

Six Functions That Impact the Education of Students with Chronic Illness

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PART A: OVERVIEW AND THEORY

- Chronic illness and education
- Importance of accommodating students
- Efficacy theory
- The Fennell Four-Phase model of CI
- Six Functions/Capacities that impact students with CI

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Efficacy Theory and Four Phase/CI Theory—WHY?—Mutually Add Value

- Interface/Blend application with CI/disabled
- Blend has universal application

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Chronic Illness is Increasing

- Childhood rates of chronic health problems doubled in just 12 years, to 1 in 4 children in 2006, up from 1 in 8 in 1994.
- Rates of chronic illness are higher among boys and Hispanic and black children.
- Older children are more likely than younger children to have a chronic health conditions.

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Chronic Illness is Increasing

Chronic illness is rising among the student population due to factors such as:

- Better medical care
- Infant mortality declines
- Increased prevalence of conditions like diabetes, asthma, autoimmune diseases, depression, autism, obesity

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Chronic Illness & Education

- Students with chronic conditions (or who are caring for family members with chronic conditions) are at higher risk for school absenteeism and drop-out.
- Dropouts are more likely to suffer from illness or disability.

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Chronic Illness

- Intermittent, waxing and waning symptoms
- “Invisible” illness – students don’t look sick
- Sudden emergencies
- Bed or housebound; general frailty
- Less time available due to illness symptoms and management of illness (doctor’s appointments, social service management, medications, etc.)

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Accommodating Students With Chronic Illness

- Legal mandates (IDEA, Section 504, ADA)
- Maintain student’s participation in learning
- Avoid disparities among the traditionally disabled, chronically disabled, and non-disabled - equal access
- Reduce dropping out and poverty
- Prepare students for workforce

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Health, Well-Being & Schooling

SERVING THE “WHOLE CHILD”



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Relationships: Health and Learning

- Impact of health status on educational outcomes
 - Definitions of health (mental health, behavioral health, physical health)
 - Definitions of “educational outcomes” (achievement test scores, grades, retention, attendance, graduation rates, employment)

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Ready to Learn, Empowered to Teach 2008

- National Association of School Psychologists’ document is available at <http://www.nasponline.org/advocacy/readytolearn.aspx>.
- Foundational policy document provides guiding principles for educational policies and practices.

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Five Guiding Principles

- Comprehensive curricula matched with individualized instruction.
- Sufficient student support services to address barriers to learning for all students on a continuum of care that engages families and community providers.
- **Comprehensive accountability and progress monitoring measures that provide a valid picture of student and school functioning.**

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Guiding Principles

- Professional development and supports for teachers and other educators necessary for instructional excellence.
- Federal leadership and **school-based research to promote effective services that support the whole child in the learning context.**

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Some Specific Charges

- Education professionals promote development of children's communication and social skills, problem solving, anger management, self-regulation, self-determination, and optimism.

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Perceived Self-Efficacy

- Individual's beliefs about his/her capabilities to produce designated levels of performance that exercise influence over events that affect their lives.

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Self-Efficacy

- People's beliefs in their coping capabilities affect how much stress and depression they experience in threatening or difficult situations, as well as their level of motivation.
- *Perceived self-efficacy to exercise control over stressors plays a central role in anxiety arousal.*

Bandura, A. (1994)

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Self-Efficacy

- A strong sense of efficacy:
 - Enhances human accomplishment and personal well-being.
 - Promotes heightened and sustained efforts in the face of failure. Sense of efficacy after failures or setbacks is recovered quickly.

Bandura, A. (1994)

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Relevant Research

- "Research has shown that children's developmental competence is integral to their academic competence (Masten et al., 2005).

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Positive Schools and Sense of Well-Being

- Huebner, Gilman, Reschley & Hall (2009)
Positive schools = Majority of students experience positive emotions and a strong sense of overall well-being.
- SWB linked to:
 - Positive student engagement
 - Behavior
 - Interpersonal relationships
 - **Coping skills**
 - Academic achievement

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Research

- Antaramian, Huebner, Hills, and Valois (in press):
- Research on Middle School Students
 - “**Flourishing**” = high SWB & low psychopathology
 - “**At Risk**” = low SWB & high psychopathology
 - “**Vulnerable**” youth display significantly lower behavioral, cognitive, and emotional engagement scores and GPA compared to “flourishing” youth.
 - “**Vulnerable**” = *lower levels of perceived academic competence, psychosocial skills, and physical health.*

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Research

- Interesting outcome of study:

Vulnerable students would **not have been differentiated from flourishing** students on **traditional mental health screenings** (focus on assessing symptoms of disorders).

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Research

- Interesting outcome of study:

Researchers conclude: **Vulnerable students are “at risk” despite their apparent lack of symptomatic behavior.**

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Research

- Research suggests:
 - Need for developing a more comprehensive understanding of students’ functioning in schools when used in a multi-trait, multi-method framework.
- Fennell and Paul-Dona conclude: Far too little attention paid in research and practice to the role of physical health/illness in relation to student learning .

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Current Research Needs

- Increased understanding of how physical capacities interact with learning outcomes
- Valid, practical measurement system to capture capacities based on “state” not “trait” models
- Progress-monitoring paradigm for designing effective interventions
- Intervention design that adheres to current research regarding self-efficacy, self-determination, self-regulation, coping, and optimism (positivity)

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The Fennell Four Phase Treatment (FFPT™) Approach

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Philosophy of the Phase Method

- Systemic approach
- False dichotomies
- The phenomenon of chronicity
- Traumatization and chronicity
- The integration assumption
- Palliation
- Clinician as active equal participant

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Condition/Syndrome Trauma

- Chronic condition/event trauma
- Iatrogenic trauma
- Cultural trauma
- Vicarious trauma

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- Pre-morbid / Co-morbid trauma

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Traditional Disability vs. Chronic Conditions

- Chronic conditions on a continuum
- Static vs. dynamic disability/illness
 - Fixed disability
 - Relapse and remission
 - Waxing and waning
- Legal definitions of disability/chronic illness
- Social or colloquial definitions
 - Disability
 - Illness
 - Disease/condition/syndrome

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Chronic Care in Context and Culture

- Delivery systems
- Levels of discourse
- Socio-cultural factors
- Domain assumptions
- Traumagenic effects

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Socio-Cultural Factors

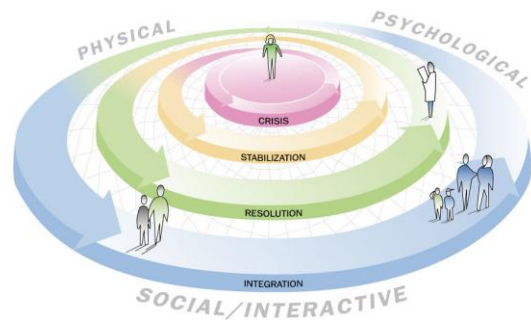
- Cultural intolerance of suffering
- Cultural intolerance of ambiguity
- Cultural intolerance of chronic vs. acute syndromes
- Pre-existing cultural climate toward chronic syndromes
- Media
- Initial syndrome illegitimacy and subsequent enculturation

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The Four Phases of Chronic Change:

Nicole's Story



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Phase I – Trauma / Crisis

- **Physical /Behavioral**
 - Coping stage
 - Onset stage
 - Acute / emergency stage
- **Psychological**
 - Loss of psychological control/ ego loss
 - Intrusive shame, self hatred, despair
 - Shock, disorientation, dissociation
 - Fear of others, isolation, mood swings
- **Social/Interactive**
 - Others experience shock, disbelief, revulsion
 - Vicarious traumatization
 - Family/organizational maturation
 - Suspicion/support continuum

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Phase II –Stabilization / Normalization Failure

- **Physical / Behavioral**
 - Plateau
 - Stabilization
- **Psychological**
 - Increased caution / secondary wounding
 - Social withdrawals, social searching
 - Service confusion/searching
 - Boundary confusion
- **Social/Interactive**
 - Interactive conflict/cooperation
 - Vicarious secondary wounding
 - Vicarious traumatic manifestation
 - Normalization failure

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Phase III – Resolution

- **Physical/Behavioral**
 - Emergency stage/diminishment/improvement
 - Continued plateau/stabilization
 - Relapse
- **Psychological**
 - Grief reaction/compassion response
 - Identification of pre-crisis – “self”
 - Role/identity experimentation
 - Returning locus of control
 - Awareness of societal effects
 - Spiritual development
- **Social/Interactive**
 - Breaking silence/engulfment in stigma
 - Confrontation
 - Role experimentation – social, vocational
 - Integration / separation / loss of supporters

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Phase IV – Integration

- **Physical/Behavioral**
 - Recovery stage
 - Continued plateau/improvement/relapse
- **Psychological**
 - Role/identity integration
 - New personal best
 - Continued spiritual/emotional development
- **Social/Interactive**
 - New/reintegrated supporters
 - Alternative vocation/activities

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6 Functional Capacities

- Pain
- Fatigue—“tired but wired” “tired but awake”
- Sleep quality
- Mood / presentation
- Mental focus / cognition
- Movement / ambulation

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PART B: PRACTICE TOOLS / INSTRUMENTATION

- Six Functions/Capacities that impact students with CI
- Universal screening instrument:
Physical Capacity Awareness Tool (PCAT)

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6 Functional Capacities

- Pain
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Practice Tools/Instrumentation

- Universal Screening Instrument:
 - Physical Capacity Awareness Tool (PCAT)
- CI Disability Phase of Illness Inventory:
 - Fennell Phase Inventory (FPI)

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Physical Capacity Awareness Tool What Does it Do?

- Need for tool that teaches “Physical Awareness” *AND* collects data
- A progress monitoring assessment tool—**Daily and Dynamic**
- **Teaches Self Management → Creates Insight**
- Physical Awareness → Self Efficacious/Self Management → Well Being → Learning

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Dual Purpose of PCAT

Physical awareness for self-management, well-being and optimal learning

Contextualized data together with self report for assistance/support/intervention

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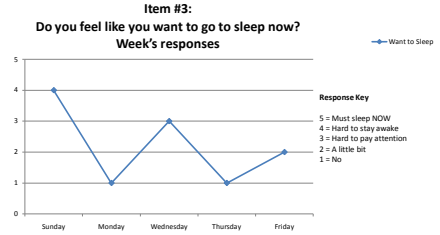
PMCT Physical Capacity Awareness tool

- 6 Capacities – 10 items
- Daily collection
- Weekly summaries
- Aggregate summaries

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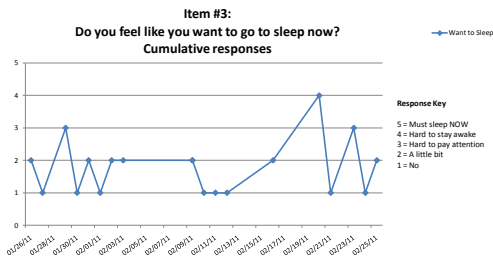
Weekly Graphs



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Cumulative Graphs



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Weekly Feedback Report



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PART C: DATA COLLECTION

- The 6 FCs, the Four Phases and the Classroom
- Participate in the Research

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Aligning the 6FCs, Phase Theory and the Classroom

How do we do it?

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Participate in the Research

- Online participation
- Clinical experts
- www.AlbanyHealthManagement.com – click on the special “Conference Attendees” survey link at the top of the home page

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