



Chronic Illness and Schooling: An Introductory Overview Outline*

Peyton Clausen, a UCLA undergraduate working at our Center had a personal interest in how chronic illness can interfere with a student's education and other school-related activities. She decided she wanted to learn more about this and how teachers and other school staff, parents, peers, and an affected student can work together to address the problems that arise.

The following shares what she learned from reviewing the literature. It is offered in the form of an introductory topical outline. The outline is designed as a starting point for individuals and groups wanting to begin an investigation into or just beginning to think about a presentation on chronic illness concerns as related to schools. It is organized to highlight key questions and concerns surrounding the topic.

Some data and content notes are provided. These are drawn from a variety of resources, all of which are cited in the list of references. These notes are meant mainly as an aid in preparing a presentation.

The outline presents information about:

- *What defines a chronic illness and how many school-aged children have one or more chronic illnesses?*
- *How does chronic illness affect educational and social experiences at school?*
- *What can be done to avoid the negative educational and social effects?*
- *What are the school's responsibilities with respect to such children?*

*The information presented here was culled from the literature and drafted by Peyton Clauson as part of her work with the national Center for Mental Health in Schools at UCLA

The center is co-directed by Howard Adelman and Linda Taylor and operates under the auspices of the School Mental Health Project, Dept. of Psychology, UCLA, Phone: (310) 825-3634
Email: smhp@ucla.edu Website: <http://smhp.psych.ucla.edu>

Feel free to share and reproduce this document; no permission is needed.

If you have comments, suggestions, examples you would like to share, please let us know.
Send comments to ltaylor@ucla.edu

1. What defines a chronic illness and how many school-aged children have one or more chronic illnesses?

A. Definitions

>Several definitions of “chronic illness” can be found in the literature on the topic:

1. A chronic illness can be defined as “a condition which lasts for a considerable period of time or has sequelae which persists for a substantial period and/or persists for more than 3 months in a year or necessitates a period of continuous hospitalization for more than a month” (Thompson & Gustafson, 1996)
2. “Chronic illness includes those diseases involving a protracted course that may be fatal or result in compromised mental, cognitive, and/or physical functioning and that are often characterized by acute complications, which may result in hospitalizations or other forms of intense treatment” (Brown & DuPaul, 1999)
3. Chronic illness is the “lived experience, involving permanent deviation from the normal, caused by unalterable pathological changes” (Cameron & Gregor, 1987)

>The Maternal and Child Health Bureau’s Division of Services for Children with Special Health Care Needs defines children with special health care needs as follows:

“Children with special health care needs are those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally” (McPherson, Arango, Fox, McManus, Newacheck, Perrin, Shonkoff, & Strickland, 1998)

Note:

Chronic diseases vary in stability and predictability (Brown, Daly, & Rickel, 2007; Hoard, 2004; Eiser, 1993). For example, children with arthritis have a high degree of stability in their health, leading to greater stability in daily life whereas other conditions are less predictable, such as asthma, epilepsy, and diabetes, leading to a lesser degree of stability in the life of the child with a chronic illness and in his or her family’s life.

B. What types of conditions are included in the category of “chronic illnesses”?

>The following are some of the most common chronic conditions:

AIDS, allergies, asthma, cancer,
cystic fibrosis, diabetes (type 1 and 2),
epilepsy, kidney disease, lupus,
multiple sclerosis, rheumatoid arthritis,
sickle cell anemia

C. How many school-aged children have chronic illnesses?

>Most reports indicate that between 13% and 17% of children in the United States have chronic illnesses (Stein & Silver, 2002; Torpy, Campbell, & Glass, 2010)

Notes:

>>Estimates of the prevalence vary due to differing definitions.

Using the Maternal and Child Health Bureau's definition, the figure is 18% or 12.6 million American children (Newacheck & Halfon, 1998)

>>Prevalence estimates divide children living with chronic illnesses the degree their condition limits activity (Barlow & Ellard, 2006). The percentages are:

1. 66% have a *mild condition* (not actively limiting)
2. 29% have a condition of *moderate severity* (limiting of some activity)
3. 5% have a *severe condition* (frequent bother and limitation of activity).

>>Prevalence figures for children have increased in the past few decades (Halfon & Newacheck, 2010). The increase is seen as the result of

1. advances in medical technology which have increased the survival rates of patients with chronic illnesses (this include advances in diagnostic tools)
2. expanded definitions -- moving from only including physical disabilities to encompassing developmental issues and other non-physical disabilities.

II. How does chronic illness affect educational and social experiences at school?

A. Absenteeism

>Chronic illnesses means missed school days (due to short hospitalizations and extended hospital stays, medical appointments, overprotective parents, and days of not feeling well)

>Absenteeism can lead to academic difficulties and hinder forming positive social relationships, as well as interfering with other facets of socialization within the school environment

B. Cognitive Problems

>Some chronic illnesses, although not all, negatively affect cognitive abilities such as attention and concentration, memory, sequencing of tasks, and comprehension

>Treatments for some diseases have been linked to cognitive impairment (e.g., medications used to control asthma and epilepsy, treatments used for leukemia) (Eiser, 1993)

>Cognitive difficulties on academically-related tasks affect school success (e.g., may result in the child being held back a grade; increases the risk of dropping out)

C. Behavioral and Emotional Problems

- >On average, children with chronic illnesses display more behavioral and emotional problems than children without chronic illness (Hysing, Elgin, Gillberg, & Lundervold, 2009)
- >Although different chronic illnesses have unique characteristics, there are psychosocial commonalities (Bakwin & Bakwin, 1972; Wallander & Varni, 1998). For example:
 - When the illness interferes with the normal activity, frustration increases.
 - Because the child feels different from peers, self-concept decreases.
 - The illness may foster inappropriate parental attitudes and behaviors, ranging from overprotection to rejection.

1. Vulnerabilities

- >As a whole, children with chronic illnesses are more vulnerable to maladjustment compared to children without chronic illnesses (Eiser, 1990).
- >The chronically ill child often shows the most difficulty in gaining independence (Bakwin & Bakwin, 1972)
- >Physically ill children show social maladjustment, low self-concept, increased anxiety and immaturity, and social isolation much more frequently than any normative group of children (Tavormina et al., 1976)
- >Children with physical disorders are at increased risk for overall adjustment problems and internalizing and externalizing symptoms compared to children without such disorders
- >The relationship between levels of adjustment and disease severity has to yet to be concretely defined. However, Perrin et al. (1989) state that parental perception of disease severity appears to be more influential on a child's level of adjustment than the actual severity of the disease (as rated by a health professional)

2. Gender and age differences

- >Boys show more problems than girls (e.g., the trend is for boys to be more unstable, restless, and mood; less verbally expressive; make fewer socially desirable responses). Girls (specifically ages 11-13) behave less maturity than boys (Tavormina, 1976).
- >Differences in behavioral issues between chronically-ill children of different ages. For example:
 - Younger children show more adjustment issues in the area of school tasks and achievement (Eiser, 1990, 1993)
 - Older children show more problems in terms of social adjustment (Eiser, 1990, 1993)

3. Coping

>Chronically-ill children referred for adjustment problems were found to use different coping strategies compared to chronically-ill children who showed no adjustment problems (Spirito et al., 1988)

Note:

>>This may have important implications for the types of intervention strategies employed by psychological health professionals, school staff, and family members (discussed in the next section)

4. A few behavioral correlates of specific conditions:

>Diabetic children show more maladjustment than non-diabetic controls (Swift et al., 1976)

>Asthmatic children show increased psychopathology and have more adjustment problems (Barlow & Ellard, 2006)

>Children with cystic fibrosis show more dependency, less maturity, and more problems in school and with their physical appearance (Tavormina, 1976)

III. *What can be done to avoid the negative educational and social effects?*

Some General Intervention Strategies

The following synthesizes strategies recommended by those with expertise in helping children with chronic-illnesses (e.g., Hayman, Mahon, & Turner, 2002; Singer, 2010). Many of these represent good parenting in general.

1. *Educate the chronically-ill child about his/her disease.*

Note

This strategy has been partially successful in improving adjustment levels, however knowledge alone doesn't predict better adjustment in chronically-ill children (Eiser, 1990, 1993)

2. *Allow for more self-care, emphasizing age-appropriate responsibilities.*

Note

For children with diabetes and those with asthma (Eiser, 1990, 1993) this has been found to foster greater self-knowledge about how the disease impacts daily life and enhances self-confidence

3. *Encourage participation in activities that will help develop the personal and social skills needed to manage chronic illness.*

Note

This involves the child in learning to self-manage his/her disease at home, at school, and in other social situations (Eiser, 1990, 1993).

Examples of Activities for Peer Involvement

- An increasingly popular activity is enrolling in a summer camp specifically designed for children with a certain illness
- Participation in an interactive support group for children with a certain illness
- Encourage the child to teach his/her close friends and peers about his/her illness (age-appropriately, and only as much as the child desires to) and provide ways for friends of the chronically-ill child to help the chronically-ill child take care of him/herself (for example, accompanying the ill child to the nurse's office should it be needed).
This makes the disease less mysterious to peers and enables interaction between the chronically-ill child and his/her classmates in a less intimidating way

4. *Recognize and respond to the emotional and stigmatizing impact of having a chronic illness.*
5. *Listen if the child is willing to talk about how s/he is feeling and avoid giving unsolicited advice.* (Sometimes feeling heard is more important than being told what step to take next.)
6. *Encourage healthy expression of feelings through different mediums such as art, writing, playing an instrument, etc.*
7. *Facilitate development of coping skills and use of stress management techniques* (e.g., interpersonal and problem solving skills for dealing with verbal and physical teasing; understanding of treatment side effects; relaxation strategies) (Russ & Ollendick, 1999).
8. *Ensure there is professional help when needed.*

Note

>Reasons for seeking such help include: lack of interest in doing things that used to be fun, appearing depressed, severe problems at school or with friends, major and intolerable changes in the child's behavior.

A Few Strategies Related to Moderating the Impact of School Absences

If absence from school is necessary, alternative educational support may be sought, such as bedside schooling and homeschooling. Bedside schooling and homeschooling are for children who are unable to leave the hospital or who cannot enter the school environment due to weakened immune system and the necessity of avoiding germs, but who are well enough to continue their education

Bedside and home teachers are licensed and work with ill students to prevent them from falling behind due to their condition; they work with the regularly-attended school staff and lesson times can be scheduled for when the child feels well enough to work and around medical procedures or doctor appointments

While the child may stay on track academically with home or bedside-schooling, prolonged absence from school may interfere with development of healthy social interactions, especially with peers.

There are several ways to help the child stay connected:

- Encourage and allow participation in online social networking sites (with age-appropriate supervision)
- Maintain email correspondence with classmates
- Text and instant messaging with peers
- Facilitate talking on the phone with peers
- Ask the child's school teacher to encourage letter-writing and email correspondence with classmates
- Arrange for visits from friends if the child is well enough and encourage, if possible, the child to attend social events even if for short periods of time

IV. What are the school's responsibilities with respect to such children?

It's the Law! The school's legal responsibility under federal law is mainly in providing the chronically-ill child with the resources he/she needs to progress through his/her education

>Schools must follow requirements outlined in the *Americans with Disabilities Act* (ADA) and the *Individuals with Disabilities Education Act* (IDEA). Note also that *Section 504 of the Rehabilitation Act of 1973* states:

"No otherwise qualified person with a disability in the United States... shall, solely by reason of...disability, be denied the benefits of, be excluded from participation in, or be subjected to discrimination under any program or activity receiving federal financial assistance."

>State laws regarding the role of the school in caring for a child with a chronic illness vary across the U.S.

Note

The U.S. Dept. of Health and Human Services has made it a goal for each school to have a ratio of no more than 750 students to every nurse, while the National Association of School Nurses (NASN) recommends that one nurse should attend to more than 225 students in schools where students with special healthcare circumstances are “mainstreamed with other students” (<http://nasn.org>)

A. What School’s Do

- >As with anyone diagnosed for special education, responding to the needs of chronically ill children at school requires communication among all involved with the student (e.g. school staff, the family, the student, healthcare providers) in order to create a support system that will enhance the child’s educational experience and minimize effects of his/her chronic illness.
- >School districts often have protocols in place for staff in dealing with students who have chronic illnesses. These include guidelines about confidentiality and safety, staff training to eliminate stigma and encourage inclusion, compliance monitoring, and meetings with parents, school staff and healthcare providers.

Responsibilities of the School District and School

- Ensure both the student and parent/guardian are aware of available special accommodations and that requests for accommodation are reasonably met
- Ensure special activities, such as school field trips, are accessible for all students
- Ensure staff understand the basics of the chronic illness and learn to recognize symptoms of immediate danger (e.g., the symptoms of a hypoglycemic episode in a student with type 1 diabetes or the symptoms of an asthmatic episode in a student with asthma)
- Maintain contact with the student and family in order to stay up-to-date on any changes in circumstances that may impact the student in the classroom and wider school environment (e.g., changes in medication dosage or schedules)

B. The Parent/Guardian and the School

>One of the most important things a parent/guardian can do is to provide the school with all necessary information about the child’s problems, special needs, current treatment/medications

Notes

>>Notifying the school administration, the school nurse, and/or the teacher of medication schedules, a written description of the child’s condition, and authorization to administer medication, as well as emergency treatment plans created by the parent/guardian and the healthcare provider.

- >>Providing documentation of the chronic condition from a healthcare provider so the school and school district are aware of how the illness may interfere with carrying out specific tasks, participating in certain activities, etc.
 - >>Identifying specific reasonable accommodations that the student and/or parent/guardian would like the school to make (i.e., allowing extra time to complete tests, allowance for absent days, permission to use the restroom whenever needed, permission to see the nurse whenever necessary, etc.)
- >Many cases call for developing either a 504 Plan or an IEP (Individual Education Program plan).

Notes

- >>Not all students identified as having disability need “specialized instruction” and the choice between developing a 504 Plan or an IEP should be made based on whether the chronically-ill child needs specialized instruction.
 - >>A 504 Plan is designed to ensure a child at an elementary or secondary school who is identified as having a disability receives *accommodations* to enable success at school
 - >>An IEP is designed to ensure a child at an elementary or secondary school who is identified as having a disability receives *specialized instruction and/or related necessary services*
- >Reasonable modifications and accommodations for students with disabilities include, but are not limited, to the following:
- Authorizing campus transportation services
 - Moving classroom assignments for better access
 - Providing textbooks in alternate formats visual impairments
 - Providing services, such as readers to accommodate visual impairments or qualified interpreters and note-takers for students with hearing impairments
 - Enabling use of computer programs or other assistive technological devices
 - Allowing additional time to complete tasks and tests
 - Permitting tests to be individually proctored/monitored, dictated, or typed

References

- Bakwin, H., & Bakwin, R.M. Behavior disorders in children (4th ed.). Philadelphia: W.B. Saunders, 1972
- Barlow, J.H., Ellard, D.R. The psychosocial well-being of children with chronic disease, their parents, and siblings: An overview of the research evidence base. Journal compilation. Blackwell Publishing, Limited, 2006.
- Brown, R.T., & DuPaul, G.J. (1999). Introduction to the miniseries: Promoting school success in children with chronic medical conditions. *School Psychology Review*, 28, 175–181.
- Brown, R.T., Daly, Brian, P., & Rickel, A.U. (2007). *Chronic illness in children and adolescents (Advances in psychotherapy; evidence-based practice)*. Hogrefe Publishing.
- Cameron, K. & Gregor, F. (1987). Chronic illness and compliance. *Journal of Advanced Nursing*, 12, 671-676.
- Eiser, C. (1990). Psychological effects of chronic disease. *Journal of Child Psychology and Psychiatry*, 31, 85-98.
- Eiser, C. (1993). *Growing Up With a Chronic Disease: The Impact on Children and Their Families*. Jessica Kingsley Publishers.
- Halfon, N., & Newacheck, P.W. (2010) Evolving Notions of Childhood Chronic Illnesses. *Journal of the American Medical Association*, 303, 665-666.
- Hayman, L. L., Mahon, M.M., & Turner, J.R. (Eds) (2002). *Chronic illness in children: An evidence-based approach*. Springer.
- Hoard L.R. (2004). *Chronic illness and behavior problems in children: Mediating and moderating influences*. Thesis. Maryland: University of Maryland.
- Hysing, M., Elgen, I., Gillber, C., Lundervold, A.J. (2009). Emotional and behavioural problems in subgroups of children with chronic illness: Results from a large-scale population study. *Child: care, health, and development*, 35, 527-533.
- McPherson, M., Arango P., Fox, H., Lauver, C., McManus, M., Newacheck, P., Perrin, J., Shonkoff, J., & Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics*, 102, 137-140.
- Newacheck, P. W., & Halfon, N. (1998). Prevalence and impact of disabling chronic conditions in childhood. *American Journal of Public Health*, 88, 610-617.
- Perrin, J.M., MacLean, W.E., & Perrin, E.C. (1989). Parental perceptions of health status and psychological adjustment of children with asthma. *Pediatrics*, 83, 26-30.
- Russ, S. W., & Ollendick, T. H. (1999). *Handbook of psychotherapies with children and families*. Springer.
- Singer, A.T.B. (2010). *Coping with your child's chronic illness*. Robert Reed Publishers.
- Spirito, A., Stark, L.J., Williams, C., Stamonlis, D., & Alexan, D. (1988). Coping strategies utilized by referred and nonreferred pediatric patients and a healthy control group. Poster presented at the Society of Behavioral Medicine Annual Meeting, Boston, MA.
- Stein, R. E., & Silver, E. J. (2002). Comparing different definitions of chronic conditions in a national data set. *Ambulatory Pediatrics*, 2, 63-70.
- Swift, C.R., Seidman, F., & Stein, H. (1967). Adjustment problems in juvenile diabetes. *Psychosomatic Medicine*, 29, 555-571.
- Tavormina, J.B., Kastner, L.S., Slater, P.M., & Watt, S.L. (1976). Chronically Ill Children: A Psychologically and Emotionally Deviant Population? *Journal of Abnormal Child Psychology*, 4, 99-110.
- Thompson, R.J., Jr., & Gustafson, K.E. (1996). *Adaptation to chronic childhood illness*. Washington D.C. American Psychological Association.
- Torpy, J.M., Campbell, A, & Glass, R.M. (2010). Chronic diseases of children. *JAMA*, 303, 682.
- Wallander, J.L. & Varni, J.W. (1998) Effects of Pediatric Physical Disorders on Child and Family Adjustment. *Journal of Child Psychology and Psychiatry*, 39, 29-46.

More information

See the Center's Online Clearinghouse Quick Find on *Chronic Illness*

<http://smhp.psych.ucla.edu/qf/chronicill.htm>

Also see the following material excerpted from resources compiled by Kyla Boyse, RN, Lina Boujaoude, MD and Jennifer Laundry, MD and reviewed by faculty and staff at the University of Michigan. Online at -- <http://www.med.umich.edu/yourchild/topics/chronic.htm>

>Your Child Series:

- [Siblings of Kids with Special Needs](#)
- [Pain](#)
- [Medical Procedures and Pain: Helping Your Child](#)
- [Hypnosis](#)
- [Biofeedback](#)

[>Resources from the Center for Children with Special Needs](#)

[>Children with a Chronic Illness: The Interface of Medicine and Health](#)

[>How to Care for a Seriously Ill Child: Suggestions for Parents](#)

[>Helping your child cope during procedures](#)

[>Moving on with Life](#)

[>Supporting Students with Asthma](#)

Books for kids:

[>Young People and Chronic Illness: True Stories, Help and Hope](#), by Kelly Huegel and Elizabeth Verdick

[>My Book for Kids with Cansur: A Child's Autobiography of Hope](#), by Jason Gaes

[>Books for kids about going to the hospital.](#)

[>Books and movies about siblings of kids with special needs](#)

Books for parents:

[>When Your Child Has a Disability: The Complete Sourcebook of Daily and Medical Care](#), Revised Edition, by Mark Batshaw.

[>Coping With Your Child's Chronic Illness](#), by Alesia T. Barrett Singer.

[>Whole Parent, Whole Child: A Parent's Guide to Raising a Child With a Chronic Illness](#), by Patricia M. Moynihan and Broatch Haig.