

Incidence and survival rates for children with other health care conditions

Childhood Onset Chronic and Disabling Conditions: Overall Characteristics

- Onset before age 21
- Specific conditions have low incidence
- Diverse causes
 - Congenital
 - Related to prematurity, delivery & neonatal period
 - Acquired (illness & trauma)
- Heterogeneous manifestations & impacts
 - Progressive vs. static
 - Constantly present or episodic (predictable?)
 - Invisible or visible (stigma?)
- Co-morbidity - multi-system involvement

Condition	Incidence Per 1000	% Survive to 21
■ Asthma	20.	98%
■ Autism & other PDD	10.	?
■ Congenital Heart Disease (CHD)	5.	50%
■ All inborn errors of metabolism	3.	varies
■ Hydrocephalus	3.	(90% to 10 years)
■ CP	2.	“near normal”
■ Kidney disease	2.	?
■ Hearing impairment	2.	normal
■ Diabetes Type 1	1.7	(life expectancy = 54 years)
■ Cleft Lip & Palate	1.4	normal
■ Downs syndrome	1.2	
■ Without CHD		(79% to 30 years)
■ With CHD		(50% to age 30)
■ White		50 year life expectancy
■ Black & other		25 year life expectancy
■ Seizure Disorders	1.0	(86% to 10 years)
■ Neural tube defects	0.7	80%
■ CF	0.5	50%
■ Sickle Cell Disease	0.36	86%
■ Blind/visually impaired	0.33	normal
■ Fragile X	0.25	normal

■ Muscular Dystrophy	0.14	?
■ Cancer	0.13	72% survive 5 years
■ Hemophilia	0.10	90%
■ Juvenile Arthritis	0.08	? (remission)
■ Crohn's Disease	0.07	normal
■ Ulcerative Colitis	0.07	normal
■ PKU	0.05	normal