

Model for a Comprehensive Autism Screening Program

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This is a model for a comprehensive autism screening and diagnostic program. The initial screening would be done in the school systems and then followed up with a comprehensive ADOS work up. This would all go to support the development of Utah's centralized Autism Registry.

Introduction and Overview

The current model used for the centralized autism registry is predominantly compiled by a record review. All diagnosed cases are counted and records are also reviewed to determine more diagnosis. Due to the expansion of the diagnostic criterion for high functioning autism, Asperger's, and pervasive developmental disorders not otherwise specified, many old cases are able to be reclassified to reflect current standards. This program has made great strides in uncovering more accurate prevalence rates (Autism and Developmental Disabilities Monitoring Network [ADDMN], 2002).

The purpose of this project is to take the next step beyond the record review to an actual screening program. In considering this model, a key criterion was finding a way to get to as many children as possible. Due to this, the model was designed to be implemented in the schools. In order to align data with the center for disease control, the target group are eight year olds in second and third grade. The screening tool would be initially filled out by the teachers.

As teachers are not adequately trained and screening tools are limited, a positive outcome on the screener would serve as an indicator that further diagnosis is required. At this point in the model a clinician such as a licensed clinical social worker or a clinical psychologist with specialized training would be brought in to do a full diagnostic write-up.

Once a child is officially diagnosed they would be included in the centralized autism registry. The value of such a program would be to attain as accurate an autism prevalence count as possible. This could be used to adequately appropriate resources to the individuals and areas in need of special services. Additionally, as Autism and Autism Spectrum Disorders (ASDs) gain public awareness many people have theorized that there has been a swing to over diagnosis. Others like Dr. William M. McMahon, professor of psychiatry at the University of Utah say, "increase in prevalence reflects better diagnosis and referral of milder cases." In either case, a comprehensive and standardized model for screening and diagnosis would go along way towards illuminating some of these concerns.

Ultimately, the goal of this project is to begin the discussion about the value of such a program and means by which it could potentially be accomplished. The hope in this discussion is that it can lead to more ideas and eventually a model that could actually be implemented.

Project Outline

This project is divided largely into two phases. The first is model construction and costing. In this step decisions were made such as should the children be reached at school or do we provide clinics that families could voluntarily bring their children? Do you do both? Then it was important to determine what screening and diagnostic tools to use.

Once those decisions are made, cost is a consideration? Is there a cheaper way to do it? Are there cost advantages to employing psychologists or would it be best to use independent contractors? In this process there is clearly overlap since any cost question had to be balanced within a question as to the clinical ideal. It may not make sense to save money when the quality suffers and if the quality between two options is negligible it would be important to save money whenever possible.

The second phase of this project dealt more with the marketing component of this screening model. If teachers are participating, how do they feel about it? What do they think about the screening tool? Are they comfortable talking to parents about it? Another crucial side to this is the parents. How would they like to be approached about this? The benefits of a screening program and centralized autism registry may seem clear from a public health perspective but does that mean anything to the affected family?

In order to address these concerns in depth interviews were conducted with a few teachers and parents and then focus groups were held for larger groups of parents (Ahern, March 20, 2008) and teachers (Ahern, March 14, 2008).

Project Tools

In researching the right tools for this model, the structure of the model created specific requirements. Since the model was designed to parallel the CDC's information dealing with eight year old children, this had to be considered. If a child were to have a significant developmental delay due to autism, by this age, it is most likely to have already been diagnosed. That would mean that the true target of the screening tool would have to be on ASDs. The difficulty is that nearly all screeners were developed with a sample of children that have already been diagnosed. This leads to good specificity but poor sensitivity to children on the spectrum (J. Miller, personal communication, October 23, 2007).

That being said the Australian Scale for Asperger's Syndrome (Attwood, 1998) was developed with a prospective study so it has very good sensitivity for the spectrum. It was also developed for lay use. This is particularly useful given that it would be administered by teachers with limited training in autism. This screening tool in particular is a free download so that the only cost associated is in printing.

The second tool chosen for this model was the Autism Diagnostic Observation Schedule (ADOS). This along with the Autism Diagnostic Interview, are considered to be the 'gold standard' for Autism diagnosis. The ADOS was chosen for this model because it has a combination of observation of the child as well as interviewing of parents and others that interact with the child.

Focus Group Procedure

As mentioned above, focus groups were conducted with a group of teachers as well as with a group of parents in order to get feedback on the screening tool itself, the structure of the model, and what would be the best way to approach both groups.

With respect to the teachers' group the first step was to do a couple of one on one exploratory interviews to give an indication of what questions would be best to ask the group. Two elementary teachers were chosen. The first was a young teacher that has only been teaching for two years and the second was a masters level teacher that has been working with second and third graders for thirty plus years. The intention was to see if there were different views based on exposure, experience, and to see if there was any difference in the educational training due to recent public awareness of Autism.

After the interview, I used connections through the teachers to assemble a focus group of three second grade teachers and three third grade teachers, all of different ages and years of experience.

In a similar way, the parent focus group started with a mother of two autistic children. One of whom is diagnosed at eight with Asperger's Syndrome and the other with more significant delays. Though the one on one interview the focus group questions were developed. Through this contact, as well, we arranged to have a focus group with seven parents of children with varying autistic diagnosis and at different stages of the process.

Focus Groups

Both the teachers' and the parents' focus groups resulted in very useful and insightful information. The first question explored was what they thought of the screening tool itself. The first thing generally said about the model, by teacher and parents, was about the behavioral examples after every question. One parent said, "I loved it. I just thought it was better and more inclusive with its question. And it gave really good examples...This was better as far as narrowing down what your looking at." Another common sentiment was that both the teachers and the parents felt comfortable with teachers' ability to accurately fill out this screener, though teachers said they may not be able to answer questions 7, 8, 18, and 22. Another thing that the teachers made clear was that they did not feel it was reasonable to fill this out for every child every year. One teacher said, "That would be a nightmare to try and evaluate every one of my children," (Ahern, March 14, 2008) and that it would take too much time to observe every child with the granularity required for this type of evaluation. They felt that given their discretion to administer they would screen about 5 students each year. The parents also felt comfortable with this choice. Additionally, the parents said that they specifically feel more comfortable with the teachers administering the screening tool because they spend a significant amount of time with their child.

The next main question was about how one might approach the parents after the screening has been done. Though the teachers thought that it might be best coming from the clinician that would administer the ADOS, the parents unanimously thought that the clinician alone would be a bad idea. Though they recognized that generally, "The teacher is not going to know enough to comfort you", they said that the teacher is, "the one you have a rapport with, and hopefully you feel that they love your child and if you feel like they love your child then it is better to hear that kind of stuff." (Ahern, March 20,

2008) They expressed pretty clearly the sentiment that any efforts that can be made to ease them into this the better.

With respect to the message the parents tended to prefer a more positive approach. One woman said “I think that its always better to come to a parent and say your know we’re doing this to help your child because we want to learn how to help them and help them learn better and help them to have a positive experience in school. Instead of there’s something wrong with your child. Because if anyone comes to me saying I want you kid to succeed in life, I’m like yeah, anything you want to do to help my son succeed we’re good, but if your like there’s something kind of off with him I’m like excuse me, you don’t talk about my son, I may talk about my son like that way but you cant talk about my son that way.” Another parent said, “I think it would be helpful to site instances because, my son that has Asperger’s, he doesn’t come home and talk about his day, that’s part of his problem, he’s not sharing and he functions pretty well at home so you’re assuming that things are going well at school and so unless things like that are being reporting to you, you don’t really know.” (Ahern, March 20, 2008)

Another main question was with respect to what the value of a diagnosis would be to a parent deciding about this. One woman summed this up well saying, “It is helpful because it helps you celebrate all of their successes instead of getting angry at all of their short comings. As soon as you get that diagnosis you just feel a complete turnaround in your family like you can start feeling happy about what they can do. If you can tell their teacher, this is what their child is working with, here is some literature on it, they all of a sudden become the child’s advocate instead of having to put the kid out in the hall every day” (Ahern, March 20, 2008)

References

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