

BEYOND LIMITATIONS

By Laura Watts,
Program Director

Empty faces pressed against the black iron bars and stared out at the road. We drove by quickly. I saw no ages, no gender – only vacant eyes with open mouths and closed minds. This was Willowbrook in Staten Island, the institution for the “mentally retarded” that conjured up visions of horror and mystery in my five-year-old mind. This was my introduction to the limitations placed on the expectations of those diagnosed with a disability.

When our son was born 15 years ago there was a myriad of “black bars” surrounding him – the most significant of which was the diagnosis of Down syndrome. The prognosis was grim: “He may not walk, he may not talk and he most likely won’t be toilet trained until he’s 16.” Now he not only walks but he jogs. He talks, in fact, he chatters and he was toilet trained at age two. And as a bonus he reads, writes, loves the Jaguars (especially Coach Coughlin) and can party the night away. Terrific medical treatment? Great parents? Perfect therapists? More likely a combination of a consistent flow of unbiased intervention, unconditional love and unlimited expectations.

Clients come to the Down Syndrome Center on a regular basis with stories of limitations and low expectations placed by well-meaning family, friends and professionals. “He can’t read; he has Down syndrome.” “He behaves like that because he has Down syndrome.” “You won’t have any adolescent problems with him - these children are always so sweet.” Then there is my personal favorite: “Don’t worry; that’s just the way Downs kids are.”

Unfortunately these statements are based on past history and statistics derived from cases of adults with DS who did not receive the early intervention or ongoing therapies and education our children have available now. And unless those working with the child have seen a variety of children with Down syndrome in recent years,

they are not aware of the successes and accomplishments now becoming a way of life for these individuals.

At the Down Syndrome Center we have seen close to 400 families of children with Down syndrome from around the country and the world. We have seen children born with

heart defects excel at sports and non-readers begin to read in their teenage years. We have 18-month-old babies recognizing word cards and high school students tackling geometry. We have students on the A-B honor roll in typically developing elementary school classes and others thriving in special education environments. And we have witnessed the transformation of students labeled as “behavior problems” become model students after appropriate intervention. These children have taught us not to place limitations. They have

disproved the “one size fits all” prognosis.

The Staten Island institution has since been shut down and empty faces peer through the bars no more. Attitudes about those who resided there have changed and progress has been made. Ironically, such institutions that robbed the lives of hundreds have provoked the need for change and been the catalyst for facilities such as Hope Haven, committed to seeing the potential and watching it grow. Our children have faces full of expectation and eyes reflecting hope.

Knowing our limitations is a good thing. It helps us to set goals, discover our strengths and strive to overcome our weaknesses. But accepting these limitations without challenge brings us back to open mouths and empty lives.

It brings us back to Willowbrook.



The Down Syndrome Center at Hope Haven Children's Clinic and Family Center is a non-profit organization dedicated to bringing positive, strength-based assessments and information to the families of children with Down syndrome.

An interdisciplinary team evaluation consists of an education consultation, behavioral / medical evaluations, physical, occupational and speech therapy evaluations.

In-school visits are available upon request.

Families receive a comprehensive report describing their child along with home and/or school suggestions for further growth.

For information or to schedule an appointment contact

Ann Schwelgin

(904) 356-5100 ext. 254

AnnS@hope-haven.org

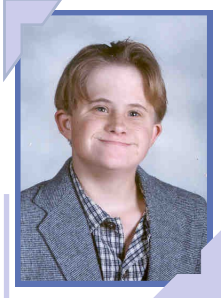
www.Hope-Haven.org

**These evaluations are not intended to replace primary care or services already in place.

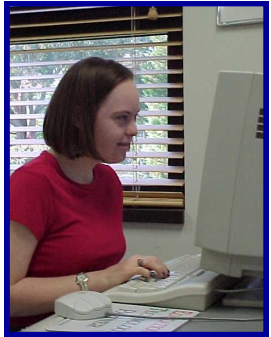
Application forms are available upon request. Current funding allows families to pay only a minimal co-payment for evaluations.**

We are thankful for the
**JESSIE BALL DU PONT
FUND**
and other
community donors.

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 ☆ ANNOUNCEMENTS... ☆
 ☆ Welcome to the DSC new administrative assistant, ANN SCHWELGIN. ☆
 ☆ Ann will be scheduling appointments, researching information on Down syndrome, preparing the Team for client visits and producing the newsletter. ☆
 ☆ Welcome to ELISABETH MOODY, M.S., CCC-SLP. ☆
 ☆ Ms. Moody specializes in oral motor and feeding strategies and will be focusing on our early childhood population as well as clients needing assistive devices. ☆
 ☆ Many thanks to the HAYES FAMILY FOUNDATION for their generous donation of our state-of-the-arts Sensory Integration Equipment. ☆
 ☆ Debbie Lennon, Kris Owen, Alyssa Pierce, and Elisabeth Moody will be working as a team to address the sensory needs of our children both in evaluations and ongoing therapies. ☆
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STRETCHING THE LIMITS THROUGH OCCUPATIONAL THERAPY: SCHOOL SKILLS
 By Deborah Lennon,
 Occupational Therapist



In order to help your child go beyond his comfort zone, you may need to make various adaptations to everyday activities. All of us use various strategies throughout the day to help us complete certain tasks that are difficult. Some of us chew gum to help us concentrate, some of us need music in the background to complete reports, and some of us keep cleaning supplies in a thick handled bucket for easier handling. Children need help adapting basic activities to make it easier for them to complete their work. A child may appear lazy and noncompliant by not finishing a certain task. Adaptation and motivation are the keys!

- For handwriting or other types of school tasks, it may be helpful to limit distractions. Put work on a slanted or vertical surface, or add a cushy pencil grip to the pencil.
- Make the activities fun!! Practice handwriting in shaving cream on a mirror, in whipped cream on a baking sheet, or by tracing letters on sandpaper.
- Vary the position that the child must work in and introduce "stations" for the child to make writing a game. Station 1 could be lying on his belly on the floor, Station 2 could be sitting at a desk, and Station 3 could be paper taped to the wall. The child could stay at the Station for short periods of time (i.e. play one song per Station).
- Provide your child with a "just right" challenge; allowing her to succeed and encouraging her to go farther than she usually does. If your child tries to get you to complete her task, act innocent. Do something wrong and ask her for help.

- Every child is different and needs his own motivator. If a child needs more structure, try sticker charts to reward good work. Play with your child. Make it structured and fun! Think "out of the box" when trying to help your child learn through play. It is easier to learn the word apple after tasting, touching, and smelling than by simply looking.
 - Use *Highlights* magazines for children. This resource has many activities such as Hidden Pictures, which can increase visual motor and visual perceptual skills. You can also have him practice visually tracking objects held approximately 12 inches from his face.
 - Use party blowouts to knock down figurines in a left to right progression to help your child remember to always start on the left side of the paper.
- Visual motor skills are an important aspect to all areas of life; not only do they affect hand writing but also self-care skills. Challenge him without letting him know he is being challenged. Learning should be something your child enjoys and is excited to do. Stretch his potential by meaningful, interesting, and novel learning experiences!



A PIANO CONCERT BY DR. JOHN IBACH AND SILENT AUCTION
 PROCEEDS WILL BENEFIT THE DOWN SYNDROME CENTER
 At Hope Haven Children's Clinic and Family Center
THURSDAY EVENING NOVEMBER 21, 2002
 AT **FRIDAY MUSICALE**

HAPPENINGS.....
 CONTACT ANN SCHWELGIN AT 346-5100 EXT. 254 FOR FURTHER INFORMATION ON THESE FUNDRAISING EVENTS

OCTOBER 12—10am-7pm
 MANDARIN FOLK FESTIVAL
 Mandarin Community Center
 Local artists, food and fun!
 Proceeds to benefit the DSC and other local charities

OCTOBER 19—8am-12pm
 GARAGE SALE
 Hope Haven Children's Clinic
 Proceeds to benefit the DSC

NOVEMBER 21—5:30-8:30pm
 HOLIDAY CONCERT BY JAZZ PIANIST DR. JOHN IBACH
 SILENT AUCTION/ APPETIZERS
 Friday Musicale
 Proceeds to benefit the DSC