

Responding and Identifying to Developmental Delay in Children

Aryan Kumar

Abstract:-

BACKGROUND: This paper specialises in the diagnosis of children with developmental delays and behavioural difficulties. This is important as parents often bring their child's behaviour or development issues to paediatric providers first. Over 1/3 of paediatric visits involve questions in these areas. Fifteen per cent of children are diagnosed with developmental disabilities, and yet only 3% receive early intervention services before the age of 3. Early identification of developmental delays and appropriate referral to early intervention can lead to better outcomes for children and for society as a whole. Only a small percentage of developmental issues are identified before a child enters school. Primary care doctors can make a difference in identifying children at an early age.

INTRODUCTION: Disabilities affect more than one billion people in the world. Nearly one in four people in the United States is affected by a disability. Mental illness affects 1 in 5 people in the first 18 years of a child's life. These developmental and behavioural issues are so prevalent, that paediatrics is certain to interact with children and family members with these conditions.

OBJECTIVES: The goal of this paper is to help differentiate developmental screening from developmental surveillance, discuss the American Academy of Paediatrics recommendations for routine developmental screening and surveillance, and develop a plan for implementing them in your practice setting. Additionally, the paper covers interpreting and implementing routine developmental screening in a clinician's practice, describing eligibility criteria for Early Intervention services, and understanding what services are available through Early Intervention. Lastly, this paper covers in great detail and depth recognizing when and how to make Early Intervention referrals in a clinician's geographic area, reading and explaining an Individualized Family Service Plan (IFSP), effectively communicating with and supporting families through the process of developmental screening and making Early Intervention referral.

METHODS: A case study that is provided by Stanford University is presented of an 18-year-old boy called Trevor who displayed risks of potential developmental delays and went through developmental surveillance and screening to detect potential development delays. The M-CHART-R was utilized with 20 questions with Yes or No as the option to answer where Yes is a typical response and No is the response the answer where the child may show potential risk. However, questions 2, 5, and 12 are reverse scored meaning No is a typical response and Yes is the response where the child shows risk. The screening

results of Trevor are revealed in this paper as well as discussed. On the basis of a mixture of the case study, independent research by the faculty, and additional sources, this research was issued and explored.

RESULTS: Trevor's parents were concerned as the only words Trevor is able to speak are "mama" and "dada" and are concerned about Trevor's risk of possible language delays. The M-CHART-R of Trevor's results has 3 at-risk responses with questions 5, 8, and 12 answering No indicating potential risk for developmental delay. After evaluating Trevor, it was concluded that Trevor presented a moderate risk of developmental delay and should be followed up with additional questions. As the primary concern for Trevor is his speech and language. Upon review by the clinician assigned to Trevor's case, it was concluded that Trevor was not at risk for autism. However, a follow-up appointment was required in terms of Trevor's speech and language.

CONCLUSION: This paper is designed to help physicians, paediatrics, and other medical professionals as well as any individuals understand the importance of using developmental screening and surveillance at recommended intervals, and how to refer to early intervention services when indicated. One of the primary aims of this paper was to increase awareness and give the tools, language, and the desire to identify developmental issues early. It should also be known when and where to refer the patients. In addition, helping children who one may know in working with their developmental delays and disabilities.

I. INTRODUCTION

A. INTRODUCTION TO COMMUNICATING EFFECTIVELY ABOUT DEVELOPMENTAL BEHAVIORAL ISSUES

In the medical model of disability:

- People are disabled by their impairments or differences
- Thus, these impairments should be "fixed" with medical treatments
- The model often looks at what is "wrong" with the person rather than how that person can make choices to increase their participation in the world.

The social model of disability where a person is unable to participate successfully in the world encompasses:

- Disability is caused by the way society is organized rather than a person's impairment
- For example, a child in a wheelchair has full mobility when ramps and accessible bathrooms are available.
- Additionally, a child with autism can access the curriculum with the help of behaviour support.

The social model focuses on removing barriers so that people with disabilities can be independent with choice, and control over their own lives.

Language matters and children can be helped just by the way others talk. In “People First” language, the person is emphasized rather than the disability. When People First language is used, a child with autism is described rather than an “autistic child”. We speak to an intellectual disability person rather than an intellectually disabled person. And, we know a person who uses a wheelchair rather than someone who is confined to a wheelchair.

But some people with disabilities prefer to use “Identity First” language. This includes, “Autistic individuals” where we understand autism is an inherent (natural) part of individual's identity. Autism is not something to be ashamed of but is important to an individual's identity to be embraced.

It is good to know from the individual which language would they like to be expressed in.

In 2010, the term intellectual disability replaced the terminology “mental retardation” in all federal laws.

In summary, effective communication about developmental and behavioural issues is an important skill for paediatric primary care providers.

B. INTRODUCTION TO DEVELOPMENTAL SURVEILLANCE & SCREENING

The two biggest tools in the primary care Practitioner toolkits to identify developmental delays are developmental surveillance and developmental screening. In this section, it will be explained why it is important to use both these interventions to identify delays in young children. The risk factors are well known including poor maternal health during pregnancy, birth complications, prematurity, infections, genetic disorders, and exposure to toxins or trauma. The first years of life are widely recognized as a period of rapid brain development. Studies show that benefits of early intervention include better intellectuality, and social and adaptive behavior later in life when children receive services early in life. Studies have shown also an increase in high school graduation, employment rates, and decreased criminality for children who receive services over their peers.

C. WHY DOES THE AMERICAN ACADEMY OF PAEDIATRICS RECOMMEND ROUTINE DEVELOPMENTAL SCREENING AND SURVEILLANCE?

Fifteen out of a hundred or 15% of children in the US will be diagnosed with a developmental disability before they reach adulthood. Most of them will have developmental delays from early in life. Only about 3% of children receive early intervention services before the age of three. Another 3% of children will receive a developmental service by the time they reach the age of 5. However, over half of the children will not be identified with developmental issues until kindergarten or beyond. Early intervention helps children achieve their potential and strengthens families.

Paediatric family providers who have relationships with families from the time of infancy (childhood) are in an excellent position to identify children with delays. There are two types of intervention: Developmental Surveillance and Developmental Screening.

Developmental Screening is the ongoing monitoring of the children's development by a clinician using parents' concerns, identifying known risks and clinical observation and knowledge as tools. Paediatrics use their knowledge to interpret the history and physical to determine if the child has developmental delays. If a clinician is concerned, he or she makes referrals to early intervention and speciality services for further developmental assessments.

Developmental screening is the use of the standardised developmental questionnaire at regular intervals to search the general population of children for delays. When concerns are raised in the developmental screening test, the clinician refers the child to early intervention and speciality services for further evaluation and assessments. The American Academy of Paediatrics (AAP) recommend developmental surveillance at all well-child visits with the use of a reliable and developmental screening tool at the 9th Month, 18th Month, 24th Month and 30 Month visits.

An autism-specific developmental screening tool is recommended to be used at 18 months and 24 months of age. Despite these recommendations, paediatrics developmental screening rates remain below 50% nationwide. Clinicians have identified the reasons for not screening universally: lack of time, cost, lack of training in how to screen and lack of options for referral when a screening test is positive. Over 2000 children were randomized in an experiment to developmental screening or developmental surveillance arms where twice as many children from the developmental screening group were referred for early intervention as were from referred from the developmental surveillance group. Additionally, twice as many children from the developmental screening group qualified to receive developmental services compared to the surveillance group. Out of the children who received early intervention services, children from the screening group received services almost 70% sooner than the children in the surveillance group. For every 14 children screened, one child received early intervention sooner than they would have without routine screening. Another study shows that adding routine developmental screening to all well-child care visits in paediatric practice increased early intervention referrals by 200% from the previous year despite an overall decrease in patient volume for the study year. Once again, twice as many children were identified when developmental screening was used then were identified by developmental surveillance alone.

While developmental screening identified by an experienced clinician identifies many children who need developmental services, using a standardised developmental screening tool doubles the number of children identified who need developmental services. The AAP recommends developmental surveillance at all well-child visits, the use of an available developmental screener at 9 months, 18

months, 24 months and whenever a parent raises a developmental concern. An autism screening tool should be used at 18 months and 24 months of age.

II. METHODS

A. CASE STUDY – BACKGROUND OF TREVOR

“Trevor is an 18-month-old boy who you are seeing for a health supervision visit. His mother is concerned that he says only “mama” and “dada,” specific for his parents, and points and gestures. He reaches to be picked up, and he waves “bye-bye.” His mother has no concern about his eye contact, but shares that she is worried that his language is delayed.

He was born at term and is healthy. He has normal growth parameters including head circumference. He has a normal physical examination. He reaches for your stethoscope when you examine him, and places it first on his heart, then on yours, while making well-coordinated eye contact and smiling at you.”

B. CHOOSING AND IMPLEMENTING DEVELOPMENTAL SCREENING IN A PRACTICE

Before This part of the paper encompasses choosing and implementing developmental screening tests. There are three commonly used developmental screening tools and one autism screening tool. When selecting a screening tool, it is important to take several factors into consideration and there will be three categories that will influence the choice of the screening tool that needs to be used such as the psychometric properties of the screening tool, the unique characteristics of your clinic’s patient population and the resources available at your clinic. When evaluating a screening tool, it is important to understand how well it understands children with developmental delay and if it produces consistent results.

Reliability refers to the ability of a measure to produce consistent and reproducible results over time. While validity refers to discrimination between a child at risk for delays and the population. In order to discriminate the child for the delay and the rest of the population, the sensitivity and the specificity of the screening tool must be considered.

Sensitivity is the accuracy of the test in identifying children with delay. While specificity is the accuracy of the test in identifying the children, who are not delayed.

In order for a developmental screening tool to be useful, the AAP recommends that a screening tool must have a sensitivity of 70% and specificity of 70%.

Other factors to take into account when choosing a developmental screening tool are the unique characteristics of the patient such as the literacy rate, family’s access to computers and online services, and languages spoken by your patient.

Lastly, it is important to know what resources are available at your clinic before choosing a developmental screening tool such as how much time is there in your workflow for a parent to complete your measure, should a

parent complete it online or in the waiting room, who will score the screening test, how will the results be communicated to the provider and so forth. Finally, it is important to consider whether time or money is a more valuable resource in your clinic when selecting between various developmental screening instruments and their online and paper formats.

There are four tools that have good validity and reliability in developmental screening tools. The most commonly used general screening tools are:

- Parents Evaluation of Developmental Status (PEDs)
- Ages and Status Questionnaires – Third Edition (ASQ-3)
- The Survey of Well-Being of Young Children (SWYC)
- The Modified Checklist for Autism (MCHAT-R/F)

It is recommended to use both a general developmental screening tool and autism-specific tool. The PEDs, ASQ-3, and MCHAT-R/F meet the recommended validity and reliability threshold.

C. PEDS

The PEDS is a general developmental screening tool that is available both in online and paper format. It has a single questionnaire with 10 questions for all ages from birth to age eight. This can be completed on their own which takes 3-5 minutes. PEDs is available in English, Spanish, and 40 other languages. In PEDs, the parent can answer yes or no and an option to add a little extra comment.

D. ASQ-3

The ASQ-3 is also a general developmental screening tool that comes in 21-age-specific questionnaires available both in paper and online format as well. The ASQ is validated for ages one month to 66 months of age. It takes 10-15 minutes to complete the ASQ-3. The ASQ is available in English, Spanish, Chinese, and many more. The parent answers with a yes, no, or sometimes.

E. SWYC

The most recent developmental screening tool that has been developed is the SWYC. The SWYC is also a general developmental screening tool with additional questions about behavior and family risk factors. Twelve age-specific questionnaires can be downloaded for free for the ages of two months to 60 months of age. Like the ASQ, the SWYC takes 15 minutes to complete the questionnaires. The SWYC is also available in English, Spanish, Chinese, and many more. The parent can answer with not yet, very much, and somewhat.

F. MCHAT-R/F

This is a 20-question autism-specific developmental screening tool that is used between 16 to 30 months of age. This is a vital aspect that is often overlooked. The MCHAT takes 5 to 10 minutes to complete and takes 2-5 minutes to score. However, follow-up questions can take additional time for proper administration. The MCHAT can be downloaded for free and is also available in English, Spanish, Chinese, and many other languages. A parent can answer yes or no to the questionnaire.

G. IMPLEMENTATION PLAN

Once the adequate and appropriate screening tool is selected, it is vital to create an implementation plan. The first is to designate an office “Champion” who is enthusiastic and persistent to lead the program. Once the format of the screening tool, online versus paper has been selected, the champion will need to work with your team to create a screening and ordering workflow. It is substantial to provide training for all necessary personnel on the use, scoring, and interpretation of the chosen screeners. The publishers of each of the screening tools provide manuals and support for the proper implementation of the product.

Procedures for rooming, scheduling, patient flow, and scoring that are specific to your clinic will be created. Standardized report templates and document routing procedures specific to your medical records system will encourage efficiency and optimized billing. In order for the developmental screening tool to be successful over time, it is vital to regularly assess the program for the successes and challenges and to adjust your program if required.

Screening Test	Domains	Forms	Parent Completion Time	Psychometrics	Cost	Languages Available	Website
Ages & Stages Questionnaires, Third Edition (ASQ®-3)	Behavior, Language, Motor, Problem Solving	21 age-based forms (between the ages of 2 months and 60 months)/available online and print	10-15 minutes	Sensitivity=86% Specificity=85%	\$295 per language one-time fee (Screeners can legally be photocopied after purchase)	English, Spanish, Arabic, Chinese, French, Vietnamese, and many others	Brookespublishing.c
Parents' Evaluation of Developmental Status (PEDS); PEDS Developmental Milestones (PEDS:DM)	Behavior, Language, Motor, Problem Solving, Social-Emotional	Same form used for ages 0-8 years/available online and print	3-5 minutes	Sensitivity=91-97% Specificity=73-86%	\$1/screening when using print version; \$4/screening for online (for PEDS, PEDS:DM and MCHAT-R™)	English, Spanish, and more than 40 others	Pedstest.com
The Survey of Well-Being of Young Children (SWYC)	General Development, Behavior, Family Risk Factors	Twelve age-based forms between ages 2 months and 60 months/available online (may be freely downloaded)	15 minutes	Sensitivity=76% Specificity=77%	Free online	English, Spanish, and several others	floatinghospital.org of-wellbeing-of-you children/overview

Fig. 1: Summarizes all the common general developmental screening tools used in identifying child developmental delays

Commonly Used Autism Screening Tool							
Screening Test	Domains	Forms	Parent Completion Time	Psychometrics	Cost	Languages Available	Website
Modified Checklist for Autism in Toddlers (MCHAT-R/F™)	Autism	Only 20 question form for children between the ages of 16 and 30 months old	5-10 minutes	Sensitivity=87% Specificity=99% when Follow-up Questions are used	Free online	English, Spanish, and more than 50 others	Mchatscreen.com

Fig. 2: Review of the common autism screening tool utilized on children

III. RESULTS

A. SCORING THE M-CHAT-R/F™ FOR TREVOR

The practice used on Trevor is the ASQ-3 and M-CHAT-R as the developmental screening tools. For the ASQ, Trevor scored beneath the cut-off for the communication domain but above the cut-off for all the other domains indicating isolated concerns in communication.

B. The M-CHAT-R

is typically scored with 20 Questions with Yes or No as the option to answer those questions by the caregiver. For most of the questions, Yes is the typical response and No is the response that indicates risk. Items 2, 5, and 12 are

reverse scored meaning No is a typical response and Yes is the response where the child shows risk. Once the at-risk responses are calculated, the M-CHAT-R can be used to determine the risk level of the patient.

A score between 0 to 2 indicates low risk and no follow-up is needed based on the screening. 3-7 indicates a moderate risk level and the child should be referred for early intervention and developmental assessments. If 8-20 responses are in the risk category then the caregiver then there is no need to administer follow-up questions as the child is determined to be at risk. Thus, they should be referred for early intervention and developmental assessment.

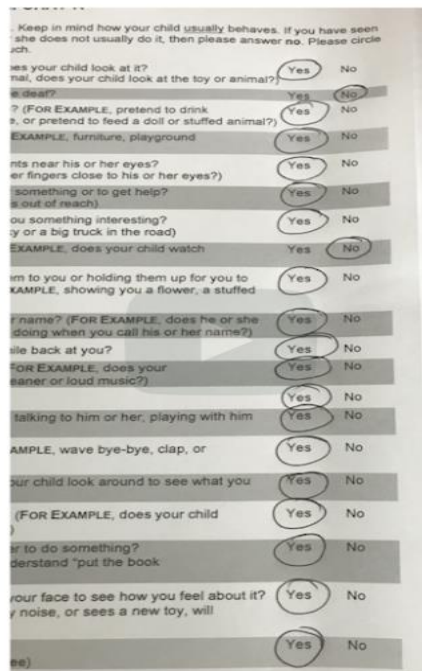


Fig. 3: Shows Trevor’s Screening Teat Questionnaire Answers

There is a Yes response for questions 5 and 12 indicating at-risk answers. All the other remaining items are answered Yes except for question 8 and thus, Trevor has 3 at-risk responses. Here are the at-risk responses for Trevor:

- Does your child make unusual finger movements near his or her eyes? – Yes
- Is your child interested in other children? – No
- Does your child get upset by everyday noises? – Yes

By reviewing the M-CHAT-R, Trevor is at risk for moderate risk that should be followed up by follow-up questions. Follow-up questions increase the specificity of the M-CHAT-R.

C. THE M-CHAT-R/F™ FOLLOW-UP QUESTIONS

The main concern for Trevor is his speech and language. When a game is played such as “peekaboo” he moves his fingers in an unusual way in front of his eyes, Trevor only does this while playing this game. Trevor is really shy and he would hide behind his mother’s back when he meets kids he does not know. He smiles back at them but is just really shy. Trevor gets upset by everyday noises such as the vacuum cleaner. He only gets upset by the vacuum cleaner and not any other noises. When he hears the noise, he cries and covers his ears. From the review by the clinician, Trevor is not at risk for autism. A follow-up is required in terms of his speech and language.

D. COMMUNICATION GUIDELINES – FAILED SCREENING RESULTS TO PARENTS

Effective skills are required for many clinicians such as responding to a family’s reaction, involving a family in decision-share making, dealing with stress in the family unit, and working with multiple family members who are not always present at the same time. Communicating the results of the developmental screening test is a unique task because screening tests are not diagnostics. At-risk results may be shocking and surprising for the family. It indicates that further action is needed. Discussions help before a definitive diagnosis that allows conversations about the benefits of early intervention and can encourage them to view their child from a strength-based perspective. Three effective steps can help effective communication of at-risk developmental screening results. Firstly, the clinician should ensure that the family understands what the specific concern is. Second, the clinician must determine how the family perceives the results of the at-risk screening. And lastly, the clinician should set up the next steps and a concrete action plan with the family.

How the family perceives the screening results influence how the family will respond to them. A family in denial about potential delays is much less likely to follow through on action steps such as early intervention referrals than parents who are concerned or simply neutral about the results.

Listening skills are required and look for unspoken concerns as a clinician. Ask empathetic and open-ended questions such as “You seem concerned about Trevor’s speech; can you tell me more?”. A child at risk for developmental screening disorder may not be at risk for

delays. The only action after the screening test is more in-depth assessments. Clinicians can encourage action taken by the parents and motivate them by simple language such as “I am very concerned about Trevor’s language” without committing to a diagnosis and a prognosis.

The last step to communicating at-risk screening results is to set up the next steps such as a referral plan for an at-risk patient for further developmental assessments through early intervention. It is important to make a follow-up appointment to check on the status of referral recommendations.

In summary, when you identify a child at risk for developmental delays, the clinician should gather more information and refer to the appropriate clinician. Next is to guide the family into taking the next steps and schedule a follow up appointment with the family as well as the child.

IV. DISCUSSION

A. INTRODUCTION TO EARLY INTERVENTION

The local early intervention and early start program is the very first thing to think of when there are concerns about development in a patient less than three years old. Early intervention is designed to evaluate and serve the needs of children and their families with developmental delay or risk factors for a delay during the first three years of life. And early intervention is always free and for those who qualify, the services are also free to all but the most affluent families. Both are available without regard to immigration status.

Early intervention has been mandated by federal law since 1986 as Part C of IDEA the Individuals with Disability Education Act. Part B of the same act is special education for kids aged 3 to 21. Early Intervention is more family-centered than special education and has a more holistic approach. Although its federally mandated, early intervention is administered differently in different states. Each state decides how delayed a child needs to be qualified, and the extent to which they will serve the kids with just risk factors. They also differ in how they fund the program. In California, it’s called the early start and runs through regional centers and some regional education offices. This can be confusing because regional centers also serve older kids and adults with severe disabilities however that is a different program mandated by a different federal law. The two programs have different eligibility criteria and require separate referrals.

Early Intervention provides a prompt reliable assessment of a child’s developmental functioning and whether or not they turn out to be eligible for services. The assessment will determine whether the child qualifies, and even if they don’t, the findings are valuable and can help guide the parents about what should come next. Watchful waiting is never a good idea when the concern is about development, and early intervention is the best first step in the evaluation, before referral for other services or assessments such as to a developmental-behavioural paediatrician or speech pathologist. The other concepts may take longer and could consequently delay help for the child

or patient. Even if a referral is made to other specialties, early intervention should always be part of the first wave of things to be done. Generally, early intervention law includes a mandate that service be provided in a natural environment such as the home or community setting unless there's a specific clinical reason not to. This is due to infants and toddlers tend to learn best in familiar environments and when the lessons are built into their daily routines. This also allows therapists to utilize a coaching model with family caregivers which increases the likelihood of the child practicing the skill between formal sessions.

If the patient is found eligible, a wide range of help is then made available. Early intervention typically provides family training or counselling to help parents know how to stimulate their child's development, and support them in the most productive ways.

Home visits by a trained developmental specialist to work directly with the child. Speech, occupational or physical therapy are often sent to the child's home although they sometimes may be center-based. Toddler playgroups are also very popular with parents. In addition to promoting socialization with same-age peers for the child, they provide peer support for parents and can lead to positive effects on parenting behavior. All children receive service coordination and case management that includes periodic assessments of their progress to ensure nothing is being missed.

If needed in some states, early intervention can also provide specialized instruction up to and including Applied Behaviour Analysis or ABA for children with autism, or severe behavioural dysregulation, nutrition services and feeding therapy or children with failure to thrive, swallowing issues, or who are tube-fed, assistive technology or communication, diapers, safety equipment to child proof the home, vision or audiology services for those with sensory impairments, home wealth, medical or nursing services when medical challenges impact developmental and those services are not covered by insurance, psychological and social work services or the family especially when these issues impact a child's development, and sometimes reimbursement for transportation cost.

Early intervention should be the go-to referral when there is a concern about a child's development. This should be the first thing to do even if the child does not qualify, the assessment is free and will help guide the next steps to be taken.

B. ELIGIBILITY & INTAKE

There are generally three ways to qualify for services under-diagnosis, delay, or risk. States and even individual counties in California set the details within each category. Thus, specifics vary according to where the individual lives. Eligibility is automatic when a qualifying diagnosis has been established by a medical professional. Qualifying diagnoses differ state by state however, typically include prematurity or very low birth weight, sensory impairment, congenital heart disease, cerebral palsy, seizure disorders, genetic syndromes, metabolic conditions, or congenital infection. Significant delay in at least one area of development is the most common reason children get early

intervention. Each state sets its own threshold. It is 33% in California however, ranges from 25% to 50% around the United States of America. Despite the provisions in Part C of IDEA, currently, only five states and a few California counties serve at-risk children without a delayed diagnosis. Among the few places that do, there is a variability about which risk factors get recognized.

Eligibility for early intervention is determined by the assessment, not the person making the referral. A parent must consent. Then depending on the state, either a full assessment is carried out or screening is done to determine whether the full assessment is necessary. A variety of trained professionals may be used. They usually come at home, and in full assessment, developmental levels are measured in a variety of areas. They usually come to the home, and in a full assessment, developmental levels are measured in a variety of areas. This establishes a baseline for children who qualify by a medical diagnosis and determines eligibility for most of the others. If parents agree with the referral, a developmental expert will observe and talk to their child, ask them to do things, and perhaps administer some standardized tests. This will determine how their child is developing and determine what services they need and qualify for in order to optimize development. It is important for the medical professionals to let the families know that both the evaluation and service are free to most families and available regardless of immigration status. The assessment finishes with the development of a written document called the Individual Family Service Plan or IFSP. It is finalized in a meeting with the family and the early intervention staff. Children who qualify are assigned to a service coordinator as their point of contact. The entire evaluation process from referral to IFSP meeting is supposed to take less than 45 days provided the parent consents immediately. An IFSP document is produced even when the child does not qualify for the services. It contains a description of the child's motor, cognitive, communicative, social-emotional, and adaptive levels. Medical professionals should not just refer the child who qualifies but any child whose development they are worried about. The concern might come from the parent or caregivers, or it might come from the screening and surveillance that is done during a well-child visit. It may relate to an actual delay or it may be simply that you view the child as at risk. It is ideal not to pre-judge the process and only refer children that they think will qualify. The evaluation results are valuable even if it does not lead to services. It may be good in putting one member of your support staff in a change of early intervention referrals. If a medical home navigator or care coordinator is not available then this is known as the early intervention champion. They may collect and score the screening tools that were mentioned previously. They should ideally get to know the service coordinator at their local programs and get competent at closing loops, ensuring early intervention referrals land, that you get copies of the IFSP, check-in with parents, and evaluating how services are going. An early intervention champion can either be a nurse or a medical assistant. He or she could assist you in talking to parents about the referral upfront and the services later on. They should especially emphasize the importance of family members learning the techniques used by the

therapists and using them every day when the therapist is not present. The early intervention champion could also enquire about obstacles that parents face with early intervention as some families may have a hard time fitting this system into their schedules or they may be reluctant to have people visit their home. Some will need help filing forms for the early intervention program, or they may need someone to help mediate scheduling and staffing conflicts. Too many missed appointments are the only thing that will cause a child to drop out or lose their early intervention services. When a child turns three then maybe the child has made so much progress that services are no longer needed. Early intervention will always reassess the child's approaches to turning three to see. If not, they will be a handoff to the public schools to be assessed or special education. Early intervention programs and school districts usually work well together to make these handoffs go smoothly. The two systems are very different; thus many parents struggle with a transition. Some children will not qualify for special education even when the early intervention staff thinks they should. In these cases, private service referrals can be thought of as an option such as speech or occupation therapy. Additionally, special education is not the only potential source of support beyond the age of three, especially for severe developmental delays, cerebral palsy, or autism.

C. BARRIERS OF ENTRY TO EARLY INTERVENTION

These can be family factors such as housing insecurity/instability, limited parental English or literacy skills, differing cultural expectations/attitudes regarding development and disabilities, work/financial/transportation/child care challenges, and possibly lack of trust in government/agencies/professionals. However, can also be Medical Home factors like Clinician "wait and see" attitude, reluctance to give "bad news", lack

of knowledge about normal development and program value, use of medical jargon leading to lack of family understanding, paternalism/lack of family-centered approach and insensitivity to cultural/religious diversity.

D. READING AN INDIVIDUALIZED FAMILY SERVICE PLAN (IFSP) FORM

After the patient is evaluated by early intervention or early start, a meeting is held with the parents, the service coordinator, and often key therapists and other providers. Parents are given the opportunity to present their hopes, concerns, and priorities for the child, and the results of the assessment and service recommendation are shared with them by the early intervention staff. Based on all this, an Individual Family Service Plan is drawn up in agreed upon. Subsequent meetings happen every six months to review progress and update the IFSP. Unfortunately, paediatricians do not always get the IFSP automatically even when the referral is made. Sometimes, the parents or caregiver would need to request it. Even after, the parents or caregivers have sent a release of information, their early intervention champion or other staff members may need to follow up with a phone call. Ideally, there should be systems for timely two-way communication between the early intervention program and the medical home. The parents or caregivers are working towards the same goals and should be a team. Families should not have to bear the burden of being the go-between. Even though there are legal and administrative obstacles to this. The earliest antidote is if there are individuals in both places who know one another and feel comfortable emailing or picking up the phone when it is in the interest of the patient. However, it is well worth it to get the IFSP. It can be helpful in the medical professionals' clinical thinking, and your discussions with the family.

SANTA CLARA COUNTY EARLY START PROGRAM
INDIVIDUALIZED FAMILY SERVICE PLAN (IFSP)
for Children Birth to Three Years

Child's Name: _____ Birth date: _____ Age: 20 mo. Sex: F M

School District of residence: _____ School District _____ IFSP dated: 11/2/

IFSP TYPE: Initial Assessment & IFSP 6-month Review of IFSP Annual Review IFSP Other Review of IFSP

Projected review (w/in 6 mo.) 5/2/ Projected annual review 11/2/ Tentative IFSP exit 2/15/

Parent(s)/Guardian(s): _____ Phone: _____
Dad
Mom

Address: _____ City: San Jose ZIP: _____

Service Coordinator Name	Agency	Phone	Date Appointed	Date Ended
<u>Rocio King, MA</u>	<input checked="" type="checkbox"/> SARC <input type="checkbox"/> COE		<u>11/2/</u>	<u>/ /</u>
	<input type="checkbox"/> SARC <input type="checkbox"/> COE		<u>/ /</u>	<u>/ /</u>

Fig. 4: Illustrates the IFSP for Children Form

IFSPs from different areas can be formatted differently, but they all share common elements. Near the beginning, there is an indication of what type of meeting it was and demographic information about the child and family. Medical professionals should note how old the child

was when the IFSP was done. They may be older by now, but their age at the time of testing is what counts when looking at the assessment results. The role of the service coordinators is to monitor the implementation of the services outlined in the IFSP. This may be one of the child's

therapists, or it may be an individual specific to that role. That is who should be called for questions or concerns. If more than one agency does early intervention or the district

where the patient lives, the agency serving this case is also indicated.

Family's priorities, concerns & resources as they relate to their child's development (Voluntary on the part of the parent.)

was referred to Early Start by his pediatrician due to concerns with his communication skills. The pediatrician also recommended a referral to a Developmental Pediatrician for further assessment regarding his communication and behavior concerns, as well as referrals for speech therapy and ABA therapy. Regarding [redacted]'s behavior, parents are concerned with how [redacted] expresses excitement. Per parent report when excited, [redacted] will flap arms, walk on tip toes, and sometimes spin in circles. [redacted] also has some repetitive behaviors such as opening and closing doors and turning on and off the lights. Parents expressed concern that [redacted] cries when he hears the noise of the blender or vacuum. Regarding communication, parents shared that [redacted] does not have any words to communicate. He primarily communicates his wants and needs by leading parents to desired items and sometimes pointing. He used to say *mama* and *dada*, but no longer does so. Dad reported no concerns regarding [redacted]'s receptive language skills and described [redacted] as a bright boy who understands most of what is said to him. Parents also describe [redacted] as an active boy who moves quickly from one activity to the next. Parents are interested in knowing how [redacted] is doing and what they can do to help him continue to progress. Mom is able to transport and participate in services as needed. Medical needs are provided through United Health Care.

Natural Environment(s): Everyday routines, activities and environments for this student include:

[redacted] lives at home with his parents and grandmother. Mom works part time during the day while Dad works full time outside of the home. While parents are at work, [redacted] stays at home with Grandma. [redacted] has aunts and uncles that live in the area that he sees on a regular basis. [redacted] enjoys going to the park, playing "Peekaboo", watching YouTube, and going to his swimming classes.

Fig. 5: Demonstrates the Narrative Section of the IFSP

The narrative section of the IFSP can vary quite a bit in its content and form. Sometimes it states the eligibility criteria under which the child is qualified for services. In other times it is a less formal history and reason for referral.

There may be details here that the medical professional may not know especially about the family's perspective, goals, or, priorities.

ALL ABOUT US!
My family calls me: _____

The important people in our life are: Mom Dad Mima (Grandmother)	Important events/celebrations for our family include: - Thanksgiving - Christmas - Birthdays
What are your family's enjoyable/playful moments throughout the day/night? - Going to the park - Going to the library, mall, etc - Bath time - Nighttime routine/story time	Are there activities or times throughout the day/night that are challenging for your family? If so what/when: - Sometimes [redacted] wakes up at night and it's hard to put him back to sleep, but doesn't happen often.
We enjoy watching our child... - Play with his toys - Smile/ facial expressions - Get excited/happy when we come home from work	We would like to learn more about... - Speech delay - Why is he not talking yet? - Possible ASD? - Repetive behaviors, stimming
We look forward to when our child... - Does something new/learns a new skill - Smiles/ plays happily - We look forward to when [redacted] learns new words and talks, and is able to better communicate his needs/wants.	

Fig. 6: Shows the parent input in the IFSP

Some programs include an excellent patient questionnaire like the one shown above inside the narrative portion of the IFSP.

**SANTA CLARA COUNTY EARLY START PROGRAM
INDIVIDUALIZED FAMILY SERVICE PLAN (IFSP)
for Children Birth to Three Years**

Child's Name: _____ Birth date: _____ Age: 20 mo. Sex: F M

School District of residence: _____ School District _____ IFSP dated: 11/2/

IFSP TYPE: Initial Assessment & IFSP 6-month Review of IFSP Annual Review IFSP Other Review of IFSP

Projected review (w/in 6 mo.) 5/2/ Projected annual review 11/2/ Tentative IFSP exit 2/15/

Parent(s)/Guardian(s): _____ Phone: _____
Dad
Mom

Address: _____ City: San Jose ZIP: _____

Service Coordinator Name	Agency	Phone	Date Appointed	Date Ended
<u>Rocio King, MA</u>	<input checked="" type="checkbox"/> SARC <input type="checkbox"/> COE		<u>11/2/</u>	<u>/ /</u>
	<input type="checkbox"/> SARC <input type="checkbox"/> COE		<u>/ /</u>	<u>/ /</u>

Fig. 7: Illustrates the Assessment Results section in the IFSP

Next in the IFSP is the assessment results. It starts with who participated, and what tools were used long with any relevant medical diagnosis.

PHYSICAL
Health
Vision ... demonstrated appropriate responses to the *Functional Vision Assessment* by tracking an object and light in all directions (to/past midline, up/down, and in a circle). There are no parental concerns in this area.
Hearing ... demonstrated appropriate responses to the *Informal Observational Assessment of Hearing* by responding and localizing to the presented noisemakers (bell, horn, phone, and rattle). There are no parental concerns in this area.
Health History:
Prenatal Health... Mom reports that she became anemic during the middle of her pregnancy and was recommended to take iron supplements. Mom also reports that the birth was a vacuum-assisted birth. *lbs. 10z.* was born after a full term pregnancy. His birth weight was ~~29 pounds 16 ounces~~ 29 pounds 10 ounces. He was 21.5 inches in height. He was discharged home from the hospital with Mom after 2 days.
Current Health... Parents report that *has been a healthy child. No significant illnesses or injuries were reported.*
Allergies: None reported
Medications: None reported
Current Weight: 29 pounds 10 ounces
Current Height: 35 inches

Fig. 8: Shows the Health Status section in the IFSP

Then there is a health status section which can either be skipped or checked for accuracy. Note that the hearing assessment they do is very informal especially when there is a speech delay, the medical professional may want to refer the child for a more thorough audiogram.

COMMUNICATION (language and speech)... Parents reported that both Spanish and English are the primary languages spoken at home. The intake was conducted in English with some directions given in Spanish by Mom.
Receptive (Understanding)... demonstrates or is reported to do the following skills:

- Responds with awareness, acceptance, and in socially appropriate ways when a familiar person approaches, touches, or talks to him
- Responds to different tones of a person's voice
- Attends to other people's conversation for 30 seconds
- Associates spoken word with familiar objects or actions
- Identifies family members or pets when named
- Responds to simultaneous verbal and gestural commands

 BDI-2 Raw Score: 24 Age Equivalent: 16 months % Below Age Level 20
Expressive (Making sounds, gestures, etc.)... demonstrates or is reported to do the following skills:
 vocalized excitedly using high-pitch vocalizations and ran to Dad to get his attention in order to show him the bubbles. Toward the end of the session when he wanted to leave the assessment room, he was observed to pull Dad by the hand towards the door.
 BDI-2 Raw Score: 15 Age Equivalent: 10 months % Below Age Level 50

Fig. 9: Section of the IFSP that indicates the current level of the child's development in all areas

This part is the most vital part for medical professionals and can be called different things, but it is where the child's current level of development in all areas based on the assessment is laid out. As shown in Figure 2.5, it can be seen that the beginning and the end of the language or communication section. In receptive language, the child is 20 percent delayed. This was calculated by subtracting the age equivalent score of 16 months from the chronological age of 20 months at the time of testing and dividing it by the

chronological age. In the figure above, full description to show scores were cut off but in expressive language, this child was found to be even more delayed, and that is why he qualifies for the services. There are similar sections in every IFSP for motor skills, self-help skills, social-emotional functioning, and cognitive development. These results should be reported even in an IFSP that finds no eligibility for services. This is why the IFSP can decide what else to do. There may be several pages of goals outlined next.

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Dad _____ Mom _____

Address: _____ City: San Jose ZIP: _____

Service Coordinator Name	Agency	Phone	Date Appointed	Date Ended
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	<input type="checkbox"/> SARC <input type="checkbox"/> COE		<u>/ /</u>	<u>/ /</u>

Fig. 10: Outcome and Areas of Need in the IFSP for Children Form

In Figure 2.6, each addresses a specific area of need and should have criteria for judging progress. But this is a level of detail that can be skipped over. It is ideal to make sure there is at least one measurable goal or every area of delay, however.

Required Services & (Method) <input type="checkbox"/> Continue Prior Services <input checked="" type="checkbox"/> Initiate Add Services <input type="checkbox"/> Other <input type="checkbox"/> Modified services	Type of Specialist	Frequency/Duration	Location Natural Environment* <input type="checkbox"/> Prog Calendar Given <input checked="" type="checkbox"/> Calendar DNG by	Start/End	Responsible Agency
1. Service Coordination	Service Coordinator	2x per year, 120 min each	*home or natural environment	11/2/ to 5/31/	<input checked="" type="checkbox"/> SARC <input type="checkbox"/> COE <input type="checkbox"/> Other _____
2. Specialized Instruction	Early Interventionist	1x per week, 60 min each session	*home or natural environment	12/2/ to 5/31/	<input checked="" type="checkbox"/> SARC <input type="checkbox"/> COE <input type="checkbox"/> Other _____
3. Speech Therapy	Speech Therapist	1x per week, 60 min each session	clinic	12/2/ to 5/31/	<input checked="" type="checkbox"/> SARC <input type="checkbox"/> COE <input type="checkbox"/> Other _____
Other (Public) Services: WIC, PHN, CCS (medical services, not therapies), SCFHP, Medi-Cal					
Non-Required (Private) Services: (Health insurance privately funded PT/OT/SLP etc.)					Parent
LOCATION JUSTIFICATION. If any ESP Required service is not provided in a natural environment, check one: <input checked="" type="checkbox"/> Insurance funded services are clinic based. <input type="checkbox"/> Due to lack of in-home services are in the clinic. <input type="checkbox"/> Other Justification:.....					

Fig. 3.7: Illustrates what services will the child need in the IFSP

Following in the IFSP comes the section with the services the child will be receiving through early intervention. It lists the type, provider, location, and anticipated dates OF service. The justification for any service not being given in a natural environment will be somewhere in this section as well. Consider recording these services somewhere in the medical professional's medical record where they and their staff can easily record and be aware of them during office visits.

The final section with the IFSP is the consent page. As the child's third birthday approaches, a final transition meeting will be held to review the child's progress and recommend to parents what further services may be needed after they graduate, including possible referral to the school district for special education.

The final IFSP can be reviewed as a developmental status report on exit from the program. Early intervention shares many of the same goals and values as the Medical Home. By collaborating, clinicians can better help all their patients.

V. HOME VISITS

The unique thing about early intervention is that most of the services are delivered at home. Typically, home visits last about an hour. Ideally what would happen is that the early interventionist would come in and would debrief with the parents or the caregiver on what has happened since their prior visit and spin them, the majority of the visit working on the developmental outcomes that you are addressing within that child's daily routine. If the early interventionist happens to be there during lunch then they might be working on things during mealtimes. Sitting and eating with family and working on language and adaptive skills during that home visit. There are some families that prefer their home visits to be in the community such as in the park,

library, and so forth in the case of families who share homes and rent some space for others. Before the early interventionist, they usually give things for the parents to work on in the time that they are gone to solidify the fact that the early interventionist may come in and out but the parents are believed to be the child's best and primary teacher and they are the ones who are really going to make a difference in how the child is doing. It is vital for the early interventionist to bridge between the expectations and hope that by them coming the child is going to talk, they are going to walk and solely bring them into the process which is hard for some of the early interventionists because sometimes to achieve these goals and meet expectations of the parents it can take a few visits and sometimes it takes a few years. It is substantial to have this conversation with families as early interventionists about what works for them. In the case of both parents working and the child being in daycare, early interventionists found that daycare can be a great environment for a child to be in. A program that the early interventionist has to ensure that parents are involved somehow and it is not just the daycare providers just involved. For example, early interventionists require that the parents attend some of the sessions so that they learn too and that when the child is at home, the parents can incorporate what the child has been learning.

Sometimes early interventionist has to decide that the service should not be in a natural environment and instead be service-based. This usually happens during critical problems where the families say they do not want the service to be at home or there is a safety factor where the environment is not safe. Sometimes there are a lot of families living in one place and thus may not be conducive to a good place for that child to be intolerant.

Additionally, there are cultural variables that impact Home Visits as well such as making a child eligible because of an adaptive delay if culturally they are not expected to feed themselves. For some families early interventionists may be conscientious if they know that the mother is at home with the child, she cannot be home with a man, and thus early interventionists ensure that they do not send a male interventionist versus a female interventionist.

VI. RELATED-HELPER PROGRAMS

Although early intervention should be the first program the child should be referred to for and who have delays or risk factors to, there are many other programs available to help children with developmental concerns. All these programs consist of different missions and serve different populations. It is vital to note that each program has unique eligibility criteria.

There are national programs available to a child such as the Early Head Start program. This is a family-centered, child-focused program that aims at increasing the school readiness of young children in those who are coming from a low-income background. The services are designed to promote the development of children as well as to allow parents to fulfil their roles as parents. The eligibility for the Head Start Program is based on family income.

Help Me Grow is also a national program that consists of a national network with the goal of making sure that all children reach their full potential. This system model uses and builds upon local resources to aid in identifying young children who are in need of services as well as connecting families with those services. Across the US, there are several funders who have made investments in early identification and intervention systems to help improve long-term developmental outcomes for young children. Among the nation, some counties have progressed beyond the discussion stage and are either developing or implementing their own unique Help Me Grow system.

VII. CONCLUSION

This paper covers many aspects of early developmental delay in children including as mentioned before: differentiating developmental screening from developmental surveillance, discussing American Academy of paediatrics recommendations, developing a plan for implementing them as well as interpreting and implementing routine developmental screening in a clinician's practice and with a significant focus on Early Intervention and Early intervention services that are available including referrals and being able to interpret an Individualised Family Service Plan (IFSP) while effectively communicating and supporting families throughout the process. Unfortunately, only a small number of developmental issues is identified before a child enters school. This is why it is vital for primary care physicians to intervene and make a difference in identifying children at an early age.

DISCLOSURE STATEMENT

The authors are not aware of any affiliations, memberships, funding, or financial holdings that might be perceived as affecting the objectivity of this review.

ACKNOWLEDGEMENTS

The writing of this article and some of the research reported herein were all supported by edX and Stanford School of Medicine Online content and materials.

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