

## Did You Know?

Did you know that the Parent Network is:

- A New York State Education Dept. Parent Center TAC (Technical Assistance Center)
- A Parent Member of the Commissioner of the NYS Education Dept.'s Advisory Panel on Special Education
- A member of the Developmental Disabilities Alliance of WNY (DDAWNY)
- A Parent Member of the Vocational & Educational Service for Individuals with Disabilities (VESID) Statewide Transition Coordination Site Committee

*We are parents helping parents and professionals enable individuals with disabilities to reach their own potential!*

Your support of the Parent Network is an invaluable gift to all parents. Donations are tax-deductible and can be made payable to the **Parent Network of WNY.**

## We Want YOU!

Reaching out to parents, especially those who are "hard to reach" is a major priority of Parent Network.

This year, we are recruiting volunteers for an advisory committee to assist us in finding creative ways of getting information out to those parents who really need it.

If you are interested in being part of the committee, or would like more information, please contact **Max Donatelli** by phone at **(716) 332-4172** or by email at [med@parentnetworkwny.org](mailto:med@parentnetworkwny.org).



The Parent Network of WNY  
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# Special Insights

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## Plans Are Our Safety Net

**L**aura and Steve have four children. Their youngest child, Justin, is 15. Justin has autism. Laura and Steve have encountered obstacles in their son's education from the beginning. Today, Justin attends his local high school, takes general education courses, and earns "As" in art and wood shop. In the following excerpt, Laura and Steve describe the importance of **planning**.

"Do we have a clear view of what we want for our son? Yes. We started out, as many parents do, with goals and aspirations for our son. With the diagnosis of autism, how-

ever, we had to modify what we saw as his path. We had to get through the grieving process before we could look forward to a future for our son.

Forming a plan and thinking about the path that lay ahead for Justin helped us to heal and to adjust our perspective in a positive way. We did not give up on our vision for him, we just modified it.

When you have a child with a disability, you battle with insurance companies and schools, negotiate with employers and co-workers for time off, respond to the needs of family members, and deal with the unexpected. As these

demands increase, your stress level increases too. It is easy to be sidetracked and forget what is important. What keeps us sane? Planning! This cannot be emphasized enough for parents.

A master plan helps us stay focused, anticipate problems, and prepare for the future. Our master plan includes goals for our son in academic and non-academic areas — hobbies, interests, sports, play, and friendships. Master plans are clear, focused, concise, and flexible.

We make lists of expectations. We write out our goals. We list

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## Max's Message



The State Commissioner's Advisory Panel for Special Education Services (CAP) advises the Governor,

Legislature, and Commissioner of Education on unmet needs in the field of Special Education. Recently, I have been asked by the State Education Department to serve a second, three-year term on the panel.

It is my job to actively represent Western New York as a parent, and to share issues related to the Individuals with Disabilities Education Act (IDEA) as it is implemented in New York. In addition, I am the Vice Chair of the panel's subcommittee on Transition. Why am I telling you all of this? I can provide you access to state decision-makers on the issues that affect your family.

The beginning of each of our meetings allows for public

comment, and I have been very willing to bring your concerns to Albany. Please

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## Plans, Cont.

outcomes of what we want to see happen. We also have contingency plans. Plans are our emotional safety net. If things do not go as expected, we have plans to fall back on. We make the best of the present situation or make temporary fixes until we can put changes into place.

We realize that Justin may never be completely independent. We have planned for that, too. We realize that when you have a special-needs child, you have to modify your

expectations more often. But sometimes there are obstacles not seen until it is too late.

Our main goal has always been for Justin to have the most fulfilling life possible. In the beginning, our goals were very basic, consisting of things like communicating or cleaning his room. During modification times, we would add to these goals. Now, some are:

- Life skills: cooking; cleaning; personal hygiene
- Social skills: answer phone; greet people

• Communication: express wants, needs, desires

• Job skills: develop talents and interests; identify fields of employment

Now we include the word “functional” in our goals. When developing Justin’s IEP, we bring our list of outcomes. When the teachers state a goal, we see how it connects with these outcomes and if it is “functional.””

*This page printed from: <http://www.fetaweb.com/success/plan.laura.steve.htm>*

## Max, Cont.

contact me with any concerns you may have. Also, you should visit the VESID website frequently so that you’ll know which issues the panel will be addressing. Remember that by being informed and educated, you can better serve your child(ren). See [www.vesid.nysed.gov/special](http://www.vesid.nysed.gov/special)

In addition to this effort, VESID and other partners have created what is being called Learning Communities. The focus of one, the Family and School Collaboration, is being facilitated by me. This program will identify best practices throughout the state, allowing us all to share and learn what’s working and not working. If you are interested in participating in this wonderful new initiative, contact me at via email at [med@parentnetworkwny.org](mailto:med@parentnetworkwny.org) or by phone at 332-4172.

## Reader Forum



arent Network have been thrilled with the response to *Special Insights*. Please submit article ideas, suggestions, or any questions to: [newsletter@parentnetworkwny.org](mailto:newsletter@parentnetworkwny.org).

Please contact us if you’d prefer to receive an electronic version of *Special Insights*, delivered via email, let us know. Just send a quick message to the email address above or call Kim at 332-4174.

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The  
**Parent Network**  
of WNY

## Meet the Parent: Ron Butcher



Ron Butcher did not own a crystal ball. He did not have a magic wand. And he had nothing up his sleeve. But, without using any magic tricks at all, Ron Butcher could see the future of his son, Ron, Jr., and it scared him.

“I could see friends, cousins, guys I went to school with, all end up in jail, in Attica. I could also see the neighborhood around myself and Junior. I could see his future, and I knew that if I didn’t do something, there was little chance that my son would succeed,” remembers Ron, a retired prison guard.

And that call to action, that steadfast commitment to doing everything he could for his son, was one that would forever change not only Ron, Jr’s life, but his own.

Ron’s days as a parent advocate had their beginnings on a row of uncomfortably hard plastic-and-steel chairs. After an open house tour of a Montessori program, Ron knew that the school was the best place for his son. Unaware of the program’s lottery-based admissions system, he was crushed when informed that there were no guarantees Ron, Jr., would make it in. The next morning, he started to a advocate.

“Every day for two weeks, I would get home from a

midnight shift at the prison, shower and change, and then head down there to the school. I sat in the office everyday for like two weeks. I just wanted them to know that I was serious about Junior going to school there,” Ron says. “I was polite. I was respectful. But I wasn’t going to take ‘No’ for an answer, and I wanted them to know that.” Ron, Jr., was admitted shortly after.



**“I was polite. I was respectful. But I wasn’t going to take ‘No’ for an answer.”**

As his son grew older, though, Ron began to find himself drowning in a sea of acronyms, legalese and red tape. Ron, Jr., was in need of Special Education, and Ron soon found himself in need of a little tutoring, too. He was turned on to the Parent Network and fell in love with the agency’s staff and services.

“Whenever I would attend IEP hearings, I found myself

getting intimidated. I’d look around the room at all the PhDs and become scared to talk, scared to ask questions. After a few went by like that, I knew I needed some help. In just a short time, Parent Network helped me to feel more comfortable about myself and gave me the confidence to ask the right questions and get the answers we deserved,” he says.

Today, Ron, Jr., is on the road to success. A graduate of DaVinci High School (with a Regents diploma), he is a sophomore at Medaille College, majoring in Communications. He loves high-tech gadgetry and has proved to be very proficient with cameras. Thankfully, Ron, Jr.’s bright future seems far removed from the tragic, orange-jumpsuit-clad image that had appeared in his father’s crystal ball. And that thought is not lost on the likeable Ron, Sr., who knows how close his son was to ruin. But when asked who deserves the credit for Ron, Jr.’s success, he smiles and humbly replies:

“I am nothing special. As a parent, I did what every other parent should be doing - getting involved and getting educated. Parent Network should be bursting with parents coming to learn how to be more involved with their children,” say Ron. “Man, that place is a diamond in the rough.”

— Tom Lucia