



Who's Driving the Bus?

Wow – I didn't know the bus stopped at the doctor's office, too!

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OK, I'll admit it – I thought we were doing pretty well with self-determination and transition issues at the doctor's office. I make the appointment, pick Jake up from school, wait patiently (all right, maybe not so patiently) in the examining room, and zip my lips while the doctor has a conversation with Jake, with me speaking only when spoken to or when absolutely necessary. I'm a good mom - I'm doing a great job! A few more visits like this and Jake will be able to take over for himself! Nothing to it...right?

Attending the 8th Annual Chronic Illness and Disability: *Transition from Pediatric to Adult-Based Care Conference* in early November 2007 caused me to rethink the high opinion I had of myself. So, back up the bus. Maybe the way I'm doing this isn't really going to give Jake the information or experience he needs to be in charge of his own health care. Hmmmmmm.....

From one of our presenters, Patti Hackett (Team Lead & Co-Director, Healthy & Ready-to-Work National Resource Center), we received a checklist that really caught my attention: *Transitions – Changing Role for Youth*. The checklist doesn't indicate a suggested age for implementing or working on developing these skills, but that's going to be different for each of our kids, anyway - different ages, abilities and needs. (The checklist is at the end of this article.)

Look at #3: ***"I carry my health insurance card every day."*** Jake doesn't even carry a wallet, much less an insurance card (besides, we only received one card this year – probably an insurance company cost-saving measure - ha!). #11: ***"I have a part in filing my medical records and receipts at home."*** Hmphh... do I really have to admit that I've become one of the folks who needs a bulldozer to excavate her desk to even find the files? Now you've probably figured out that Jake doesn't do #11, either.

Try #8: ***"I know I have an option to see my doctor by myself."*** Eureka! Got one right! Or do we? Well, at least I always *tell* Jake that he has the option to see the doctor by himself. Even if he never actually does it, that counts, right? But, if he goes in to see the doctor all by himself, how will I know what they talked about? Will Jake take notes that I can read later? What if the doctor prescribes something and gives Jake verbal instructions? What if he needs a blood test, x-ray or mri? What if...what about....stop!

This is all workable – I can do this – it should be a piece of cake compared to some of the things we've had to do before. How to begin? With one step and then another – then it's not overwhelming. I know – systems, charts & calendars - my friends! This is all beginning to sound familiar to me – figure out (1)what he can already do, and (2)what he needs to learn how to do (wow – just like on the chart!).

Let's focus on just a few of the skills on the checklist for now:

#3: ***"I carry my health insurance card every day."*** Jake doesn't carry a wallet, so I guess he needs to start. What if he loses his wallet? By looking at the insurance card, I can see that there's not really a lot of personal information on it that would put us at risk if it fell into other hands. Perhaps we can start with a copy of the card. We can write a social story or put together a list of do's and don't's about carrying a wallet. This will help make it part of his routine (he's really good with routines!). Practice, practice, practice!

5: ***"I track my own appointments and prescription refill(s) date."*** Not! But he can! All this takes is a calendar, a little information & practice. The huge refrigerator calendar we have will really come in handy for this. For medication, we try to utilize the 90-day mail order feature of our insurance policy. So, it's a pretty simple matter to figure out when it will run out and back up 2 or 3 weeks, complete the paperwork and put it in the mail. Piece of cake!

#6: ***"I call for my own doctor appointments."*** Jake and I can write a script about the conversation and practice it. We've used scripts for a lot of things before, and I think they'll work nicely here, too. I can also call the doctor's office in advance of Jake's phone call and let them know to expect a call from Jake. I think it will



help pave the way for a good experience for him if I call the doctor's office first (I haven't been able to find anything that says this is against the rules!). Since he's new to this, he will need quite a bit of practice speaking up, *really listening*, and responding appropriately. Coordinating calendars and appointment times could be a little tricky, so we'll make a list of our available days and times before the call. We'll role-play the situation a few times before the first call, and problem-solve as we go along. Piece of cake!

#8: ***"I know I have an option to see my doctor by myself."*** I *really* have been telling Jake this, but what I haven't done is *make it happen*. I can do this. Jake can do this. Maybe this will work: Jake and I are in the examining room - when the doctor comes in, we'll tell him our plan - that it's time for Jake to take charge of this part of his life, but that Gary and I are still part of it and need to know what's going on. We'll ask the doctor for his suggestions on how we can make this happen. Maybe for the first couple of times, I'll need to come back in when the exam is finished and hear from Jake (hopefully) or the doctor (if necessary) how it went. Perhaps we'll set a system in place where I only get involved if Jake needs to do something (blood test, etc.) or if there's a problem of some sort. Kind of a "no news is good news" event. This is an instance where we really need a system, because Jake doesn't always relay complete information to us. Not a piece of cake, but certainly not impossible!

#9: ***"I call in my own prescriptions."*** Since this would only apply to refills and the pharmacy we use has an automated system, this won't be too difficult. We can both listen in as the automated system gives directions ("If you're calling to refill a prescription, press 1.") We can write down the steps and prepare a template so that Jake can gather the required information and write it down before beginning his call. Our pharmacy's services also include the ability to request a prescription refill online. The directions are visual and very clear. This is a task that would be very easy for Jake to complete successfully and without a great deal of confusion or frustration, even the first time! Using a computer is one of Jake's strengths. Piece of cake!

And, finally, #12: ***"I pay my co-pays for medical visits."*** Jake doesn't have a checking account, and you've already heard about our filing system, so you know that a cash receipt would probably get lost (OK, I admitted it). So, for now, I think I'll take a shortcut here and just give Jake a check for the co-pay. At our clinic, we check in at the front desk and give them our co-pay before the office visit. Jake and I can role-play what to say and do ahead of time. I'm confident he will easily make the connection when he's on his own and has his own bank account.



Are we finished? No! Is there more to do? Yes! But, if we let this overwhelm us, we won't get any of it done. One step at a time...

Our children each have different medical issues, some more complicated than others. Some of our kids don't have verbal communication skills or the ability to understand everything that's on the checklist. That's OK. The checklist has a ***"Someone else will have to do this - Who?"*** option for the tasks/skills our kids can't do. I think the real point is to change the way we, as parents, think. It will help us better prepare our children to do *as much as they can* for themselves, and to *make a plan* for the things they can't do. We won't be around forever, and it's our job to teach our children as much as we can about how to advocate for themselves and to make informed decisions about their lives - this includes their health care. Look at it as OJT (on-the-job training) - it starts right here, right now - and there's no time to waste.

Take some time to explore the [Health & Ready to Work](http://www.hrtw.org) website (www.hrtw.org). It has a wealth of helpful information. And, while you're on the web, be sure to visit http://usfpeds.hsc.usf.edu/adolescent/pdf/Curriculum_Students.pdf. This site provides an amazing tool to help teach our kids how to make informed decisions about their health care: ***"What's HEALTH Got to Do with TRANSITION?"*** Curriculum.

Share your ideas about how to help kids develop the skills on the checklist by emailing me at jeanine@txp2p.org and we'll publish your ideas and comments in an upcoming newsletter. The more information we have, the better prepared we'll be to help our kids drive their own buses by becoming effective self-determined self-advocates! Happy navigating! ♥