The Andrew Rypien School Program
at Sacred Heart Children’s Hospital
School Nurse Conference, August 15, 2019
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Why should these huge systems team up for kids? Not to mention, How??

4,000 Employees, 644 Beds

3,226 Employees, 29,275 Students

Spokane Public School District
Chronic Illness
- Cancer, Crohn’s/Colitis, CF, Asthma, Migraines, Diabetes, Eating Disorders, Lupus, Heart & Kidney Disease

Acute Illness or Injury
- Pneumonia, Appendicitis, Pancreatitis, Trauma, Acquired Brain Injury

Psychiatric Emergency
- Suicidal/Homicidal Ideation, Behavioral Health Emergencies
Typical Interface with Schools

- Home/Hospital tutoring
  - Continuous or Intermittent
- Filling out Healthcare Plan forms
- Directing schools to Medical Records
- Helping parents to understand IEP and 504 law
- Referring families to neuropsychological testing

This all sounds well and good, but what gets in our way?
Cultural Attitudes around School and Hospitalized Kids

“School is not a priority right now.”

“You’ll pick right up where you left off.”

“Your only homework is to get better.”

“The School will figure it out when you get home.”

Image source: https://www.thismamacooks.com/recipes
Where is the sense of “Future-Orientation” when the present is TOUGH?

My life is on pause

I don’t contribute anything to my family

My goals feel so far away

My friends are moving on without me

When will this be OVER???
How this can play out

• “I’m a 15 yo girl with Crohn’s Disease. I missed 156/184 (85%) school days of my Sophomore Year. I have a 504 plan, but I just got a letter telling me I need to show up at truancy court. When I’m having a flare I really can’t do homework. Like, not at all. I’m not sure if I have all of my credits…”

• “I was born with mild Cerebral Palsy, but then got diagnosed with cancer at 13. I had an IEP before I got diagnosed, so school was already tough. I missed 2 years of school with my chemo, and did Home/Hospital. But over time my anxiety got really bad. Once I could go back to school, I was having panic attacks in the car and couldn’t make myself go inside my high school. I never graduated, and can’t pass the GED due to memory issues from my chemo.”

• “I’m an 11 yo girl with Lupus. I missed all of my 5th grade year, and started school late at Spring Break for 6th grade. Most of my hair fell out from the chemo, and the steroids made me gain 50 pounds. I didn’t really work with my Home/Hospital tutor. Then I tried online, but I never really opened the computer. Now I’m trying to go back to school. I am working my way up from half-days, but I had crippling school anxiety. However, my therapist discharged me for coping so well... Now I’m in middle school and the Truancy Court put an ankle bracelet on me.”
Psychiatric Center for
Children and Adolescents
(PCCA)

• “I attempted suicide by taking pills at school. Once I was in the ambulance, the school told my
parents I was suspended for bringing narcotics to school. Now I’m at PCCA, I’ve missed two
weeks of school, and I don’t know if I can go back or not.”

• “I’ve been suspended many times for behaviors, but I don’t have a Behavior Plan or an IEP. I
wander around the school when I don’t feel like being in class. I have a 504 plan that gives me
a water bottle and some playing cards to manage my anxiety.”

• “I got expelled and the school won’t take me back. I guess I’ll go to a different district??”

• “I have a history of trauma and I can’t dress down for PE without panicking. My PE teacher
didn’t know and failed me.”
I'm in middle school and have Sickle Cell Disease, and have memory and attention issues after a silent stroke. I have frequent pain crises and miss 2-3 days/week. I have a 504 plan for a water bottle and snacks. I was told I won't qualify for an IEP, but I'm failing every class, and it's impossible to know if it's because I'm always in pain, because of my identified learning disabilities, or because I'm rarely there. I tried to use Home/Hospital, but the scheduling never worked out, plus when I am well enough to go, I really want to! There aren't enough textbooks to send some extras home, so I can't even do the homework I have when I'm not at school. I tried online school, but I wasn't really motivated and missed my friends. My history teacher feels really bad for me. To catch up in American History, I was told to watch Heath Ledger in ‘A Knights Tale’ and write a paragraph.
Equal Education

Students who are unable to attend school for medical reasons (including psychiatric hospitalization) do not have equal access to education.

“With limited knowledge and resources to draw from, well intended teachers and administrators respond to acute health episodes with impromptu plans, inadvertently creating educational barriers, eliminating the possibility of an equitable educational experience for students with an illness” (Irwin & Elam, 2011, p.73)

Important Protections are found under:

- Americans with Disabilities Act (ADA)
- Section 504 of the Rehabilitation Act
- Individuals with Disabilities Education Act (IDEA)

As we live in “the rare,” we are in a unique place to provide support to schools, and to collaborate around a plan.
If we don’t team up, we may see...

- Kids who don’t have educational plans, or plans that aren’t specific enough to be helpful
- Decreased High School Credit Attainment (Super Seniors)
- Increased risk of Drop-Out
- Transferring to Online School, or attempts at Homeschooling
- School Avoidance and School Refusal, leading to Truancy
- Recidivism to PCCA for mental health issues
- Overall decrease in Educational Attainment
- Overall decrease in Employability
- Increase in Poverty and decrease in Quality of Life

“Chronic absenteeism is one of the strongest predictors of dropping out of high school, stronger even than suspensions, test scores, and being over-age for grade” (Byrnes & Reyna, 2012).
Long-Term Social Attainment

St. Jude Study on Children with Brain Tumors:

• “increased risk of reduced educational attainment, unemployment, and non-independent living.

• increased risk of not graduating from college.

• The risk of unemployment was two times greater in survivors with impaired attention, memory, or executive function.

• Survivors with severe impairment in intelligence, academics, memory, or executive function, had an approximately 50% increased risk of non-independent living compared with survivors without such impairment.” (Brinkman, T. et al, 2016, p.16).

• In a series of 1,560 adolescent survivors of childhood ALL treated with chemotherapy alone, the CCSS identified a significant proportion of survivors who still experienced problems with headstrong behavior, inattention-hyperactivity, and social withdrawal, which were associated with an increased risk of special education placement and predicted reduced adult educational attainment.

Late Effects of Cancer Treatment

• "As elapsed time since treatment increases, the gap in abilities between the survivors and the general population increases. This presents challenges for some survivors in problem solving, academic attainment, independent living, and quality of life." (Askins & Moore, 2008, p.1162).

• "Difficulties may not manifest during the primary grades because rote learning may be relatively intact, but they become evident as children transition to the challenges of middle and high school, when organizational, reasoning, and time management skills become essential to successful school performance, exposing subtle executive functioning deficits." (Children’s Oncology Group, 2007, p.802).
In Summary: “The Slow-Moving Train Wreck”

“The combination of chronicity, absence, and side effects of illness and treatment are subtle, but the cumulative effect is potentially damaging. Falling behind academically leads to catching up, and catching up takes time away from keeping up. Self-confidence and achievement motivation are undermined.” (Thies, 1999, p.395)
Moving on from “Cookies for Breakfast.”
Our new model:

- **Keep school a priority the entire way through treatment.** Kids can learn anywhere, and can make small progress every day.

- **Create accountability systems to keep these kids on track,** with aggressive organization.

- For many chronic populations, refer for **IEPs or 504 plans at diagnosis.**

- Detailed support and **transition services** to have a safe hand-off back to school, with **regular follow-up** to see if the plan is working.

- **A system of communication** between the hospital and the schools for the safety of the child.

- As much easy to access **tutoring time** as possible (outside of Home/Hospital Tutoring 3 hours/week).

- Get kids **back to school** and off of the Home/Hospital program as fast as possible.

- Assess for **school refusal/avoidance** as early as possible and work on the social/emotional aspect of being separated from school.
The Andrew Rypien School Program at Sacred Heart

Our school program was formed in **Fall of 2016**.

We are completely grant-funded by the Andrew Rypien Initiative, part of the Community Cancer Fund.
Continuity in Education

Brand new, open access, peer reviewed journal for the education of children and young people with medical and mental health needs.
Current Program Structure

Medical Classroom

Bedside Tutoring

School-Based Support

Psychiatric Center for Children and Adolescents (PCCA)

Outpatient Clinic Consultation
School-Based Support

This is the most requested service we offer. Hospital school professionals oftentimes travel up to 60 miles to support parents in meetings.

Services include:
- Attending Special Education and 504 meetings
- Working with school counselors and administrators on transition plans to better support the child with the disruption of hospitalization
- Working with school counselors to educate classrooms of students on the patient’s illness, and how to be a compassionate friend upon re-entry
- Working at the District and ESD levels to coordinate our efforts
Strategies for Elementary Students

http://www.monkeyinmychair.org/program

School Re-Entry Presentations
• Open 10-12pm and 1-3pm, Monday-Friday for direct student support

• Elementary in the morning, Middle and High School in the Afternoon

• Focus on making academic progress, as well as educational activities in a fun, social atmosphere

• We welcome Home/Hospital or Homebound tutors to this space to teach!
Our Volunteer Force

Volunteer Shifts:
10-12pm
1-3pm

Seeking current or retired educators, or people with specific content expertise.

Growing relationships with Avista engineers, and Whitworth Education Students

Joe Staebell, known as “Mr. S.” at the hospital, has been a regular volunteer for 7 years
Continuing to Think Outside the Box

When kids are drastically behind in credits and refusing to re-engage with High School, a GED can be a major renewal of hope for the future.

3 patients earned their GEDs!
Our Reach:
Number of Patients Served

- **2016-17 School Year**: 290
- **2017-18 School Year**: 708
- **2018-19 School Year**: 625
- **2019-20 School Year**: 90

475 Unique Schools, 125 School Districts
Working on a Community Level

- Partnering with School District Student Services, Special Education, and Health Services Departments to share ideas and team up.

- Attending Spokane Public Schools Community Partnerships Meetings

- Collaborating with ESD 101 for trainings

- Attending Superintendent’s Work Groups, School Board Meetings, Special Education Parent Advisory Committee (SEPAC) meetings, all in the hope of collaborating around our kids.

Our hope is to partner around these tricky cases so everybody wins...

Most Importantly the CHILD!
Come Join Us In Our Focus on

- Educational equity
- Staying positive about school
- Staying connected to school and peers throughout treatment
- Combating the social isolation of chronic illness
- Safeguarding the school health of all of our patients
- Hope for the future!
Thank You!

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