



Policy Brief

Lessons from Sandy Hook

Traci Sawyers, March/April 2015

THE PROBLEM

“Nothing is more expensive than a missed opportunity”.....

H. Jackson Brown, Jr.

Adam Lanza (AL) was 20 on December 14, 2012. That is also the day he shot and killed his mother, then went to Sandy Hook Elementary School, killing 20 first-graders and six educators, before taking his own life. At the time of the shooting, he lived in virtual isolation and was severely anorexic. The Office of the Child Advocate (OCA) investigates all child deaths in Connecticut for prevention lessons. While there have been other reports on the Sandy Hook incident, the OCA released its own report in November of 2014, focused specifically on Adam Lanza's developmental, educational and mental health profile from birth until the shooting. This very important report identifies numerous potential missed opportunities by his parents, schools, primary care providers and mental health professionals to understand Adam Lanza's significant social and emotional disabilities and offers critical lessons that must inform work with children and families in Vermont.

THE REPORT AND KEY LESSONS

The OCA report is based on a comprehensive collection and review of records as well as interviews and other research on AL's life beginning at birth. The authors are clear that no one factor led to this horrible event and AL

bears ultimate responsibility for his actions. However, there is much to learn from this very tragic story. A link to this report is included in the endnotes, and most of the information below is referenced directly from that document. Although the report identifies many key findings and recommendations that span AL's life, at least ten themes are critical to examine.

1) Children need assessment and treatment from the earliest possible time. AL did not receive any early intervention services until he was almost 3 years old. The period from birth to 3 is a critical time in a child's development, and research has shown that early intervention before age 3, can significantly lessen or mitigate developmental problems.¹ The report cites a recent longitudinal study of children who received early intervention services prior to age 3. More than a third of these children did not need special education once they started school. Another 2014 study found that treatment at the earliest age when symptoms of Autism Spectrum Disorder (ASD) appear - sometimes in infants as young as 6 months old - reduced symptoms significantly by age 3.² Research clearly shows that early intervention can vastly improve outcomes for children and is the most effective way to promote healthy development. The American Academy of Pediatrics recommends that screenings be done by health professionals at 9, 18, and 24 or 30 months.³ Screenings for autism can now be done at 18 months.⁴ Once screened, primary care providers should work with families to ensure appropriate services and treatment.

2) The diagnosis was not responsible for the tragedy.

Those with Autism Spectrum Disorder and Obsessive Compulsive Disorder typically internalize problems, and do not act out aggressively. However, the combination of severe and untreated mental health issues, an atypical fascination with violence and access to guns was a very dangerous combination. If autism is present and early intervention is provided, children have a significant potential for advancement at a young age and beyond.⁵ A Swedish study of individuals who committed violent crimes also found that they were significantly more likely to have other psychopathological conditions such as psychosis – and not Autism Spectrum Disorder.⁶

3) Untreated mental health issues worsen. AL exhibited social and emotional problems from a very young age and but was not diagnosed with Asperger's Syndrome and Obsessive Compulsive Disorder until eighth grade. This diagnosis came when his mother took him to the local emergency room for a crisis evaluation. At the time, she told the hospital that he had had "borderline autism" earlier in his life but had outgrown it. She said they came because she needed a note to allow him to stay home from school because of his anxiety. There were essentially no well-child visits after fifth grade (2003) but several sick visits. The pediatric records only indicated obsessive/compulsive tendencies. AL was not on medication and received very few mental health services throughout his life. As a result, his mental health challenges progressively worsened without treatment. His parents were concerned and did seek evaluations over the years. However, these evaluations were largely limited in scope and did not take into consideration his history and consistent social and emotional challenges.

The only evaluation that began to capture the extent of his problems was done by the Yale Child Study when he was in ninth grade. This evaluation recommended daily medication, extensive special education services, therapeutic supports, and a neurological evaluation. Yale strongly discouraged taking AL out of school and

advised against a strategy of accommodating his needs, citing that this would lead to a worsening of his mental health condition. His parents ultimately did not follow these recommendations. Instead, he received limited mental health counseling between ages 13-15 from a community psychiatrist. AL refused to take medication, and he was supported by his mother in that decision.

4) Social and emotional issues were evident in his early years but special education in preschool and elementary school focused solely on speech. From his earliest years, AL resisted touch, had severe temper tantrums, was delayed in communication and made up his own language. AL's parents sought out Birth to Three services just before his 3rd birthday as a result of his communication challenges. That initial evaluation found "significantly delayed development of articulation and expressive language skills" and recommended speech services and preschool attendance to "stimulate development in all domains." In preschool, he had an Individualized Education Plan (IEP) created to address issues that could affect learning and development. The plan focused solely on speech and language. However, as early as preschool, it was also noted in records that he had fine and gross motor delays, was withdrawn and had limited participation in class or with other students and was overly sensitive to smells. He also demonstrated repetitive behaviors in class including repeatedly hitting his head. These behaviors could also affect a child's learning and development and should have been addressed in an IEP.

Studies of children with social impairments, repetitive behaviors in particular, have linked communication challenges to behavioral challenges.⁷ The authors also highlight research showing "a longitudinal relationship between behavioral, emotional and social difficulties of students with a history of specific language impairment." In addition, the report suggests that including both language and social and emotional development into AL's educational plan may have suggested autism at an earlier age. However, AL's educational plans were limited to services for speech

and occupational therapy only – specifically on articulation and tolerance for touching school materials while in class. Special education services ended entirely for AL when he was in fourth grade.

5) Parent’s mental health needs are strongly linked to children’s mental health. While AL’s mother certainly cannot be blamed for this tragic event, families can help or hinder the development of their child. In AL’s case, his mother was his primary caregiver after his parent’s divorce when he was in fourth grade. AL had limited contact with his father after this point and no contact with him for two years prior to the shooting. AL’s significant mental health issues were extremely challenging for his mother to deal with on a daily basis and caused her significant and increased stress and anxiety. She wanted desperately to help her son, but his needs were substantial. Without ongoing guidance from trusted professionals and support for her worsening mental state, she was completely overwhelmed.

She eventually passed the point to change the unhealthy dynamic that developed between them early in his life. Her only coping strategy was to avoid upsetting him and to keep him comfortable at almost any cost. His demands and requirements were significant. For example, the doorbell could not be rung, the smell of food and cooking upset him, she could not enter his room, and the clothes that he changed several times a day needed to be washed continually.⁸ At the same time, they both became increasingly isolated as she quit her job to care for him and he withdrew from school and was put on homebound status. In the last few years of her life, she told family and friends that she was given a terminal diagnosis but this was not substantiated in the medical record. No one in AL’s family received mental health services after 2008.

This tragic story shows how deeply parents suffer in the face of a troubled child and demonstrates the need for intensive help for parents and children together. Labeling a child with a psychiatric disorder

and prescribing medication is not enough. Caregivers often need mental health supports including respite and peer supports from other parents raising children with disabilities.

6) Abnormal infatuation with violence, combined with access to guns, must be addressed. AL showed an abnormal infatuation with violence at a young age and there were assault weapons in the house. In fourth grade, he and a classmate wrote the *Book of Granny*, which included very violent stories and drawings focused on hurting children. It appears that this book was not carefully examined by the teacher or his parents. This demonstration of extreme thoughts of violence should have led to a specific discussion with the parents and a possible referral to a mental health professional to assess emotional disturbance. The authors also point out that this happened the year after special education services ended for AL and school staff could have re-considered his special education eligibility based on inappropriate feelings or behaviors illustrated in the book. However, teachers have limited training and time to address social and emotional issues. If a student is progressing academically and not causing disturbances in the classroom, he or she often avoids attention. Social isolation is also often dismissed as shyness and left alone.

AL’s family also engaged in recreational shooting when he was young. Despite his deteriorating mental health condition, he retained open access to his mother’s gun collection containing significant firearms. In addition, in his final years living in virtual isolation, his only social connections were mass murder enthusiasts via a cyber community.

7) Denial plays a powerful role. It is very difficult for a parent to accept that their child is different or has significant problems. Therefore, they often justify a child’s behavior and hope he or she will grow out of it and things will get better. Parents want the best for their child, and a mental health diagnosis can feel threatening.⁹ Parents also may think it reflects badly on their parenting or that it means there is something

wrong with them. Mental health resources and services can be hard to find or come with long waiting lists, and they can be expensive as well. Therefore a parent might justify not accessing this level of help, and instead hope things will get better on their own. Parents are also forced to admit that they need outside help.¹⁰ There is significant stigma associated with mental illness that can cause shame, denial and isolation. Further, with regard to social and emotional difficulties, teachers may also believe a child just needs to mature and will grow out of his or her behavior, especially if the child not taking up a significant amount of their time.

8) Extreme Isolation contributes to mental health deterioration. AL's social and emotional trajectory, lack of adequate services and supports and his mother's strategy of appeasement made them both more isolated each year. He was placed on "homebound status" in eighth grade and did not return to school. His mother requested this based on his anxiety. "Homebound status" in Connecticut is not the same as "homeschooling." "Homebound status" is an accommodation for children too disabled to function in a classroom setting. He ended up graduating early and finished high school mainly through independent study and tutors. There was minimal oversight of his progress by the school. There was also a lack of post-high school special education services which he could have been eligible for. At the end he was living in total isolation and though living with his mother, they only communicated through email in the house. His windows were blacked out with garbage bags and his door reminded locked. As noted above, the only other contact he had was with a cyber community of mass murder proponents with whom he was in email contact.

9) Parents need help understanding and addressing the needs of children with complex developmental and mental health disorders. Although the parents – especially AL's mother – spent a significant amount of time trying to care for AL and his condition, they needed outside help to understand and address the complex mental health and developmental disorders AL

was exhibiting from a very early age. The Yale Study psychiatrist specifically noted in the record that the Lanza's needed "tons of parental guidance – without that any office based approach to his [challenges] will fail, certainly if it is without medication."

Schools, medical homes, community-based providers and state agencies should serve as a critical safety net for parents. For example, care coordination by a physician or mental health professional can help a family access needed services and supports over time. However, if there is little or no meaningful communication or partnering between parents and service providers, well-intentioned parents can make decisions which result in poor outcomes. As a result, AL's mother coped with his condition by trying to make home and school "as tolerable as possible" for him and the school followed her lead. A note from a school guidance coordinator wrote these instructions for AL's teacher: "As for your other students, when in doubt IGNORE AL. Any attention is tough....No loud noises, no strong smells, no sudden movements, no unpredictable actions, noises or smells, speak with a purpose..." and "AL may be uncomfortable around boys but I don't know that for sure. I am sure he will tell us whatever is a problem...." It seems that the school saw his mother as a present and concerned person who they believed knew how to manage her son's complex needs. And in fact, parents should be at the core of services and supports for their children. However, given significant complexities in the child and possible denial outlined above, relying solely on a parent – without a team of support - can have detrimental effects on progress.

10) There must be effective family engagement and a family centered approach. As the authors point out, many families struggle with their children's mental health needs. They often seek help, but this doesn't mean they will follow through on recommendations. Studies suggest that true family engagement in diagnosis and treatment is key to follow-through and success. As the report references:

“Engagement is often synonymous with involvement. Involvement of families in child welfare services is important but real engagement goes beyond that. Families can be involved and compliant without being engaged. Engagement is about motivating and empowering families to recognize their own needs, strengths, and resources, and to take an active role in changing things for the better. Engagement is what keeps families working in the long and sometimes slow process of positive change.”

In addition, family centered approaches that expand the view of how family impacts the health of a child are critical. It includes understanding the parent’s experience and helping the whole family. Given the stress the mother faced daily, the eventual estrangement with the father, and the complete lack of contact with the brother, this family desperately needed an approach that took all this into account in addition to the mental health issues AL alone presented.

While we will never know for certain that mental health treatment for AL could have prevented this tragedy, it is hard to deny this likelihood. AL’s steady and progressive deterioration throughout his short life is clear. And while such deterioration will very rarely lead to an event of this tragic proportion, it can still be extremely destructive to the youth, his or her family and society. It is also striking how no one factor led to the ultimate event, but that the family, schools and providers all contributed to part of the story of missed opportunity. Finally, the report does not attempt to reduce AL’s responsibility for his actions. However, individuals do not live in a vacuum, and there is both opportunity as well as a significant cost if we choose to act on these lessons....or not.

WHAT IS BEING DONE IN VERMONT

The scope of the OCA report is too broad for this brief to identify all relevant services and systems in Vermont that could learn from the Sandy Hook incident. This brief concentrates on birth-to-school entry services and systems, given the importance of this period in preventing or mitigating social and emotional challenges. Although not detailed further, four fundamental supports for parents related to prevention are: (1) prenatal care, (2) pediatric primary care and the medical home, (3) evidence-based home visiting and (4) high quality early care and education programs that nurture children’s social and emotional development.

More specifically related to targeted supports or treatment, the Individuals with Disabilities Act (IDEA): Part C – Early Intervention program for infants and toddlers provides an array of services with special needs, birth through three years of age and their families. Part C in Vermont has broad eligibility serving any child who has an observable or measurable delay or a medical condition that may result in a delay. Part C services are provided at little or no cost to the family. According to the Vermont Part C/Early Intervention Annual Performance report submitted in February of 2014 to the Office of Special Education Programs, 754 children were served statewide in Part C Early intervention programs.¹¹ Part C, combined with federally mandated Early Periodic Screening, Diagnosis and Treatment Services (EPSDT), ensures funding for early intervention. Those who continue to need services may then be eligible for Essential Early Education and before a child turns 3, a plan is developed for this transition.

Children’s Integrated Services (CIS) is a resource for families when they have questions or concerns about their child’s development during pregnancy, infancy, and early childhood and is Vermont’s approach to providing coordinated children development and family support services. CIS brings maternal, family and child support early childhood and family mental health and

early intervention services together to coordinate supports for families with children up to 6 years old and pregnant women. The CIS early intervention program is governed by federal regulations defined in Part C and serves Medicaid and non-Medicaid children.

In addition to the critical importance of pediatric primary care and its unique opportunity to prevent and address behavioral health in the medical home, high quality care coordination within this setting is being piloted in Vermont and is a very important tool to support children and families with complex needs. Care coordination is defined as a patient-and-family-centered, assessment-driven, team-based approach designed to meet complex needs of children and youth while enhancing the care giving capabilities of families. Care coordination is typically delivered by nurses or clinical social workers and can be centralized or embedded in a pediatric primary care practice. It addresses interrelated medical, social, developmental, behavioral, educational and financial needs to achieve optimal health and wellness outcomes. Care coordination has been found to decrease unnecessary primary care or emergency department visits and hospitalizations, as well as improving family satisfaction and engagement in treatment over time.¹²

Act 264, passed in 1988, requires that human services and public education work together, involve parents and coordinate services for better outcomes for children and families.¹³ The Act developed a coordinated system of care so that children and adolescents with a severe emotional disturbance and their families receive appropriate educational, mental health, child welfare, juvenile justice, residential, and other treatment services in accordance with an individual plan. While Act 264 was enacted on behalf of children and adolescents experiencing a severe emotional disturbance and their families, the 2005 Interagency Agreement between the then Vermont Department of Education and the Vermont Agency of Administration expanded the target population beyond those eligible under Act 264 to include children and

adolescents with disabilities who are eligible for both special education and disability-related services, including service coordination, provided by AHS. This provides another important foundation to help children and families in Vermont access needed services.

The non-profit Vermont Family Network and Vermont Federation of Families for Children's Mental Health both work towards a system of care which includes family engagement and much more. The importance of engaging families as peers in particular is increasingly recognized as best practice in providing quality and effective services.

A helpful framework in addressing social and emotional development in both early care and education and school settings is the *Pyramid Model for Promoting the Social Emotional Competence of Infants and Young Children* developed by the Center on the Social and Emotional Foundations for Early Learning (CSEFEL) and the Technical Assistance Center on Social Emotional Intervention (TACSEI). The pyramid model – through Vermont's Multi-Tiered System of Supports (MTSS) – is being piloted in early care and education settings and schools through Vermont's Early Learning Challenge to increase the social and emotional competence of all children. The pyramid organizes activities along the mental health continuum and emphasizes: “nurturing and responsive relationships” and “high-quality, supportive environments” for all children (promotion); “targeted social emotional supports” for children at risk for behavioral problems (prevention); and, “intensive intervention” for children exhibiting challenging behavior (intervention). In addition, the bottom level of the pyramid addresses the importance of an effective workforce of teachers who are trained in promoting optimal development of all children.

Finally, Vermont Project LAUNCH (Linking Actions for Unmet Needs in Children's Health) funded by the federal Substance Abuse and Mental Health Services Administration (SAMHSA), is being piloted in Chittenden County. Project LAUNCH focuses on early screening

and assessment, mental health consultation in early care and education settings, evidence based home visiting, and family strengthening to support the positive social and emotional development of all children birth to 8-years-old.

RECOMMENDATIONS

Below are recommendations based on critical lessons learned from the Sandy Hook incident that should inform our work with children and families in Vermont.

- Recognize that ensuring children’s social and emotional wellness is all of our jobs – parents, schools, pediatric primary care providers, family support workers, social workers, early care and education providers and mental health specialists.
 - Strengthen community mental health resources and allow this expertise to be imported in to other settings such as schools, primary care and the home – and provide reimbursement for these services. Child psychiatry assistance can also be provide via telehealth and is currently available in Vermont through the University of Vermont and Dartmouth Hitchcock Hospital. Also ensure treatment is provided at the therapeutic level needed.
 - Prioritize early intervention and prevention services in early childhood. Research clearly supports the importance of a child’s healthy development and social and emotional wellbeing from birth.
 - Decrease easy access to guns and particularly assault weapons with high capacity ammunition clips. Widespread access to guns in an urgent public health concern and steps to address this must be taken. Autism Spectrum Disorder or other psychiatric problems alone did not cause AL’s actions. An atypical preoccupation with violence and ready access to guns were critical factors in this tragic outcome.
- Ensure universal screening for behavioral health for children birth to 21 and provide reimbursement to incentivize this. Also ensure follow up to services and treatment if needed.
 - Focus on social and emotional development - in additional to cognitive development – in early care settings and schools.
 - Evaluate children in all areas of suspected disability, not just the “primary disability.”
 - Prioritize and support true family engagement strategies and family centered approaches to provide care to children in the context of the family and address related resource and reimbursement barriers. This includes increasing awareness of parent support organizations that can help families. Remove the stigma of needing help and accessing services that builds on family strengths.
 - Ensure mental health treatment and support for families. Children live with families, so focusing on the family unit – instead of the individual child – creates better outcomes.
 - Provide education and training to help parents, caregivers, teachers and other support providers identify mental health needs and warning signs in children and adolescents and know what to do if concerns are detected.
 - Support high quality care coordination in pediatric primary care practices. This approach addresses interrelated medical, social, developmental, behavioral and educational needs over time to achieve optimal health and wellness outcomes for the entire family.

- In Vermont, EPSDT provides access to mental health treatment and Act 264 provides access to coordination. Continue to ensure and improve these important mechanisms so communities and families are accessing what they are entitled to in a coordinated way. This includes revisiting the need for Act 264 training at the local level.
- Ensure adequate and post secondary supports for disabled youth. Regardless of the level of support a child may get through high school, post-graduation is a time of great change and transition requiring preparation.
- Address gaps in services for children with mental health issues. The federal Substance Abuse and Mental Health Services Administration (SAMHSA) reports that the United States has only one-fourth of the child psychiatrists it needs. The shortage in Vermont has resulted in long waiting lists for treatment. Finding community mental health programs for children can also be challenging and expensive for a parent and it can be hard to navigate through the private and public mental health systems.
- Institute an Office of the Child Advocate in Vermont. The Office of the Child Advocate in Connecticut monitors and evaluates public and private agencies that are charged with the protection of children, and reviews state agency policies and procedures to ensure they protect children's rights and promote their best interest.

Sources:

Please note that the main source document is the Office of Child Advocate Report (unless footnoted otherwise) which can be found at:

<http://www.ct.gov/oca/lib/oca/sandyhook11212014.pdf>

¹ <http://www.zerotothree.org/child-development/>

² Rogers, S, Vismara, L, Wagner, A, McCormick, C, Young, G and Ozonoff, S. *Autism Treatment in the First Year of Life. A Pilot Study of Infant Start, A Parent-Implemented Intervention for Symptomatic Infants*. Journal of Autism and Developmental Disorders, 2014.

³ <http://www.cdc.gov/ncbddd/autism/hcp-recommendations.html>

⁴ <http://www.cdc.gov/ncbddd/autism/screening.html>

⁵ Rogers, et al.

⁶ <http://www.myaspergerschild.com/2008/10/autism-comprehensive-overview.html> - <http://www.autismspeaks.org/about-us/press-releases/early-intervention-toddlers-autism-highly-effective-study-finds>

⁷ T. Tervo, Language Proficiency, Development, and Behavioral Difficulties in Toddler, *Clinical Pediatrics*, 2007.

⁸ <http://www.stamfordadvocate.com/local/article/Report-Mother-said-Adam-Lanza-had-no-feelings-5011614.php>

⁹ <http://goodmenproject.com/featured-content/5-reasons-parents-deny-existence-of-childrens-mental-health-conditions-wrd/>

¹⁰ Ibid.

¹¹ http://dcf.vermont.gov/sites/dcf/files/pdf/cdd/cis/part_c/vt-apr-2014c.pdf

¹² American Academy of Pediatrics, *Patient-and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems*, Pediatrics, 2014.

¹³ <http://mentalhealth.vermont.gov/cafu/act264>

About These Policy Briefs:

This is one in a series of policy briefs designed to focus our collective attention on issues that affect our young children and families. These briefs, as well as an annual *How Are Vermont's Young Children and Families?* report are part of an initiative by Building Bright Futures State Advisory Council, connected to the Vermont Early

Childhood Framework recently unveiled at Governor Shumlin's Early Childhood Summit in 2013. For more information, call Building Bright Futures at 802-876-5010 or find out more on line: www.buildingbrightfutures.org

About Project LAUNCH:

Project LAUNCH (Linking Actions for Unmet Needs in Children's Health) is a federal initiative funded by the Substance Abuse and Mental Health Services Administration (SAMHSA). The Vermont Department of Health (VDH) received a five-year SAMHSA Project LAUNCH grant in 2012. Project LAUNCH is being piloted in Chittenden County and is grounded in a comprehensive view of health that addresses the physical, emotional, social, cognitive and behavioral aspects of well-being. Building Bright Futures State Advisory Council, Inc. serves as the grantee of VDH for Project LAUNCH implementation.

About the Author:

Traci Sawyers holds a M.A. in public policy from Tufts University and has 25 years experience in child and family policy, maternal/child health and behavioral health. In these areas, she has been a writer, lobbyist, researcher, planner, program administrator, consultant, facilitator, grant writer/administrator, elected official, and organizational director. She is currently the Early Childhood Health Policy Expert for Building Bright Futures and Vermont's Project LAUNCH initiative.