ABOUT "GIRLS WITH RETT SYNDROME"

LETTER FROM RJ COOPER - Pioneer in Assistive Technology

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Hi,

I am RJ Cooper, president of a small, but dedicated company that creates Assistive Technology (AT) for special populations. I've been doing it since 1983. Many credit me with helping to create this field, as I was one of only a handful that had the vision to see computers being used for special needs. My background is Electrical Engineering and then Developmental Psychology. That gives me a unique perspective from both a techie viewpoint and a clinical viewpoint, ideal for my field.

I have worked with tens of Girls With Rett Syndrome (GWRS) over the years. I have spoken at 2 IRSA conferences. And I do have some generalizations about your girls. They come from *oodles* of experience, lots of desire to see them do well, expertise to help them do well, tools that have been fine-tuned over the years, and the ability to truly connect with GWRS.

1) GWRS have complete control over their head and face.
2) The cognitive ability of GWRS is still a question of debate, and different in each girl. This is usually a point of contention between parents and school staff.
3) Your goal, when asked "What is it that you want her to do that she is not doing now? at my popular RoadTrips (where I come right to your school!), is almost always about communication.
4) GWRS can show happiness through facial affect (most can smile, but many cannot).
5) GWRS have very decreased hand function. They *can* sometimes reach out and 'whack' at things, but purposeful, voluntary, reliable hand control is lacking.

So, with all that said, and I hope you read those several times, I wanted to describe some of the successes I've had over the years. I hope this serves as some type of help in planning your technology strategy.

I was working with a GWRS, trying to motivate her to stop hand-wringing long enough to hit a bit round button (a Jumbo Switch) placed on a table in front of her, within her reach. I had one of my cause/effect music programs playing one of her favorite songs. Each time the music stopped, and the screen went black, she was to bash her button. The full screen animation and music would instantly start again. She was well within reach of the button. And when it was her turn, she would move her interlocked hands up and down and rock her body more than *during* the music, so I could tell she knew that her participation was required at that point. But she couldn't get to the button. I helped her with her hands.

One time, she rocked so much that her face got right next to the button. The next time, when she rocked close, it seemed to me that she was trying to user her face to get the button! When I look at the

video, it is very obvious. So I put the button at the end of a Magic Arm, one of my positioning devices, and placed it near her upright head.

The next time it was her turn, she bashed the button with her cheek, quite forcefully, as if she was surprised the button was up there! She then explored the button with her cheek. From then on, she was almost 100% with the task, pushing nicely against it when it was her turn, and staying off it when it wasn't her turn. The video clearly shows it. Beautiful.

Now, one of the benefits of working with *hundreds* of Learners all year, during my RoadTrips across the country, and here in my home area, where I'm asked to consult regularly, is that...well, I get to work with a LOT of Learners. But the 'down' side is that it is only for a short time, and I don't get to be involved, *directly* over time. When I leave the scene, I'm hoping that things will continue nicely. Unfortunately, they rarely do. Parents call me up sometimes a *year* later, asking me what I did with their Learner, indicating to me that nothing had been done during that time.

So I can't say that the GWRS that I describe above graduated to better and better tasks. The same is true for almost all the Learners I've worked with. Sometimes, people will let me know how things turned out years later, but most often not :(

Sometimes, parents call (or email or even send me a video via email) and ask for my advice. The most frequent thing I tell them is to do *something*, anything, just get going, and keep going. Don't be looking for 'perfect' things. Don't be planning too far ahead. Pick something that seems to work and move with it. Video it at home. Edit the video. Show it at the next IEP (bring coffee and donuts!). Just get going!

Now, I make things for GWRS, and it's good stuff that really works. I know because when I'm in front of a room of 100 parents, professionals, administrators, etc., working with 'your' GWRS, I need for things to be really, not just good, but *great*! I need to make your girl look good, and they make *me* look good. It's a win-win situation. In working with *thousands* of challenging Learners, I've gotten quite good at it. I know what works and what doesn't.

And the hands are a 'cruel tease'. They *almost* work well enough to think they will be *functional*, but the rarely are. Yes, I've heard of cases where your GWRS can use her hands nicely, but I've not seen a lot of these cases. And remember, I've seen a *lot* of cases!

So I almost always go with a cheek switch. My setup is usually like that pictured here <Picture of Buddy Button in user> and here <image of emma and Magic Arm>. This first picture shows me using my Magic Arm to get the Gumball Switch into position. I don't use the Magic Arm for this purpose anymore but this little lady has Rett and it shows the switch in good position. I use my Mini-Arm these days, which is in the second picture. The switch needs to be closer to her cheek but it's a good picture of the hardware.

I always use their cheek, not their temple or the back of their head. I need the switch to be visible, feel-able, click-able, lick-able, you name it. I want it obvious to the GWRS.

Now the switch choice. There are 2 possibilities here. You can use a Mini-Click, which is a 2.5" round switch that has the switch interface built right in, so that you can plug it directly into the computer. That is great! No extra hardware necessary. Perfect for home where you don't have to plug different switches in for different kids. But not so perfect for school situations where you *do* have to use different switches. For those you'll need the Gumball Switch (or Jelly Bean) *and* a switch interface (I make a bunch, with my most popular SwitchHopper pictured here).

Now there *is* a down side to using the Mini-Click. It won't plug into battery operated toys that have been switch modified (like the great variety from <http://enablingdevices.com>. So you'll have to weigh both factors into your hardware decision. Personally, once you're past about age 6-7, I go with the computer more than toys.

Once you've got your switch into the computer, it's time to pick software that will be: 1) Obvious; 2) BIG; 3) Loud; 4) Motivating; 5) Fun!!! And there is truly not a lot out there that fits all this criteria. Here is where I come in again. Remember, I like to consider myself both a resource (as you can, hopefully, tell from this article) *and* a 'vendor' (whereby I feed my family by my sales!). I make several programs that fit, with my favorite tool, Children's Switch Progressions (I also make Teenage Switch Progressions). Use my MP3's or put your own in, and then cause/effect takes place with fullscreen, real-world (computer generated) clear animations. Things are very obvious. And you record *their* name into the computer (buy a microphone, RadioShack, BestBuy, Wal-Mart, etc., about $12), the prompts. The program keeps data. With these tools, things should become very clear about their cognition.

Yes, your GWRS might be 'above' this level. But I say, start here, with something that should be easy for her, where she can demonstrate that she 'gets it'. Then graduate to greater things (more on this if enough respond to this article).

Most people think of cause/effect as just 'hit the switch to make stuff happen'. There are actually 3 things to look for:
1) Press the switch to make stuff happen.
2) Do NOT be pressing the switch WHILE the stuff is happening.
3) When the stuff stops, press the switch again within a short period (technically known as "latency").

The software should track these.

Now IF I'm correct, and your GWRS is better off as a switch user, than a 'direct selector' (using her hands independently, individually, voluntarily, consistently to directly touch things like areas on a touchscreen, Intellikeys, or keys on a keyboard), then "scanning" is going to be your, and her goal. This is where some type of highlighter moves between on-screen choices, and she presses her switch when her desired choice is highlighted. Auditory Scanning is just this but with a "label" (sometimes in your voice,

sometimes the computer voice) speaks each choice as it's highlighted.

With this ability, as close to 100% accurate as possible, she can do *anything* you do with mouse and keyboard. She can 'point and click' using just 1 (or 2) switches. She can 'type' using an on-screen keyboard. Yes, it's slower than direct select in some cases, but it's even slower in the direct select case for most GWRS, even if the cognition is there (and remember, that is still debatable!).

So there are programs that I, and others, have made that will take you past cause/effect and even into literacy areas. But let's not put the 'cart before the horse'.

Do something! That my credo. And do it...tomorrow. Make it happen. Start on your technology journey ASAP. Start with something *too* easy, and get 100% accurate with it. Keep it motivating.

I truly hope you'll contact me personally and ask follow-up questions. Or give me your suggestions and/or needs. Send me videos of *your* GWRS*. Tell others about me and my work!

Bye for now.

RJ :)