

Medical Home Phone Conference
June 26, 2007
“Transition From Hospital to Community”
Lisa Samson-Fang, MD and Elaine Pollock

Lisa Samson-Fang: On the phone today with us is Elaine Pollock, who is part of Primary Children’s Medical Center where she is an Education Consultant. For me she is the first person I go to whenever I am not sure how to deal with something that interfaces with the school system and she’s been so helpful for me so we wanted to let you meet her and let you know that she is available as a resource. Elaine, can you go ahead?

Elaine Pollock: I am an educator and a certified teacher, I do speak the language of school and I’ve been with Primary Children for 15 years so I speak the hospital language as well. I think I’m in a good place because I can take the children from the medical world into the school world and I can talk back and forth to make some of these things work. There are medical issues that you all see that are not just related to the hospital but affect the kids in school. School is such a normal place for kids even in their steps in recovery from an illness or an accident but its so anxiety provoking. I see it in the patients all the time and I see it in their families. The kids are worried about missing work and eventually not getting a diploma and then they worry about their peers- that will be out of the mix and they are missing too much. They also are a little bit worried that they are going to become the “sick friend” that’s become their role and they don’t know how to get out of that. Then they are not sure about getting caught up and how they are going to get excuses for everything and that’s where I can play a big role and your practices can play a big role for them too. The anxiety for the parent is that their child is too far behind or they are not going to be safe at school so they want to keep them home. We try to deal with both on this end so it waxes and wanes as they get closer to discharge here. In general, the idea of going to school and being a part of school in some way to a child is a message that they are doing better physically and that they need to be there. In order for this all to be successful I start from the get go, sometimes as early as in the intensive care unit even if just to answer questions that the child or the family has and try to reduce some of the stress related to school or truancy issues. For a lot of kids and families that is becoming quite large these days. Then we like to start the discussions early and mention just a few little things because we sometimes go into too much detail and overwhelms them and the child is so sick that the parent just tunes it out with too much information. Sometimes it takes a little while that the child is not in school but we do get them there. I look at meeting the individual needs in three categories one are **frequent flyers**, those are kids with chronic illnesses and I find with the schools I have to teach and re-teach about what those kids need. I find it pretty efficient to get a basic letter into the school files, and sometimes thats 3 or 4 different files in the school. Also for those children who are older to get a basic letter attached to a transcript for someone who wants to go to college so it opens the door so the college doesn’t think the child has been truant, that there is a good reason for missing school. That is a whole group of kids I treat differently and work with and work with the school on an ongoing basis and become pretty good friends with some in the schools so its’ easy to ask for what is needed for the kids. Another group are those kids with **new onset** – with a new diagnosis of diabetes or an identified allergy to peanuts that the school has no knowledge of and this is the first time the family has heard about it and they have no clue of what to say to the school or who to talk to or what information needs to be given to the school or not- sometimes families don’t want to give information with a new onset and it doesn’t work in their favor, we really need to get some basic information into those schools so we teach the parents

how to do that, they have probably never had experience of what we are asking them to perform. And then there are the children from **3 to 5** who have not ever had any services but really could get some services in school. Sometimes if we don't address medical issues early we get a lot of kids who get into academic or behavioral problems or sometimes their medical issues get bigger because they are not getting medication at school and not getting a treatment. It has to be so individualized but the approaches are so different for those three different sets I find myself putting in a lot of time on the chronic kids.

I'm sure you've all heard that the school offers a lot of different options kids really could go from hospital to school the next day on a very partial day. There is nothing set in stone that says a child has to reenter school when he's been very ill in any particular way. I like partial days. I like to take a look at if the child really has an interest in going, if we wait too long will they become a little school phobic, could they go for an hour a day, or an hour every other day if they have a lot of appointments. And then to look at endurance as a big piece because its' cumulative for these secondary kids, their fatigue is noticeable by midweek. They do really well Monday and Tuesday but by Wednesday they start to drop off and their academics slow down by Thursday they don't want to get out of bed and Friday just a lost cause. Sometimes just noting how tired the kids get over a week determines that maybe we should Monday/Tuesday, rest on Wednesday then try going Thursday/Friday. Kids are open to that too. Starting with a modified day can be really workable for them. I like to try visits to school. We have a lot of kids who look different when they are ready to leave the hospital so I try some short visits to school with their favorite teacher, right after school when there is no one around and they can try and experiment a little bit. Maybe they are in a wheelchair or maybe they have crutches, so just to try to get around when no one is there really helps them to start on a partial day. Some kids can do a combination of going to school and being at home on a homebound program. Homebound is where the District provides services to students who have usually been out of school for two consecutive weeks of school. Then they are able to get services at home but it is so minimal because our secondary students really miss a lot. They miss a lot socially from peers and what's going on in sports, they miss a lot in the classroom lectures that homebound doesn't provide enough for kids who are high school students. But that is one option, and maybe the child can start with homebound and ease into school for an hour or two a week so that combination might be doable. Oftentimes the school district will tell you "no, we can't do that, its either homebound or they are going to school," because their budget money comes from two different sources, so initially I like to say that we will put them on homebound and then just experiment and sometimes the teacher will let them come an hour or two and that usually works into a nice return to school. For homebound services, parents like to shop a little bit – they will doctor shop with you and tell you that they just need their child on homebound for six weeks and we may feel they don't need it so they will shop around again until they find a doctor that will write them an excuse. It is tenuous. It's a tough place for all of us to be.

The other option students have is to have them attend school for much of the day with accommodations and accommodations might be through a health care plan that really needs to address absences and toileting needs and dietary needs and even a need for a rest break. Each kid should have a health care plan written by a school nurse run by your offices and then put into place with this family going through the whole process with the nurse.

Lisa Samson-Fang: Does the family meet with the school nurse to initiate that process?

Elaine Pollock: Everybody could really initiate it. Your offices could initiate it, I sometimes initiate it sometimes it's the family who says they would like to meet with the school nurse so the

contact is made to the school nurse and then they orchestrate the plan. Because it is on computers we need to watch and make sure it's individualized enough. The school nurse really does want to get to know the family sometimes they will do the plan with just the parents, sometimes they will do the plan with you and the parent and the child if they are an adolescent sometimes they will do it with the whole team- the special ed team that is involved with the student.

Dr. Samson-Fang: Elaine, as an example, if you had a child with diabetes the school health plan would say how they should respond if the child is acting drowsy or when they should call an ambulance or who should give the child food, or if the child has an allergy when to use the epi pen or how to keep peanuts out of the classroom.

Elaine Pollock: Yes, specific information like that and who is responsible for following the plan and once the plan is complete there are many districts that are starting books in the school that the school secretary will have a copy of that plan at school. Its very possible that only nurses will have a copy off site so parents should have copies and feel very free to point it out to teachers who have forgotten who have said "oh I'm so sorry, we're having a treat day and its going to have peanuts in it," and you have a child with a peanut allergy. Sometimes I just encourage families to keep a copy of that and at the beginning of the school year, particularly with elementary students, give a copy to the teacher so they can have it in the classroom. With a health care plan, if you see students and you make changes in their medications, additional suggestions by all means the health care plan should be updated and that can be through direct contact with the school nurse, I like to empower families to take the information you're giving them and take it to the school nurse, and say "I need to make changes to the health care plan" Lots of teams will tell you "well we really don't need it we're just going to do this automatically for your child, " and I'm just not comfortable with that. I prefer there be a health care plan.

Another type of plan that will accommodate some of the needs of kids who have just come from the hospital or from a medical need is a 504 Plan. That is for children who are in regular classes they don't necessary have any special ed services but they have a lot of absences or they need rest breaks or they really are so fatigued they need some big breaks in taking tests. Maybe just need some juice or they have some dietary need. That can be written with the school administrator and its' pretty much the same process, any one of us can ask for a review for a 504 Plan.

Dr. Samson-Fang: But don't you have to qualify as having a disability for a 504 Plan?

Elaine Pollock: Not necessarily. You do under an IEP but under 504 you do not. You just need your regular setting accommodated. 504's are hard to understand both in our system as well as in the school. They are kind of a grey area no one really knows too much about it.

Dr. Samson-Fang: If you had a child with extreme obesity and you wanted to ensure that they had a low fat diet at school, would you do that through a health plan or a 504 plan or neither of those?

Elaine Pollock: I would do it through a health care plan at school. With a lot of in-services I think parents become great advocates with a lot of training from your offices so that they know who to approach and they are knowledgeable and they know what their child needs and are very willing to say to the school, "I'd love to sit down with you and explain what the needs are, we have a health care plan but I'd love to explain what the needs are." With your example, Lisa,

that may include the cafeteria staff, they might need to keep a watchful eye or create a different kind of meal.

Dr. Samson-Fang: So it would be through a health plan that somebody would sort out who is going to oversee this?

Elaine Pollock: Yes. That is why I always use a health care plan because it always identifies who is responsible.

Dr. Samson-Fang: Are there any questions that people have?

Elaine Pollock: I have a little more that I can share. I always take a look at a child who can't go to school. We have a lot of our oncology patients who have counts that won't allow them to go to school or they just have to be home they are so weak. Keeping them connected and in the loop somehow is incredibly important. It might even be just strictly social, it might be that the classroom emails this child all the time, or it might be that this child is enrolled in one correspondence course or he's doing one packet through the school district that they have a year to do this whole packet. But it's incredibly important to stay connected. We've also been able to get schools to bend a little bit to give diplomas to children who have terminal illnesses and I think that is a great advocacy place for us to be. It means a lot to the students and their peers. I just find that medically, if they can be proactive with the schools we do better than trying to play clean up on the back side. So if we get real simple documentation on file ahead we already have a signed two-way communication; school to doc, doc to school that we can do a lot to avoid problems with behavior at school, with failing academics with everybody's medical issues. In talking with some of the kids, they don't want to tell you that they are having difficulties at school, but I feel when the truancy increases or depression increases or sometimes they are just real stressed it may not be anything but the school program is just too much for them and they just can't make it.

Dr. Samson-Fang: Elaine, as you know, the No Child Left Behind has some situations about absenteeism in schools and that has created some pressure to have physician excuses for missed days. How do you see that interplaying with what we interface with the school system?

Elaine Pollock: I like to see it ahead of time again, rather than making it a punishment to that family...

Dr. Samson-Fang: That they have to get a doctor's note

Elaine Pollock: Right. That it is established ahead of time that they will have so many excuses that either a Health Care Plan or a 504 may indicate that the child may only have 50% attendance but in their case that is considered full attendance. It may dictate how the parent is going to cover the absence whether at the end of the month call in on all these absences or if it is a secondary thing the family may have to call in every day, or not, this is a piece that can be established beforehand. You medically they are not going to be there all the time. The same thing with a lot of appointments, you kind of know a diagnosis and have a feel for how much follow up you're looking at or whether or not this child is going to have pretty intensive PT or speech services and you can set that up as part of a Health Care Plan; they will be absent for these days and they have two weeks to make up all the work or they will do half the work and that will count as full.

Dr Samson-Fang: How much resistance do you encounter with individual teachers, because I hear that from parents “we have a teacher that won’t work with us” How do you overcome that?

Elaine Pollock: I always like to start out at the very beginning when I know something medically is involved, and meeting with everybody whether it be a phone conversation with the school or actually with my longevity of being around I can call teachers that I have known over the years. Just creating that relationship with the people ahead of time gives you the credibility to be able to say, “this is what we need, this is what is going to help this student, how do we make this happen?” And see if the teachers can give you some suggestions to start with to bring them in as part of the process. Just a note if you are in a small community, if you step up a faculty meeting or if someone in your office steps up to a faculty meeting to talk about something real simple they will view you as part of their community rather than a threat. So if you are in a practice where you interface one or two school districts, you can build those relationships. There are a couple of large districts across the Wasatch Front who have a lead school nurse and just getting to know that person will get you in the door with many teachers. They will be willing to make a phone call to a teacher or they will tell you the best way to go about working with a teacher or you can just call me.

Dr Samson-Fang: Tell us about your parent hour and how one might contact you and how you can help us.

Elaine Pollock: Every Tuesday at Primary Children’s here at the hospital we do one to two o’clock hour for parents to come and talk about any school issue they would like to talk about. If they have specific questions or they have an IEP they are not sure of or they just have some general questions about “are we really going to get through school, or are there other alternatives for us”, its just an open hour to talk about school and there is no charge and there are no reservations, they just need to show up.

Dr. Samson-Fang: And they don’t even need to be hospitalized.

Elaine Pollock: No. Another piece you can access is the *Lets Talk About* on the Primary Children’s website. We just prepared a new piece on school issues and that can be downloaded and given to families and that answers a lot of different questions. I have an office at Primary Children’s and I’m happy to take a call.

Bob Terashima: **May I ask a quick question? If you have a patient that may not be immuno-suppressed to the extent of an oncology patient but would really be set back by common illness like colds, they may have cystic fibrosis, is there any thing that you have found helpful in the medical climate that could be written that might help for them to avoid normal kinds of instances that are significant for them?**

Elaine Pollock: I have known teachers who are very willing to circulate a letter to stay away from the classroom saying that “we have a child who is immuno-compromised and if you think your child is coming down with something would you consider giving the teacher a call or keeping your child home.” We’ve had teachers who did a lot with lessons to the kids about hand washing and cleaning the room and keeping wipes around the room, that were very helpful. And talking to the other kids so it’s not so frightening, why this child might be out for two weeks again, is helpful.

Bob you brought up an interesting population of kids with cystic fibrosis. It is such an interesting place for an adolescent to be. They don't want to tell their friends that they have cystic fibrosis, they don't want to do their treatments, they don't want to take their enzymes and it's nice to start when they are younger to get them equipped to talk to people about it, talk to their friends, talk to the school, that its okay -they are not contagious, and what the school can do to support them- they have a lot of resistance when it comes to graduation for kids with cystic fibrosis because they haven't been there enough.

Dr. Samson-Fang: Elaine, I've encountered a situation of a little boy who did have cancer and I think it was known that he was going to die during the year, he was a first grader and I'm wondering what roles could have been taken to help that teacher prepare that class. Do you have any thoughts on that?

Elaine Pollock: I do. We had connected a little third grader, about a year ago, to her classroom and it was very therapeutic for the kids to know that she was probably not going to be there very much our bereavement counselor from the hospital went out to the school to talk to these kids on their level about grief and opened it up to another parent meeting as well so the parents knew how to talk to their kids and then when this child did not survive the year the bereavement counselor went back again and talked to the kids about what had happened and answered their questions on their level. ...

Dr. Samson-Fang: So really a lot of interfacing can be done and there are people who can be accessed who do have the training.

Elaine Pollock: Absolutely. School districts say they have a few people trained but I think it's more in terms of on a large scale basis when a tragedy happens at the school. But again, I like the entire approach so that it's not quite as surprising, they've talked about it before and the kids actively have done something to be with their peer, in this particular case the kids took turns emailing, they had a computer set up in the room so they took turns emailing the peer. So these kids felt like they had contact and all had done something for their peer that died.

Dr. Samson-Fang: Elaine, how would one contact you?

Elaine Pollock: My office number here at Primary Children's is (801) 662-4914 and I'm also on email through Intermountain, its Elaine.pollock@intermountainmail.org

Dr Samson-Fang: Our next conference call would be in July but we're going to skip July, as that is Pioneer Day, We will be planning a conference call in August and we will apprise everybody as to the topic as that time approaches.

In attendance: Dr. Samson-Fang, Elaine Pollock, Al Romeo, Barbara Ward. Bob Terashima, IHC Sandy, Dinosaurland Vernal, , Montezuma Creek, UVP Cherry Tree