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Addressing Resource Gaps for Autistic Adolescents and Adults

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The problem – Lack of confidence, lack of resources

- Autism is most commonly diagnosed in early childhood (between 1-5 years of age)
- Children and adolescents may go undiagnosed for many reasons
 - E.g. complex, heterogenous diagnosis, gender bias (Dx M>F), complicated home situations, parents may not recognize need for evaluation, etc [1]
- Social dynamics, unclear history, psychiatric/medical comorbidities, conflict with established identity, etc. make later autism diagnoses harder to establish and manage [1]
- However, delayed diagnosis is related to increased executive dysfunction, anxiety, and depression [2]
- Many healthcare providers lack the training or confidence to work with autistic patients [3,4,5]
- Those that are trained/comfortable often lack resources to adequately support patients with autism diagnoses [4]
- *AHEC Topic Area: Interprofessional Education (team-based care delivery, patient-centered care)*

Impact – Poorer health outcomes

It is difficult to estimate the economic impact of delayed diagnosis or undiagnosed autism

Some estimates suggest a prevalence of autism at 1.5 - 2.5% of the overall population in developed countries [6, 7]

- Likely higher given deficient population data, combined with diagnostic/screening practices that have improved in the last 2 decades [7]
- Improved screening/diagnosis has seen an increased incidence of autism in Vermont up to 20% annually [8]

Confirmed autism diagnosis is associated with:

- Increased annual healthcare cost (avg \$3020, 95%CI \$1017-4259)
- Increased annual non-healthcare costs (\$14,061, 95%CI \$4390-24,302)
 - Including higher school costs (\$8610, 95%CI \$6595-10,421) [9]

Adult-diagnosed autistics are more likely to report co-occurring psychiatric illness (OR 2.71) [2]

Complex healthcare needs amongst autistics and lack of physician confidence leads to increased barriers to care and worse outcomes for autistics, driving up costs [10]

Community Perspective

Interviews were conducted with experts and community stakeholders to learn more about challenges facing care for autistic adolescents and adults

Dr. Jeremiah Dickerson, a child psychiatrist at the University of Vermont, points out that autism is diverse enough in its presentation. Patients inevitably become more complex as they age, so developing management plans for autistics diagnosed outside of early childhood requires immense flexibility and creativity on providers' parts. "There is no one-size-fits-all approach." This can be particularly challenging when so few resources exist at baseline.

Dr. Sarah Morgan, a family medicine physician at HAHC who was recently certified to assess and diagnose young children (0-5 years) with autism, explains that many more resources are required to assess, diagnose, and support older children/adults than exist in much of rural Vermont. Offices that do assessments in older patients are often long drives away, and are interdisciplinary with subspecialist physicians, speech and language pathologists, psychologists, and more. She says better knowledge of resources available to support autistic people would greatly improve her ability to provide care to her patients now and in the future.



Intervention

To address resource gaps facing autistic patients in Hardwick, VT, a list of community organizations, support groups, various specialists, and options for quality information were compiled.

This list was developed through a combination of online research and conversations with community leaders and advocates. Contributors included psychiatric social workers and researchers in groups like the UVM Autism Collaborative.

The list was then delivered to providers at HAHC for use in supporting their patients.

Results

The resource list delivered to providers at HAHC aggregated local, state, and national resources for autistic individuals and families across several different domains. Some examples include:

- Local specialists (e.g. executive function coaching in Plainesfield, VT; physical therapy in Montpelier, VT; psychotherapy options through PsychologyToday.com)
- Community organizations and support networks (e.g. [All Brains Belong VT](#), Montpelier, VT; the [Vermont Family Network](#))
- State-wide resources through the State of Vermont Agency of Human Services, Integrating Family Services ([Autism Resources for Vermont](#))
- References to various national organizations (e.g. the [Autistic Self Advocacy Network](#))
- Quality information for patients and families through the [CDC](#), [Harvard Health](#), etc.

Proposed Outcomes & Limitations

This intervention aims to decrease barriers to treatment planning and access to support for autistic patients following diagnosis.

If providers are readily equipped with options that patients can take advantage of, the time between diagnosis and next-steps referrals can be decreased.

Long term, this may help to improve trust between autistic patients and providers and increase provider comfort working with autistic patients in the Hardwick community [10]

Development of similar resource lists may contribute to improved health equity for autistic patients elsewhere

Limitations to this project currently include:

- Lack of long-term follow up to assess patient and provider satisfaction with resources
- Uncertainty about patient access to some resources (e.g. do specialists accept most insurance plans?)
- Prevailing status quo of deficient autism competence amongst professionals (doctors, therapists, etc) may further limit patient options despite thorough resource lists [2,3,4,5]

Future Directions

Future work in this area may consider:

- Focus group style interviews with autistic patients and/or families of autistic patients in Hardwick and the surrounding areas to learn more about their perspectives, resource and support needs, etc.
- Long-term, follow up assessment of efficacy of resource lists
- Developing training for nursing, MA staff on trauma informed care when working with autistic patients, sensory accommodations
- Continued refinement of resource list
- Development of informational handouts for patients

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