Dell Children's (S)TAAR Model of Early Autism Assessment

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Abstract Here, we describe a transdisciplinary effort to efficiently and equitably improve access to comprehensive evaluations for young children at-risk for autism and related neurodevelopmental disorders in the Austin, Texas community. What emerged from this collaboration between Dell Children's Medical Group and The University of Texas at Austin is a flexible clinical approach that emphasizes patient-centered care, community partnerships, best practices, and provider satisfaction. This chapter outlines integral components of our (Sin Exclusión) Transdisciplinary Autism Assessment & Resources (S)TAAR model, with the hope of providing an example of early autism assessment that can be implemented in medically underserved communities through pediatric specialty clinics. Future iterations of the model are aimed at increasing professional training opportunities for students and early career clinicians and further increasing post-diagnostic family supports. The benefits and limitations of the current model are discussed and avenues for expansion are considered in greater detail.

Introduction

Current practice parameters recommend that all children be screened for autism spectrum disorder (ASD) (hereafter, autism) at age 18 and 24 months, along with regular developmental surveillance (Zwaigenbaum et al., 2015). It is an integral function of developmental-behavioral pediatricians (DBPs) and psychologists to address concerns related to children who screen positive for the risk of autism (Hansen et al., 2016). DBPs and psychologists working with this population are trained to provide

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complex developmental evaluations, including history of present illness, developmental testing, and assistance in the coordination of a treatment plan. DBPs also provide medical expertise in response to a variety of concerns expressed by the patient and referring physician. For example, DBPs routinely assess the impact of pre-existing health conditions (e.g., prematurity) and the presence of related disorders (e.g., seizure activity). They prescribe medications, order tests as needed, and frequently direct patients to relevant subspecialties for more extensive workups (e.g., genetics for whole-exome sequencing). Psychologists with specialized training in autism assessment provide complementary expertise to thoroughly address psychosocial and behavioral concerns, cognitive abilities, academic skills, and family functioning. Additionally, psychologists serving this population are extensively trained in the administration and interpretation of standardized cognitive and academic measures, gold-standard autism diagnostic instruments (e.g., ADOS-2) and are prepared to rule-out or diagnose comorbid psychological disorders.

For both DBPs and psychologists alike, autism assessment is often a time-intensive process that is minimally reimbursable by insurance, produces an arduous amount of documentation (e.g., electronic medical records, report-writing), and limits the number of patients who can receive comprehensive care in a reasonable timeframe. Barriers include (1) time and resources needed to address complex patients, (2) burnout incurred from the time required to document complex concerns, and (3) resultant long waitlists that plague the profession and the community at large. Accordingly, there is a burgeoning movement in the field to update existing diagnostic pathways through evaluation models that increase collaboration across systems and providers (Gerdts et al., 2018; Gordon-Lipkin, Foster, & Peacock, 2016; Williams-Arya et al., 2019).

To address this challenge in the Austin, Texas community, a transdisciplinary team was formed through the Developmental-Behavioral Pediatrics Program within Ascension/Seton Dell Children's Medical Group and Pediatric Psychology within Dell Medical School/The University of Texas at Austin. This collaboration formed the Comprehensive Autism Program (CAP) housed at Dell Children's Developmental-Behavioral Pediatrics Program (hereafter, CAP). Through a comprehensive needs assessment, barriers to quality care were identified and used to inform program objectives. In the pursuit of these objectives, the *(Sin Exclusión) Transdisciplinary Autism Assessment and Resources Model ((S)TAAR)* was developed to address challenges through innovative transdisciplinary procedures. Here we discuss the results of our local needs assessment, introduce our approach to addressing each barrier, describe programmatic activities and objectives, present an example patient case, and describe future avenues for improvement and expansion.

Barriers to Quality Care in Autism Assessment

A multi-method needs assessment was conducted by the CAP team to guide program development. Goals of the assessment were to (1) determine the expressed level of need within the community through analyzing the clinic waitlist; (2) explore qualitative accounts of family experiences with autism assessment in the literature; (3) determine community characteristics and expected number of children with autism in the region; (4) collate a list of local agencies, service providers, and resources serving families of children with autism in the region; (5) determine areas of overlapping expertise and clinical capacity within clinic staff; (6) identify possible gaps in clinic expertise to inform hiring; (7) review the criteria for autism assessment provided by each major insurance provider billed by the clinic; (8) monitor clinicians' adherence to best practices in autism assessment; and (9) review the literature on healthcare disparities and unmet needs in autism assessment related to patient sex, race, ethnicity, language, and socioeconomic status.

Sources of information included a review of relevant literature, census data, national surveys, analysis of the clinic waitlists, caregiver report, live observation monitoring fidelity of best practices in usual care, and an investigation of community resources. Four primary barriers to quality care were identified through this process, including: (1) accessibility to diagnostic services (e.g., length of time from initial parent concern to receiving a diagnosis; excluding medically underserved communities), (2) efficiency of assessment procedures (e.g., patients lost-to-follow-up due to multiple diagnostic appointments), (3) threats to diagnostic accuracy in autism assessment (e.g., under-identification of racial minorities), and (4) negative caregiver experiences (e.g., high frustration and parental stress during diagnostic odyssey).

Strengths were also identified, which provided CAP with a roadmap to address challenges by leveraging existing capacities within the clinic and community. These included (1) multilingualism within clinic staff and access to in-person interpreting services, (2) clear areas of overlapping and complementary expertise across clinic staff; (3) high level of adherence to best practices in usual care; and (4) enthusiasm from community organizations to partner with the clinic. Each aspect of the (S)TAAR model directly corresponds with an identified barrier and addresses it through an existing clinic/community strength. First, accessibility issues are addressed through a staff commitment to inclusivity, community outreach, and language access (S). Next, inefficiency and redundancy are targeted using a transdisciplinary team approach (T). Diagnostic accuracy is prioritized by continuing to use gold-standard assessment procedures (AA). Finally, social work and community partnerships were leveraged to improve caregivers' experiences and connections to local resources (R). In the next section, the results of our needs assessment are described and contextualized to provide background for CAP's objectives and activities.

Accessibility

Access to care is arguably the largest obstacle faced by patients and developmental-behavioral health providers alike (Mansell & Morris, 2004; Miller et al., 2008). Although valid ASD diagnoses can increasingly be made in infants and toddlers (Mandell, Novak, & Zubritsky, 2005), the median age of identification in the United

States is 5.7 years (Shattuck et al., 2009). This gap is due, in large part, to a nationwide shortage of clinicians specializing in the diagnosis of pediatric behavioral and developmental disorders (Mayer & Skinner, 2009). The primary consequence of this bottleneck is a delay in access to appropriate interventions, which causes many children who have already been identified and referred for an evaluation, to miss out on opportunities for early intervention (Zwaigenbaum et al., 2015). This pattern differentially impacts families who are unable to afford out-of-pocket fees for private evaluation services (Bisgaier, Levinson, Cutts, & Rhodes, 2011; Chiri & Warfield, 2012). Additionally, it is well-documented that later age of ASD diagnosis is associated with race and lower socioeconomic status (SES) (Jo et al., 2015; Mandell, Listerud, Levy, & Pinto-Martin, 2002).

Although diagnostic bottlenecks have been reported across the country, the 2005-2006 National Survey of Children with Special Healthcare Needs further revealed large variations between states in terms of difficulty accessing ASD services (Thomas, Parish, Rose, & Kilany, 2012). In Texas, 53% of families of children with ASD experienced problems getting referrals, 13% had delayed or forgone care, 47% had unmet care coordination needs, and 24% experienced difficulty utilizing services (Thomas, Parish, Rose, & Kilany, 2012). Presently, Dell Children's Medical Group (DCMG) employs one of the only medical providers (DBP) specializing in autism assessment that accepts insurance, including Medicaid, in the greater Austin area. Therefore, CAP operates within the national, state, and local systems that perpetuate well-documented inefficiencies and obstacles to adequate care for families of children with ASD.

Texas is also one of five majority-minority states in the U.S. whose population is composed of less than 50% Non-Hispanic White residents (U.S. Census Bureau, 2018). Further, over 35% of Texans speak a language other than English. Consistent with these statistics, many patients referred to Developmental-Behavioral Pediatrics at Dell Children's are demographically, culturally, and/or linguistically diverse. Given that healthcare disparities differentially impact children with ASD from minority backgrounds, and minority families experience additional delays in the age of initial diagnosis (Fountain, King, & Bearman, 2011; Magaña, Parish, Rose, Timberlake, & Swaine, 2012; Mandell et al., 2002), CAP is committed to creating a diagnostic model that is responsive to the needs and barriers impacting the local community.

Efficiency

As of June 2018, the waitlist for new patients at Dell Children's Developmental-Behavioral Pediatrics clinic was upwards of 18 months. Therefore, a child exhibiting for a comprehensive evaluation by a general pediatrician during their 18-month well-child visit could spend an additional 18 months awaiting their first appointment. Once evaluated by the clinic, families were typically scheduled for multiple appointments prior to receiving the final diagnosis. Therefore, a child exhibiting atypical development in infancy would likely experience a lag of nearly 2 years before receiving an autism diagnosis that qualified them for intervention services. On average, caregivers report lags between 2 and 3.5 years between their initial developmental concerns and the date of diagnosis (Chamak, Bonniau, Oudaya, & Ehrenberg, 2011; Crane, Chester, Goddard, Henry, & Hill, 2016; Siklos & Kerns, 2007), with long wait times cited as a key cause of parental stress (Crane et al., 2016). Early access to a streamlined diagnostic service is crucial in lessening the impact of stress on families and improving overall satisfaction.

In addition to lengthy new patient waitlists, inefficiencies in the diagnostic process prolong the time between referral and diagnosis. By design, existing interdisciplinary diagnostic models require 2–3 visits prior to diagnosis (Gerdts et al., 2018). Multiple clinic visits disproportionately impact families with limited resources because transportation, childcare, and time off from work pose substantial limitations. Given the clinic's location within Central Texas, families from rural areas often travel for hours to attend visits. For these reasons, the clinic has made a concerted effort to limit the amount of face-to-face assessment time required by patients and families, without sacrificing quality or diagnostic accuracy.

Diagnostic Accuracy

Given that ASD remains a behavioral diagnosis, it is inherently subject to potential limitations including gender bias, linguistic, and cultural norms that vary across individual patients, and an individual provider's subjective lens (Chapman, Kaatz, & Carnes, 2013; Peris, Teachman, & Nosek, 2008). Racial and ethnic disparities in quality healthcare plague the process of autism diagnosis (Blair et al., 2013; Ennis-Cole, Durodoye, & Harris, 2013; Magaña et al., 2012). For example, African-American children were diagnosed an average of 1.4 years later than White children (Mandell et al., 2002) and are much more likely to have received a previous diagnosis of conduct or adjustment disorder (Mandell, Ittenbach, Levy, & Pinto-Martin, 2007). Hispanic children are diagnosed almost one year later than White children, receive fewer specialty services, and have higher unmet service needs (Magaña, Lopez, Aguinaga, & Morton, 2013). Additionally, girls with autism continue to be more likely to be missed or misdiagnosed (Bargiela, Steward, & Mandy, 2016; Fuss, Briken, & Klein, 2018; Gould & Ashton-Smith, 2011; Werling & Geschwind, 2013).

In addition to these known sources of bias that have the potential to skew the perception of any provider, patients frequently present to this clinic with complex histories that further complicate behavioral diagnostics. For example, pre/perinatal complications (e.g., in utero toxic exposure), trauma histories (e.g., fleeing danger in a home country), interruptions to caregiver support (e.g., foster care), and forms of ongoing instability (e.g., housing) commonly surface during our evaluations. The transdisciplinary aspect of this model has evolved to deliver culturally-sensitive and truly comprehensive evaluations to a highly heterogeneous patient population and, in doing so, hopefully, increase diagnostic accuracy. A primary component of this approach involves diagnostic consensus between providers, each of whom represents diverse backgrounds and clinical orientations. This safeguard against accidental bias has been built into the (S)TAAR model to address the potential for diagnostic inaccuracy and increase accountability across providers.

Negative Caregiver Experiences

Caregivers of children with autism typically engage in intensive self-education, beginning when they first develop concerns about their child's growth and behavior (Stoner et al., 2005). Time spent looking for information and services reportedly detracts from other activities and leads to feelings of burnout (Weiss, Wingsiong, & Lunsky, 2014). This information-seeking process continues after the child's initial diagnosis because parents report that information about ASD is typically only delivered during one visit in an overwhelming fashion (Carlsson, Miniscalco, Kadesjö, & Laakso, 2016), and during a time when they are also experiencing emotional turmoil around their child's prognosis (Stoner et al., 2005).

Caregivers of children with autism consistently report high levels of stress in response to parenting demands, even beyond those endorsed by caregivers of children with chronic illnesses or other developmental disabilities (Blacher & McIntyre, 2006; Mungo, Ruta, Arrigo & Mazzona, 2007; Olsson & Hwang, 2001). These feelings of stress have been linked to low awareness about autism, inadequate service provision, difficulty accessing existing services, and difficulty understanding the disorder (Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012; Keen, Couzens, Muspratt, & Rodger, 2010). Families of children with autism who have access to fewer financial resources are particularly affected (Pickard & Ingersoll, 2016; Stuart & McGrew, 2009), as are single parents (Meadan, Halle, & Ebata, 2010), and those responsible for multiple children (Harper, Dyches, Harper, Roper, & South, 2013). Although clinicians set out to serve families, clinical and educational programs have been implicated as an additional source of stress for caregivers of children with autism (Altiere & von Kluge, 2009).

Caregivers whose children are diagnosed with special healthcare needs, such as autism, further report that their first step following the appointment is to search for information and practical advice (Jackson et al., 2008). They typically seek information regarding associated symptoms, the course and prognosis of the disorder, and available treatments (Hodgetts, Zwaigenbaum, & Nicholas, 2015). Other common questions are related to the causes of autism, whether there are blood tests to diagnose the disorder, whether a cure exists, and how to plan for having another child (Gona et al., 2015). When parents encounter difficulty acquiring or accessing this information, they tend to develop increased levels of anxiety (Kai, 1996), further compounding the degree of stress they experience related to their child's special educational and healthcare needs. Therefore, given the amount of information parents must learn about autism, and the number of systems they are tasked with navigating for their child, these families may require more family-centered care and extensive case management throughout the diagnostic process. In response to the evident need for family-centered practices in autism assessment, this model incorporates aspects of family navigation, therapeutic assessment, and post-diagnostic support.

Program Objectives and Activities

(Sin Exclusión)

(S)TAAR was developed to be inclusively responsive to the needs and goals of a specific patient population: children under the age of four with a chief complaint of delayed or disordered development, including primary concerns related to language development, behavior, and/or specific concerns for autism. The Developmental-Behavioral Pediatrics Department at Dell Children's Medical Group provides more than 500 new patient visits per year. Of those, at least 50% are diagnosed with autism. About 50% of all DBP new patients are seen in the CAP clinic.

The (S)TAAR model of autism assessment does not exclude patients based on language spoken, insurance provider, or other sociocultural factors. As described above, a majority of Texas residents are Non-White (U.S. Census Bureau, 2018). In addition, the Hispanic population is projected to be the largest demographic group in Texas by 2020. Given that approximately 1 in every 10 children in the United States lives in Texas (7.3 million; State of Texas Children, 2016), addressing state-specific barriers to autism diagnosis through culturally and linguistically-inclusive practice is an essential component of public health. Over 35% of Texans speak a language other than English, with approximately 30% comprised of Spanish speakers (U.S. Census Bureau, 2018). To ensure language access for non-English speakers in our clinic, bilingual providers were utilized and the hospital system frequently arranged for in-person interpreter services. In the past year, bilingual services have been provided in Spanish and Mandarin. Live interpreting services have been arranged for a variety of languages, for example, including Spanish, Farsi, Nepalese, Amharic, Kurdish, and American Sign Language.

Insurance type has also been implicated as an important predictor for time to diagnosis, access to services, and an overall financial burden (Wang, Mandell, Lawer, Cidav, & Leslie, 2013). In our current healthcare system, availability and quality of services is largely dependent on insurance coverage. However, insurance reimbursement rates vary significantly, and therefore, the number of qualified providers accepting all major insurance plans presents another barrier to equitable care and early diagnosis. In Texas, 44% of children are covered by employer-provided insurance, and 43% receive care through federally- or state-funded public insurance programs. Dell Children's Developmental-Behavioral Pediatrics clinic accepts all major insurance, including Medicaid and other state-contracted managed care health plans (e.g., STAR, STAR+Plus, CHIP). Importantly, these statistics are reflected in the patient demographics of those seen in Dell Children's DBP clinic where 40% of patients are insured through Medicaid. Clinic staff is available to assist with insurance support and case management prior to the appointment, and insurance limitations are taken into consideration when providing resources and referrals.

Transdisciplinary

The terms multidisciplinary, interdisciplinary, and transdisciplinary are increasingly used in the literature, but often ambiguously and interchangeably. While each term implies a team approach that draws upon the knowledge and expertise from different disciplines, multi and interdisciplinary approaches typically dictate that professionals from each discipline stay within their boundaries of expertise. In contrast, transdisciplinary work suggests an integration of expertise that transcends traditional professional boundaries. The (S)TAAR model is intentionally transdisciplinary in nature, creating a whole developmental assessment team that is greater than the sum of its parts.

(S)TAAR clinical assessment team, as defined by the subset of staff involved in direct patient care during the diagnostic appointment, is composed of a developmental-behavioral pediatrician (MD/DBP), nurse practitioner (FNP-C), licensed pediatric psychologist (Ph.D./Psych), and a licensed clinical social worker (LCSW) with support from medical assistants. Each team member provides a unique clinical contribution; however, the synchronous model allows overlap between skill sets of each provider, ensuring flexibility in the delivery of services. Medical providers (e.g., FNP-C and DBP) can flexibly deliver diagnostic interview and medical examination procedures. Diagnostic providers (e.g., DBP, Psych) flexibly administer developmental and diagnostic assessment procedures. Behavioral health providers (e.g., Psych/Social Work) flexibly provide counseling and provision of resources.

Through a transdisciplinary approach involving each specialty listed above, the amount of direct provider care within a single appointment always exceeds the length of the visit itself, providing the patient and family with the most value for their time in clinic. For example, during a 90-min visit, a family may have 45 min of face-to-face time with the DBP, 60 min with the psychologist, 80 min with a nurse practitioner, and 15 min with a social worker because providers work alongside one another, moving in and out of the exam and adjoining observation rooms as needed (see Fig. 1). Essential to the overall evaluation procedure is the additional role of nurse coordinator who serves to manage referrals, waitlists, patient communication, triage, scheduling, and gathering of pre-existing records. It is through this role that much of the evaluation process is initiated prior to the new patient assessment appointment, including documentation of past medical history and previous test results.

Documentation time is an issue that plagues comprehensive assessments in that there is a large amount of pre- and post-visit workflow. Care that occurs after the visit, or post-visit workflow, largely refers to time spent completing reports and documenting procedures, which can average three to five pages according to the

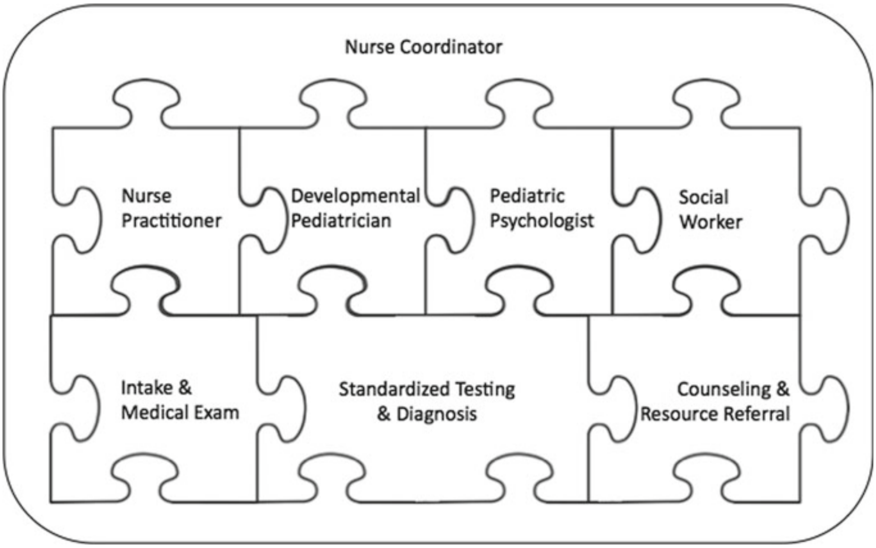


Fig. 1 Interconnection and overlap of (S)TAAR transdisciplinary providers

DBP workflow paper (Soares, Baum, & Frick, 2015). The (S)TARR model addresses this challenge by delegating the pre-visit workload to the nurse practitioner who is responsible for reviewing and documenting the visit prior to the appointment. The post-visit medical decision-making and plan of care is documented by the physician or nurse practitioner after the visit. Testing results and interpretations are delegated to psychology during and after the visit. In this way, charting is shared among providers and highlights unique clinical skills from each discipline. In practice, this has allowed for minimization of computer use in the room while increasing provider engagement with family members and patients. The nurse practitioner actively charts during the visit while the psychologist and physician are freed from the electronic medical record (EMR) to perform assessments and orient themselves more responsively to the patient and their family members. This is especially valuable when some EMRs do not allow for multiple people documenting in the chart at the same time and represents an area for medical residents to integrate into future iterations of the model.

Autism Assessment

At the time of referral, patients meeting inclusion criteria for the (S)TAAR program are identified by the nurse coordinator. This includes patients under the age of four with a chief complaint of developmental delay, behavior, speech, or autism.

Chief concerns are typically expressed in referral paperwork as physician and/or parent concern and may include failed developmental screeners from well-child visits, school districts, or community programs. A minority of patients in the (S)TAAR program also present with provisional diagnoses of autism seeking second opinions and require more comprehensive evaluations and case management to qualify for and access appropriate services.

Prior to scheduling, (S)TAAR patients are categorized into one of two referral groups. Patients with existing developmental testing or behavioral screening measures (e.g., Battelle Developmental Inventory, Second Edition Newborg, 2005; Modified Checklist for Autism in Toddlers (M-CHAT-R/F; Robins, Fein, & Barton, 1999; Robins et al., 2014)) are assigned to the DATA group. Appointments for this group typically include more extensive record review and supplementary direct assessment in clinic. Patients with minimal previous developmental or clinical data (e.g., physician reported concern for autism without administration of screening instruments) are assigned to the NADA group. Appointments for this group typically include less extensive record review and more extensive direct assessment in clinic. The primary purposes of this categorization process are to (1) provide structure and balance to the demands and workflow within the clinic, (2) allow sufficient time for documentation, and (3) tentatively plan specific duties each member of the interdisciplinary team will need to complete during each patient's visit. For example, administration of developmental assessments (e.g., Mullen Scales of Early Learning (MSEL; Mullen, 1989, 1995; Akshoomoff, 2006) is typically administered during NADA visits and those materials are inventoried and placed in the room in advance of the visit. Second opinion visits typically require an ADOS-2 and those materials are prepared in advance as well.

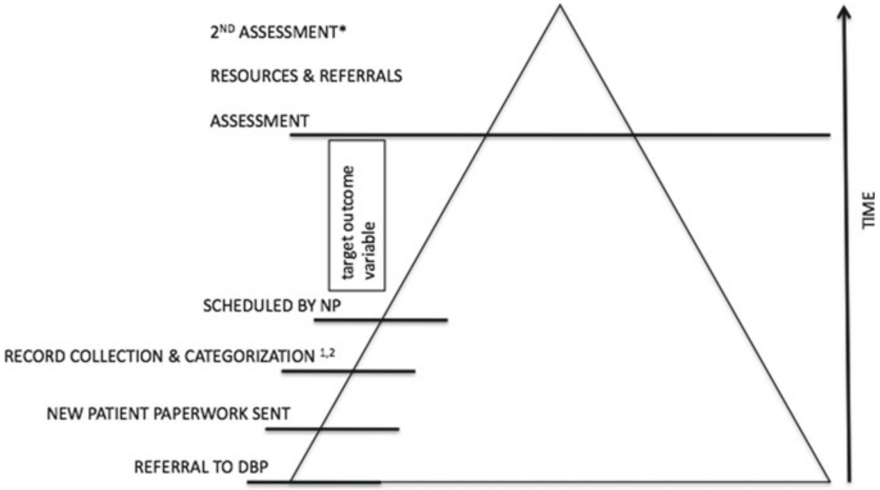
Presently, the (S)TAAR model is implemented during one clinic day per week. These days begin with a team huddle, at which point the DBP, nurse practitioner, psychologist, nurse coordinator, and social worker discuss the day's patients. Providers review existing patient records, including referral questions, chief concerns, medical history, any prior developmental testing or screening instruments, and new patient paperwork. This information is used to determine which assessments are necessary to inform the diagnosis and treatment plan, identify families who will utilize an interpreter, and screen for families that may require unique support from social work (e.g., those who have disclosed housing or food insecurity on new patient paperwork). During these discussions, the nurse practitioner begins the documentation of history and previous assessment results.

(S)TAAR currently provides five new patient appointments per clinic day. While data collection and the evaluation process begins much prior to the appointment, families participate in 90-min, face-to-face consultation/assessment with the transdisciplinary team. Appointment duration varies slightly based on the breadth of previously acquired background information and the complexity of information needed to make a diagnostic determination. Consistent with a transdisciplinary approach, providers work together from start to finish, fluidly blending clinical skills and perspectives from DBP and psychology. For example, developmental testing is conducted with the child while thorough clinical background information is collected via a caregiver interview. Each provider observes the child from their lens of expertise while also working together to form a well-rounded conceptualization of the patient. This assessment approach reduces redundancy that can often occur in interdisciplinary assessment, requires less time from the patient and family, less repetition from parents interacting with different team members at separate times, and improves communication between specialists.

After direct testing, providers inform the family that they will briefly conference in another room. At this point, the team conducts a brief case conference to reach consensus regarding diagnosis, referrals, treatment recommendations, and follow-up plans. Same-day feedback is typically provided by the DBP unless further diagnostic information is required. Feedback is delivered empathically and collaboratively such that the family's initial questions are reiterated and addressed one by one. Diagnoses are provided clearly and an emphasis is placed on avenues for intervention and support. Feedback is delivered with 1–2 staff in the room to allow the family greater privacy. One staff member is primarily oriented towards the parent(s) while another staff member is available to entertain the patient and start showing parents examples of how they can build therapeutic supports into their daily interactions (e.g., show parents how to elicit speech or eye contact by withholding the desired object, improving social reciprocity by engaging in peek-a-boo or tickling, etc.). An emphasis is placed on strengths, introducing parents to recommended intervention services, and helping families prioritize their treatment goals and balance their time/resources according to their child's needs and the family's values. Families that receive a same-day diagnosis are immediately introduced to the clinic's social worker who helps them process the diagnostic experience, provides resources, and explains the role of social work in ongoing case management. If further testing is needed or the parents express a lack of receptiveness to an autism diagnosis, families are referred to the pediatric psychologist for an additional workup. If the referral is due to a lack of diagnostic consensus among staff, the family will return for additional testing and is provided with autism rating scales for teachers, and/or other caregivers to complete. This is often the case for more mild cases of autism particularly those involving co-occurring medical disorders such as a child with epilepsy presenting with social communication deficits. If the referral is due to a lack of buy-in from the parents regarding a potential developmental disability, the psychologist will follow-up about parental concerns which sometimes include cultural norms, stigma, or highly elevated parental stress/depression. The clinic prioritizes efficiency in delivering an accurate diagnosis, but not at the expense of family autonomy or buy-in. Therefore, these rare cases involving significant push-back from parents are treated with particular care and curiosity on the part of CAP providers (Fig. 2).

A typical new patient appointment may include the following procedures:

1. Transdisciplinary morning rounds focused on initial case conceptualization, visit plan, and coordination with social work.
2. The patient is checked in for the appointment and their caregiver is asked to complete a standardized developmental rating scale.



*optional, for limited number of cases

(1) DATA group: existing evaluation data
(2) NADA group: no existing evaluation data

Fig. 2 Timeline of (S)TAAR evaluation, highlighting pre-appointment process and efficiency of assessment procedures

3. Assessment team members enter the room, introduce themselves, and provide an overview of visit procedures.
4. Caregivers are asked to identify chief concerns and their goals for the appointment.
5. Simultaneous delivery of the following clinical services:
    a. Diagnostic interview with the caregiver, derived from The Diagnostic and Statistical Manual of Mental Disorders (5th edition; American Psychiatric Association, 2013) and Autism Diagnostic Interview-Revised (Rutter, Le Couteur, & Lord, 2003)
    b. Standardized developmental assessment with patient
    c. Gathering information from the parent interview and direct observation of the patient to complete a standardized observation rating scale used to determine the existence and severity of autistic symptoms.
6. Medical provider performs a physical exam and discusses co-occurring or differential medical conditions.
7. Providers exit the room to privately conference about the patient. Diagnostic impressions are discussed, standardized assessments are scored, data are reviewed, and the treatment plan is formulated.
8. Feedback is provided to the patient:
    a. Psychologist shares assessment results, including strengths and weaknesses
    b. DBP delivers relevant diagnostic information and explains the treatment plan

   c. Nurse practitioner begins to visit documentation and referrals process
   d. Social worker joins team members to provide support and answer questions.

9. Each patient is scheduled for a one-month follow-up visit to check on the status of referrals and provide an additional opportunity for questions and support.

Resources

Essential to the (S)TAAR model's success is collaborative partnerships with community providers in the areas of early childhood intervention services, general pediatrics, private therapy providers, and connections with high-risk developmental follow-up clinics through local hospital services. Referrals *from* such providers significantly increase the amount of clinically useful information received prior to the assessment appointment. Referrals *to* these providers and other community resources aim to bridge the gap between diagnosis and intervention. Early detection often assumes early intervention, however, parents often report confusion regarding immediate next steps, difficulty accessing services, and general difficulties navigating autism service delivery (Kogan et al., 2008; Moodie-Dyer, Joyce, Anderson-Butcher, & Hoffman, 2014). Despite being well-documented, the process of accessing intervention services post-diagnosis has not improved much over time (Kohler, 1999; Sperry, Whaley, Shawn, & Brame, 1999). In contrast, parents who reported positive experiences emphasize the importance of increased collaboration and social support (Moodie-Dyer et al., 2014).

To provide this level of social support, the (S)TAAR model includes the role of social work as a vital part of the diagnostic process. After receiving the diagnosis and having individual questions answered by the diagnostic team, the clinic social worker is introduced to families through a "warm handoff" procedure. Warm handoffs are a common and often recommended feature of programs that integrate behavioral health services into medical care. Typically, this transitional procedure is designed to facilitate engagement and further appointment attendance with behavioral health providers within the clinic. However, the role of social work in the (S)TAAR model is to provide empowerment and support in helping families access outside community supports in a timely fashion that minimizes feelings of isolation and confusion. The social worker provides an informational packet of vetted, evidence-based informational resources and ongoing assistance to connect with community agencies and quickly enroll in appropriate interventions. Parents are also connected with educational and support services available in-house through clinic psychologists or in the community through nonprofit agencies (e.g., pro bono educational advocacy services for parents of children with autism). Conversations regarding existing and available social and financial supports take place, questions are answered, and families are provided with the social worker's direct phone number to be contacted with additional questions and concerns.

Case Example

We present an example case from spring 2019 to illustrate the flexibility of the (S)TAAR model in meeting individual needs through efficient and comprehensive evidence-based evaluations. This example highlights the experience of Sonia (pseudonym), a 32-month-old female referred for an evaluation by her pediatric otolaryngologist due to significant speech delays and global developmental concerns. Her parents are Middle Eastern refugees that resettled in the greater Austin, Texas area. She was born in the United States and experienced a complicated and premature birth due to a congenital infectious disease affecting the central nervous system. Sonia's disease caused her to develop vision impairments and bilateral sensorineural hearing loss (for which she received cochlear implants). Sonia resides with her parents and extended family in a suburb of Austin, Texas. English and Pashto were spoken in the home.

Sonia was seen in Developmental-Behavioral Pediatrics within 3 months of her referral date. Prior to the appointment, records from otolaryngology, audiology, neuropsychology, speech therapy, physical therapy, occupational therapy, and the local school district's early intervention program were obtained and extensively reviewed during the team huddle and documented by the nurse practitioner. The previous testing included a failed M-CHAT-R, and severely delayed development based on the Mullen Scales of Early Learning and Bayley Scales of Infant and Toddler Development, Third Edition. New patient paperwork including symptom checklists and parental concerns were reviewed prior to the appointment. A full summary of her developmental and medical history, previous test results, and parental concerns was summarized by the nurse coordinator and reviewed by the full assessment team during the team huddle. The assessment team spent approximately 10 min discussing Sonia's case and determined that the Childhood Autism Rating Scale, Second Edition, Standard Version (CARS2-ST; Schopler, Van Bourgondien, Wellman, & Love, 2010), the Developmental Profile 3 (DP-3; Alpern, 2007), a semi-structured parent interview, and physical exam were appropriate to provide additional information regarding developmental and behavioral functioning and evaluate concerns for autism spectrum disorder.

Results of the full evaluation indicated that Sonia was not communicating with any spoken language, used limited eye contact, pointing, and gestures, did not seek comfort from familiar caregivers or engage with others, did not engage in play, repetitively threw or mouthed objects on a regular basis, engaged in hand-flapping, hand-posturing, and repetitive pacing, occasionally sought physical play with adults but did not engage with peers, and did not spontaneously imitate others' speech or actions. The CARS2-ST was completed based on direct observation of Sonia's behavior and parent-report during a semi-structured interview. Scores indicated severe symptoms of autism spectrum disorder. Sonia's parents reported severely impaired adaptive, social-emotional, cognitive, and communication abilities on a norm-referenced measure.

The assessment team met for approximately 10 min and reached a consensus that autism spectrum disorder, speech impairment, and global developmental delay were appropriate diagnoses. Appropriate referrals and resources were discussed during the brief case conference and a plan was developed to deliver feedback and connect the family with ongoing support.

The patient's family was immediately provided with feedback regarding Sonia's developmental delays, lack of progress in speech therapy, and behavioral symptoms consistent with an autism diagnosis. Applied behavior analysis (ABA) was discussed as an appropriate intervention option with her parents, including a specific referral to a local agency accepting Medicaid. Parents were counseled regarding eventual placement in a public school or school for the Deaf. The team made referrals to ophthalmology for a second opinion regarding vision impairment, ABA therapy to support developmental, communicative, and behavioral gains, and ongoing speech, occupation, and physical therapies to continue addressing additional areas of Sonia's delayed development. Genetic testing and an electroencephalogram (EEG) were ordered, the family was introduced to the social worker for ongoing case management, and a medical follow-up visit was scheduled for 6 months.

This family was highly vulnerable to barriers outlined in our needs assessment. They were recently resettled asylum-seekers with public insurance whose primary language is Pashto. Additionally, Sonia presented with a complex medical history (prematurity, disease affecting the central nervous system) and multiple disabilities (vision impairment, hearing impairment), which complicated the diagnostic process. Despite these factors, Sonia was seen within 3 months of referral date and required only one 90-min office visit. She was provided with a comprehensive, evidence-based, transdisciplinary evaluation resulting in same-day feedback regarding multiple diagnoses, referrals back into the community, and post-diagnostic social and medical support.

Discussion

The (S)TAAR model has positively impacted our community's access to care via significant reductions in waitlist time (approximately 77% reduction) and significantly increased the number of new patients seen per month (approximately 190% growth). It is our hope that reductions in time to diagnosis, partnered with a high quality transdisciplinary assessment, ultimately reduce caregiver stress and translate to efficient access to early intervention. As such, we believe that our assessment process targets many of the issues in autism care that plague caregivers and providers alike. Qualitatively, our team reports high provider satisfaction in terms of quality and efficiency with the assessment process. Additional benefits of the (S)TAAR model include an infrastructure that lends itself well to training. The team-based approach offers the possibility of live supervision and observation of assessment techniques.

(S)TAAR is unique from other published models involving collaboration across multiple specialties in that it does not utilize a speech-language pathologist (SLP).

Much discussion occurred surrounding the cost/benefit of including an SLP in the assessment team. Most insurance providers only reimburse two speech evaluations per year and SLPs in the community reported to CAP that they conduct their own speech assessment as part of the process of initiating therapy and developing individualized treatment goals. Therefore, while our team evaluates broad receptive and expressive language using developmental assessments (e.g., MSEL) and notes unusual or aberrant vocalizations and patterns of communication, we chose to leave more comprehensive speech evaluations to SLPs in the community who provide the service when speech therapy is initiated. This minimizes the threat of test-retest effects that occur when patients are redundantly evaluated within a short time period and reduces the amount billed to insurance for the patient's appointment at CAP.

Though (S)TAAR is limited in its age range, improvements that emerge through this model have secondary impacts on patients of all ages. Because high-risk infants and toddlers constitute a significant portion of overall referrals, activities implemented for this group of new patients were anticipated to indirectly benefit the broader clinic population as well. In addition, as children age, other community providers (e.g., public school systems) often capture those who demonstrate developmental or behavioral differences. As the model continues to improve access to care for the youngest members of our community, it is our plan to expand the age range to include 4- and 5-year-olds in order to capture all children who are not yet eligible for enrollment in public kindergarten programs. In future iterations, older patients might benefit from more extensive evaluation, including speech/language (e.g., pragmatics, semantics), academic skills, adaptive and social-emotional behavior.

Program evaluation for the (S)TAAR model is ongoing and outcome data have not yet been published. The team hypothesizes that quality and cost-effectiveness metrics will increase in relation to the single-provider multi-visit model that was previously in place. In terms of quality (determined through fidelity checks and quality monitoring), the team is actively collecting data regarding the timeline from referral to diagnosis, patient satisfaction, and provider satisfaction. In terms of cost-effectiveness, billable hours, no-shows, and rate of follow-up will be compared between baseline and the initial implementation phases of the (S)TAAR model. Future program goals include expanding the model with fidelity to further increase the number of new patient appointments, with particular emphasis on increasing training opportunities for graduate students and medical residents.

Finally, the nature of transdisciplinary work poses unique, and often subtle implementation challenges. Through our execution of the (S)TAAR model, we have experienced a team synchrony that appears integral to the success of the model. This synchrony requires hidden parameters related to leadership, communication, coordination, and an emergent "flow." In positive psychology, flow is a mental state in which a person performing an activity is fully engaged in a feeling of high focus, complete involvement, and enjoyment in the process. It has been our experience that effective leadership from the CAP team, individual responsibility for components of the assessment process, clear communication, and genuine enjoyment of working as a group to support families has helped to foster a flow that appears to have a significantly positive impact on the providers' and patients' experience. Future research may help to elucidate the key components to our model's successes that go beyond fiscal or productivity goals, but also speak to the heart involved in being the beginning of a family's lifelong journey with autism.

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