

Take Action! Empowering families of children with disabilities as leaders in advocacy and policy development.



Anita Tevanian, LEND Family Trainee

Introduction

Families of children with disabilities are at the forefront of advocating for positive change in their communities. The policy development process can be intimidating and at times seem like a foreign language. Through development of leadership skills and networking, families can translate their lived experience into actionable steps toward a goal of policy change for the benefits of the wider community. The framework presented here reflects my personal story of advocacy work with the foundation of families as meaningful partners.

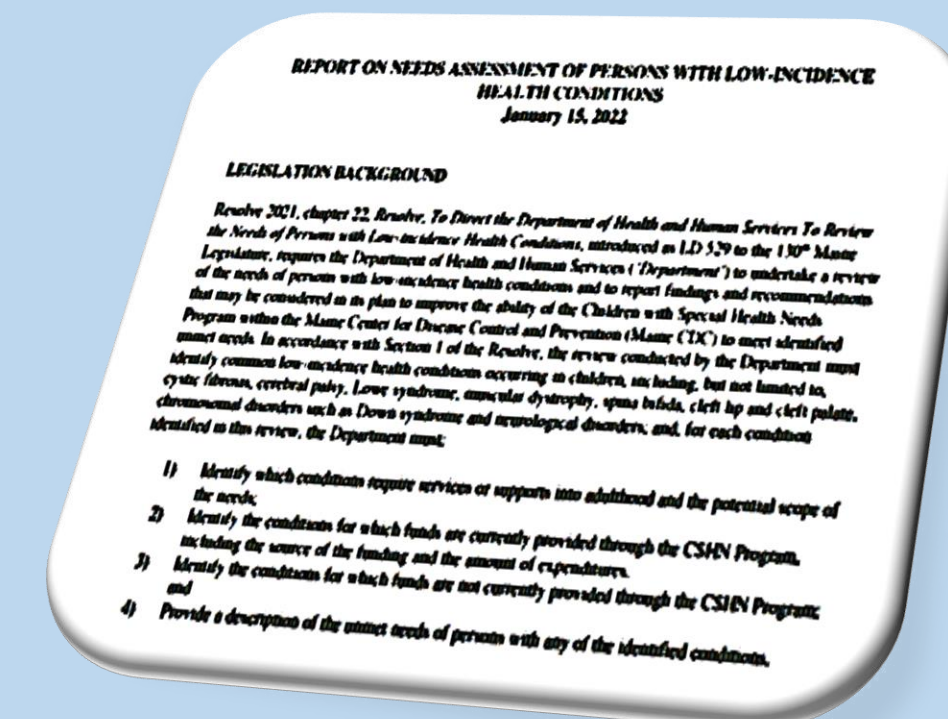


Child in walker with big smile .

“Alone we can do so little, together we can do so much”~Helen Keller

Project Activities

Unmet Health Care Needs Report Resolve (LD 529)

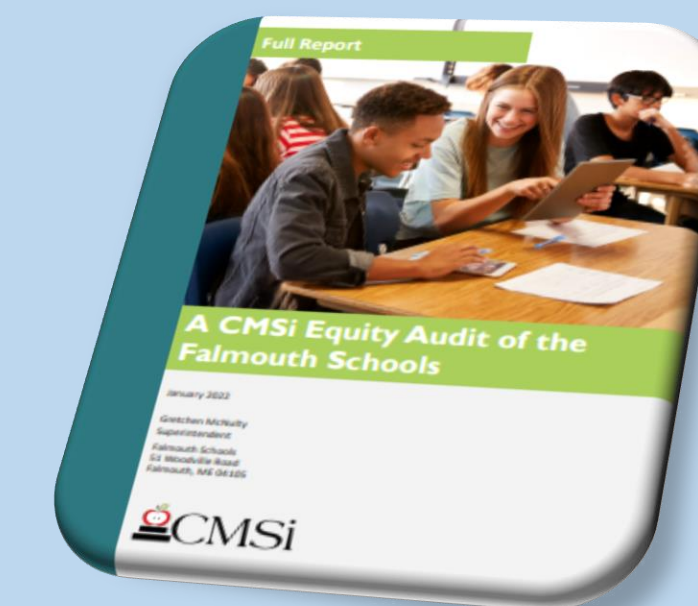


To quote the report~ *“The low-incidence conditions identified, except for Cleft Lip and Palate and Cystic Fibrosis, do not receive funds through the Title V MCH Block Grant or the Maine CDC Newborn Bloodspot Screening Program”*

“The Care Coordinator aids in helping families with navigating the systems of care. However, navigating the systems of care is only one step. Some families cannot access recommended services due to their costs. This can contribute to poor long-term health outcomes.” – Anita Tevanian

Key Outcome: This collaboration provided me with the opportunity to advocate for children with low incidence conditions, such as my son, in respect to their unmet medical needs while understanding budget priorities at the state level.

Inclusion Community Presentation in response to “A CMSi Equity Audit of the Falmouth Schools”



Worked with CCIDS Mentors, developed speaking points and presented publicly in advocacy of inclusion.

To quote the report, *“Without data, the district is in a real sense flying blind”*

- What measures do you have on how much access students with disabilities have to the regular education curriculum and environment?
- What are plans for recognizing disability rights and the history of the disability movement as part of the curriculum?

Key Outcome: I worked on several projects with the help of the Center for Community Inclusion & Disability Studies (CCIDS) team to examine and gain knowledge in state and federal policy.

Maine Hill Visit and POLICY BRIEF: Medicaid and Children with Special Health Care Needs.



Key Outcome: Developed and Presented a Policy Brief as part of the 2022 Cohort of New Hampshire-Maine Leadership Education in Neurodevelopmental and Related Disabilities Program Trainees.

Also attended the Disability Policy Seminar.

Attended the 2022 Council of Parent Attorneys and Advocates Conference



Key Outcome: I expanded my knowledge of special educational law, networked with advocates and continued public policy engagement by joining the COPAA Government Relations Committee.

In conclusion:

1. Change requires support from a community of people yet starts with one person.
2. Advocacy and Policy requires persistence toward continued efforts for outreach while balancing emotion and data/policy analysis.
3. Advocacy comes in all shapes and forms, does not require extreme actions and can range from creating awareness through our day-to-day interactions to public speaking at large public events.

Tools to get started

1. **Set the agenda:** Who and What am I advocating for? Start by identifying what you hope to change. For example, one of my project activities was collaborating with Maine CDC Maternal and Child Health-Children with Special Health Needs Team in support of LD 529 to understand the needs of underserved children with low-incidence disabilities; like my son.
2. **Research and Data Collection:** Research organizations and gather data to ask better questions and participate more effectively in decisions.
3. **Getting Involved and Networking:** Participate in awareness campaigns and legislative meetings while growing your network (Ex: Maine Parent Federation, Disability Rights Maine, UMaine LEND Program, Rare Action Network, Little Lobbyists and COPAA)

References:

CCIDS Partners:
 Alan Cobo-Lewis, PhD, Director, Center for Community Inclusion & Disability Studies
 Susan Russell, MS ABD, Associate Director, Center for Community Inclusion & Disability Studies
 Maine CDC Partners:
 Holly M. Richards, MPH, Newborn Screening Program Manager
 Pamala Martin, Healthcare Coordinator
 Erin Wood, Fellow LEND Trainee
 Marnie A. Morneault, M.Ed.(LEND Mentor)
 RARE Action Network. <https://rareaction.org/get-involved/do-something/>
 COPAA. <https://www.copaa.org>
[Unmet HC Needs Report Resolve 2021 chapter 22 \(LD 529\) final draft\[6106\].pdf](#)
[A CMSi Equity Audit of the Falmouth Schools. Falmouth Equity Audit Executive Summary 1.26.22 FINAL.pdf copy \(2\) \(1\).pdf](#)

