

The Expectation of Being Heard

By Nicole Dejean



My advocacy journey stemmed from desperation rather than desire. In the words of my husband, our original goal as partners and parents was to live a quiet, peaceful life. Life takes on a different perspective when you realize you are faced with co-parenting not only with your spouse but medical specialists, school systems, government programs, and the community at large. We have all heard the saying “It takes a village to raise a child” which comes to fruition when you are raising a child with special needs and even more so when the child has a rare disease.

Our daughter Lillian is 16 years old and has an extreme love of life. She is grounded in who she is, seemingly so unusual in a child her age. I think this is a result of understanding the tenuousness of life and how quickly it can change. Lillian was diagnosed with Mitochondrial Disease at the age of 6. This diagnosis came after many years of searching for answers about the things that made Lillian unique. Her life is balanced on a regiment of medications, infusions, tube feeds, oxygen, ventilation, and therapies.

When Lillian was a small child, I suspected something was developmentally different about her. I had multiple conversations with her pediatrician, family members, and friends asking their opinions about my observations. Because I was a “new mom” with only one child AND I happened to be an early interventionist specializing in the education of special needs children ages birth to three, I was always put off as overly attentive. I will never forget the pediatrician’s words to me “Just be happy with what you’ve got. She’s just a variant on a scale of normal.” Regardless of all the great care she received

from this pediatrician, these are the only words I remember from him. However harsh the words were, I needed to hear this. I needed to hear it not because it was true, but because it was the moment I realized that her father and I were her voice. I knew we would always have to advocate for Lillian.

As I mentioned before, children with special needs are embedded in multiple systems. Advocacy becomes a necessity to access, at the very least, what they need. Notice, I used the word NEED, not WANT. The feeling of desperation is also part of parenting a child with special needs because getting what they need can be elusive at best. It’s not about making them “normal,” but through effective advocacy we can at least move towards something that’s our own version of normal.

Advocating happens in endless settings through a variety of methods. Through trial and error I have learned what is effective and ineffective. Advocating from emotion can be persuasive, but also alienating if that emotion is anger. I’ve learned to speak from experience and use phrases like “Lillian’s normal is ____,” “Lillian’s Mitochondrial disease looks like____,” “Our goal is ____.” By using these phrases, professionals get an idea of what our “normal” is, our goals, and what we need help changing.

In the middle of all of this, Lillian is growing up. She is blessed to have the cognitive ability to describe what’s going on with her body. We realized that the most accurate information about her health comes straight from her. We have worked diligently to develop a medical team who values her input and defers to her about her symptoms. They have encouraged her to speak her truth and how her symptoms impact her life. They want to know her as a person and not just a patient. Everyone’s goal is to improve her quality of life, and by everyone, I am referring to our medical team. I use the term *team* because it indicates a group of people, with equal roles, working towards a common goal. No one person is more or less important. This has been the foundation to raising our child to effectively advocate for herself throughout life.

By encouraging her to speak her truth we have been propelled on an advocacy journey which has taken us all over the country. Lillian has watched her team collaborate for years and became empowered to tell her perspective, and in effect, she became an active participant in her own future. We have to do some preparation and prior to doctors visits we go through a list

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VOTING TIME

* * Check out our Board Member Nominations * *

All nominations must have required previous board experience to serve as Vice President and Secretary.

Position: Vice-President

4-year commitment: 2018 – 2022



Nominee: Hilary Case Bordelon

Hilary lives in Slidell, Louisiana with her husband and two sons. Her teaching career started in 2000 as an English teacher at Salmen High School after completing the Alternate Certification program at Southeastern Louisiana University. After her son, Morgan, was

born with Down syndrome, Hilary became interested in early childhood special education and returned to Southeastern for a Master's degree in Education and certification in Early Intervention.

Hilary has been a Special Instructor for Early Steps serving St. Tammany Parish since 2008. She is currently membership chair for the LACEC and the LADEC.

Hilary is passionate about advocating for children and adults with disabilities. She sits on the Louisiana Developmental Disabilities Council as a parent representative for Region 9 and is a 2015 graduate of Partners in Policymaking. She hosts an advocacy group for mothers of children who have disabilities called Eat, Drink & Advocate.

Hilary believes that partnerships with families are one of the most important components of special education. She loves that working in early intervention gives her opportunities to support families in nurturing the development of their young children.

Voting Link:

<https://goo.gl/forms/uO9Fce6qSQIrpt472>

Or go to our website

<http://community.cec.sped.org/la/home>
and click the link

CEC 2018 Board Elections **SAMPLE** Ballot

Vice President: _____ Hilary Case Bordelon
_____ Write- in Candidate

Secretary: _____ Maggi Bienvenu
_____ Write- in Candidate

Position: Treasurer

2 year commitment 2018 – 2020



Nominee: Maggi Bienvenu

Maggi Bienvenu is currently an Ed.D. student and Graduate Research Assistant in Educational Leadership at the University of Louisiana at Lafayette. Following a ten-year hospitality and training career with the Disney Corporation in Florida, Maggi returned to Louisiana in 2015 and entered

the family business: special education. In December 2017, she completed her Master of Arts in Teaching degree with a concentration in Elementary Special Education. Her research is influenced by her life and work experience: improving the way that educational systems recognize and care for exceptional learners.

With the Disney Corporation, Maggi learned to spot common needs in the tens of thousands of guests from dozens of cultures she interacted with every year and how to blend the services they needed to have an excellent experience. She taught others to do the same as a Disney trainer and Disney University facilitator.

Maggi currently lives in Lafayette, Louisiana with her fiancé, Rusty and their two school-aged children. She has worked as a para-educator for adult education and for severely disabled children. She helps to care for an extended family that includes both gifted and autistic children.

Her service to the Louisiana Council for Exceptional Children started as a volunteer for the State Super Conference for the past three years and as the interim Government Relations Coordinator since November. She is excited to renew her commitment to Louisiana's exceptional learners as your Treasurer.

Save the Dates

February 25-26, 2019

Join us in Lafayette!

Super Conference 38:

Elevating Expectations for Exceptional Learners

and

CEC 2019

special education
convention & expo
Indianapolis • Jan. 29-Feb. 2
ALL EDUCATORS. EVERY CHILD. NO LIMITS.

CEC Members:

Check this out on the CEC website: www.cec.sped.org

Expectation of Being Heard *Continued from page 1*

of questions. Examples of the preparatory questions include: Who are we going to see today? What part of your care do they oversee? What new developments do we need to report? What would you like to improve? What's working? We have applied these same principals to our advocacy at the state and federal levels. Professionals and fellow self-advocates alike have taken notice of the child advocate that shows up at the capital or legislative events to speak her voice about services that she is counting on to have an independent future.

Lillian has testified at the state capital in front of the House Appropriations and Ways and Means Committee representing herself as a self-advocate. We boarded a bus to Washington DC to protest federal cuts to Medicaid and as a result she was highlighted on CNN. She is currently the youngest member of a state council and serves as a self-advocate on the Louisiana Developmental Disabilities Council. As a result of all these activities, she was awarded the Governor's Office Leadership in Disability Youth of the Year Award for 2017.

Lillian and I recently had the pleasure of speaking at Louisiana's CEC's Super Conference about the shared responsibility of advocacy. Sharing responsibility for advocacy simply means

that we all play a role in advocating for children but we also teach them to advocate for themselves within their ability level. As a parent, we are told that we are our child's best advocate. Well, what does that mean? And how do we get to that point? Educators play a key role in teaching students and their parents about advocating effectively in the education system. These skills can easily be generalized to other settings. Again, by applying the team mentality, everyone is empowered and accountable and in the midst is the child who has their own unique perspective, goals, and desires.

By teaching students to set and pursue goals based on their abilities, they are less likely to develop a sense of apathy or learned helplessness. We then begin to have individuals who are active participants in their own lives and communities. Don't we want people who can effectively express their wants and needs, or speak out if they've experienced some sort of injustice or abuse? We all need to recognize our shared responsibility in setting the expectation of self-advocacy for individuals with special needs. One of the greatest gifts that we can give to our children and ourselves is the determination, confidence, and expectation that they will always be active participants in their own care and the trajectory of their future.

First LIFE Class Completes from the College of Education

The University of Louisiana at Lafayette LIFE Program had 5 of its students participate in the College of Education Commencement Ceremonies on May 11, 2018. Brooke Hebert, Mary Martina, Elliott Venable, Charli Webre, and Robert Zepernick were the first five completers of the program established in 2014. Two of them presented and participated in previous Super Conferences.

Congratulations to these awesome students and best wishes in their future from LA CEC.



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Research2Practice pod casts lets you read between the lines of popular articles from CEC's journals *Exceptional Children* and *TEACHING Exceptional Children*. Publications Manager Lorraine Sobson talks to the top practitioners and researchers in the field about cutting-edge interventions and strategies that you can implement in your classrooms and school.

***Find podcasts in the CEC catalog,
on the website, or on iTunes***

2019 LACEC Super Conference CALL FOR PAPERS
“Super Conference 38: Elevating Expectations for Exceptional Learners”
FEBRUARY 25 & 26, 2019 - Cajundome Convention Center- Lafayette, LA

- **IMPORTANT- ALL QUESTIONS MUST BE ANSWERED AND ATTACHMENTS COMPLETED FOR SUBMISSION TO BE SUCCESSFUL.** “Hands On” presentations are encouraged when possible.
- **Submission Deadline:** Call for Papers must be submitted by **September 30, 2018**. Presenters must register and pay by **November 15, 2018** to be on the conference program. Presentation applicants will be notified of their acceptance or non-acceptance by **October 31, 2018**.
- **Instructions for Electronic Submission (visit www.louisianacec.com for this feature if you need a PDF version):**
Please select the appropriate boxes with your mouse cursor and type in the correct responses where required. Please save this form as a PDF and title it using the following format: last name, first name, LACEC2019. For example: DoeJaneLACEC2019. Please email the form along with your attached **Maximum** 250 word detailed proposal description and your National CEC Standards based participant outcomes (see link at the end of page 2) to the following address: laceccallforpapers@gmail.com
- **Instructions for Hard Copy Paper Submission:** Please select the appropriate boxes and complete the appropriate information and mail the Call for Papers to the following address:
LACEC Call for Papers c/o Chantal Gibson, 31531 Linder Road, #107, Denham Springs, La 70726

Topic Areas: Please choose ONE General topic area by selecting the box next to the area.

☐ Cultural and Linguistic Diversity ☐ Assessment ☐ Law and Compliance

☐ Collaboration and Inclusion ☐ Instructional and Evidence Based Practices ☐ Arts
☐ Transitions and Post-Secondary Education ☐ Early Childhood ☐ Families

- **Please indicate Session/Presentation Title:**

- **Please provide up to a 50 word description of your proposal to be printed in our program if accepted:**

- **Please submit the Session Leader Name and Job Title:**

- **Session Leader Email Address:**

- **Phone Number of Session Leader (provide best number to reach you and best time to call):**

- **Session Leader Address:**

- Please submit names and titles of other members of the presentation (write none if applicable):
-

Please indicate the group(s) your presentation will apply to:

(Circle all that apply) Early Childhood, Elementary Middle school, High School, College

Please indicate presentation format by selecting the box:

- ☐ **Demonstration: 50 minute session in which presenters demonstrate and involve participants in learning activities (e.g., developing and using curriculum materials or assessment tools; developing instructional plans, using software programs or technologies). Demonstration sessions are intended to be interactive.**
 - ☐ **Presentation with Q&A: 50 minute session in which individuals present material about a specific topic. Interaction in this format is typically limited to questions and answers. It is mandatory to allow at least 10 minutes for question and answers. Panel: 1-hour sessions that are moderated and designed to present multiple perspectives on a topic.**
 - ☐ **Poster Sessions: (50 minutes) Visually present a research study, program, or project. This format is particularly appropriate for works in progress. (Research in progress will not be accepted as a Presentation or Panel session.) Poster sessions are designed to foster maximum interaction with the audience. Typically attendees move through the room from poster to poster. Poster session presenters must: (1) prepare a poster exhibit of high quality that can stand alone in conveying information; and (2) attend the entire poster session and address questions from attendees.**
- **Screens and LCD Projectors will be provided, all other technology is the responsibility of the presenter**
 - **Please provide and attach 1 to 3 participant outcomes in addition to the proposal description based on National CEC Standards that describe skills, knowledge, and/or behaviors participants will know or have following the session. (e.g. Participants will learn 3 strategies for using social stories with students with autism.) National CEC Standards can be found at the following site:
<http://www.cec.sped.org/Standards/Ethical-Principles-and-Practice-Standards>**

Questions: Please contact Chantal Gibson: chantalgibsonlace@gmail.com

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