

**Working Together For Jessica**  
**Theresa Meininger Sanders Speaking Notes**  
**for**  
**Children's Treatment Network Symposium**  
**October 6, 2009**

- I had to laugh at the introduction notes that Michelle had about me. During her introduction, she said that we decided to participate in the McMaster University research study to measure the effectiveness of integrated care
- When McMaster and Children's Treatment Network contacted me about the integrated care and basically told me that:
  - My core team would stay with us, and;
  - They would have the ability to work together as a team, have team meetings, and a program to help them communicate with each other – I basically begged to be a part of the study!
- There was no “deciding to participate”. I was pushing people out of the way to be at the front of the line to sign up!
- This team approach is essential to us. And I'm going to spend the next few minutes explaining why.
- As Michelle said, my name is Theresa and I'm a stay-at-home-mom of 6 year old twins, Alexander and Jessica
- Alexander is an exuberant and active, typically developing healthy boy. He's into all things dirty and anything with wheels and an engine.
- Jessica was born globally developmentally delayed. We've been connected with various service providers since the age of 6 months
- At age of 2, Jessica contracted encephalitis, which attacked her brain causing sustained seizures. These left her paralyzed on the left side and regressed in all areas
- She was left without the ability to crawl, stand or walk. She also lost her speech and had to be fed with a feeding tube in her stomach
- After Jessica's trauma, we were introduced to a whole new set of service providers – the first of which were Barb Wenzel, physiotherapist with Closing the Gap and Laurie Rife, occupational therapist, also with Closing the Gap. They are still a part of our team and here today

- After 4 years, Barb and Laurie are a part of our family as well as being strong team members who help new members get acquainted with Jessica and caught up to where we are with Jessica's goals and the activities to meet those goals
- Third member of our team that's present today is Kirsten Goodman, a family support worker with Simcoe Community Services. Kirsten is responsible for coordinating the team for meetings, communication between team members and updating our electronic record
- The final core team member is Joyce Hignett, speech and language pathologist with Speak Freely - who couldn't make it today
- These four members are the centre of our team now. Every year new members join the team – teachers and EA staff, speech therapists from school, other school staff. The four core members help the new members and keep the cohesion of our team strong
- So, what are the benefits of this integrated system?
- First and foremost, I don't have to tell my story over and over again anymore. Even if new members come on board, assuming they have access to the electronic record, they get the entire history – which is extensive and complicated and quite painful to relive.
- New members quickly become acquainted with Jessica and familiar with the goals we are trying to meet and the methods for meeting those goals
- The members of our team have a huge amount of respect for each other and acknowledge that we are all working towards a common end – meeting Jessica's goals
- Communication happens regularly between members. Even outside of team meetings, they are doing regular therapy sessions involving not just Jessica and I, but other team members as well. And they are talking to each other and making sure that everyone is working together
- This simply didn't happen in the old outdated way. All the service providers worked independently of the others and it was our responsibility as parents to keep everything straight and to incorporate all the therapies. That caused so much more stress for us – honestly too much some days
- Finally there are regular team meetings that happen 3 to 4 times a year. These are essential for us to maintain Jessica's goals, to come up with new activities for everyone to incorporate and to make sure that we are on track

- The electronic record means that these meetings are streamlined and successful and there's a method to track the progress we are making
- How has this teamwork, respect and communication helped us and made our lives better?
- As parents, we KNOW that Jessica's progress is a direct result of this teamwork.
- We know that as each team member helps others in their respective fields - as the goals are all combined and everyone is working together as one - she's accomplishing things previously unimaginable to us
- She's crawling and pulling herself to a stand. She's maintaining a sustained standing position and working towards walking. She's regained a significant portion of the use of her left side. She's feeding herself – the feeding tube was removed. She's gaining new words every day and is interacting with her peers and with others successfully
- This is progress that we weren't sure she was ever going to meet. Now we feel that her possibilities are limitless
- As parents, we feel truly blessed that Children's Treatment Network has allowed this team to bond and work so smoothly towards helping our daughter
- Because I have worked with these service providers for so long, we now feel that they are a part of our family and that they all want the same things that we do - for Jessica to succeed and have the best quality of life that she can.
- To know that we are not alone in this ongoing effort is hugely supportive for us. We are again blessed to have these positive people in our lives and in Jessica's corner
- We know that this team has helped Jessica to reach goals that she may never have reached without them. And we know that Jessica's future is bright because so many are working together to help her get there
- It is possible to make sure that even with changes to the team, the members maintain a bond with each other. They can understand that even if they come from many service providers, both public and private, all of them in the end are working to the same goals. That connects them and helps them to work together to help a child in need – our beautiful daughter Jessica
- We have high hopes for Jessica's future – and we couldn't do it without our team

- I have found a quote from Lisa Peters, a mom whose son has Prader-Willi Syndrome. As parents, we like to share our stories with each other and know that we are not alone. Lisa was able to put into words the feelings in my heart for my team:

*“As I became accustomed to my new sight, I saw we were surrounded here on Earth by many disguised angels – intelligent, kind, compassionate human beings devoted to curing and healing the sick. Why hadn’t I seen them before? Why hadn’t I appreciated them? Once again, this imperfect child had opened my eyes. I could now see these special souls who travel among us. These selfless, gifted, healing guardians who would now be a part of our lives forever. Wrapped in their wings, this horrifying new life of ours seemed a little less scary”.*

- Thank you for listening to my story about teamwork – and thank you to my team of special souls