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Keara M. Lynn

The University of Vermont

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Autism Resources for Primary Care Patients and Families

KEARA LYNN, MS3

HINESBURG FAMILY MEDICINE

JULY-AUGUST 2021

PROJECT MENTOR: MICHELLE CANGIANO MD

Problem Identification

- ▶ Although there are many resources available for Vermonters with autism spectrum disorder (ASD), there is no common database of resources that is organized in a patient centered way.
- ▶ Due to long wait times to access community resources for ASD, patients and families may feel like they must do their own research of programs, which can be time consuming and confusing
- ▶ The COVID19 pandemic has made resources even more scarce and lengthened wait times
- ▶ There is often a delay between a parent recognizing signs of autism and an official diagnosis being made (average 2.7 years). There is also a delay between diagnosis and families beginning to work with community programs due to waiting periods.³
- ▶ We hope that organizing different autism resources into one document could help streamline the process for families to access care

Public Health Cost

- ▶ the United States in 2014, the annual cost of autism services was approximately \$235-262 billion.²
- ▶ Over a lifetime, the cost of caring for a person with ASD averages between \$1.4million and \$2.4 million, depending on whether the person has an associated intellectual disability. ¹
 - ▶ Behavioral therapy alone can cost between \$40,000 and \$60,000 per child per year. ¹
- ▶ Usually, private insurance plans in the US do not cover most ASD-specific treatments, leaving many privately insured children with ASD without adequate insurance coverage unless they can apply for Medicare. ⁴

Community Perspectives

“There are some big [care] gaps right now and I blame COVID for a lot of this. There are children who are not getting any services, period, for over a year! In the life of a two year old, that is hugely significant. Some families have been feeling desperate and showing up at the emergency room.”

–Nora Sabo, MSW

“COVID definitely stripped some people of their services, one big example being riding the bus. Kids [with ASD] aren’t allowed to have support people on the busses so parents are being forced to drive kids to and from school. “

“For future project directions, either a dot phrase or an electronic document would be helpful. Something I could search in my email”

–Michelle Cangiano, MD

Intervention and Methodology



- ▶ We have created a handout that organizes several community resources for patients with ASD and their families. We hope that these resources will guide families as they navigate the many options for community supports.
- ▶ Many physicians find that time constraints do not allow them to review resources in person with families. We hope that this handout will streamline patient education and allow for more thorough review of options.
- ▶ Ideally, this handout would be available for providers to hand out at clinics throughout Chittenden County

Results

Advocacy groups and Legal Resources Cont.:

Social Work: Accessed through your primary care doctor. Aids families in coordination and access to resources including guidance for navigating the healthcare system and easing the paperwork burden.

The Vermont Federation of Families for Children's Mental Health: A group dedicated to providing information, peer support, empowerment, and advocacy to youth (ages 0-22) and their families who are experiencing mental health, emotional or behavioral challenges. Contact: (802) 876-7021

There are several groups in Vermont that provide advocacy and if necessary legal services to individual with disabilities these include:

Disability Rights VT- (802) 229-1355

National Disability Rights Network: Contact: <https://www.ndrn.org/>

Social and Behavioral Resources:

Howard Center: Offer a wide range of resources to support children and adults with developmental disabilities as well as their families. Provides group and individual therapy, including dialectical behavioral therapy to aid children in controlling their personal emotions, resolving interpersonal conflict, and tolerating distressing situations. (cont. below)

Advocacy Groups and Legal Resources

Vermont Family Network: An advocacy group for children and their families with any disability. VFN supports a family from birth through transition to adulthood via early intervention services, parent connections and support, and expertise in education laws and policies. Contact: (802) 876-5315 or email info.vtfn.org

Autism Speaks: Provides the autism community with resources in their region to meet personal and family needs throughout all stage of life. Also provides educational material regarding financial planning, safety planning, schools, technology, health, wellness, behavior, medical resources, the transition to adulthood and others.



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Autism Spectrum Disorder Resources and Support



Education Support Cont.

Mosaic Center: This individualized strength-based program combines a structured school-day routine with rich community experiences to promote student growth. Academic instruction can occur at their two locations or staff can work with instructors at your child's school. Staff consists of special educators, SLPs, behaviorists, and occupational therapists. Contact: 802-658-9176

Assistive Technology Tryout Center: Assistive Technology is any piece of equipment that is used to increase or maintain the functional capacity of people with disabilities. This program aids families in finding helpful assistive technologies, allow trials of technology, and provide short term equipment loans. Contact- 1800-750-6355

VOICE Augmentative and Alternative Communication: for people with little to no natural speech and/or those whose speech is not functional for them. SLPs work with children up to age 22. Contact: 802-371-9867

Resources for Adults

Stern Center: learning specialists work one-on-one with college students and adult learners to help them reach their academic, social and professional goals. They accept students with diverse learning needs including those with dyslexia, ADHD, autism, and other learning disabilities. Contact: 802-878-2332, learning@sterncenter.org

Howard Center: Aids adults in finding meaningful employment through Project Hire. Offers individualized support based on a person's interests and goals that can include on-the-job training, and on-going support. Provides multiple tiers of housing support and assistance for those who want to become more involved in their community.

Champlain Community Services: Provide employment support through the Way 2 Work program as well as home and shared living support, respite, and school programs. Contact: 802-655-0511



Social and Behavioral Resources Cont.

Howard Center Cont.: also help high school age children prepare to live as independently as possible and gain meaningful employment through project search. They also provide family and sibling support. Contact: 802-488-6500

Stern Center: a paid out-of-pocket service focused on education that also provides a social learning team of special educators, certified speech-language pathologists and psychologists providing individual and group instruction for students with social and cognitive challenges. Also aids parents with working with schools to develop IEPs. Scholarships are available. Contact: 802-878-2332, learning@sterncenter.org

Education Support:

The Responsibility of Your Child's School: Schools must provide a free appropriate education for students between 3 and 21 years. This includes an Individualized Education Program for eligible students, Speech and language pathology, Physical therapy, and occupational therapy. The state provides early intervention to children younger than 3.

Stern Center: Provides evaluations, individualized tutoring, social learning and communication. Educational staff includes speech language pathologists, special educators and psychologists.

Evaluation of Effectiveness and Limitations

▶ **Evaluation of Effectiveness**

- ▶ Elicit feedback from patients at follow up visits who had been previously supplied with the handout
 - ▶ We would also ask about barriers that patients faced while seeking out these resources
- ▶ Elicit feedback from clinicians who are handing the document out

▶ **Limitations**

- ▶ The number of resources and amount of information is too much for a one page document
- ▶ Many of these programs are out of pocket and may not work for lower income Vermonters
- ▶ Many of these programs have demand that far outpaces the availability and wait lists can be up to two years for some services!
- ▶ The pamphlet is only in English language

Recommendations for Future Projects

- ▶ Create a dot phrase for epic that can be easily updated and placed in the after visit summary
- ▶ Translate the document into the most common languages spoken among Vermonters
- ▶ Expand to counties outside Chittenden County and include more National resources

References

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