



OUR CHILDREN WITH CHRONIC ILLNESS IN SCHOOL

Finding and Bridging the Gap

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WHICH CHILD IS CHRONICALLY ILL?



WHAT DOES A CHILD WITH A CHRONIC ILLNESS LOOK LIKE?



CHRONIC ILLNESS:

- Affects between 10-20% of children in the US
- Defined as “a health condition that lasts anywhere from three months to a lifetime” (healthychildren.org)
- One out of five children under the age of 18 have a chronic illness



EXAMPLES INCLUDE:

- Asthma
- Diabetes
- Cystic fibrosis
- Cancer
- Sickle cell anemia
- Cerebral palsy
- ADHD
- Autism
- Spina bifida
- Down Syndrome
- Congenital Heart Disease
- Lupus



OBJECTIVES



- Impact of Chronic Illness in School



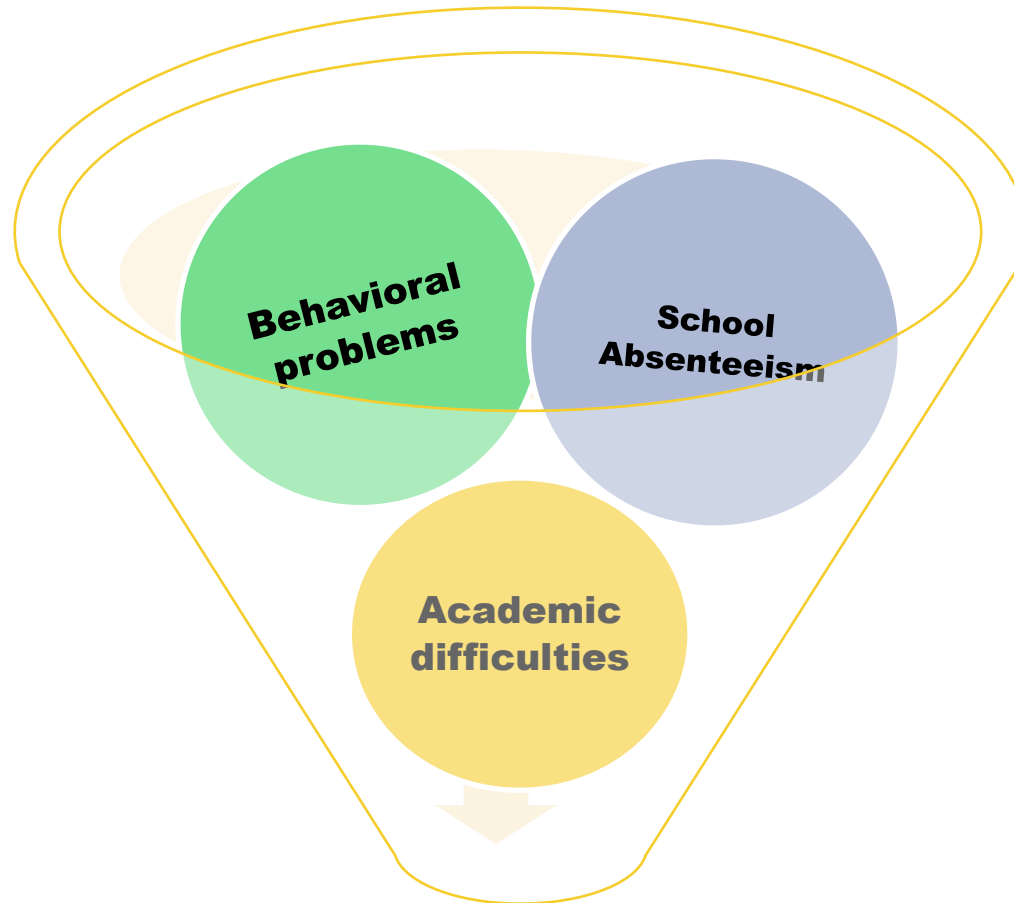
- Inquiring Minds Want to Know



- Now That We Know More, What Can We Do Better?



WHAT IMPACT DOES CHRONIC ILLNESS HAVE IN EDUCATION



**Student
Performance**



ACADEMIC DIFFICULTIES

- Majority return to classrooms with minimal education accommodations
- Difficulty meeting curriculum requirements
- Trying to play "catch up"
 - Increased anxiety
 - Complicate academic difficulties
- Certain medical treatments affect academic functioning
 - drowsiness
 - fatigue
 - nausea
 - increase irritability
 - decrease attention span
 - impaired learning



ACADEMIC DIFFICULTIES

- Many have average intelligence
 - Significantly lower achievement test scores
 - No known cognitive impairments
 - Not correlated with school absences
- School performance does not change when student is diagnosed with CI (Sexson & Madan-Swain, 1995)
 - Becomes more pronounced
- Some experience diagnosable learning disorders
 - Increased incidence of severe reading problems
 - Illness may exacerbate prior history of learning problems
- Teachers attribute problems to effects of illness
 - Overlook academic difficulties
 - Refrain from making referrals



MY LIFE WITH ITP- IDIOPATHIC THROMBOCYTOPENIC PURPURA



- Immune system destroys platelets
- Normal platelet count 150,000–450,000
- Has ITP since age 4 (now 12)
- Current count- 25,000
- Has not played PE or recess since 10/12 this school year
- Speech to pre-service teachers- living with a disability/ chronic illness



EXCERPT FROM SPEECH:

Having ITP stinks. ITP means I have low platelets and I bruise easier than other kids. I have to be really careful not to get hurt. If I get cut it takes a very long time to stop bleeding, and can be dangerous. If it's really low I can't do anything but Art and Music at school, and sometimes it gets so low I can't even go to school because it is too risky for me to get hurt. I hate going to the doctor because it hurts whenever they take blood. I have to go often because it is the only way they can check my counts. When my counts are low I get really big, ugly bruises.

Sometimes the kids in my class are mean to me. Kids in my class tell me to cover up my bruises and they say it's gross. It hurts my feelings a little because I can't stop the bruises. They call me names like "Ding-dong" and sometimes say I'm weird. It makes me very sad. I don't know why I get picked on.

If I could tell you one thing you could do to help kids like me is that if you see someone getting picked on, stand up for that person. Don't make fun of anyone because they seem different. Don't laugh at them and if you hear someone being mean, stop them. No one is perfect and who knows, they might end up being a really good friend.



BEHAVIORAL PROBLEMS

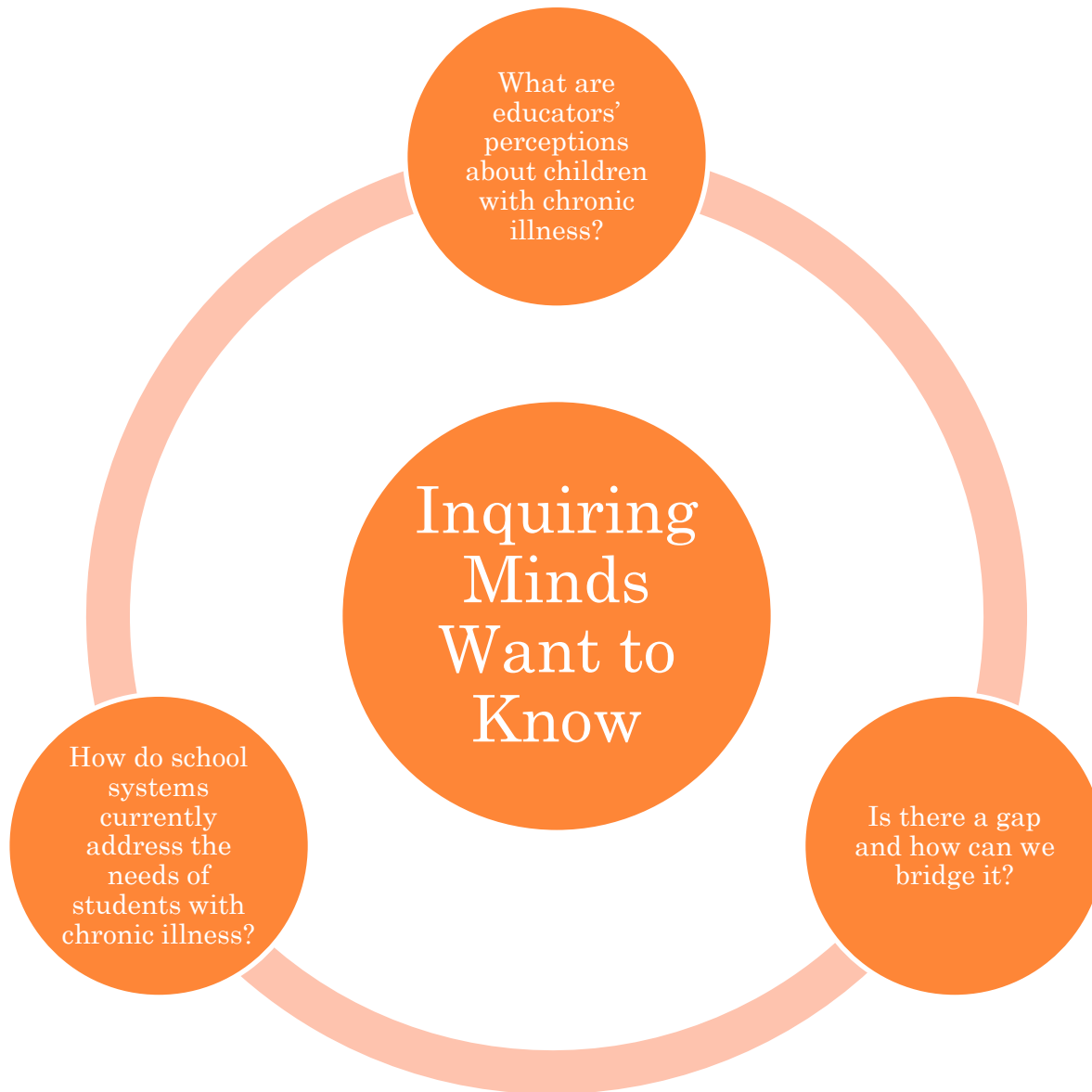
- Prolonged absences with little peer contact creates social discomfort
- Difficult adjusting to the social demands of school
- Fear peers may shun because concerned that the disease is contagious
- Pre-teens and teenagers avoid interaction for fear of associating with someone who is different
- Students concerned about physical appearance
 - hair loss
 - amputations
 - ambulatory devices (wheelchairs, walkers, canes)
- *School phobia or separation anxiety*



SCHOOL ABSENTEEISM

- **Critical** for social survival
- Provides opportunities to
 - learn
 - socialize with peers
 - experience success
 - develop increased independence and control over their environment
- Only place where viewed as children rather than as patients
- Inability to attend school may lead to
 - decreased self esteem
 - **hopelessness about the future**







EDUCATORS' PERCEPTIONS

COMMON FINDINGS:

- Unique educational needs that require close collaboration
- Lower scholastic expectations placed on them by teachers and parents
- Increased knowledge of illness and teacher support are beneficial
- Awareness of the impact in the classroom



COMMON FINDINGS CONTINUED:

- Classroom teachers provide
 - specialized care
 - disease management
 - individualized instruction
- Dissemination of information and collaboration
- Educators do not have easy access to health information
 - Teachers unprepared and/or untrained



CLAY ET AL. (2004)

98.7% knew a child in school with CI
Highest Knowledge-Asthma (96.8%)

Extent to which they feel responsible

- **43%** felt moderately to very responsible regarding the student's education
- **21.9%** were specifically concerned with student's absenteeism

Amount of training received

- **59.4%** no academic training
- **64%** no on-the-job training
- **36.1%** received any formal education in the workplace

How they faced problems

- **54.3%** used school nurse as primary source
- **27.4%** consulted parent
- **6.1%** consulted student

NABORS ET AL. (2008)

- Indicated having some knowledge of the medical conditions selected
 - Few teachers indicated high knowledge or confidence
 - Special Education teachers -greatest indication
 - Higher levels of confidence reported than knowledge
- Special education teachers reported significant levels of knowledge:
 - Cerebral Palsy,
 - Epilepsy,
 - Hemophilia,
 - Renal Failure,
 - Spina Bifida,
 - Allergies
- Additional training needed to meet social and academic needs



BROOK & GALILI (2001)


Combined level of knowledge was 62%

- High school teachers showed higher level of positive comprehension and regard for CI (71% vs 65%)

None of the teachers received any class instruction or seminars by medical professionals

- All felt every teacher should know about their students
- **63% continued to remain in contact with the former students**





**HOW DO SCHOOL SYSTEMS
CURRENTLY ADDRESS THE NEEDS OF
STUDENTS WITH CHRONIC ILLNESS?**

CHILDREN WITH CI AND THE SCHOOL SYSTEM

- Medical advances have increased the survival rate and functional capability
- Guaranteed a free and appropriate education (FAPE)
 - IDEA
 - Section 504
- Additional specific and specialized services *Possible* through IEP
 - ❖ **MAY NOT QUALIFY FOR AN IEP BUT**
- Some type of school intervention *might be necessary*



LIGHTFOOT ET AL. (2001)

- Support appeared idiosyncratic
 - Critical to support
 - An “understanding” teacher
 - Access to a wide range of information
 - Weaknesses to support
 - Lack of communication,
 - Lack of coordination between team members,
 - Non-understanding teacher



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**IS THERE A GAP AND HOW CAN
WE BRIDGE IT?**

SEXSON & MADAN-SWAIN (2001)

FOCUSED ON THE ISSUES OF SCHOOL REENTRY

Dependent on attitudes and preparedness of educators

- Limited resources
 - Medical interventions
 - Educational accommodations/
devices
- Limited literature examining reentry process from a multidisciplinary, programmatic point of view

4 guidelines from cancer research can be applied:

1. Preparation of child and family
2. Preparation of school personnel
3. Preparation of class
4. Continued follow-up after the child returns to school



SHAW AND MCCABE (2008)

- Suggested development and monitoring by a multidisciplinary team

- Four common components to included in all transition (school reentry) programs:
 1. Homebound Instruction
 2. Flexible Attendance
 3. Differentiated Instructional
 4. Social Support and Affective Issues.



HOMEBOUND INSTRUCTION

Define:

- System of educating students who are unable to attend school due to illness (mental or physical) or injury
- Certified Teacher

Problems

- Managing the time with students
- High cost to school systems
- Requirement parent involvement
- Low motivation of students
- Pedagogic teaching students at home

Solutions

- Provide families with computers with Internet for limited time
- Allows to send/ receive assignments via email
- On-line chats and Skyping with teacher/entire class
- Allow parents and teachers to call one another



FLEXIBLE ATTENDANCE

Utilize half days

- Homebound services on one day,
- One-half day of school the next,
- Full day of school on the third day

Minimized confusion through the use of technology

- Email or phone assignments
- Utilize an agenda



DIFFERENTIATED INSTRUCTION

“To accommodate the different ways that students learn involves a hefty dose of common sense, as well as sturdy support in the theory and research of education” (Tomlinson & Allan, 2000).

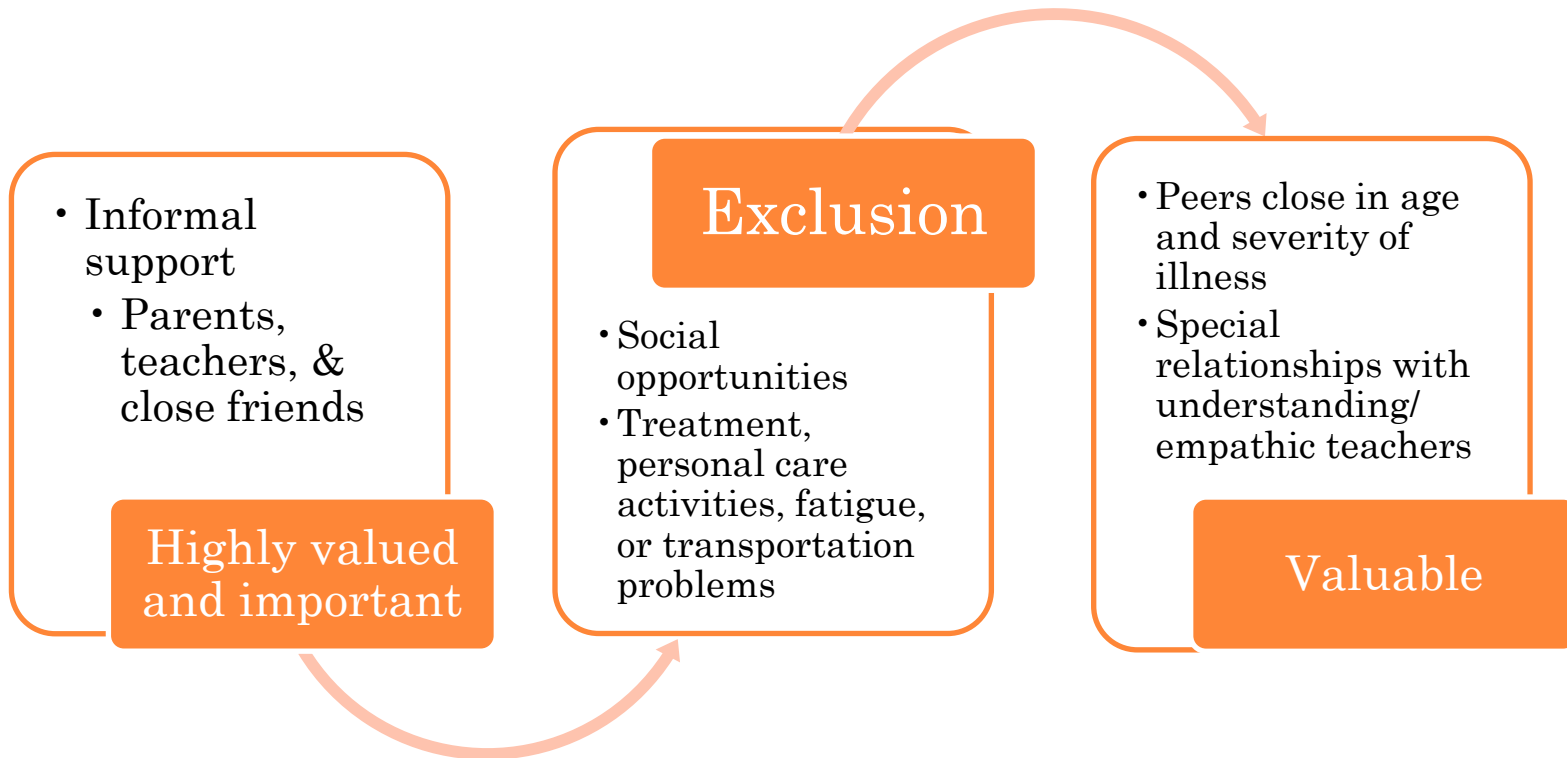
Advocates active planning for differences in classrooms

Applies to ALL students in the classroom

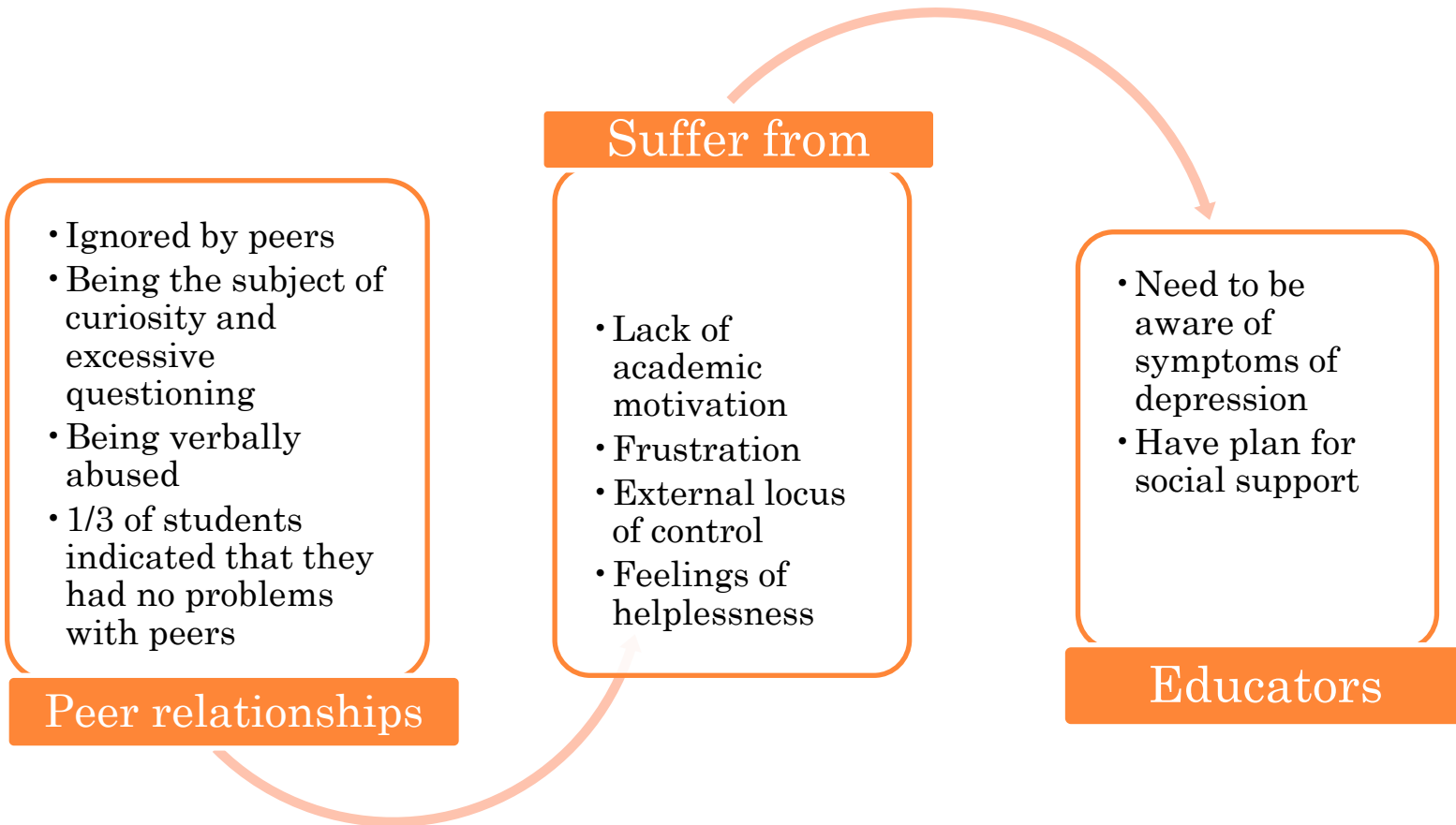
Especially valuable for students with CI with require specific individualized instruction



SOCIAL SUPPORT AND AFFECTIVE ISSUES



SOCIAL SUPPORT AND AFFECTIVE ISSUES





NOW THAT WE KNOW MORE, WHAT CAN WE DO BETTER?

Your Turn! Think about the children in your school, maybe even your own. Let's collaborate ideas together.

BRIDGING THE GAP

- Collaboration with Special Education
 - IDEA
 - Federal Legislation and Policy
- Professional development and in-service
 - School nurses
 - Health care professionals
- Academic preparation and training
- Interagency Collaboration



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