

**Providing Primary Care
for
Children with Special Health Care
Needs
(CSHCN)**

Grace F. Maguire, M.D.

Medical Director

Thomas H. Pinkstaff Medical Home Clinic

Commission for Children With Special Health Care Needs

333 Waller Avenue

Lexington, KY

**Who qualify as CSHCN?
(Children with Special Health Care Needs)**

Maternal and Child Health Bureau defines as:
“those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who require health and related services of type or amount beyond that required by children generally”.

Estimated as **13.9%** of pediatric population
Allergies, asthma, ADHD, depression, autism, cerebral palsy, etc
Some much more complicated than others

Healthy People 2010

- Maternal & Child Health Bureau identified specific and measurable goals for Children With Special Health Care Needs
- Bottom line: All CSHCN need a medical home

What is a Medical home?

- An approach to providing health care in a high-quality, cost effective manner, which creates a partnership between professionals and families, to identify and access services
- Care is:
 - Accessible
 - Continuous
 - Comprehensive
 - Family-centered
 - Coordinated
 - Compassionate
 - Culturally effective



Medical Care of CSHCN

- Requires an individualized schedule of visits (not just routine WCC), with attention to all organ systems
- Patients should be identified somehow to staff, to insure special triaging and scheduling
- Billing/coding is different. Care management/oversight codes exist.
- Specialized encounter forms are helpful. Many available from program websites.
- Home visits can be very beneficial for both the family and the physician. Funeral attendance or written condolences are also greatly appreciated.

Practical issues:

- Nutrition and growth
- Neuromuscular
- Visual impairment
- Education (IDEA)
- Assistive Technology

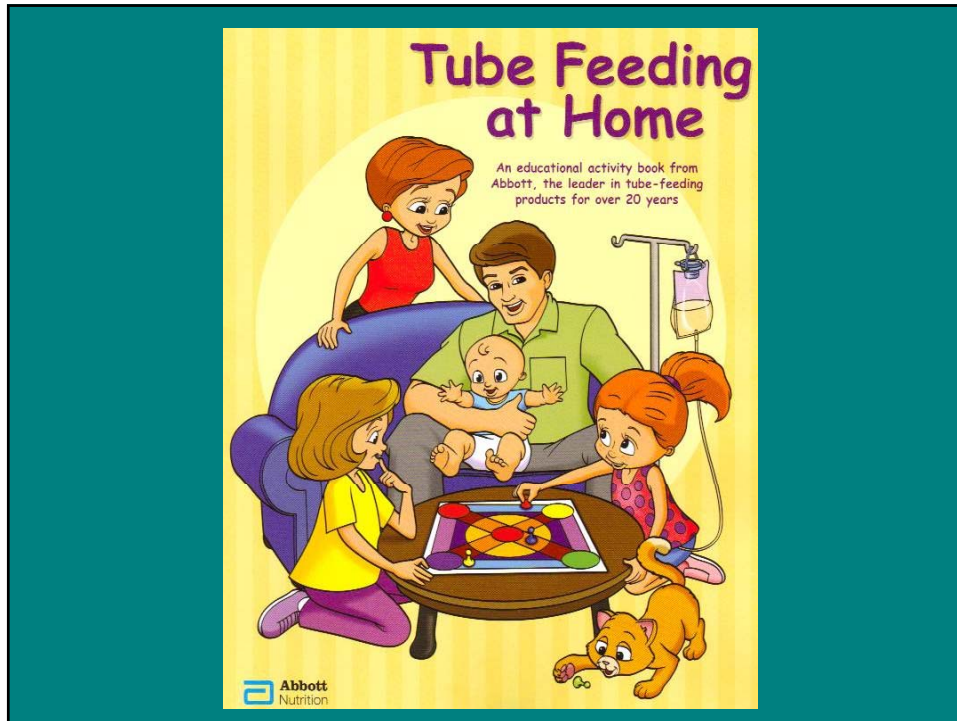
Roles:

Surgeon: Places gastrostomy

PCP: Decides when to send to surgeon

Indications for gastrostomy feeds

- Inadequate growth pattern
- Low weight for height
- Excessive time needed for oral feeds
 - May take 12-15 times longer to feed
 - Some children can initially maintain themselves on oral feeds, but need G-tube in second decade
- Choking/aspiration/swallowing dysfunction
 - 90% of CP pts have some oral/motor dysfunction
 - GERD common
- Delay in initiation of gastrostomy feedings may result in limited stomach capacity and lost potential for catch-up growth.



Gastrostomies

- Most often inserted percutaneously
- Usually have indwelling feeding tube for 6-8 weeks before button is placed (sometimes get button initially)
- Surgical complications are rare

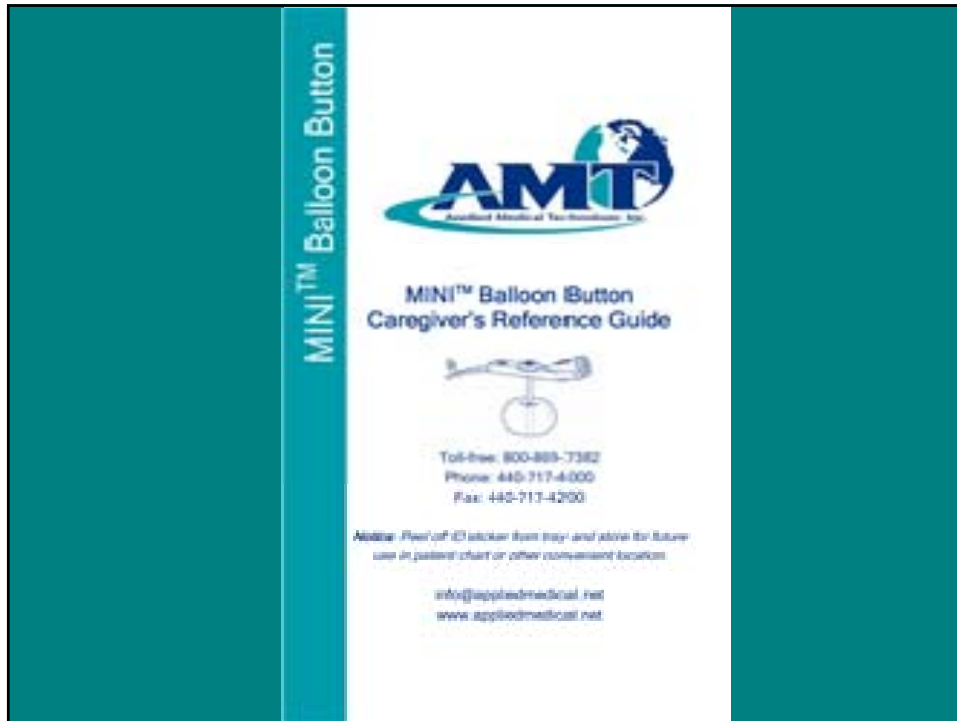
Mic-Key Button

- Most used brand of LPGRD (low profile gastrostomy replacement device)
- Easier to replace than others
- Tubing attached at time of each feeding
- Easier to dress child. No pulling at tube

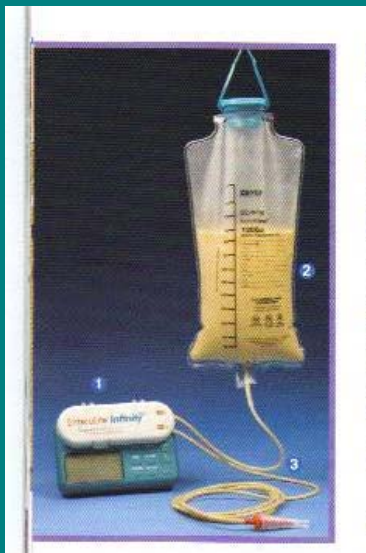


Mic-Key Button

- Size: diameter (usually 12 or 14F) + stem length
- Bulb is inflated with 5 ml water through side port
- Button is rotated 360 degrees daily
- Flush if clogged (carbonated water, cranberry juice)
- May need Maalox, barrier cream, or skin barrier patch around edges if irritated
- Each button costs about \$200
- Replace at least every 6 months



Feeding bag, tubing, pump



- Illustration from Abbott pamphlet

Potential Problems:

- Leakage
 - Make sure size is correct
- Skin infection
 - Culture and treat
- Skin breakdown
 - Use barrier cream or gauze; check size
- Granulation tissue
 - Silver nitrate or steroid cream
- Dislodgement
 - Put something (?Foley) in the hole quickly!

Mic-Key button sizes

R_x Prescription Kimberly-Clark* MIC-KEY* Low-Profile Gastrostomy Feeding Tube

Patient Name: _____ Date: _____

Kimberly-Clark* MIC-KEY* Low-Profile Gastrostomy Feeding Tube MIC-KEY Accessories

12 FR		14 FR		16 FR		18 FR		20 FR		24 FR		Catalog Number	Description	Units / Case
STOCK NUMBER	SIZE	STOCK NUMBER	SIZE	STOCK NUMBER	SIZE	STOCK NUMBER	SIZE	STOCK NUMBER	SIZE	STOCK NUMBER	SIZE			
120-10-0.0	120-10-0.0	120-14-0.8	120-14-0.8	120-16-0.5	120-16-0.5	120-18-1.0	120-18-1.0	120-20-1.5	120-20-1.5	120-24-1.0	120-24-1.0	0121-12	Extension Set with SECUR-LOCK Right Angle Connector and 2 Port 12" and Clasp 12"	5 ea/cv
120-10-1.0	120-10-1.0	120-14-1.0	120-14-1.0	120-16-1.0	120-16-1.0	120-18-1.5	120-18-1.5	120-20-2.0	120-20-2.0	120-24-1.7	120-24-1.7	0121-24	Extension Set with SECUR-LOCK Right Angle Connector and 2 Port 12" and Clasp 12"	5 ea/cv
120-10-1.2	120-10-1.2	120-14-1.2	120-14-1.2	120-16-1.2	120-16-1.2	120-18-1.7	120-18-1.7	120-20-2.3	120-20-2.3	120-24-2.0	120-24-2.0	0123-04	Flexion Set with Cath Tip, SECUR-LOCK Straight Connector and Clasp 24"	5 ea/cv
120-10-1.5	120-10-1.5	120-14-1.5	120-14-1.5	120-16-1.5	120-16-1.5	120-18-2.0	120-18-2.0	120-20-2.5	120-20-2.5	120-24-2.5	120-24-2.5	0123-08	Flexion Set with Cath Tip, SECUR-LOCK Straight Connector and Clasp 24"	5 ea/cv
120-10-1.7	120-10-1.7	120-14-1.7	120-14-1.7	120-16-1.7	120-16-1.7	120-18-2.5	120-18-2.5	120-20-3.0	120-20-3.0	120-24-3.0	120-24-3.0	0124-08	Extension Set with Cath Tip, SECUR-LOCK Right Angle Connector and Clasp 12"	5 ea/cv
120-10-2.0	120-10-2.0	120-14-2.0	120-14-2.0	120-16-2.0	120-16-2.0	120-18-3.0	120-18-3.0	120-20-3.5	120-20-3.5	120-24-3.5	120-24-3.5	0124-12	Extension Set with Cath Tip, SECUR-LOCK Right Angle Connector and Clasp 12"	5 ea/cv
120-10-2.3	120-10-2.3	120-14-2.3	120-14-2.3	120-16-2.3	120-16-2.3	120-18-3.5	120-18-3.5	120-20-4.0	120-20-4.0	120-24-4.0	120-24-4.0	0124-16	Extension Set with Cath Tip, SECUR-LOCK Right Angle Connector and Clasp 16"	5 ea/cv
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120-10-3.0	120-10-3.0	120-14-3.0	120-14-3.0	120-16-3.0	120-16-3.0	120-18-5.0	120-18-5.0	120-20-5.5	120-20-5.5	120-24-5.5	120-24-5.5			
120-10-3.5	120-10-3.5	120-14-3.5	120-14-3.5	120-16-3.5	120-16-3.5	120-18-5.5	120-18-5.5	120-20-6.0	120-20-6.0	120-24-6.0	120-24-6.0			
120-10-4.0	120-10-4.0	120-14-4.0	120-14-4.0	120-16-4.0	120-16-4.0	120-18-6.0	120-18-6.0	120-20-6.5	120-20-6.5	120-24-6.5	120-24-6.5			
120-10-4.5	120-10-4.5	120-14-4.5	120-14-4.5	120-16-4.5	120-16-4.5	120-18-6.5	120-18-6.5	120-20-7.0	120-20-7.0	120-24-7.0	120-24-7.0			
120-10-5.0	120-10-5.0	120-14-5.0	120-14-5.0	120-16-5.0	120-16-5.0	120-18-7.0	120-18-7.0	120-20-7.5	120-20-7.5	120-24-7.5	120-24-7.5			

Refill Allowed - No Substitution

Granulation tissue



Initiation of G-tube Feeds:

- Surgical placement of tube, usually plus Nissen fundoplication
- Feeds started at basal rate plus estimated “activity factor” (see charts to follow), with adjustments based on closely followed weights.
- Usual formula choice:
 - <1 year: standard infant formulas
 - 1-10 years: (PediaSure, Nutren Jr., KinderCal) 30kcal/oz
 - >10 years: may use adult products
- Can start as continuous drip with pump; progress to bolus feeds, or combination. Bolus done by gravity, syringe, or pump
- Flush after each feeding with 15-30 ml water
Patients need at least 8 oz water/day

Calculating BMR

World Health Organization Equations

	MALES		FEMALES	
AGE(YRS)	BMR (kcal/d)	AGE(YRS)	BMR (kcal/d)	
0-3 YRS	60.7 x wt - 54	0-3 YRS	61.0 x wt - 51	
3-10 YRS	22.7 x wt + 495	3-10 YRS	22.5 x wt + 499	
10-18 YRS	17.5 x wt + 651	10-18 YRS	12.2 x wt +746	
18-30 YRS	15.3 x wt + 679	18-30 YRS	14.7 x wt + 496	
(weight in kgs)				

Calculating total caloric need

Calories /day = (BMR x muscle tone factor x activity factor)
+ growth factor

Muscle tone factor:

- 0.9 decreased muscle tone
- 1.0 normal muscle tone
- 1.1 increased muscle tone

Activity factor:

- 1.15 bedridden
- 1.20 dependent (wheelchair)
- 1.25 crawling
- 1.30 ambulatory

Growth factor: 5 kcal per gram of desired weight

Case example

Jeremiah: 8 yr. old, 61 lbs.(27.7 kg), wheelchair bound, not spastic.

$$\text{BMR} = (22.7 \times 27.7) + 495 = 1124$$

$$\begin{aligned} \text{Kcals/day} &= (1124 \times 1.0 \times 1.2) + \text{growth factor} \\ &= 1349 + \text{growth} \end{aligned}$$

(but we had to cut back when he gained too rapidly on this amount)

Periodic laboratory assessment of nutrition

- CBC
- Serum: Iron, Ca, Phosphorus, vitamin D, albumin, BUN, creatinine
- Urine calcium/ creatinine ratio

CONSTIPATION

- Frequent problem due to poor diet, decreased muscle tone, inactivity
- May develop impactions; secondary loss of appetite or vomiting; increased risk of renal stones
- Increase fiber in oral diet. Use formula with fiber for G-tube feeds
- Most need daily medication (e.g.: *Miralax*)
- Rarely need flush system
 - Antegrade continence enema (ACE)

Neuromuscular issues

- Many children with neuromuscular disabilities have normal intelligence, but their poor motor function does not allow them to show it, especially since they cannot speak
- Not all children with disabilities have seizures
- Seizures increase caloric requirement and may interfere with intake
- V-P shunts may need replacement due to growth of child




GMFCS

Gross Motor Function Classification System (not Guided Missile Fire Control System)

International classification system to describe function in children with CP, divided by age group, with emphasis on real world abilities and interaction. Much more specific than “mild”/ “moderate”/ “severe”

Very helpful in understanding the child, as a communication tool for care providers, and as a common language for research.

Similar systems for communication, fine motor, etc



CanChild Centre for Childhood Disability Research
 Institute for Applied Health Sciences, McMaster University,
 1400 Main Street West, Room 408, Hamilton, ON, Canada L8S 1C7
 Tel: 905-525-9146 ext. 27859 Fax: 905-522-8688
 E-mail: canchild@mcmaster.ca Website: www.canchild.ca

GMFCS – E & R
Gross Motor Function Classification System
Expanded and Revised

GMFCS - E & R © Robert Palisano, Peter Rosenbaum, Doreen Bartlett, Michael Livingston, 2007
 CanChild Centre for Childhood Disability Research, McMaster University

GMFCS © Robert Palisano, Peter Rosenbaum, Stephen Walter, Dianne Russell, Ellen Wood, Barbara Galuppi, 1997
 CanChild Centre for Childhood Disability Research, McMaster University
 (Reference: Dev Med Child Neurol 1997;39:214-223)

INTRODUCTION & USER INSTRUCTIONS

The Gross Motor Function Classification System (GMFCS) for cerebral palsy is based on self-initiated movement, with emphasis on sitting, transfers, and mobility. When defining a five-level classification system, our primary criterion has been that the distinctions between levels must be meaningful in daily life. Distinctions are based on functional limitations, the need for hand-held mobility devices (such as walkers, crutches, or canes) or wheeled mobility, and to a much lesser extent, quality of movement. The distinctions between Levels I and II are not as pronounced as the distinctions between the other levels, particularly for infants less than 2 years of age.

The expanded GMFCS (2007) includes an age band for youth 12 to 18 years of age and emphasizes the concepts inherent in the World Health Organization's International Classification of Functioning, Disability and Health (ICF). We encourage users to be aware of the impact that **environmental** and **personal** factors may have on what children and youth are observed or reported to do. The focus of the GMFCS is on determining which level best represents the **child's or youth's present abilities and limitations in gross motor function**. Emphasis is on usual **performance** in home, school, and community settings (i.e., what they do), rather than what they are known to be able to do at their best (capability). It is therefore important to classify current performance in gross motor function and not to include judgments about the quality of movement or prognosis for improvement.

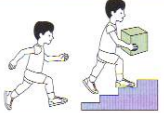
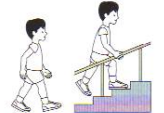



The title for each level is the method of mobility that is most characteristic of performance after 6 years of age. The descriptions of functional abilities and limitations for each age band are broad and are not intended to describe all aspects of the function of individual children/youth. For example, an infant with hemiplegia who is unable to crawl on his or her hands and knees, but otherwise fits the description of Level I (i.e., can pull to stand and walk), would be classified in Level I. The scale is ordinal, with no intent that the distances between levels be considered equal or that children and youth with cerebral palsy are equally distributed across the five levels. A summary of the distinctions between each pair of levels is provided to assist in determining the level that most closely resembles a child's/youth's current gross motor function.

We recognize that the manifestations of gross motor function are dependent on age, especially during infancy and early childhood. For each level, separate descriptions are provided in several age bands. Children below age 2 should be considered at their corrected age if they were premature. The descriptions for the 6 to 12 year and 12 to 18 year age bands reflect the potential impact of environment factors (e.g., distances in school and community) and personal factors (e.g., energy demands and social preferences) on methods of mobility.

An effort has been made to emphasize abilities rather than limitations. Thus, as a general principle, the gross motor function of children and youth who are able to perform the functions described in any particular level will probably be classified at or above that level of function; in contrast, the gross motor function of children and youth who cannot perform the functions of a particular level should be classified below that level of function.

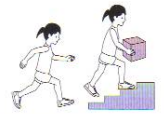
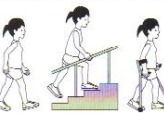



General Headings	
Level I	Walks without limitations
Level II	Walks with limitations
Level III	Walks using a hand-held mobility device
Level IV	Self-mobility with limitations; may use powered mobility
Level V	Transported in manual wheelchair

GMFCS E & R between 6th and 12th birthday: Descriptors and illustrations

	<p>GMFCS Level I</p> <p>Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.</p>	<p>Kerr Graham et al</p>
	<p>GMFCS Level II</p> <p>Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.</p>	
	<p>GMFCS Level III</p> <p>Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.</p>	
	<p>GMFCS Level IV</p> <p>Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.</p>	
	<p>GMFCS Level V</p> <p>Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.</p>	

GMFCS descriptors: Palisano et al. (1997) Dev Med Child Neurol 39:214-23. Illustrations copyright © Kerr Graham, BS, PhD and Adrienne Harvey.

GMFCS E & R between 12th and 18th birthday: Descriptors and illustrations

	<p>GMFCS Level I</p> <p>Youth walk at home, school, outdoors and in the community. Youth are able to climb curbs and stairs without physical assistance or a railing. They perform gross motor skills such as running and jumping but speed, balance and coordination are limited.</p>	<p>Kerr Graham, et al</p>
	<p>GMFCS Level II</p> <p>Youth walk in most settings but environmental factors and personal choice influence mobility choices. At school or work they may require a hand-held mobility device for safety and climb stairs holding onto a railing. Outdoors and in the community youth may use wheeled mobility when traveling long distances.</p>	
	<p>GMFCS Level III</p> <p>Youth are capable of walking using a hand-held mobility device. Youth may climb stairs holding onto a railing with supervision or assistance. At school they may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community youth are transported in a wheelchair or use powered mobility.</p>	
	<p>GMFCS Level IV</p> <p>Youth use wheeled mobility in most settings. Physical assistance of 1-2 people is required for transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility or a body support walker when positioned. They may operate a powered chair, otherwise are transported in a manual wheelchair.</p>	
	<p>GMFCS Level V</p> <p>Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements. Self-mobility is severely limited, even with the use of assistive technology.</p>	

GMFCS descriptors: Palisano et al. (1997) Dev Med Child Neurol 39:214-23. Illustrations copyright © Kerr Graham, BS, PhD and Adrienne Harvey.

Cortical Visual Impairment (CVI)

- Problem is with the brain pathway, not the eye
- Excellent article in *Pediatrics in Review*
November 2009 (see reference list)

Causes of CVI

Hypoxic/ ischemic brain injury
especially premature babies

CNS infection
meningitis now less frequent

Congenital CNS malformations
Lissencephaly, schizencephaly, holoprosencephaly

Trauma
Abuse, Shaken Baby

Diagnosis

- Be on alert for risk factors
- Premie may not have ROP, but have CVI
- Battered infant may not show retinal hemorrhages, but have CVI
- Exam of eye may be completely normal
- Neuroimaging may support diagnosis if abnormal (cortical atrophy, etc)

Course of CVI

- Many improve over time
90% remain visually handicapped
- Frequently varies over time

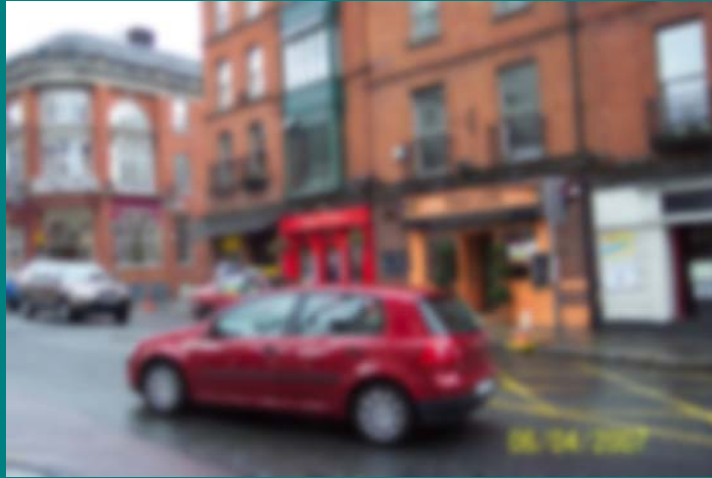
Common Characteristics of CVI

- Preference for red or yellow, sparkling object, moving object
- May have visual field preferences
- Slow response to object seen
- Doesn't use vision to direct reach
- Turns away from object and explores by touch
- Light gazing; photophobia

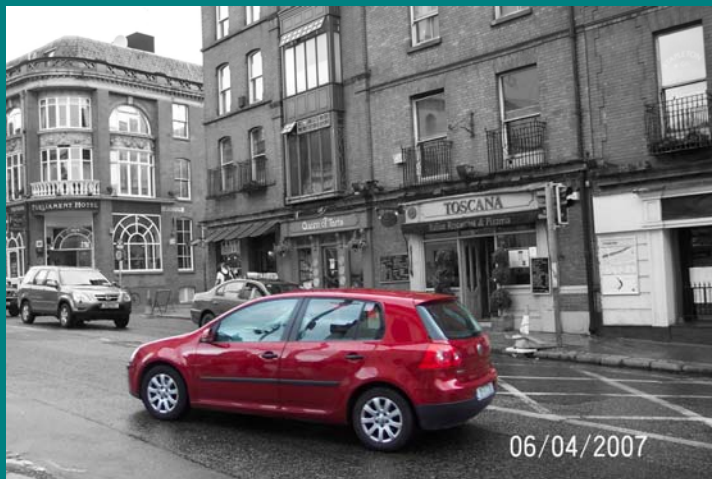
CVI vision



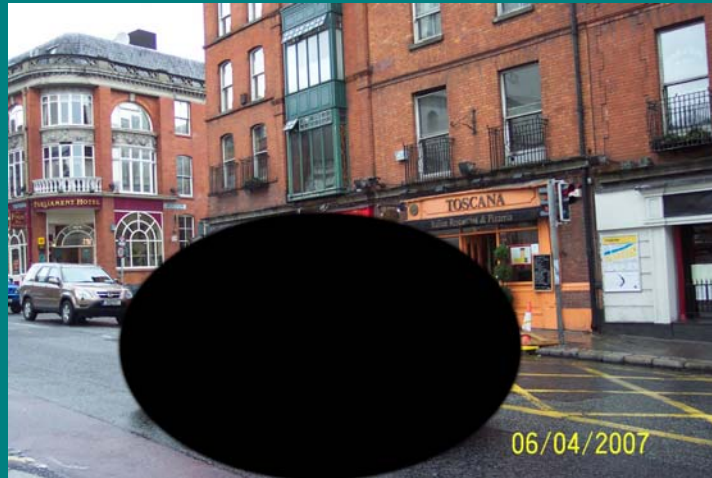
CVI – may be blurry



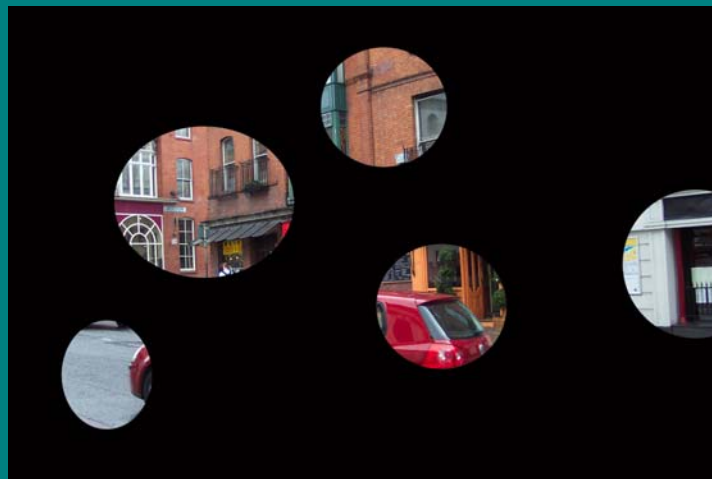
May see only red objects



Central field loss



Swiss cheese field



Strategies

- Avoid visual clutter
- Simplify environment
- Good lighting
- Allow time to see
- Use familiar objects and routines

Need contrast



Simple background



Light box/ table



Education

- 1975 – Education for All Handicapped Children Act
 - Guaranteed education for all disabled children 5-18 years old (now 22 years)
 - Eligible for related services at school (OT, PT, ST)
 - Must have IEP (Individual Education Plan)
- 1986 – Education of the Handicapped Amendments
 - Free public education for handicapped at age 3 years
 - Program to provide intervention services for handicapped from birth through 2 years
- 1990/1991 – Individuals with Disabilities Education Act (IDEA)
 - Strengthened laws
 - Establish programs for children at risk
- 1992 – “Section 504” of Rehabilitation Act (updated again 1994)
 - Must evaluate every child for use of any assistive technology that would foster participation and benefit at school

Physician’s role in School plan

- Support parents in advocating for education rights
- Encourage parents to exercise their right to be involved in IEP. I find it helpful to obtain a copy of IEP.
- Assist in instruction to school regarding patient’s medical needs (feeding, trach care, seizure mgt, etc)
- Encourage daily school attendance rather than “home bound” teacher (only a few hours/wk)
- Complete paperwork and write letters as needed. May need to speak with various school personnel

Individual Education Plan IEP

- Every child with disability 3-21 yrs must have a written plan
- Must have multidisciplinary team evaluation
- Plan is devised in collaboration with family
- Plan is reviewed annually. Complete reevaluation every 3 years
- Parents have right to due process

- IEP developed at ARC meeting (Admissions and Release Committee)
- Parents must be notified of meeting and be given copy of final IEP
- Includes present level of functioning, goals and objectives, plan for implementation, special services to be provided, plan for review

Dispute resolution process

- Mediation
- Written complaint
- Due process hearings
- Details available online

www.education.ky.gov/KDE

PREPARING FOR
ADMISSIONS AND
RELEASE COMMITTEE
(ARC) MEETINGS



A Checklist for Parents

KY Dept Education

Resources

- www.familyvoices.org
- www.handsandvoices.org

For hearing impaired, but has “Pop-up IEP” for parents to prepare for ARC. Gives sample statements (“Sorry. We don’t have the money”) and response suggestions for parents

Assistive Technology

Any item, piece of equipment or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities

AT Categories

- Architectural elements
- Vision
- Communication
- Controls
- Hearing
- Education
- Home Management
- Orthotics
- Personal care
- Recreation
- Seating
- Transportation
- Walking
- Workplace



Focus on

Transportation

Communication

Wheelchairs

- Certified therapist assesses and recommends specifications
- Physician writes prescription; signs detailed order form
- Design allows modifications as patient grows
- Insurance limitations on interval between new chairs

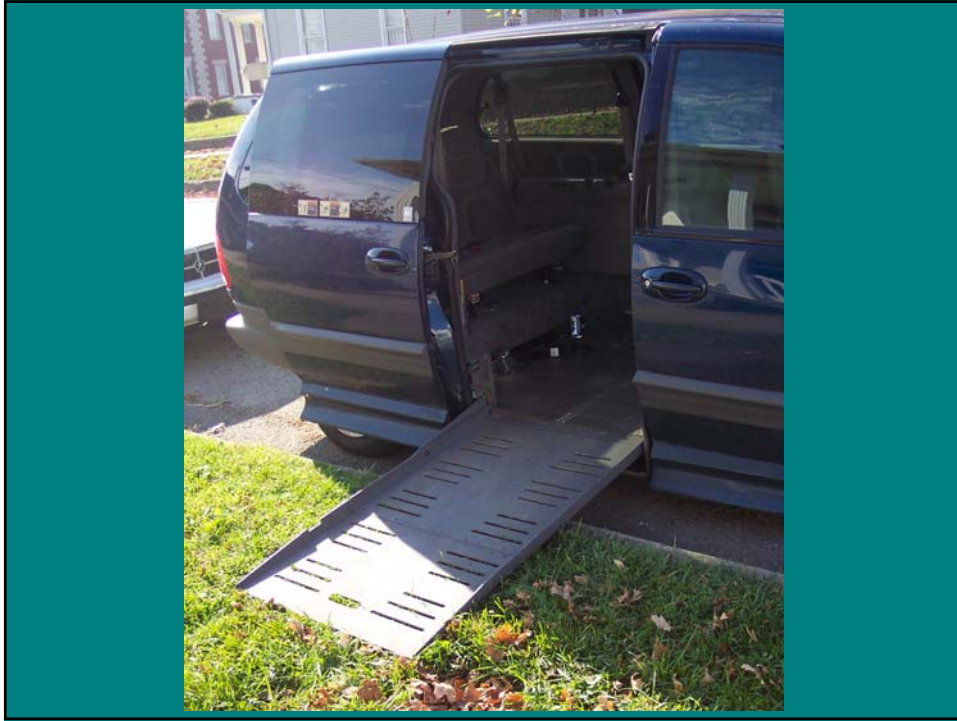


Manual vs. Powered Wheelchair

Powered:

- only if child can operate it
- requires a back-up manual chair
- requires modified van for travel
- requires home modifications





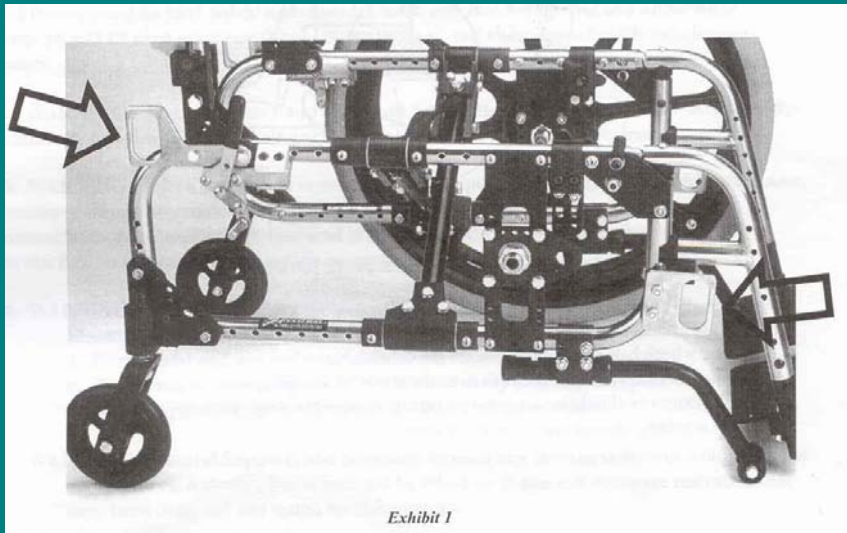
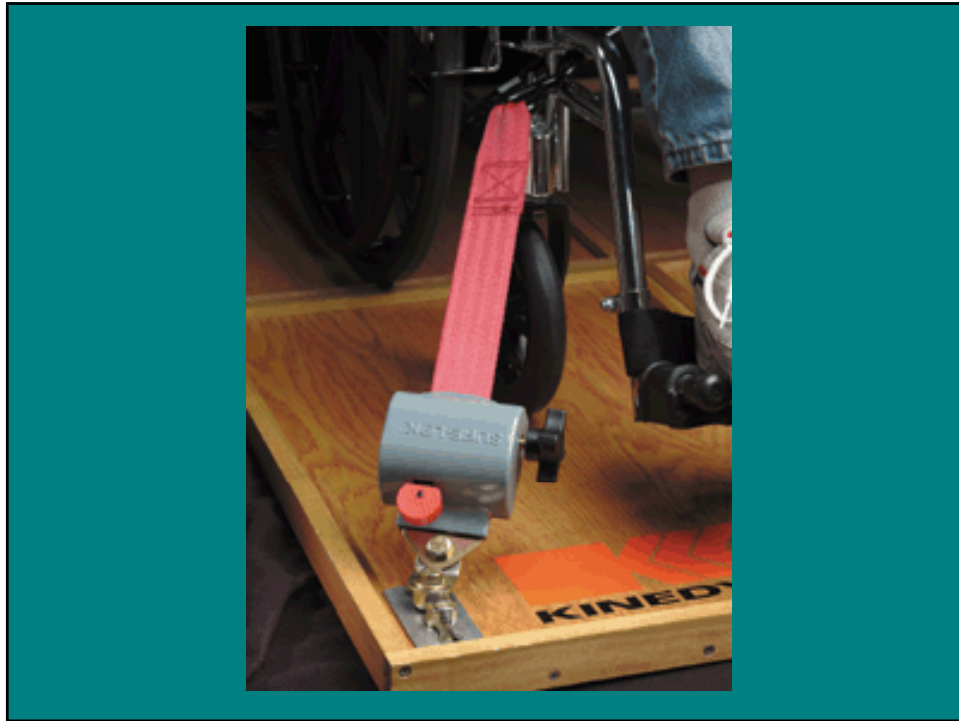


Exhibit I





Handicapped Parking

- Spaces must be provided if lot is restriped
- Must have at least one “van accessible” space (8 ft rather than 5 ft access aisle to allow room for ramp)
- All of us need to be advocates

Who is eligible?

Cannot walk 200 feet without stopping to rest
Cannot walk without use of assistive device
Lung disease (“forced respiratory and expiratory volume for 1 second is less than 1 liter” or oxygen tension less than 60)
Uses portable oxygen
Has Class III or IV heart disease
Severely limited in walking ability due to arthritic, neurological, orthopedic condition

How to apply

- Application form available online
- Requires physician signature if condition not obvious to clerk
- Notarization not necessary if physician signs
- Apply at county clerk’s office
- No charge

Augmentative and alternative communication (AAC)

Almost every child has the means to communicate with the help of today's technology.

Only one part of body needs to be functional to activate a switch (a finger, a turned chin, etc.)

Therapist must identify how each child can interface, and then open the world to him.

“Jelly switch” activated by turning cheek
(then activates communication board)

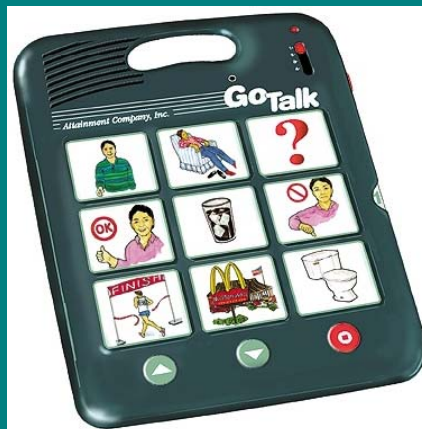


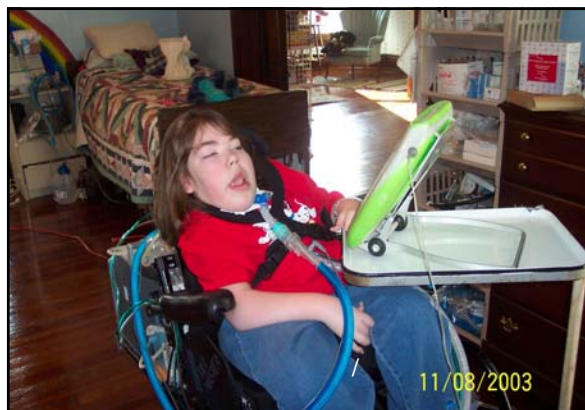
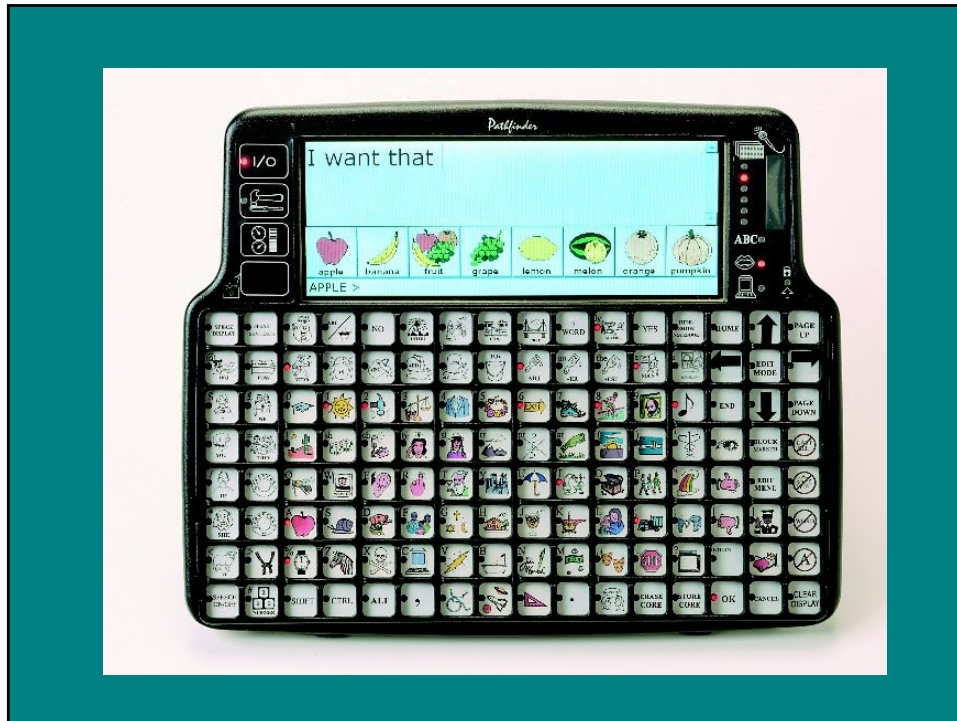
Keyboarding with toes



AAC types

Communication device may be as simple as a choice of “yes/no”, a picture board, or a full keyboard computer with “voice” output (device “speaks” out loud for child)





T.M. at home:
Ventilator-dependent
quadriplegic, with some
motor ability of left hand
and lower arm.



PCP role:

Parents need your support to push for evaluation.
Many children haven't had tech evaluation.

Need system for home also. Some rentals
available from tech centers.

No excuse for no system

Funding strategies on Medical Home website

What do these children want us to know?

See and talk to me as a person, not a
condition

Don't ever tell me I can't achieve something

See my abilities, not my limitations