**Situation**

**Problem**

Prevalence of autism in U.S. children increased by 150.2 percent from 2000 (1 in 150) to 2014 (1 in 59). Autism is the fastest-growing developmental disability.

**Optimal** change can be made when autism intervention begins before the age of 3 years—there is much more risk involved in the wait-and-see approach than in receiving early intervention.

Without effective early intervention these children are being condemned to more severe effects of autism.

Autism intervention for children under three years of age is limited, extremely costly and accessible mostly to the privileged few.

There is a critical need to provide young children with autism universal access to life altering, autism specific, early intervention.

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**Goal**

To make affordable, effective, evidence-based intervention available to all toddlers suspected of or diagnosed with autism.

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**Inputs**

**IDEA Part C Providers...**

- An existing statewide infrastructure of licensed and/or credentialed early childhood professionals able to deliver services
- Universal access to publicly funded IDEA Part C programs for children age birth-to-three
- Part C professionals who are in many cases first responders for children with disabilities

**Outputs**

**Pathways Parent Training Program...**

- A way to deliver effective evidence-based early intervention for toddlers with autism within the framework required by early intervention legislation
- An NDBI intervention which merges the sciences of Applied Behavior Analysis and Early Development which is considered best practice for toddlers with autism
- A Parent Training Program that addresses the core characteristics of autism and significantly minimizes the effects of autism
- An established training and support program developed for early childhood interventionists

Training designed to provide widespread intensive instruction to IDEA Part C service providers that will enable them to effectively train parents in the Pathways Parent Training Program model.

**Year One...**

- Initial face-to-face introduction, planning and overview for entire staff
- Professionals not designated to be Pathways providers participate in training to enable identification and program support
- Designated Pathways providers complete preparatory web-based modules
- Designated Pathways providers complete intensive step-by-step hands-on instruction course
- Designated Pathways providers participate in ongoing support via a combination of web-based and on-site consultations

**Community Healthcare Management Groups...**

- Provide educational opportunities to healthcare professionals who guide families in healthcare decisions

**Year Two...**

- More intensive ongoing training for select providers to become agency support personnel in order to develop a sustainable program
- Continue community education and outreach

**Short Term**

- Professionals within IDEA Part C system able to provide effective evidence based intervention for toddlers suspected of or diagnosed with autism
- Interventionists equipped with tools to provide evidence-based services necessary for significant change in children with autism
- Intervention billable under the professional's existing specialty, i.e. Speech Therapy, Early Intervention (SST), Occupational Therapy and Infant Mental Health

**Medium Term**

- Ability to build capacity in a relatively short time
- Empowered parents of toddlers with autism and improved family life
- Diminished autism symptoms and improved developmental outcomes for toddlers with autism
- Cost effective and sustainable way to provide effective, evidence based, early autism intervention across the state
- A collaborative team of experts working with families toward research-based goals appropriate for toddlers suspected of or diagnosed with autism

**Long Term**

- Increased quality and quantity of effective autism intervention accessible by all
- Reduced need for future intensive intervention programs for children with autism
- Sustainable program with reduced cost to families and taxpayers for years to come
SITUATION/Problem

More children will be diagnosed with autism spectrum disorder (ASD) this year than with AIDS, diabetes, and cancer combined. Prevalence of autism in U.S. children increased by 150.2 percent from 2000 (1 in 150) to 2014 (1 in 59). The Center for Disease Control and Prevention (CDC) now estimates that the incidence of autism is 1 in 59 children. Autism is the fastest-growing developmental disability. While there is no cure for autism, appropriate early intervention provides the best opportunity to prevent the cascading effects and diminish the pervasive symptoms autism causes. Current research indicates optimal change can be made when autism intervention begins before the age of 3 years, yet the average age of diagnosis is 4 to 5 years.

Autism intervention for children under three years of age is limited. It can be extremely costly for families and even cost prohibitive for those without the right insurance. It can be inaccessible for those in rural areas with limited resources and in urban areas there may be wait lists for the resources available. In many cases the interventions available are not evidence-based and/or specific for toddlers.

It is important to understand that for toddlers suspected of or diagnosed with autism, intervention must differ from the typical developmental intervention that works for toddlers with other disabilities. Additionally, intervention for these toddlers must also differ from that of older children with autism.

In recent years, more and more autism research has focused on infants and toddlers. We now understand that autism begins at birth with altered social engagement—a difference in the way a child “tunes in” and interacts with the people around him.

This altered social engagement goes on to manifest as deficits in social communication and restricted interests and behaviors. These core characteristics of autism cause a cascading and pervasive effect. Dr. Ami Klin, director of the Marcus Autism Center and one of the nation’s leading researchers, describes this process by saying, “Autism creates autism.”

Failure to orient to social stimuli represents one of the earliest and most basic social impairments in autism. From birth, typical babies are naturally drawn to people. They would rather look at people than things; they would rather hear human voices than environmental sounds. But it is different for our babies with autism. Brain studies have found that while typical infants and young children show increased brain activity when viewing people rather than objects, children with autism show the opposite pattern—they preferred objects. Children with autism do not seem to experience as much natural reward in social interactions as other children.

Because early intervention may activate typical processing mechanisms due to the plasticity of a child’s brain before age three, the capacity for learning and change is great. Autism specific early intervention has been shown to significantly increase social attention and engagement, thereby enhancing the development of cognitive and language skills of children with autism.

Autism-specific early interventions that address the core deficits of early social attunement will change the way a child tunes in and interacts with the social environment. This change can alter the child’s brain development toward a more typical learning and developmental trajectory and diminish autism symptoms.

Goal... To make affordable, effective, evidence-based intervention accessible to all toddlers suspected of or diagnosed with autism.

"The soonest that a child can get into services, the better the outcomes for the child and more likely to achieve their developmental potential. We need to do more work to get kids identified earlier, we should be identifying kids closer to age 2.”

Stuart K. Shapira, MD, Ph.D.
Chief Medical Officer
Associate Director for Science
National Center on Birth Defects and
Texas Early Childhood Intervention (ECI) is a state and federally funded program authorized by the Individuals with Disabilities Education Act (IDEA) Part C to provide services for children birth to 3 years old with developmental delays or medical diagnoses. All states have Part C programs which provide an extensive service delivery system with professional providers working with babies, toddlers, and their families in their natural environment (home, daycare, etc.). Licensed and/or credentialed specialists may include early intervention specialists, speech and language pathologists, physical and occupational therapists, psychologists, registered nurses, dietitians, social workers and counselors. All children have access to a Part C program, which cannot deny a child services because the family does not have public or private insurance. Families of all income levels can receive these early intervention services.

Pathways Parent Training Program—

The Pathways Parent Training Program (Pathways PTP) is a practice to research model with an innovative approach that sets it apart from other autism treatment models. The Pathways PTP was developed to fit the service delivery model and guiding principles of Part C early childhood programs.

The Pathways PTP meets the criteria of a "Naturalistic Developmental Behavioral Intervention (NDBI)." NDBIs are empirically supported, autism interventions that represent the merging of applied behavioral and developmental sciences.

By training parents in specific behavioral strategies that target developmentally appropriate social communication behaviors within the child’s every day routines, parents will be able to extend the intervention throughout the child’s day. This is how to achieve the intensive intervention the child needs. Providing intensive intervention in the child’s natural environment increases functional learning while developing important relationships for both child and family.

While all components of the Pathways PTP are based on current research, the program itself has also been independently studied. Five articles have been published in peer reviewed journals. Three studies have been completed including a two-year randomized large scale study. Another large scale study is now underway—results are consistent.

Research found the Pathways PTP model to be effective for developing the early foundational social communication skills of eye contact, social engagement, and verbal reciprocity in toddlers enrolled in an IDEA part C program. In addition, parents perceived the intervention as beneficial, easy to learn, and easy to incorporate into daily life.

Community Healthcare Management Groups —

Local community healthcare management groups may consist of entities such as healthcare and/or mental health provider professional organizations, managed care or insurance organizations. These professional medical groups have access to provide education to the frontline medical professionals that are charged with assisting in decision making.

The most recent research indicates that a diagnosis of autism is stable at 14 months, yet according to the latest Center for Disease Control report the average age of diagnosis is still over 4 years of age—even though the importance of early intervention has been established! The dissemination of information to community physicians that these management groups can provide helps make possible the early intervention so vital to our children and their families. It also increases collaboration between the frontline medical professionals, ECI providers and the families in need.

There is much more risk involved in the wait-and-see approach than in receiving early intervention!
OUTPUTS/Activities

**IDEA Part C Providers**

Existing Part C programs already have a very effective service delivery infrastructure in place, making implementation of the Pathways PTP feasible. These programs employ many highly qualified and credentialed personnel who, with training, will be able to build capacity to serve this rapidly growing population in a relatively short time.

Because this is a parent training program, parents will become empowered to play a successful part in their own child’s growth and development. Patents will participate in a 1.5 hour parent training session once per week. During this time interventionists will train parents to use specific behavioral strategies that target developmentally appropriate social communication behaviors within their child’s every day routines, extending the intervention throughout the child’s day—thus achieving the intensive intervention their child needs.

Providing intensive intervention in the child’s natural environment increases functional learning while developing important relationships for both child and family.

Part C organizations will provide community education and outreach. Community education increases the number of children receiving early intervention and reduced the age that the intervention begins. This outreach also builds collaboration with community physicians and other community healthcare providers.

**Pathways Parent Training Program**

Both the program and the training were developed by Michelle Campbell who is a Speech Pathologist and a Board Certified Behavior Analyst and Renee Hoffman who is a Licensed Professional Counselor and Board Certified Behavior Analyst.

The training is designed to provide widespread intensive instruction to IDEA Part C service providers that will enable them to effectively train parents in the Pathways PTP model.

The Pathways PTP training model consists of a combination of web-based and hands-on training. After an initial face to face introduction and planning, an overview of the research is provided for the entire staff.

Each interventionist to be trained will then complete a series of on-line instructional modules to provide a foundation of knowledge and understanding. Once completed, the interventionist will attend four days intensive step-by-step instruction teaching the Pathways NDBI model.

Once the intensive instruction has been completed, interventionists will begin providing services to families. Monthly follow up support is provided for one year, with a combination of hands-on and web-based consultation meetings.

A second phase of support is available and includes more intensive ongoing training for select providers to become agency support personnel. This intervention model is a sustainable and fiscally responsible model for effective early autism intervention.

**Community Healthcare Management Groups**

Local community healthcare management groups organize educational opportunities for community physicians and healthcare providers and in many cases provide Continuing Medical Education credit to physicians. These educational presentations include the very latest research on best practices for toddlers at risk or diagnosed with autism—including research in the areas of brain function, eye tracking, early identification and early intervention. The presentations cover research that supports Pathways and research on the Pathways program itself. Pedagogy, research and interventions that speak to the unique needs of toddlers at risk or diagnosed with autism has only been available in the last few years. Thinking about the special needs of the toddler with autism requires a paradigm shift away from:

- Recommendations based on antiquated research that was done on young adults and older children (often decades old)
- Recommendations that are based on therapies that are successful with general developmental issues and speech delays
- Recommendations based on the idea that ‘more is better’ even with interventions that are not working
OUTCOMES/Impact

Short Term...
Training in the Pathways PTP will equip IDEA Part C professionals with a systematic, direct, explicit, autism-specific NDBI model based on current research. These early childhood interventionists will be able to implement state of the art treatment for toddlers suspected of or diagnosed with autism. Under this model, interventionists and parents will work together to provide the recommended intensity of services necessary for significant change in toddlers with autism. The intervention is billable through Medicaid and private insurance under each interventionist's specialty.

Working with community healthcare management groups to promote educational opportunities for local healthcare providers will provide an effective referral source and increase the number of families receiving early autism intervention.

Medium Term...
IDEA Part C ECI programs will be able to build capacity to serve this large birth-to-three population in a relatively short time. Pathways, LLC has an established training program consisting of web-based training modules, intensive on-site training and a combination of web-based and on-site extended consultation support. The Pathways PTP is manualized with both parent and interventionist manuals.

Pathways PTP will empower parents and enable them to be active participants in their child's learning and development both present and future, improving family life. Pathways PTP has been shown to diminish the symptoms of autism and improve developmental outcomes for toddlers with autism.

Compared to other therapy models that require one-to-one with a therapist, for 20 to 40 hours/week, the Pathways PTP is implemented by the interventionist in one 90 minute session per week in the child's home—a cost effective and sustainable way to provide effective, evidence based, early autism intervention in all communities.

Outreach and education will build a collaborative team of experts working with families toward research-based goals appropriate for toddlers suspected of or diagnosed with autism.

Long Term...
Appropriate autism intervention provided by existing IDEA Part C professionals will increase the quality and quantity of effective autism intervention for children birth to 3 years of age and make it accessible to all families.

Children with autism who receive appropriate early intervention have a reduced need for future intensive intervention programs.

Appropriate autism intervention provided by existing IDEA Part C professionals will reduce costs to families and taxpayers for years to come.
References


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