

Step Out and Speak Up: Advice from a Self-Advocate

By Emily McKinley, Health Information Specialist

Family Voices was founded on the principle of advocacy: parents as advocates, kids as advocates, professionals as advocates. Without the brave actions and courageous words of advocates around the globe, people from every walk of life experience greater trials and less progress. Individuals with special needs are no exception to that rule. It takes fervor and faith to step out and speak up. It takes drive and the will to hear “Yes!” And, it takes leaders, such as Melody Cooper, President of Self-Advocates of Indiana (SAI) to rally the troops and motivate others to do the same.

“Self advocacy is important because it gives people with disabilities an opportunity to stand up for their rights and know what they want for their life as a person with a disability. It gives you the strength to know that you can make it.” states SAI’s 2011 annual report. These principles resonated loudly during my talk with Ms. Cooper.

Melody Cooper first realized the need to be her own advocate when she was a young high school student. Her homeroom teacher and the school basketball coach posted a bulletin announcing the formation of a team. Melody quickly signed up. Early the next morning, the coach pulled Melody aside to tell her that she could not play; after all, what if the ball hit her head?—Surely, she would be seriously injured. When Melody persisted to express her desire to play, roadblocks continued to be set in her path, even by her grandmother who raised her. “I was sheltered from a lot of stuff...I wanted to be as normal as any other child. Everyone told me ‘No!’” she said.

Despite the echoes of voices telling her no and the limitations of her cerebral palsy, Melody refused to be held back. When she independently moved from Georgia to Indianapolis, a few years later, Melody was determined she would play basketball. And so, she did. She connected with Special Olympics and enjoyed playing on a team that won their way to second place. At about this same time, Melody realized she wanted—no, needed—more satisfaction in her life, and so she began sharing her story with others. She set out to motivate others and be the “yes!” in their lives, even if she stood alone. And she did.

With her husband’s encouragement, Melody ran for and was elected president of Self-Advocates of Indiana, a nonprofit organization that works to provide resources and empowerment for individuals with developmental disabilities. During her tenure as president for the organization, Melody has enjoyed meeting others throughout the state, listening to their dreams, and hearing their 5- or 10-year plans. Not only does she find fulfillment in doing so, but she also feels that giving others an audience to express themselves is the first step to motivating them.

In fact, Melody encourages parents of children with special health care needs to “Listen to that child. Don’t stand in that child’s way. Offer support, and help foster those dreams...Do more than listen. Don’t stop them” from pursuing their dreams. In doing so, parents may foster their child’s confidence such that they are able to stand up for their rights and express their desire for their life and additional rights, states Melody.

Through her role with SAI, Melody has “enjoyed just being me—all that came because I stepped out on faith.” She encourages others to do the same. “Stand up for what you want. Nobody’s going to give you anything, but if you want something, then get it.” she advises.

Ms. Cooper also recommends being involved with others who will support you, whether that means surrounding yourself with encouraging family and friends or joining a support or advocacy group, such as Self-Advocates of Indiana (www.saind.org) or KASA, Family Voice’s affiliate Kids As Self Advocates (<http://www.fvkasa.org/index.php>).

In the meantime, Melody suggests, “Know what you want, and it’ll get done.” Meanwhile, she’ll continue her tenure as president of SIA and hopes to further the growth of the organization while helping people gain an understanding of the lives of individuals with special needs. Keep your ears open and eyes peeled, if you hear a resounding “Yes!” it might just be Melody in the room.

For more information on SAI, please visit www.saind.org or contact Melody Cooper at mcooper@arcind.org.

For more information on KASA, please visit <http://www.fvkasa.org/index.php>.

For more information on how to become an effective advocate at the local, state, or national level, please contact Family Voices Indiana at info@fvindiana.org, 317-944-8982, or visit our website, www.fvindiana.org. Family Voices has funds available to help you hone your advocacy skills and efforts.