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Moore, Louisa, "Increasing Provider Awareness Around Siblings of Individuals With Intellectual and/or Developmental Disability (IDD)" (2023). *Family Medicine Clerkship Student Projects*. 882.
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Increasing provider awareness around siblings of individuals with intellectual and/or developmental disability (IDD)

Louisa Moore

Host clinic: Middlebury Family Health

Clinical mentor: Dr. Peter Wilhelm

Community mentors: Mindy Deibler and Marie Fetterhoff



January-March 2023

Problem Identification

Population of Interest

- The focus of this project is on **siblings**
 - Siblings are typically-developing people who have a brother or sister with a special health need (often intellectual and/or developmental disabilities (IDD))
 - They are part of their brother or sister's life longer than any other family member
- Siblings have unique needs and lived experiences, which change as they age
 - Children: positive and negative impacts on mental health and personal development^{1,2}
 - Adults: roles of caregiver, advocate, legal representative, and more³
- Given the breadth of this topic, this project focuses on **adults**, rather than children

Problem

- In general, siblings have been **overlooked as a group that needs support**, despite the wide-ranging impacts on their health and wellbeing⁴
 - Emphasis has understandably been on the needs of only the individual with IDD
 - Leads to lack of awareness of the sibling population among health care providers
- Resources and support are available both in Vermont and nationally but could be shared more widely with increased provider knowledge
- AHEC focus area: **interprofessional education**

1) Hayden et al. *J Abnorm Child Psychol.* 2019.

2) Watson et al. *Clin Child Psychol.* 2021.

3) Hall and Rossetti. *J Appl Res Intellect Disabil.* 2017.

4) Arnold et al. *Intellect Dev Disabil.* 2012.

Public Health Cost

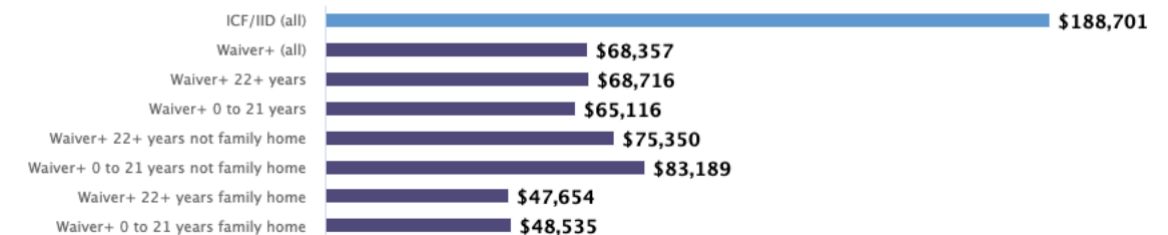
National and Worldwide Data

- Estimates of the number of individuals with IDD in the U.S. vary but fall in the range of **6.5-7.4 million**.^{1,2} **About 30% are adults.**³
- The economic cost incurred by their families can be substantial
 - In one review, the annual cost of childhood disability ranged from \$450 to \$69,500 worldwide, while lifetime costs ranged from \$41,000 to \$4,300,000⁴
 - In another study, parental costs were found to be largely due to income loss and caregiving time loss; societal costs were due to per child school subsidy⁵
- Sibling caregivers are more likely to be **socioeconomically disadvantaged and members of historically marginalized groups**⁶

Vermont Data

- Annual average spending per person varies by age, living situation (e.g., family home vs. care facility), and Medicaid authority but is substantial regardless

Average Annual Per Person Spending by Age, Setting and Medicaid Authority in FY 2019



Vermont data for FY2019. Obtained from the Residential Information Systems Project at UMN.⁷

1) <https://www.cdc.gov/grand-rounds/pp/2019/20191015-intellectual-disabilities.html>

2) <https://publications.ici.umn.edu/risp/infographics/people-with-idd-in-the-united-states-and-the-proportion-who-receive-services>

3) <https://publications.ici.umn.edu/risp/infographics/how-old-people-with-idd-in-the-united-states>

4) Shahat and Greco. *Int J Environ Res Public Health*. 2021.

5) Genereaux et al. *Disabil Health J*. 2015.

6) Sonik et al. *J Intellect Dev Disabil*. 2016.

7) <https://publications.ici.umn.edu/risp/state-profiles/vermont>

Community Perspective

Sarah Farrell (sibling)

- **Her current role as a caregiver**
 - “Right now, I’m the back-up if something happens to my mom... Currently [caregiving] is not a daily part of my life, but I know that sometime in the future, it will be and I wonder what that will look like.”
- **On future planning discussions**
 - “We talked in the car. It wasn’t like let’s sit down and hash this out... We didn’t talk exactly about what [the future] would look like, and my sibling wasn’t part of that conversation. The three of us haven’t really gone over [our plan].”
- **Her thoughts on how to better support siblings in primary care**
 - “It would be great if there was a clear list of resources or contacts for other adult siblings... There’s no road map that I know of that exists for how to support a sibling in all areas—practically, emotionally, financially.”

Sue Buckley (professional whose career is in the field of disabilities and is a guardian to someone with IDD)

- **Caregiving challenges she has observed in her career**
 - “For parents, it’s not knowing the resources available or being fearful of what the options might be... [For siblings], I’ve seen kids who can’t go anywhere, they’re going to have to do the caretaking and that’s it.”
- **On the importance of having a strong relationship with a PCP**
 - “I went to my son’s primary care doctor, and I said, ‘I need help.’ He pulled together a team meeting, with the two neurologists, the psychiatrist, and the gastroenterologist. I had a whole screen of them for one hour, just to talk about [my son] and what we should do [about his care plan]... I was fortunate to have a primary care doctor who saw him as a whole, rather than just that little piece.”

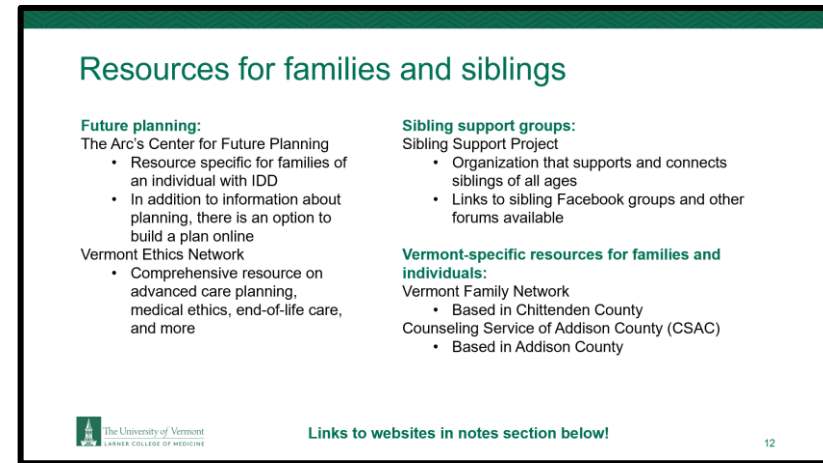
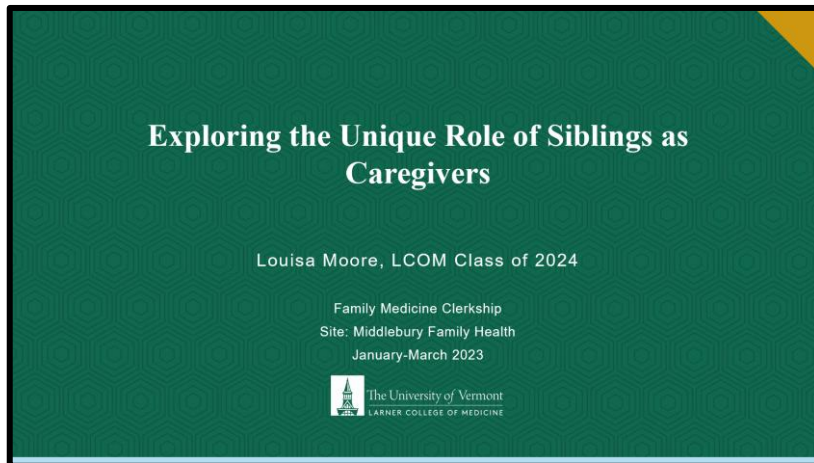
Intervention and Methodology

Objectives

- Increase health care provider awareness about the unique experiences and needs of adult siblings, particularly as they relate to caregiving and mental/physical health
- Suggest potential changes that can be implemented in the primary care setting as well provide resources that providers can share with patients

Intervention

- Created a PowerPoint slide deck that explored the above objectives



Results

- PowerPoint slide deck was distributed to the providers at Middlebury Family Health and feedback was elicited informally
- Areas of feedback include:
 - Knowledge of experiences and issues faced by siblings
 - Knowledge of resources available in the local community and beyond
 - Thoughts on changes proposed and feasibility of implementing them in the primary care setting
 - Perceived benefit of the project
- Due to the time constraints of this project, formal feedback via standardized survey was not collected, but suggestions for this type of evaluation are detailed on the next slide

Evaluation and Limitations

Proposed Evaluation of Effectiveness

- Survey health care providers directly before and after intervention to assess how knowledge and attitudes change
- Follow up with providers 6-12 months after intervention to assess if and how they have changed their practice
 - Specifically determine if they are more likely to distribute resources or prompt patients to think about future planning
- Survey siblings under the care of these providers to determine if this intervention in practice leads to more meaningful support

Limitations

- Time in primary care visits is limited, so asking providers to distribute resources or to discuss future planning with siblings may not be realistic
- It may be difficult to assess how effective the intervention is for supporting siblings
 - Providers may not be aware of a patient's position as a sibling or the extent of their involvement in their brother or sister's life
 - The experience of being a sibling varies widely, as the spectrum of IDD is vast. As well, support needs may differ depending on a sibling's socioeconomic status, level of medical literacy, and more.

Recommendations for Future Projects

- Interprofessional education project (PowerPoint or hand-out) that focuses on the needs of **pediatric siblings**
 - Consider positive and negative impacts on mental health and personal development
- **More comprehensive resource guide for families** related to both pediatric and adult siblings
 - For children, consider sibling support groups, children's books, local organizations like Vermont Family Network and Special Olympics
 - For adults, consider ways to promote medical, financial, and legal literacy (e.g., exploring Social Security benefits, Medicaid, group homes, organizations in Vermont that support families)
 - Potential contacts
 - Vermont Family Network (VFN)
 - Counseling Services of Addison County (CSAC)
 - Vermont Developmental Disabilities Services Division (DDSD)
- **Resource for parents** on how to talk to young children about their sibling with IDD and how to navigate raising typically-developing and neurodivergent children simultaneously

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