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Review Article

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Redesign of the autism spectrum screening and diagnostic process for children aged 12 to 36 months

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Abstract

Diagnosing autism spectrum disorder (ASD) is challenging, resource-intense and time-consuming due to clinical and etiologic heterogeneity. With the rapid increase in prevalence of ASD, higher demand for diagnostic assessment often means long waitlists for families, and limited access to specialized intervention and support. In 2013, the Alberta Children's Hospital-Autism Spectrum Disorder Diagnostic Clinic (ACH-ASDC) experienced a significant waitlist in the 12 to 36 months' population. A Quality Improvement Project was started in 2014; one program aim was to create an efficient, sustainable and evidence-based ASD diagnostic evaluation process. The redesigned diagnostic process included: 1) pre- and postassessment parent information sessions, 2) a screening appointment and 3) standardized clinical appointment pathways. Within its first year, the new process reduced wait times to under a month without an increase in resources, leading to an efficient diagnostic process being sustained since its implementation.

Keywords: *Autism spectrum disorder; Diagnostic assessment; Evaluation; Quality improvement; Screening tool.*

Autism spectrum disorder (ASD) is characterized by impairments in social interaction and communication, restricted interests and stereotypic patterns of behaviour (1). The prevalence of ASD has increased over the past two decades with a recent estimate in Canada at 1:94 patients (2). This increase poses challenges for families and health care providers, namely timely access to diagnostic assessment and intervention (3). The process for diagnosing ASD is challenging, resource-intense and time-consuming due to clinical and etiologic heterogeneity (4). Often, parents have an early awareness of something being 'wrong' with their child. Moreover, as customers of publicly-funded health care, parents have expectations regarding timely service delivery. Delays in receiving a diagnosis often mean limited or no access to those specialized interventions and supports that require diagnostic confirmation. Consequently, stress is likely to increase and parents may be more likely to seek alternative, nonevidence-based treatments for their child (5). The diagnosis of ASD can be made reliably by 18 to 24 months of age (6). In addition, data suggests that early intervention can improve the core deficits of ASD which positively impact family functioning (7,8).

In spring 2013, the Alberta Children's Hospital-Autism Spectrum Disorder Diagnostic Clinic (ACH-ASDC) was struggling with a waitlist greater than 12 months. With an increase in ASD referrals, a disproportionate growth in population, and fiscal restraints, the ACH-ASDC was unable to 1) meet patient demand and 2) apply newly announced provincial recommendations that ambulatory care clinics provide appointments to patients within 30 days of receipt of referral. Furthermore, ACH-ASDC leadership, community referral sources and parents were concerned about lengthy wait times.

In fall 2013, the ACH-ASDC improvement team started a substantive Quality Improvement Project (QIP) of which one aim was to create an efficient, sustainable and evidence-based ASD diagnostic evaluation process. We prioritized children aged 12 to 36 months based on the high number of referrals of this cohort, the availability of publicly-funded resources and supports for these children in Alberta and the positive impact early intervention can have on this population. Our goals were twofold: 1) create a new standardized diagnostic process, and 2) develop a backlog reduction strategy. This article details how we achieved these goals.

INITIAL PROJECT STEPS

A literature review was conducted to develop an understanding of ASD diagnostic guidelines used in other leading ASD centres (9–11). In addition, Canadian ASD service providers were surveyed. Site visits were made to three ASD centres in the USA. Throughout this process, it became clear that the numerous challenges facing the ACH-ASDC regarding wait times for query ASD referrals were not unique.

In addition to general process maps (a visual depiction of the steps in the process), the ACH-ASDC improvement team created a modified value stream map (VSM). The modified VSM depicts the major process steps plus incorporates data. Our VSM included work in progress, cycle time required, resource use and volume of patients at each step including the wait time between steps. A challenge in generating the modified VSMs was obtaining the manual data, yet when completed, the activity proved powerful in generating the necessary awareness among the leadership and ACH-ASDC team members for the need to redesign how current services were being provided. The modified VSMs were then shared with volunteer parent advisors as a means of validating the family experience and learning from families what their service priorities were. The message that the current diagnostic process could be improved to meet the needs of families proved powerful to the ACH-ASDC team. Afterwards, we ensured the requirements of families were incorporated into the design of the future state processes. The data demonstrated that the total wait from referral received to first appointment exceeded 12 months. In addition, the diagnostic process was highly variable. At the time, there were no service targets for the program, a lack of 'real time' monitoring of service demand, capacity and activity at a program and provider level.

The methodology applied in executing this QIP pulled from two main groupings: 1) the Alberta Health Services Improvement Way (AIW), a hybrid model of improvement theory created specifically within Alberta Health Services (AHS) that features four core phases and includes managing change and sharing learnings as essential elements, and 2) Alberta Access Improvement Measure, a methodology for improving access to scheduled services (12,13).

Faced with the current state data and recognition that the diagnostic model could be improved to better meet the needs of families, the leadership and ACH-ASDC made the decision to completely redesign the ASD diagnostic model starting with the cohort of children between 12 and 36 months. The redesign would be an iterative process supported by following a plan-do-study-act (PDSA) approach overseen by the ACH-ASDC improvement team and incorporating a set of data collection measures and balancing measures to monitor the impact of the process. Again, due to the lack of automated scheduling systems at the time, the data collection was largely gathered through a manual process.

DEVELOPMENT OF A STANDARDIZED DIAGNOSTIC PROCESS

In January 2014, the first cycle to test a new standardized diagnostic process for children aged 12 to 36 months commenced (Figure 1). Our initial goal was a target of 28 days from parent session to initial screening appointment and a total cycle time of 3 weeks from screening appointment to diagnosis provided to family. A PDSA approach was implemented with a subsequent test cycle in April, August and October 2014 (Figure 2). This process included: 1) preassessment Parent Information Sessions, 2) an initial screening appointment, 3) one of three subsequent clinical appointment pathways based on the results from the screening appointment and 4) a postdiagnosis parent session that provided information on ASD-specific resources and parent-to-parent support.

PHASE 1

Referral

Early in the QIP, it was identified that the referral process, criteria and forms required updating to align with the new service model and new Diagnostic and Statistical Manual of Mental Disorder-5 (DSM-5) criteria. A large group of referrals were systematically reviewed and referral sources were consulted prior to creating the new referral form. Improvements to services included the creation of a central access and referral triaging system allowing online access to program information and referral forms, confirmation of receipt of referral within 24 hours and accept/decline decisions made within specified provincial targets (less than seven business days). For accepted referrals, an intake call was conducted with the parent(s) who were then provided with program requirements regarding the information sessions. Upon completion of the information sessions, an appointment was scheduled for the ACH-ASDC assessment.

ASD parent information sessions

During our VSM review, parent advisors provided valuable insight. Their comments were aggregated into five themes:

1) As a diagnostic team, you (ACH-ASDC) need to do whatever necessary to ensure we (families) get a diagnosis as soon as possible.

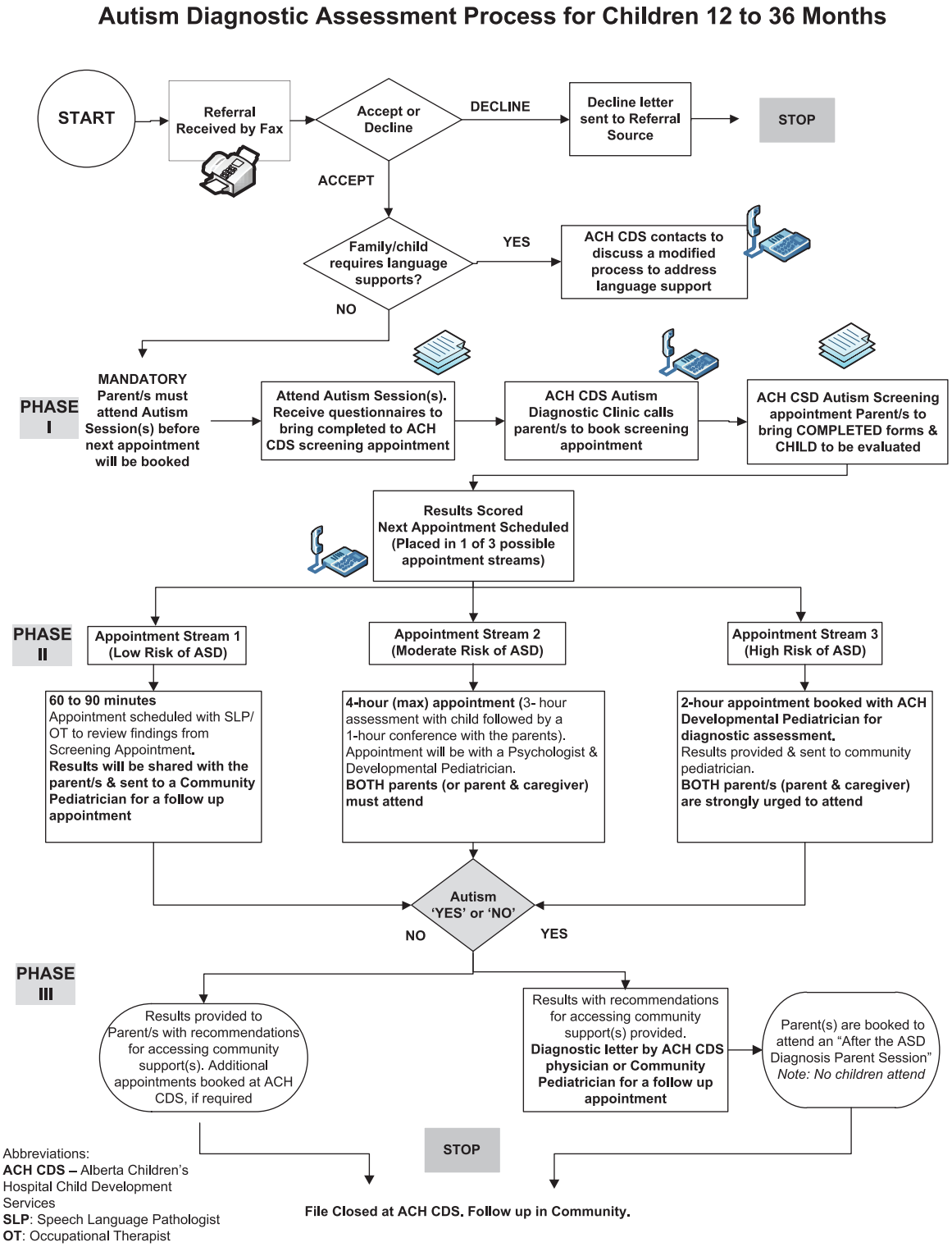

Figure 1. Autism diagnostic assessment process for children 12–36 months.

2) We (families) want to know what the diagnostic process will look like—share this with us.
3) Manage expectations—say what you do and don't do in terms of supports and services.
4) Help us connect with other families.
5) Teach us what we (parents) can do to help our children and how to find resources for them.

Guided by these comments, a major need identified by families was accessing credible information and being linked with

Figure 2. Plan-do-Study Act.

resources. To address this, preassessment parent sessions were developed allowing them the opportunity to network with other families. These sessions also provided a capacity-building opportunity for the team. As the mapping revealed, clinicians were independently providing the same information to each family over multiple appointments. Having one or two clinicians provide the information to multiple families resulted in the need for fewer downstream assessment appointments, and left families feeling better prepared for the diagnostic process. If families had significant barriers to attending the sessions, they were accommodated.

The parent session topics were as follows: 1) defining ASD and outlining ACH-ASDC's diagnostic process, 2) promoting strategies to enhance their child's communication and socialization skills and 3) providing information on resources and support. Written materials included a flowchart reflecting the diagnostic process, along with standardized and nonstandardized questionnaires that families were required to complete for the diagnostic assessment (14). The questionnaires included: 1) the Modified Checklist for Autism in Toddlers (M-CHAT-R/F), a level 1 screening questionnaire (used when applicable according to limit of age), 2) the Child Development Inventory, providing an overall developmental profile (12) and 3) an internally-developed medical and developmental history questionnaire. The sessions, totalling 5.5 hours, were offered bi-monthly, and had capacity for 30 families per month. Parents were provided with dates for the sessions within 7 days of receiving their child's referral, and were required to register within 30 days of the referral being accepted. Upon completion of the parent information sessions, families were offered an initial screening appointment for their child.

Screening appointment

Representatives from ACH-ASDC were invited in December, 2013, to attend the ASD Consortium Research day in Boston, USA, where we established an institutional connection with the Boston Tufts University ASD-group (BTUA-G). BTUA-G started a research trial of a new level 2 screening tool, the Rapid Interactive Screening Test for Autism in Toddlers (RITA-T) and invited our team to participate. Eventually, we incorporated RITA-T into our screening appointment. The RITA-T consists of nine interactive activities administered in 10 to 15 minutes (15). It assesses developmental constructs known to represent early signs of ASD in toddlers including joint attention, social awareness, reaction to emotion, awareness of human agency and object permanence. Four speech language pathologists and one developmental-behavioural paediatrician at ACH-ASDC were trained in the administration and scoring of the RITA-T. To establish intra-rater reliability, training consisted of consensus scoring of three videotaped administrations of the RITA-T,

group discussions and individual scoring by BTUA-G. Also, three additional taped assessments per clinician were scored by BTUA-G in the first 3 months following the training session.

In addition to the RITA-T, the 60-minute screening appointment included the following: 1) initial play to familiarize the child with the clinician and the surroundings, 2) review of parent-completed questionnaires, 3) developmental diagnostic history obtained from the parents, based on DSM-5 criteria and 4) informal play-based observation to gather additional functional and ASD-related behavioural symptoms. The majority of the patients referred had been previously-diagnosed or suspected of having language and/or developmental delays. Most patients had previous speech-language assessment completed; those results were reviewed by ACH-ASDC and considered with current clinical impressions.

PHASE 2

Diagnostic assessment

Three clinical appointment pathways (low, moderate and high risk) were derived based on all elements of the screening appointment. The moderate risk group received assessment with the Autism Diagnostic Observation Scale (ADOS-2) which was administered by a clinical psychologist specializing in ASD; a developmental paediatrician was also involved. Only a developmental paediatrician evaluated the low- and high-risk groups (ADOS was not performed). All patients received clinical evaluations consisting of detailed developmental and medical histories, observations of play and behaviour, as well as physical examination for pertinent clinical findings. A developmental paediatrician completed the DSM-5 checklist for all patients at the time of the clinic visit. DSM-5 checklists are ASD diagnostic criteria established by the American Psychiatric Association (1). Final diagnosis was provided by certified and experienced clinicians (paediatrician or psychologist) based on the overall results obtained during the screening and diagnostic appointments. If a diagnosis of ASD was made, parents of the child were strongly encouraged to attend an ASD postdiagnosis session. If an ASD diagnosis was ruled out, families were offered the assistance of a social worker to help them access other appropriate community resources.

PHASE 3

ASD postdiagnostic session

Parents of children who received a diagnosis of ASD were invited to attend a 2-hour evening parent session entitled 'After a Diagnosis of ASD'. The session was cofacilitated by an ACH-ASDC social worker, a Family-to-Family Connections volunteer coordinator and at least one parent of a school-aged child previously diagnosed with ASD. The goals of the session were to: 1) help parents understand their child's diagnosis, 2) understand the grief process as well as their own emotional response to their child receiving an ASD diagnosis, 3) learn about ASD-specific community supports and services, 4) connect with other parents with similar experiences and 5) clarify the immediate next steps for parents if required.

EVALUATION

Between June and September, 2015, a validated, standardized telephone evaluation survey was administered by an ACH-ASDC nurse to one-third of parents whose children were diagnosed with ASD. Parents were asked to evaluate their experience with the diagnostic assessment process. Parents stated that their wait was short, the process was efficient, the information sessions were valuable and overall satisfaction level was high. Follow-up with families played a powerful role in supporting change implementation and sustainability.

WHAT WE HAVE LEARNED

Both health care professionals and families served carry the burden of a lengthy waitlist. Each referral represents a story of a child and family searching for answers and support. A shift, not only in practice but in culture, emerged at the ACH-ASDC by implementing a rigorous evaluation of the process, by listening to and believing in the specialized knowledge and experience of clinicians, parents and community stakeholders, and by taking a perceived risk on a new and innovative idea(s). For clinicians and allied health care professionals, there is recognition that they can be valuable agents of change and inform program redesign. A PDSA approach resulted in clinician engagement and confidence that the diagnostic model would be systematically evaluated and modified in real time, while also ensuring that families were supported throughout the process. Another key learning was recognition by the team regarding the amount of time and detail that must be undertaken to 'test' new ideas.

Since undertaking this QIP, the ACH-ASDC clinic has succeeded in redefining services, clarifying expectations and engaging in open and transparent dialogues with all stakeholders—especially parents. Ensuring a degree of flexibility within the process is also important to accommodate a variety of family needs and expectations. As an example, community paediatricians who make a diagnosis of ASD in their offices can now offer support to their patients by referring parents to the ACH-ASDC postdiagnostic educational sessions only. With efficient use of capacity, our clinic can better accommodate modifications required by families who are new to Canada and/or are English language learners.

With respect to wait times, our target of 28 days from parent sessions to screening appointment and a cycle time of 3 weeks from screening to diagnosis was achieved within 12 months of implementing the redesigned process; this was accomplished without

any additional human resources and has remained sustainable. Furthermore, optimizing the use of scarce tertiary clinical providers within this population created extra capacity that was redistributed to the other age cohorts within the ACH-ASDC, further reducing the overall waitlist for all patients with an ASD query.

Another benefit of the redesigned process is that our team has improved relationships with community partners and, more importantly, re-established parents' confidence in services that are better designed to meet their needs, helping them access services for their children as quickly as possible. With a more efficient, flexible process, patients and their families are now able to access critical community supports and resources in a timely manner.

The success in redesigning the Autism Spectrum and Diagnostic Process for Children aged 12 to 36 months could not be attributed to one specific element but was the result of all changes made. In sum, our QIP led to efficient, sustainable and evidence-based diagnostic evaluation processes.

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