

RECOMMENDED RESEARCH

All About the Center for Autism Services and Transition (CAST) Model

Summarized by Caitlin Allan and Liliane Savard | Fall 2023

This summary is also available in audio format (.mp3) and as narrated slides.

Saqr, Y., Braun, E., Porter, K., Barnette, D., & Hanks, C. (2017) <u>Addressing medical needs of adolescents and adults with autism spectrum disorders in a primary care setting.</u> *Autism*, 22(1), 51–61. (Free full text)

Hart, L. C., Saha, H., Lawrence, S., Friedman, S., Irwin, P., & Hanks, C. (2022) <u>Implementation and Evolution of a Primary Care-Based Program for Adolescents and Young Adults on the Autism Spectrum</u>. *J Autism Dev Disord*, *52*(7), 2924-2933. (Free full text)

Adapted Abstract

Background and Aims: These two studies describe the evaluation and evolution of the Center for Autism Services and Transition (CAST) model. CAST is a medical home transition model for autistic adults, implemented within a primary care practice for adults.

Methods and Results: The first article includes two small studies: a focus group and a chart review of autistic patients who visited the CAST clinic between 2014 and 2015. The focus group of 10 autistic young adults aged 18 to 30 identified main problems and potential solutions to help with visits to a primary care clinic for adults.

Some of the most important problems were sensitivities to sound, light and touch, and anxiety being in the waiting room.

The CAST model provides pre-visit phone call assessment of needs and visit accommodations. The chart review of 74 autistic patient visits at the CAST clinic found that 17 (23%) needed

accommodation for their healthcare visit and seven of these patients could not complete one part of the exam, like the vital signs. The most frequent accommodation was to skip the waiting room.

The second article describes changes to the CAST clinic over time: videos of procedures for patients and for providers, "happy visits", educational sessions, and telemedicine visits were added.

Conclusions and implications: Planning the healthcare visit and offering accommodations like skipping the waiting room can improve the success of healthcare transition to a new provider for adults.

Findings -

- Problems autistic patients identified with visiting a primary care clinic:
 - Sensitive to sound, light & touch.
 - Anxiety being in the waiting room.
 - Stress about talking with the physician and medical team and around the physical exam.

Possible solutions:

- o Offer some control on the environment (earphones, lighting, etc.)
- Have things to do while waiting.
- o Provide options for how to communicate with the provider.

Accommodations used most often for the first visit at the CAST clinic:

- No waiting room, registration done in the exam room.
- Waiting to take vital signs.
- Warning before touching.
- $_{\circ}$ $\,$ Waiting in the car until provider is ready.
- Lights off.
- First appointment of the day.
- Provider videos are watched more often than patient videos.
- Social work support is important but based on grant money.
- Changes in staff is hard since patients become comfortable with their provider.

Summary

The CAST model is a medical home program that focuses on providing care for autistic adolescents and young adults within a regular primary care practice. It includes patient centered care with multiple doctors as a part of the care team. Coordination of care to other specialty doctors is arranged as needed. Urgent needs are met through extended in-person hours and alternative methods of communication between patients and providers. New patients to the practice receive a pre-visit assessment call and longer first patient visit with their healthcare provider. The follow up visits are also extended as needed. As of January 2021, the CAST clinic served 858 autistic patients in the large city of Columbus, Ohio.

This summary includes 2 articles evaluating and describing the evolution of the CAST model. The first article includes 2 small studies: a focus group and a chart review of autistic patients who visited the CAST clinic between 2014 and 2015. The focus group of 10 autistic adults discussed healthcare experiences and barriers to healthcare access. The most important barriers identified were sensory sensitivities, anxiety being in the waiting room, stress about communicating with the office staff and healthcare provider and stress around the physical exam. Possible solutions proposed were offering control over the environment, providing something to do while waiting and options for communicating with the provider.

The retrospective chart review included 74 new autistic patients aged 15 to 45 seen at the CAST clinic. This chart review included demographic information as well as information on diagnosis, intellectual disability, previous experiences in medical settings, aggressive behaviors, physical limitations, and medication use. The 74 patients received a pre-visit assessment and 17 needed modifications to the primary care setting. The concerns identified were difficulty waiting, sensitivities to noises or bright lights, fear of needles, difficulty being touched, history of aggressive behavior in a medical office, and difficulty taking vital signs. Individualized plans were created for each patient's first office visit. The most common accommodation was skipping the waiting room and completing the registration in the exam room. Other accommodations included waiting to take vital signs, warning before touching, waiting in the car until the provider is ready, lights off, first appointment of the day and a bodyguard out of sight was used for one patient. Of these 17 patients, 7 were unable to get complete vital signs or complete the full physical exam.

The second study is an evaluation of the CAST model performed after additions were made to the base model described above. Having a social worker as a part of the practice has proved to be valuable but limited due to grant or donation funding. Procedure videos have also been added. There are videos for providers and videos for patients. These videos include taking a blood pressure, having an EKG done, getting blood drawn, and receiving a vaccination. Another addition is "happy visits" where the patient comes in advance of their upcoming appointments to become familiar with the staff and the environment. Evening educational sessions have also been added. Finally, telemedicine visits are also offered.

A total of 858 patients have been seen by CAST and there are about 80 visits per month to the clinic. The procedure videos for the provider were watched 18,488 times and the patient videos were watched 7756 times. The authors note that the procedure videos may have more watches due to autistic patients watching both videos as well as other clinics nationwide using these videos to train their providers after seeing the authors talk about these videos at conferences. The "happy visits" were helpful for some but not for others.

Real-World Implications

Planning the healthcare visit and offering accommodations like skipping the waiting room can improve the success of healthcare transition of autistic youth and young adults to a new provider for adults. Additional funding is required for additional staff like a social worker, for longer provider visits and for additional services like "Happy visits" and educational sessions. This program was implemented within a regular primary care setting and might be a model for other similar clinics.

Limitations

- The program is provided in a large city and may not be feasible in more rural areas.
- Funding comes from grants which can vary over time leading to staffing changes and cuts in services like evening education sessions.
- These results are from retrospective data. We do not know if this model is better than typical healthcare experience.

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