

ALL GROWN UP: The Parent Perspective on Self Determination

Professionals who educate and serve people with disabilities use terms like “self-determination,” “transition” “mapping” “person-centered planning,” and “micro boards.” For parents of students with disabilities this is just “parenting.” This phase of parenting, like many of the challenges of raising a child with a disability, requires a lot of trial and error, patience, and a little tweaking.

Nalini Isaac is currently serving her sixth year as the Bibb County Parent Mentor. Isaac shares her insights and firsthand knowledge about helping her daughter become as independent as possible as a young adult. Her 28-year-old daughter Nandi is currently living independently with supports.

She has learned that “tweaking” has become an essential part of doing one of the most important parenting jobs there is: letting go of your child when they become an adult.



Nalini and Nandi in Nandi's home. Nandi is very proud of her home and welcomes visitors!

While she offers a definition of self-determination: “for a person to KNOW what they want, from a variety of options and to be able to choose, with an awareness of the risks and responsibilities of that choice.” She said that while defining it into words is possible, it is the actual work of putting the plan in place that is difficult to define. “Self-determination is not a one-size-fits-all plan...it is a continuum, over the life span of our children,” she said.

“You have to allow them to go ahead and make mistakes,” Isaac said.

Isaac remembers back to Nandi’s middle school years when she was having difficulties with “getting in trouble”. The worried mother and father talked and talked and made the momentous decision to homeschool her for a few years. This move, allowed her parents to really take control. “So earlier on, we wanted more control. But then as she grew and began making better decisions, we could have less control,” she said.

Step 1 Allowing a child to make choices

As Nandi began to settle down, the Isaac family allowed her to live up to her independence. She attended Georgia Academy For The Blind, in Macon for about 3 years as a residential student, during the week. She graduated in 2005. After 3 years she began living in a group home not far from her parent’s house. “We began preparing her by putting supports in place,” said Isaac. These supports were a combination of professional support staff and “buddies”.

Step 2 Putting supports in place

We are fortunate that our provider [The Arc of Macon](http://www.arc-macon.org/), values person-centered services. (<http://www.arc-macon.org/>) ARC staff is encouraged to participate in ‘Direct Support Professional’ “training which focuses on person centered care-giving, and provides tools to assist staff,” she said. The Isaacs spent a lot of time in training during Nandi’s teenage years. They still attend meetings and trainings to learn about new ways of providing opportunities for independence for people with disabilities. “When we homeschooled her, we really got to know her as a person,” said Isaac, and that was an important step in learning what supports were needed, and what the best delivery of those supports would be.



Nandi making a presentation at the APSE conference last summer, about her business.

Step 3 Goal Setting

“We were planning to sell our big house and so I began going through the boxes of pictures. They have traveled with us everywhere,” said Isaac. But the idea of moving the boxes again birthed an idea: teach Nandi to scan the pictures to consolidate the boxes. That led to another idea: there might be other people who need their pictures scanned – maybe this could be a job for Nandi. Nandi had lost a job and was feeling like she had less value. “I asked her what she wanted to do,” Isaac said. And a new business was born.

Isaac said, “Each step had to be planned. You have to think things out carefully and make everything very simple and build on it.” That was the process for the Micro-enterprise “Scan with Nan”. They started by taking Nandi into the Wal-Mart and Walgreens. Both provided, scanning self service machines. “First I stayed with her to help her. Then I started dropping her off at the machine and I would walk around the store doing other things until she was finished. Then, I just dropped her off and came back and picked her up.” It wasn’t a vertical upward track. “There was one time when she pushed a button and lost everything she had done. She learned how to do things by making mistakes,” Isaac said.



Nandi with Nancy Brooks Lane of Employment First GA (GAO), at an Employment First GA meeting last Oct, Purpose-To bring together several Microenterprise owners in GA

According to Isaac, one of the unexpected benefits was the socialization skills that Nandi achieved. “People in the store got to know her. She learned how to talk about her business,” she said. In 2008 they created a business plan. *SCANwithNAN* has a small client base and they are looking at ways to market themselves.

Step 4 The ‘what ifs’

“We started looking at micro boards,” said Isaac. (<http://www.gamicroboards.org/>)

This conversation started because of the experience many parents of children with disabilities have when their child becomes close to a care provider and that person moves on. This is, in a way, the mini version of the ultimate knowledge all parents live with: we won’t live forever.

Bob – The job coach. Isaac has already been replaced by one person. The Arc has hired a job coach, who now works with Nandi on her business.

“It is great to be **not** needed!” she said.

Nandi will be making many of the decisions about who will serve on her microboard. Isaac stresses that the road to self-determination is not flat and straight. Her family has borrowed many ideas and strategies from different resources and that not one program works for everyone. The main thing she has learned is: “Don’t lower your expectations because you have been disappointed.” She said that through all the years there have been many backslides, and failures, but as long as *parents continue to support and believe in their child*, they can live up to their highest potential.



Nandi with the famous John Lewis. They both received the ‘Award Of Courage’ from the Tubman Museum, at the Carter Center, ATL in 2007.

Resources:

Provided by Nancy Brooks Lane, Director, Employment First, Ga.

[Employment First Georgia](http://www.employmentfirstgeorgia.org/) -

<http://www.employmentfirstgeorgia.org/>

Employment First Georgia is a statewide resource promoting innovative, customized employment practice

[Real Work Stories](http://www.realworkstories.org/) -

<http://www.realworkstories.org/>

Real people, Real jobs. Stories from the front line!

[Start Up USA](http://www.start-up-usa.biz/) –

<http://www.start-up-usa.biz/>

Self Employment, Technical Assistance, Resources and Training

The self-employment project is a cross-disability effort that has its origin in a federal Department of Labor / Office of Disability Employment Policy grant titled "Jobs for All".

From this grant, which was originally hosted by the Institute on Human Development and Disability (IHDD) at the University of Georgia, then the Statewide Independent Living Council of Georgia (SILC) and then the Georgia Advocacy Office (GAO), and the diligent work of Ruby Moore, Executive Director of the GAO, Employment First Georgia(EFG) evolved. EFG is primarily funded by the GAO, its host agency, and the Georgia Council on Developmental Disabilities. Ms Moore brought in Dr.

Ruthie Beckwith to facilitate the development of the Georgia Microboard Association and to work with individuals such as Nandi to start their own business. This collaborative effort has resulted in dozens of individuals, including many people who have never worked before or who were not considered capable of working, starting their own businesses.
