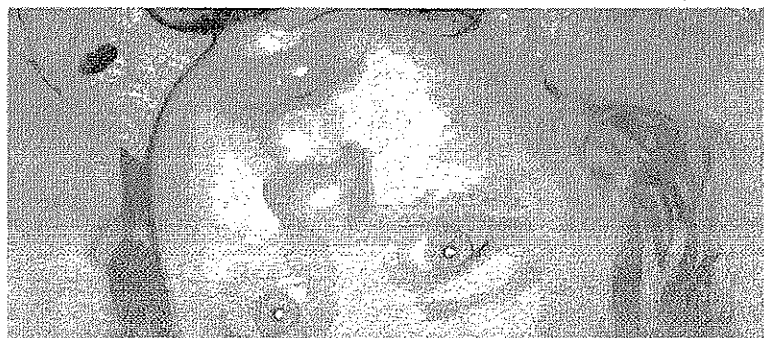
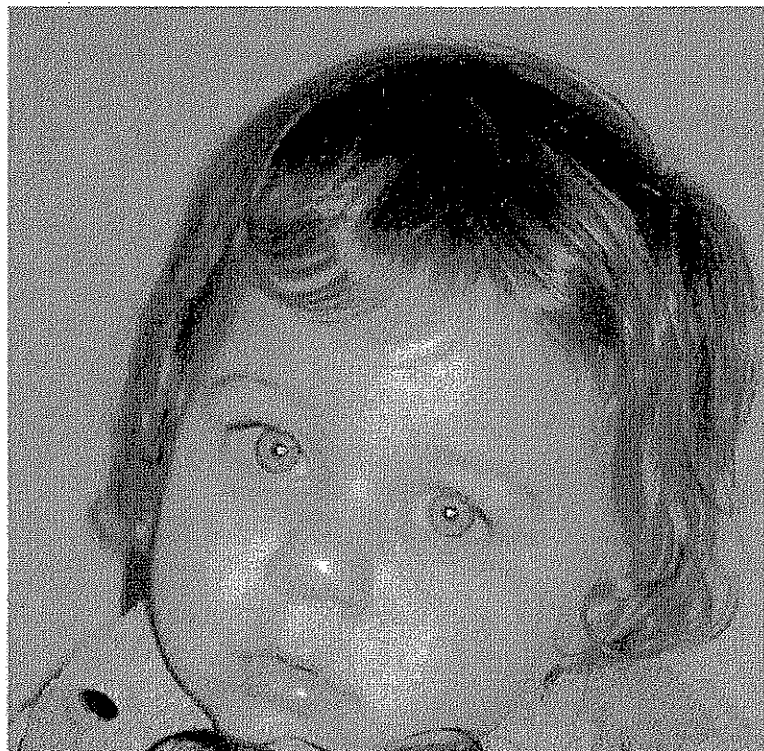


Testimony of Parent David A. Browne Westport Resident, Father of Five



Including 2^{1/2} Year Old Autistic Son Wynston



We seek to represent all CT families touched by Autism

- Residents of Westport since 1997; not covered by CT House Bill 5696 insurance statute as employer's insurance plan based in New York
- *David* - BS Economics, Wharton; MBA Columbia - organizational consultant
- *Wife Lynda Kommel-Browne* - BA Cornell, Masters London School of Economics - Asian investments

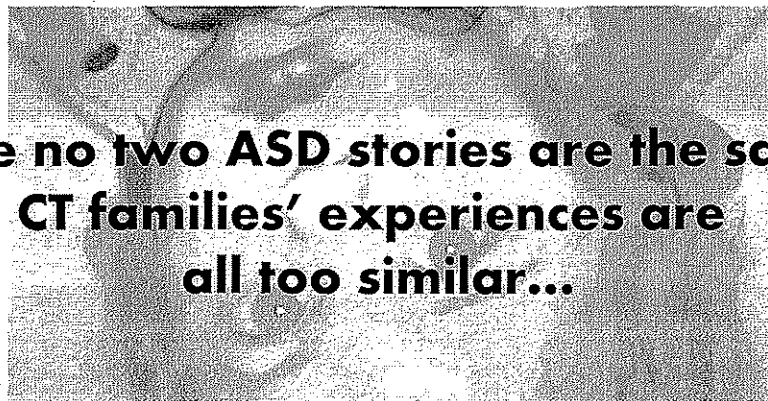


- Members of six Autism online groups, read over fifty books and 100 articles on ASDs, stay current on all clinical research studies; Associates of Yale Child Study Center
- Stored umbilical cord blood for youngest two children; *yet unusable for stem cells*
- Four children in public schools, one with ASD in *Birth to 3 program*
 - Two 6th graders in Middle School
 - - one adopted from China, in Special Ed for three years
 - One preschooler at *Stepping Stones, special needs preschool* - typically developing
 - 2 1/2 year old Wynston, diagnosed via ADOS at 19 months by Birth to Three
 - - has already participated in three clinical research studies

WYNSTON'S STORY

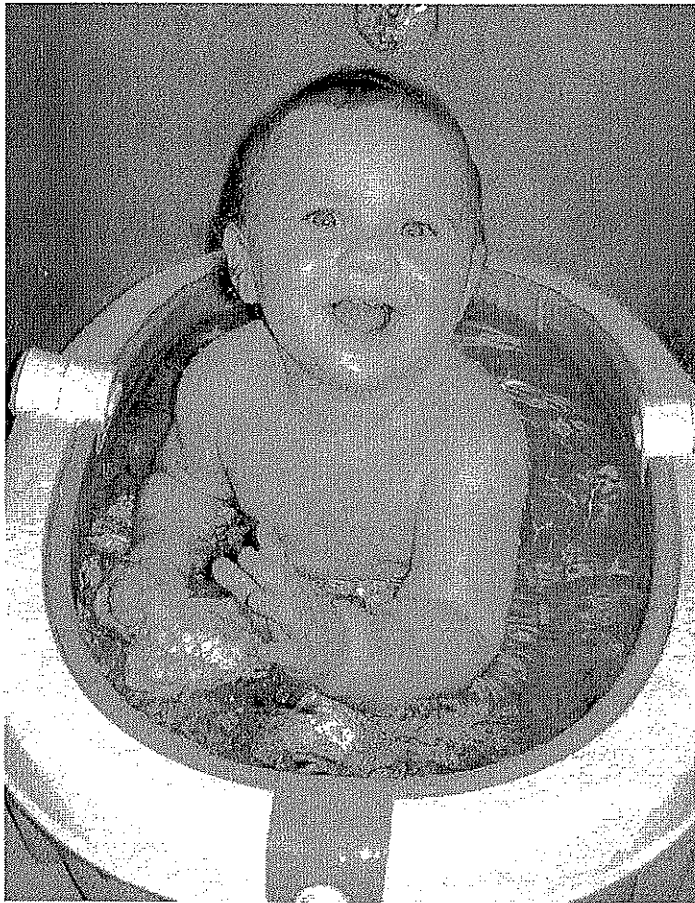


**While no two ASD stories are the same,
CT families' experiences are
all too similar...**





BABY WYNSTON – *A Typical Beginning*



- **Normal birth in high-risk OB-GYN practice at Yale NH** (parents in mid-40s) - CVS, ultrasounds; other genetic tests negative
- **Typical, healthy first year of life** – bronchiolitis and antibiotics at 7 months
- **All vaccines at typical milestones**
- **Walking normally at 14 months, responded to name, smiled a lot**
- **One year older brother talked at 21 months** – attributed to learning 2nd language (mandarin) at home
- **Pediatrician and parents missed diagnosis at four, six, and twelve months .**



WYNSTON – *Ages 15 to 24 months*

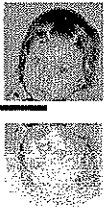


- **Pediatrician shares parents' concern about speech delay (no babbling) at 15 months and refers family to CT Birth to Three**
- **Assessment and diagnosis of ASD (via ADOS and MDOS) by Birth to Three at 18 months – earlier than usual**
- **Family faces typical shock, denial, grieving and information overload**
- **Clock starts on developing adequate skills for preschool classroom environment at age three**
- **Wynston no longer making eye contact, is floppy and disoriented, doesn't respond to his name**
- **Parents immediately put Wynston on gluten and casein (dairy) free (*GFCF*) diet**
- **Frantic search for best doctors and therapies for Wynston**
- **Get on distant appointment calendars of prominent doctors and access only to junior-most therapists at private clinics, many with multi-month waiting lists.**



WYNSTON – *24 months to present*

- **Family wrestled with confusing, often conflicting directions and experiences re: gastro-intestinal issues of autism, chelation of heavy metals, traditional western medicine vs. DAN protocols, etc. -- many quacks and well-meaning but misguided service and product providers out there!**
- **Chose a path to provide anything that will do no harm and can be introduced gradually and incrementally for study of efficacy and impact (e.g., supplements, B₁₂ injections, hyperbaric oxygen, acupuncture, etc.)**
- **Mother Lynda has become "General Contractor" of behavioral and cognitive function developmental services – initiated measurement and tracking system, became (unofficial) coordinator of team and leader of team meetings (October 2009)**
- **David has taken on daily occupational and physical therapy including becoming a "human horse" for home hippotherapy**
- **Both now work from our home to better care for the family and Wynston**
- **Wynston has started making several word-like requests, has no understandable speech, and a handful of signs. He is improving his joint attention, is healthy and happy. He is scheduled to attend Westport's Stepping Stones preschool, with his older brother, in September.**



Our family's experience with CT Birth to Three

State agency very helpful and supportive

- **Timely returned calls, empathetic listeners**
- **Refuted provider's contention of a policy cap on hours of behavioral therapy (e.g., ABA).**



Our experience with CT Birth to Three Provider



Unprofessional and facing major organizational challenges

- **Inconsistent professionalism and quality of therapies**
 - *Early Intervention Associates* have virtually no training --
fruitless play attempts for first 3 months
- **Inconsistent actions and recommendations from therapist to therapist (e.g., picture cards vs. signing)**
- **Supervisors under-qualified, not familiar enough with the case / unique needs and individualizing program (few or no BCBAs on staff, and not in supervisory role)**
- **Countless cancellations and rescheduling**
- **No measurement and tracking system provided – started upon mother's research and insistence**
- **High therapist turnover (attributed to lack of professional career path / plan, no health benefits) - compensated at less than 50% of hourly therapy wage for team meetings.**



Our experience with CT Birth to Three Provider -



Challenging and often highly confrontational

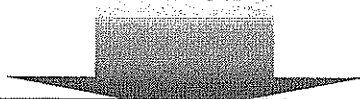


- Intensive family “lobbying” effort required to get more hours of behavioral therapy – no coherent policy guideline
- When requested as much as 40 hours of behavioral therapy for Wynston told by agency director “more than 15 hours of ABA therapy for a child could be considered abuse” (Gold standard Lovaas study recommended 40+ hours)
- Inconsistent and conflicting directions and policy, e.g., Use of *Stokke chair on the left*. Initially recommended and used by their therapists for over 6 months, hastily discontinued as an “inhuman restraint” and disavowed (CYA) by therapy team
- Inconsistent approaches to measurement and tracking of progress – *does more progress lead to more support or less?*




CONCLUSIONS


Autism remains a mystery, even to those who live with it 24/7. What we have learned and experienced along with other ASD families in CT:



1. Autism is a socially rampant multi-system form of mental and developmental retardation; affecting mental / cognitive, social, sensory-processing and physical functioning with tremendous variability from case-to-case. It is occasionally reversible and almost always treatable, resulting in improved outcomes and significant decreases in the likelihood of lifelong dependency



2. ASD is diagnosed late and over-relies on behavioral observation and the Birth to Three Program in CT



3. Research is *slowly* making inroads on the genetic, neurological and other environmental and physiological sources and issues in Autism. Until this multi-system puzzle is solved our children need more holistic solutions - integrating behavioral / social, health / nutritional , and sensory -system support delivered intensively in the first three plus years after diagnosis.



RECOMMENDATIONS

Based on our family's experience, research and interviews with Connecticut ASD families and thought-leaders, we offer the following suggestions:

How does CT cost-effectively take the lead on improving quality of life and adult independence for children with Autism Spectrum Disorder?

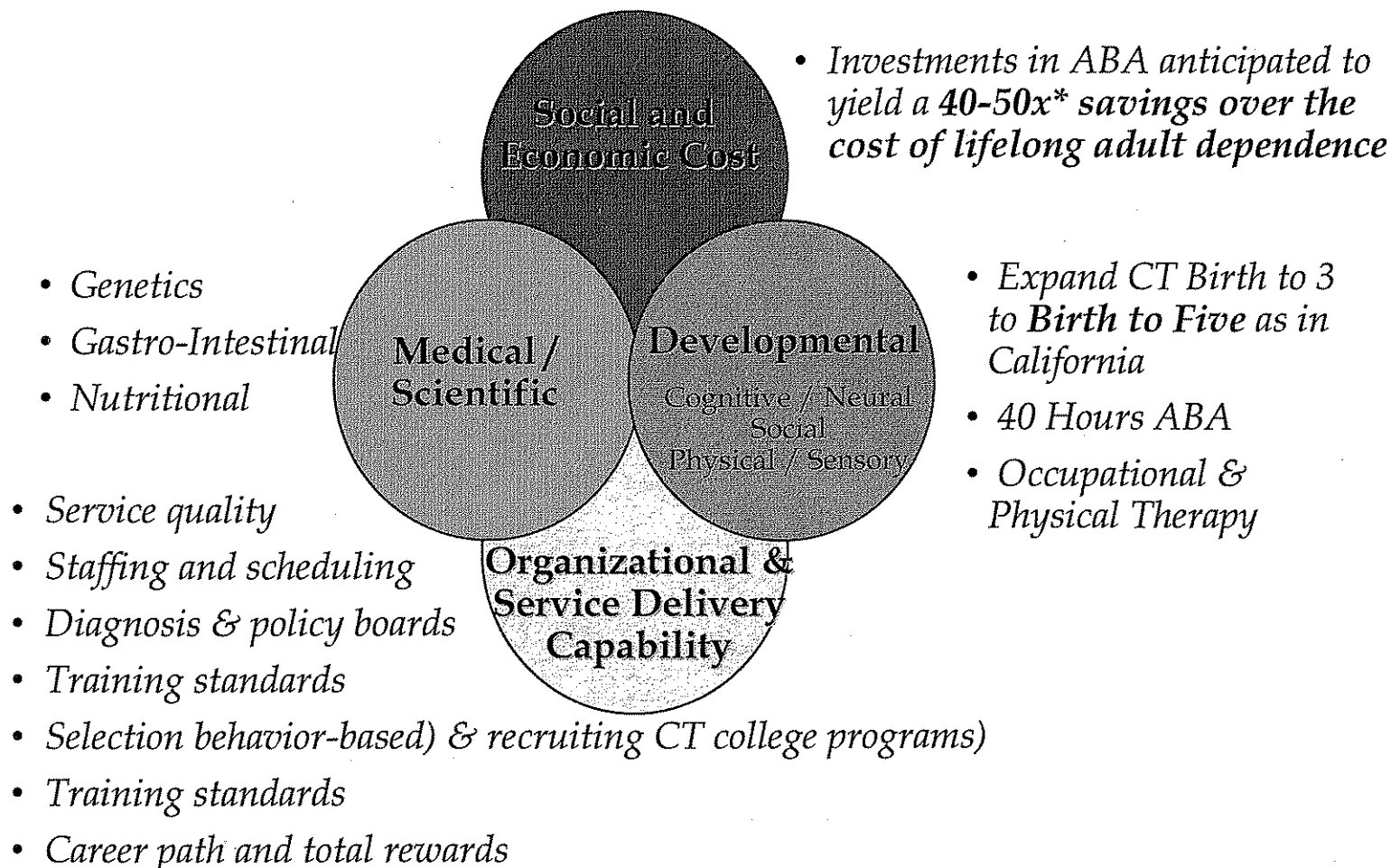
1. Earlier, multi-system diagnosis and longer home-based support ("Birth to 5" with improved, seamless transitions)

2. Ramp-up of home services capacity (scale & recruiting), quality (seeding, selection & training) and sustainability (careers)

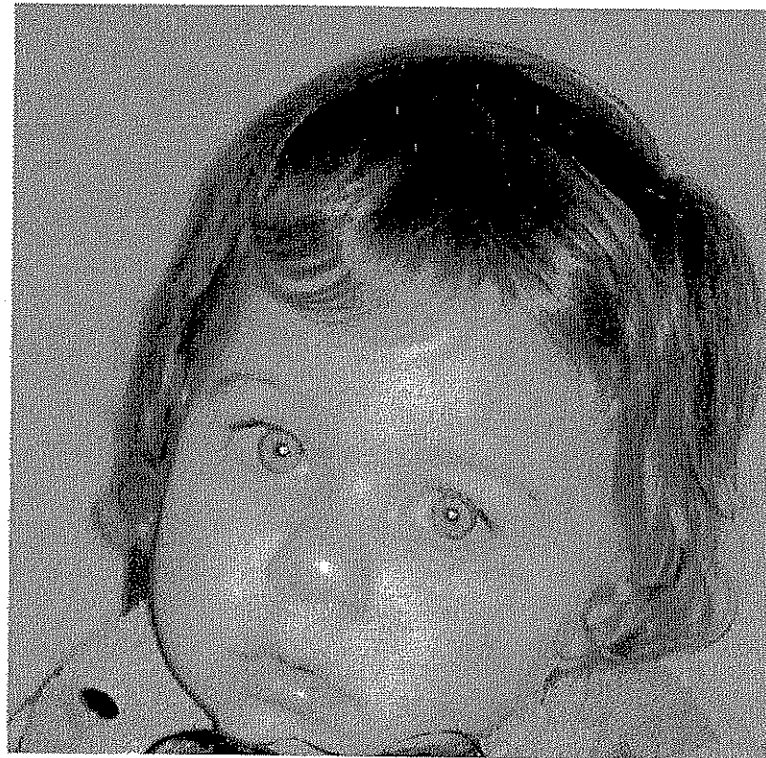
3. Holistic assessments / diagnoses and solutions - integrating behavioral / social, health / nutritional, and sensory -system support - spanning the diagnosis, Birth to Three, and Special Education life cycle stages of child development.



The cost of inaction, resulting in massive populations of highly dependent autistic adults in Connecticut, far exceeds the investments required in enhancements to Birth to Three, other early interventions and Special Education



WYNSTON'S WISH – *If he could talk...*



**NEVER, NEVER,
NEVER GIVE UP**

Winston Churchill