Despite compulsory education laws in place in the United States since 1918, many children with disabilities were routinely excluded from public school. Their options: remain at home or be institutionalized. Even those with mild or moderate disabilities who did enroll in schools were likely to drop out well before graduating from high school.

The dream... a center that helps a child to help himself
In 1958, Dr. Warner approached Dr. Robert Guthrie, to develop a convenient and effective method to monitor blood levels of Phenylketonuria (PKU). PKU is a metabolic disorder which, if left untreated, can cause brain damage and mental retardation. Dr. Guthrie invented the dried blood spot which made the mass screenings of newborns possible. In 1965 New York State began its Newborn Screening Program with testing for one genetic disorder, PKU.

Today NYS screens for over 43 diseases using the Guthrie spot.

Dr. Warner and the PKU diet


Brown, E.S. Warner, R. Mental Development of phenylketonuric children on or off diet after the age of six Psychological Medicine 6(2) 287-96
the community responds

- Deinstitutionalization
- IDEA and Amendments
- FAPE
- LRE

Therapy provided in natural environments

Recreation for the Handicapped Expo

education, camping, recreation, community activities

from exclusion
to segregated enrollment
to mainstreaming
to full inclusion

examples

- School 84 Annex-Elementary Special Education
- Adolescent Program
- Ski Program
- Camping Programs
- Early Childhood Program 1971 (began as a research project)
  - Preschool Special Education
  - Early Intervention Program

In the 1990's Michael Msall, MD and Brian Rogers, MD shared the position of Medical Director

- Surfactant research
- Researched Developmental Outcomes
- Initiated the clinic for feeding disorders
- Agency Agreements: OLV, UCPA, BOCES, Batavia State School for the Blind, School 84, Bornhava, Heritage Centers, Centers for the Handicapped
Typical Problems Treated Today

- Attention Deficit Disorder
- Autism
- Behavior disorders
- Cerebral Palsy
- Delays in Speech & Motor Coordination
- Down Syndrome
- Feeding & Swallowing Disorders
- Genetics Disorders
- Hearing Loss
- Learning Disabilities
- Limb Disorders
- Mental Retardation
- Neurologic Disorders
- Spina Bifida
- Unspecified Developmental Delay

Current Programs

- Neurodevelopmental Clinics
  - Birth To Three Clinic
  - Developmental Educational, Behavior And Speech (DEBS) Clinic
  - Comprehensive Developmental Program (formerly 3-8 clinic)
  - ADHD and Learning Problems Program
  - Medication Clinic
  - Down Syndrome Clinic

- Current Programs
  - In 2009 we saw 4,275 patients in all the clinics during 8,000 visits.
  - The team consists of Developmental Pediatrician, Pediatric Nurse Practitioners,
    Occupational Therapists, Physical Therapist, Speech/Language Pathologist
    Special Education Teacher, Social Worker
  - Children may be seen by any or all of these specialists during the visit.

- Current Programs
  - We concentrate on diagnosis, coordination of services, treatment and referral for any child with developmental delay issues.

- Current Programs
  - This may include:
    - follow up of all NICU graduates
    - Speech and Language Delay
    - Fine motor delay; Gross Motor Delay
    - Metabolic Disorders
    - Growth deficiency
    - Genetic disorders
    - Plumbism;
    - ADHD
    - Failed developmental screening;
    - Learning Disorders
Feeding Disorders Clinics

- Feeding Disorder Clinic
  - Diagnostic and Therapeutic for children with many disorders who have poor weight gain, food refusals, sensory issues with textures, behavioral issues, or food aversions.

- Oral Motor Clinic
  Concentrates on those with chewing and swallowing difficulties and those with aspiration risk.

Early Motor/Motor Clinic

- Purpose:
  - Comprehensive rehab management
  - Developmental screening
  - Functional observation
  - Muscle tone, strength, ROM evaluation
  - Equipment and Bracing needs
  - Spasticity management

Early Motor Clinic

- Inter-disciplinary approach
- Off-shoot of 0-3 Develop. Clinic
- Age range: birth to 3 years
- Referrals from: NICU; Community peds; 0-3 Dev. Clinic; PT; OT; ST
- Team includes: Rehab MD, PT and/or OT, SW prn
- Primary Diagnosis Served: Motor impairment

Early Motor Clinic

- Other Diagnoses Served:
  - Cerebral Palsy
  - Children at risk based on med. History (PVL, Cooling blanket protocol)
  - Brachial plexus injuries
  - Neuromuscular impairments
  - Apraxia/Dyspraxia
  - Connective Tissue Disorders
  - Spasticity
  - Torticollis
  - Hypotonia
  - Idiopathic toe walkers
  - Hypermobility syndrome
Motor Clinic

- Inter-disciplinary approach
- Off-shoot of Early Motor clinic
- Service children ages 3 years and up
- Team consists of Rehab MD, PT or OT, Rehab NP, SW as needed
- Referrals from: Community Peds, Neurology, Neurosurgery, Orthopedics, PT, OT, ST
- Primary Diagnosis served: Motor Impairment

Motor Clinic

- Other Diagnoses served:
  - Cerebral Palsy
  - Spasticity
  - Movement disorders
  - Neuromuscular disorders
  - Apraxia/dyspraxia
  - Connective tissue disorders (EDS)
  - Chronic Pain
  - Sensory motor issues

Traumatic/Acquired Brain Injury Rehabilitation Clinic

- Purpose: To address the medical, rehabilitative and social/emotional needs of children and adolescents who have had a traumatic or acquired brain injury
- Physiatrist acts as liaison between inpatient and outpatient setting and transition back into community/school re-entry
- Family education and support are provided
- Primary Diagnoses served: Traumatic and acquired brain injury, post-concussion syndrome

Spasticity Clinic

- Inter-disciplinary approach
- Team consists of: Neurosurgeon, Rehabilitation MD, PT and OT
- Meets the 2nd and 3rd Wed mornings of each month
- Primary Diagnoses served: Hypertonia/spasticity
- Purpose: Assess the effect tone has on functional ability and personal care and determine what interventions are most appropriate
- Consideration of medications, orthopedic or neurosurgical procedures, casting/splinting strategies, other therapy approaches, use of adaptive equipment

Spina Bifida Clinic

- Multi-disciplinary approach
- Team members: Rehab MD/NP, PT, Neurosurgery, Urology, and Orthopedics
- Meets the 1st and 4th Wed morning of each month
- Primary Diagnoses served: Spina Bifida
- Other Diagnoses served: congenital spinal cord anomalies, acquired spinal cord injury, tethered cord

Spina Bifida Clinic

- Purpose: provide comprehensive care to children and adults with spina bifida or spinal cord conditions requiring a multi-disciplinary approach in order to coordinate care to optimize patient function
- Medical management involves evaluation of hydrocephalus and VP shunt function, skin care, urological bladder/bowel dysfunction, behavioral issues, social-emotional issues, orthopedic issues, nutritional issues, and development
- Patient population statistically heavy with teenagers and young adults due to poor transition program. Only see about 2-3 new spina bifida babies per year.
**SPINA BIFIDA NUMBERS**
- 0-12 months: 2
- 13 mo-3 years: 3
- 3.1 years - 5 years: 13
- 6 years - 12 years: 37
- 13 years – 17 years: 26
- 18 years – 21 years: 20
- 22 years – 30 years: 24
- 31 years – 40 years: 10
- 41 years – 50 years: 4
- Total: 145

*As of clinic lists printed 2/3/2011*
*These are pts who were seen 2008 to the present in clinic, not including 2 pts who expired in 2010.*

**General Information**
- Location: Tanner 7
- Staff: Five OT’s, 4 full time, 1 part time
- Responsibilities: Inpatients, outpatients, and clinic coverage.
- Schedule: Monday thru Friday 8-6 (inpatient/outpatient, and clinic coverage), Saturday 8-12 (inpatients only)

**Inpatient Services**
- Evaluations and Treatment
- Pre-term thru Adult
- PICU
- NICU
- Variety Floors 8th, 9th, 10th
- Maternity (long term hospitalization)

**Outpatient Services**
- Evaluations and Treatment
- Pediatric
- All diagnostic groups (Traumatic injuries, Disease process, Developmental)
- Single evaluations to short term therapy to longer term therapy
Therapies Offered

- Developmental Play Skills
- Fine motor developmental skills
- Visual/perceptual motor skills
- Orthotic, splinting fabrication,
- Serial casting,
- Neuromuscular re-education
- Sensory integration
- Adaptive equipment prescription.

Physical Therapy Department

Physical Therapy

- Location Tanner 7
- Staff 8 Therapists
- Responsibilities, Inpatient, Outpatient Clinics
- Schedule Monday to Thursday 8am to 6pm
- Friday 8am to 5pm
- Saturday Inpatient only

Outpatient

- Evaluations and Treatment
- Pediatric
- All diagnostic groups (Traumatic injuries, Disease process, Developmental)
- Single evaluations to short term therapy to longer term therapy

Therapies offered

- Neurodevelopmental facilitation
- Infant massage
- Gait training
- Adaptive equipment prescription
- Splinting/casting/taping
- Burn and wound care
- Early intervention
- Electrical stimulation

Aquatic Therapy
Aquatic Therapy

- Aquatic Therapy is the therapeutic use of water and heat to increase mobility, joint range of motion, strength and endurance.
- Water provides the opportunity to improve balance, coordination, body image and the understanding of the body's position in space.

Aquatic Therapy (cont)

- Water is a medium in which a child can move with more independence through the use of buoyancy, hydrostatic pressure and resistance.
- Warmer temperature (94°F) of a therapeutic pool provides increased relaxation of muscles and allows for more comfortable joint movement.
- Pt's seen 1:1 with OT or PT for ½ hour

Speech Language and Hearing Department

- Location: Tanner 6
- Staff: 5 speech pathologists and 2 audiologists
- Inpatient, Outpatient, Newborn Screening follow up.
- Interdisciplinary care in Oral Motor clinic, ENT clinics, Craniofacial Center, Neurology clinic.
- Community Outreach

O.T. AND P.T.

Together in saw 9600 pts in 2010
- not including those seen in the developmental clinics or ENT.
Speech, Language and Hearing Department

• Feeding clinic
• Swallowing Disorders, Oral Motor skills
• Articulation, voice, and Resonance issues
• Fluency/Stuttering
• Hearing Impairments,
• Salivary Management.

Speech, Language and Hearing Department

• In 2010 saw 6500 visits for speech and language services.
• Not included in these numbers are the patients seen in ENT clinics, where they see patients every day.

Family Services Department

• Social Work – Karen Blersch
  – Assesses family strengths and needs, assists them in linkage and referral to appropriate community resources.
• Educational Department – Kathy Zubricky
  – Provides Early Intervention (EI) evaluations
  – Referrals and help for families through the EI, CPSE process

Family Services Department

• Recreational and Socialization Program
  – Sponsored by Variety, the Children’s Charity
  – For adolescents referred from our clinics
  – Participants enjoy community activities with supervision and support of skilled counselors and assistants to foster socialization skills.
  – Limited enrollment due to staff ratio of 1:5

Not all has been smooth sailing. We have not solved many of our most plaguing problems of scheduling, no-shows and cancellations. (We) have not been successful in luring the students and residents from the hospital into training in careers in this field. (We) have not done the professional writing in medical journals …which we should have done to make the work of this center better known outside the area.

Adapted from Dr Warner’s address to the Children’s Guild 11/19/81