an amendment into the 2025 budget, but ultimately did not pass in the 2022-2023 legislative section.
FY20	The Commonwealth should study the feasibility of requiring that public and semi-public swimming pools have emergency service activation systems or call boxes within the pool's fence perimeter and in a form that complies with ADA accessibility guidelines.	No updates at this time. 105 CMR 435.00 Minimum Standards for Swimming pools (State Sanitary Code: Chapter V) was updated in June 2023, and now require semi-public and public swimming pools to have an Emergency Phone available, as described in section 435.25.
FY20	The Commonwealth should work with providers to increase cell phone coverage in underserved areas, particularly along roadways.	No updates at this time. In 2022, AT&T began an expansion project to bring more cell coverage to Central and Western Massachusetts.
FY20	In order to practice, licensed mental health clinicians and social workers should be required to have continued education/training on suicidality, screening for suicide risk, and suicide prevention strategies.	No updates at this time.
FY20	Commonwealth executive branch agencies should collect gender identity in their data sets.	The Juvenile Justice Policy and Data Board (pg. 76), the LBGTQ+ Commission, the Human Rights Campaign, and the National LGBTQIA+ Health Education Center have all released similar recommendations.
FY20	In order to better coordinate care for children across state providers, all EOHHS agencies should use a standard confidential information sharing mechanism for client case records.	No updates at this time.
FY20	Adults operating a motorboat or other motorized personal watercraft in Massachusetts should be required to take a boating safety course.	No updates at this time. HB4941 - An Act relative to boater safety to be known as the Hanson Milone Act was passed in the House in the 2023-2024 legislative session, but did not pass in the Senate.

Appendix D. Information about Wandering and Drowning Prevention for Caregivers

See following page for a caregiver fact sheet.

2024 MASSACHUSETTS CHILD FATALITY REVIEW PROGRAM

Wandering & Drowning Prevention

Information For Caregivers of Children with Autism Spectrum Disorder

25 to 50%

Of children with ASD leave a safe area without telling anyone. This usually happens at home, but can happen at school, programming, or on an outing. Wandering can happen because a child wants something or is overwhelmed by a situation, or simply doesn't know it's not safe.

The #1 cause of death for children with ASD is drowning, and usually after the child wandered away from home.

#1

Wandering can happen because a kid wants something or is overwhelmed by a situation, or simply doesn't know it's not safe.

Curiosity, Stress, Wants

Children wander for a lot of different reasons. Understanding why your child wanders will help inform how you and your child's providers protect against wandering.

How to Protect Your Child

Each layer of prevention can work in tandem with others, and having multiple strategies to prevent wandering and drowning can increase you child's safety.

Know the Risks

If you are concerned about wandering, understand the risky areas around your child's home, school, and activities. Identify wandering triggers and work with your child's healthcare provider, ABA specialists, and educators to prevent and plan for wandering.

Building Skills

Applied Behavior Analysis (ABA) and other therapies can help children with ASD learn important skills like communicating needs, recognizing dangerous situations, and finding help when they need it. If your child gets ABA or other therapies, they can work with you and your child on skills to prevent wandering.

Home Modification

Installing door locks, window locks and guards, visual cues, and fences to prevent wandering from the home. If you have have a pool, you should put up fencing, locks, and alarms. Find more information here.

Monitoring Devices

Radio frequency or GPS tracking devices can help you and first responders find your child if they wander. Many options with various features exist. Find more information here.

Prepare for an Emergency

Maintaining a "File of Life" can help first responders locate your child more quickly if they wander. Introducing your child to first responders can help them become comfortable with first responders and help first responders get to know your child before an emergency. Find information about what to tell them here.

Swimming Lessons

Consider all of the other prevention strategies along with swimming lessons to prevent your child from coming into contact with water unsupervised. However, swimming lessons can help your child in an emergency. Find a list of adaptive swimming lessons here.

Caregiver Support

Constantly worrying about your child's safety is stressful and exhausting. If you need support, consider reaching out to an Autism Resource Center near you. These centers often provide respite care options, sibling support groups, and care coordination and navigation tips. Your local Special Education Parental Advisory Council can also help you navigate local options and connect you to other families. You are not alone.

Resource Connection

FY24 Child Fatality Review Annual Report	For in-depth information about wandering prevention
Children's Trust Find Help	For resources and services for children in MA
Department of Developmental Services	For care coordination, language support, and more
Autism Resource Centers	For care navigation, caregiver support, and more
The Autism Program at BMC	Resource guides for safety, water safety, and more
NAA's Big Red Safety Box	For safety information and free supplies
NAA's Meet the Police	For guidance on information for your local police

Appendix E. Information About Wandering and Drowning Prevention for Providers

See following page for a provider fact sheet.

Wandering and Drowning in Children with Autism Spectrum Disorder – Provider Fact Sheet

The following provides succinct talking points, resources, and additional references to support therapeutic, health care, and social services providers in discussing and addressing the risk of wandering with caregivers of children with ASD.

ASD & Wandering

- Wandering, also called elopement or bolting, is more common in children with Autism Spectrum Disorder (ASD) compared to their neurotypical counterparts after the age of four.[1,2,3]
- Once a child with ASD leaves a supervised space, they are at risk for contact with dangerous environments, including bodies of water and busy roads.[4] These interactions can be fatal.[4,5,6]

Wandering & Drowning

- *Risk of Drowning Death:* Nationally, ASD is associated with an increased risk of unintentional injury fatality in children.[5] **Drowning is the leading cause of death in children ages 1 to 17 with ASD**.[6,7]
- *Wandering and Drowning:* A 2017 study of media-reported wandering cases of children with ASD from 2011 to 2016 found that **71% of fatal outcomes were the result of drowning.**[8] While aquatic play can be a fruitful source of stimulation, relaxation and enrichment, it may also mean that in instances of wandering, children with ASD may seek out or be drawn to water environments.
- *Mechanism of Wandering and Death:* 49% of fatal wandering events originated from the home.[8] The age group with the greatest number of reported wandering events, and greatest number of fatal wandering events, was between the ages of five and nine.[5,7,8]

Actions for Caregivers to Take	Talking Points	Supporting Access
Home Modification	It is essential to install physical barriers as soon as possible once wandering tendencies are identified. These may be temporary or permanent depending on a child's wandering behavior.	Many organizations and support centers provide free or reduced-cost products like door locks, window guards, and alarms. For a non-exhaustive list of resources, see the FY24 CFR Annual Report.
Tracking Technology	Wearable tracking and monitoring devices can aid caregivers and first responders in locating a child who has wandered.	DDS, the Autism Support Centers, and the Flutie Foundation offer financial assistance for the SafetyNet tracking bracelet. For a list of products providers can recommend and the financial assistance available, see the FY24 CFR Annual Report.
Alerting Emergency Responders	Caregivers can introduce their child with ASD to local first responders, so that in a wandering event responders are aware of nearby hazards, the child's preferences, and how to interact safely.	Direct families to the local law enforcement agencies to inquire about programs for introducing their child with ASD to the agency.
Adaptive Swimming Lessons	Once a child enters a body of water unsupervised, the risk of fatality substantially increases, even with the ability to swim. Still, the ability to swim can prolong the window of time first responders have to find the child or allow a child to return to land.	Adaptive swimming lessons are not available everywhere. Providers can direct caregivers to the list in Appendix F of the FY24 CFR Annual Report. For financial support in accessing swimming lessons, providers can direct caregivers to the Autism Support Centers or the Flutie Foundation.
Enhancing Communication Skills	Therapies like ABA can curb wandering behavior by enhancing a child's ability to communicate their needs instead of wandering. ABA can also work on skills like asking for help when they have wandered.	ABA should be covered by the child's health insurance. If the child is not on MassHealth, MassHealth CommonHealth may provide additional coverage for children with ASD. Visit MAIRC for more information.

Supporting Families and Caregivers	Caregivers must cope with the very real fear of knowing the risks associated with wandering. Parents of children with ASD who wander alter their behavior to keep their children safe, like limiting outings in public or not leaving their child under family or friend's supervision.[9]	Direct caregivers to the Parental Stress Line (1-800-632-8188) and options for respite care. Caregivers may also find support through the Autism Support Centers and their local Special Education Parent Advisory Councils. For more resources, visit the OCA's Parent and Caregiver Support page.

For More Information

The following resources provide more in-depth information for providers who work with children with ASD:

- FY24 Child Fatality Review Annual Report
- Children's Trust Find Help
- Department of Developmental Services
- Autism Resource Centers
- The Autism Program at BMC
- NAA's Big Red Safety Box
- NAA's Meet the Police

References:

1. Wiggins, L. D., DiGuiseppi, C., Schieve, L., Moody, E., Soke, G., Giarelli, E., & Levy, S. (2020). Wandering Among Preschool Children with and Without Autism Spectrum Disorder. *Journal of Developmental &; Behavioral Pediatrics*, *4*, 251–257. https://doi.org/10.1097/dbp.0000000000000780;
2. Rice, C. E., Zablotsky, B., Avila, R. M., Colpe, L. J., Schieve, L. A., Pringle, B., & Blumberg, S. J. (2016). Reported Wandering Behavior among Children with Autism Spectrum Disorder and/or Intellectual Disability. *The Journal of Pediatrics*, 232-239.e2. https://doi.org/10.1016/j.jpeds.2016.03.047
3. T-Pederson, C., Reisert, H., & Adesman, A. (2021a). Wandering behavior in children with autism spectrum disorder and other developmental disabilities. *Current Opinion in Pediatrics*, *4*, 464–470. https://doi.org/10.1097/mop.0000000000001038
4. Anderson, C., Law, J. K., Daniels, A., Rice, C., Mandell, D. S., Hagopian, L., & Law, P. A. (2012). Occurrence and Family Impact of Elopement in Children With Autism Spectrum Disorders. *Pediatrics*, *5*, 870–877. https://doi.org/10.1542/peds.2012-0762
5. Catalá-López, F., Hutton, B., & Page, M. (2022). Mortality in Persons with Autism Spectrum Disorder or Attention-Deficit/Hyperactivity Disorder. *Journal of American Medicine Pediatrics*. https://doi.org/10.1001/jamapediatrics.2021.6401
6. Guan, J., & Li, G. (2017). Characteristics of unintentional drowning deaths in children with autism spectrum disorder. *Injury Epidemiology*, *1*. https://doi.org/10.1186/s40621-017-0129-4
7. Guan, J., & Li, G. (2017). Injury Mortality in Individuals With Autism. *American Journal of Public Health*, *5*, 791–793. https://doi.org/10.2105/ajph.2017.303696
8. McIlwain, L., & Fournier, W. (2012). Lethal Outcomes In Autism Spectrum Disorders (ASD) Wandering/Elopement. *National Autism Associa*tion. /https://nationalautismassociation.org/wp-content/uploads/2012/01/Lethal-Outcomes-In-Autism-Spectrum-Disorders_2012.pdf
9. McLaughlin, L., Keim, S. A., & Adesman, A. (2018). Wandering by Children with Autism Spectrum Disorder: Key Clinical Factors and the Role of Schools and Pediatricians. Journal of Developmental &; Behavioral Pediatrics, 7, 538–546. https://doi.org/10.1097/dbp.0000000000000591

Appendix F. Information About Responding to Elopement of a Child with ASD for First Responders

For Law Enforcement, Fire, and Emergency Medical Services, the following resources outline the important considerations and best practices for interacting safely and effectively with people with ASD. For more resources, see Appendix G.

- National Autism Association's free booklet for First Responders
- National Center for Missing and Exploited Children Handouts
- The International Association of Chiefs of Police Guidance for working with people with Autism

Appendix G. Additional Resources and Information about Wandering and Drowning Prevention

Fact Sheets and Brochures

Water Safety
The Autism Program at Boston Medical Center – Safety Guide Contains information about different door locks, window guards, and other safety equipment. Available in Cape Verdean Creole, Portuguese (Português), Chinese (Zhōngwén), Haitian Creole (Ayisyen Kreyòl), Vietnamese, and Spanish
Water Safety Guide - The Autism Program at Boston Medical Center
Tracking Device Options
Tracking device list in this report, page 28. Last updated September 2024.
Tracking Devices - The Autism Program at Boston Medical Center A list of tracking device options from BMC, last updated 2024
Adaptive Swimming Lessons
Reference list in this document, last updated August 2024.
Greater Massachusetts Special Needs Events Swimming opportunities in Massachusetts, continually updated.
Working with Law Enforcement
National Autism Association's Meet the Police The National Autism Association's (NAA) Meet the Police Booklet contains the information caregivers should prepare to provide to law enforcement.

Material Goods

Home Modification

Big Red Safety Box
The National Autism Association's Big Red Safety Box is a free toolkit (shipping charges may apply) given to families of individuals on the Autism Spectrum. The kit aims to educate, raise awareness and provide simple tools.
The Big Red Safety Box includes:
• A "Be REDy Booklet" containing the following educational materials and tools:
  ○ A caregiver checklist
  ○ A Family Wandering Emergency Plan
  ○ A First-Responder profile form
  ○ A wandering-prevention brochure
  ○ A sample IEP Letter
  ○ A Student Profile Form
  ○ Emotional Identification Cards
  ○ Wandering Quick Tips
• Two GE Wireless Door/Window Alarms with batteries
• One Road ID Bracelet or Shoe ID tag
• Five Adhesive Stop Sign Visual Prompts for doors and windows
• Two Safety Alert Window Clings for car or home windows
• One Child ID Kit from the National Center for Missing and Exploited Children

Available in English and Spanish
Water Safety
Autism Society Social Story Examples of social stories caregivers and educators can use to teach water safety and danger.
Working with First Responders
File of Life File of life provides wallet cards, fridge magnets, and guidelines for the important information that should be shared with first responders in an emergency.
Navigating Public Spaces
Disability Placard Children with ASD are eligible for a disability placard or disability plate. This can mean shorter walks in dangerous spaces like parking lots or roads. Apply for a disability placard at the link above.

Service Providers and Coordinators

Autism Support Centers The Autism Support Centers conduct broad outreach and provide services to families from diverse cultural, ethnic and linguistic communities in the geographic area they are serving and may create partnerships with community organizations and other resources to provide culturally responsive services. The array of services and supports to families includes: • Information and Referral • Family Clinics • Support Groups • Access to the latest information on autism • Family Trainings • Parent Networking and Mentoring, and • Social/recreational events, among other activities
Children's Trust Find Help The Children's Trust database is kept up to date to help families and providers find services and resources.
Massachusetts Autism Insurance Resource Center The Insurance Resource Center for Autism and Behavioral Health supplies fact sheets on insurance details for covering services for ASD treatment and educational materials for consumers, providers, clinicians, employers, and educators
List of ABA Providers DisabilityInfo.org updates a centralized list of ABA providers in Massachusetts. This includes: • Contact information • Location information • Website • Insurance they accept

More Information

Massachusetts Autism Commission – Resources for Families
The Flutie Foundation – Grants and financial support opportunities
Safe Routes to School Program

Appendix H. Adaptive Swim Lessons in Massachusetts

This list was last updated September 2024 and may not be fully comprehensive.

County	Town	Program	Cost	Type of Class	Caregiver must enter water with child	Notes
Barnstable	Sandwich	Sandwich High School - Aquasafe Cape Cod	$50 for ten visits, 42 for $150	Group	Yes	One inclusive swim hour/day
Berkshire	Great Barrington	Berkshire South Regional Community Center	$280-400 for group or private bundles	Private, group	No	Ages 6+
Essex	Marblehead	Jewish Community Center of the North Shore	$299 member, $325 non-member	Private, group	No	Ages 3-16
Franklin	South Deerfield	Water Wonders Swim School – Red Roof Inn	$218.40 for four weekly sessions/mo	Private or Group	No	Ages 3+
Hampden	West Springfield	Water Wonders Swim School – Healthtrax Gym	$218.40 for four weekly sessions/mo	Private or Group	No	Ages 3+
Hampden	East Longmeadow	Water Wonders Swim School – Healthtrax Gym	$218.40 for four weekly sessions/mo	Private or Group	No	Ages 3+
Hampden	Feeding Hills	Water Wonders Swim School – Fitness First Gym	$218.40 for four weekly sessions/mo	Private or Group	No	Ages 3+
Hampshire	Amherst	Amherst Adapts Swim – Amherst Regional Middle School Pool	$110 for four 90 min sessions	Group	No	Ages 6-18
Hampshire	Amherst	Water Wonders Swim School – Hampshire Athletic Club	$218.40 for four weekly sessions/mo	Private or Group	No	Ages 3+
Middlesex	Newton	West Suburban YMCA - Angelfish	$90 – 120 per lesson	Private, semi-private and group lessons	No	Ages 3 mos+

Middlesex	Reading	Burbank YMCA - Angelfish	$90 – 120 per lesson	Private, semi-private and group lessons	No	Ages 3 mos+
Middlesex	Lexington	Lexington Town Pool	$68 for residents, $78 for non-residents	Group	No	No age criteria listed, Seasonal
Middlesex	Concord	Concord Town Pool, Beede Center	$210 residents and non-residents	Group	No	Ages 5+
Middlesex	Lowell	Greater Lowell YMCA	$252 for 30 min for six weeks	Private	No	Ages 5-15
Middlesex	Newton	Leventhal-Sidman Jewish Community Center - Angelfish	Private ($68 for members, $94 for non-members, 30 min) or group ($70 for members, $88 for non-members	Private or group	Yes	Ages 3 mos+
Middlesex	Newton	Wells Ave YMCA - Angelfish	$90 – 120 per lesson	Private, semi-private, group	No	Ages 4 mos+
Norfolk	At-home	South Shore Sunfish	$60 per 30 min lesson, $455 for eight, $36 for semi-private per child	Private or semi-private		Ages 18 mos to 10 yrs, must have pool access
Norfolk	Braintree	Power Aquatics	$286-330 for 13-15 classes	Group	Yes	Ages 2 mos to 7yrs, requires diagnosis
Plymouth	At-home	South Shore Sunfish	$60 per 30 min lesson, $455 for eight, $36 for semi-private	Private or semi-private		Ages 18 mos to 10 yrs, must have pool access

Plymouth	Hanover	Power Aquatics	$286-330 for 13-15 classes	Group	Yes	Ages 2 mos to 7yrs, requires diagnosis
Plymouth	Plymouth	Power Aquatics	$286-330 for 13-15 classes	Group	Yes	Ages 2 mos to 7yrs, requires diagnosis
Suffolk	Mobile	Sunsational Swim School	$480 at 6 lessons for 30 min to $1764 at 18 lessons for 60 min	Private	No	Ages 6 mos+, mobile lessons (must have pool access)
Suffolk	Dorchester	Leahy Holloran Community Center – Boys & Girls Club	$5 membership	Semi-private	No	Ages 5+ 1:1 child to instructor ratio
Suffolk	Brookline	Goldfish Swim School		Private or group	No	Lessons by Golden instructors are available for children with disabilities
Worcester	Worcester	YWCA – Easterseals	Free	Group	No	Ages 5+, Seasonal

Appendix I. Key Terms Glossary

Key terms and abbreviations used in this report include:

ABA	Applied Behavior Analysis
ALEC	Autism Law Enforcement Coalition
ASAP	Aging Services Access Point
ASD	Autism Spectrum Disorder
BCBA	Board Certified Behavior Analyst
CBHI	MassHealth Children's Behavioral Health Initiative
CBT	Cognitive Behavioral Therapy
CFR	Child Fatality Review
CHIP	Children's Health Insurance Program
CORI	Criminal Offender Record Information
DCF	The Massachusetts Department of Children & Families
DDS	The Massachusetts Department of Developmental Services
DESE	The Massachusetts Department of Elementary and Secondary Education
DPH	The Massachusetts Department of Public Health
ECSE	Early Childhood Special Education
EEC	The Massachusetts Department of Early Education and Care
EI	Early Intervention
EIBI	Early and Intensive Behavioral Intervention
EMS	Emergency Medical Services
EOHHS	The Massachusetts Executive Office of Health and Human Services
EOPSS	The Massachusetts Executive Office of Public Safety & Security
EPSDT	Early and Periodic Screening, Diagnosis, and Testing
FY24	Fiscal Year 2024 (July 1, 2023 - June 30, 2024)
HMLP	The Massachusetts Rehabilitation Home Modification Loan Program
ICHP, IHP	Individualized Healthcare Plan
IEP	Individualized Education Program
MCPAP	The Massachusetts Child Psychiatry Access Program
OCA	The Massachusetts Office of the Child Advocate
OCME	The Massachusetts Office of the Chief Medical Examiner
RBT	Registered Behavior Technicians
SUID	Sudden Unexpected Infant Death