



Building Lyn's Future Plan: Through the Lockes' Eyes

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Janet Locke tossed her books down on the counter and got up her nerve. “Hey, Mom, there is something Lyn and I want to discuss with you and Dad. You two have done so much for Lyn all these years, making sure she had every opportunity. And she has exceeded all of our expectations. But now you are climbing up there in years. Isn't it time we seriously discuss her future?”

“You know, honey, Dad and I have been thinking about that a lot lately, too, especially with our 60th birthdays coming up. I was reading the other day that The Arc has created a Center for Future Planning®. Why don't the four of us sit down this weekend and see what they can offer us?”

Conversations like this should be happening around kitchen tables every day across America. There are almost a million adults with intellectual and/or developmental disabilities (I/DD) in the U.S. living with caregivers age 60 and over. And approximately two-thirds of these families have no plan in place for the future. Yet, too often, no one is willing to broach the topic. Fortunately, Janet had studied The Arc's “[Tips for Siblings: Getting the Future Planning Conversation Started](#)” and talked to Lyn about how to broach the topic with their parents.

The Arc's Center for Future Planning® launched Build Your Plan™, an interactive web-based tool that allows families like the Lockes to think through the different aspects of future planning online, while encouraging them to reach out to experts when they need advice and guidance.

Build Your Plan™ addresses six key areas of future planning: Expressing Wishes for the Future; Deciding Where to Live; Financing the Future; Employment & Daily Activities; Making Social Connections; and Supporting Daily & Major Life Decisions.

Supporting Lyn's Decision-Making Process Throughout Her Lifespan

Lyn's family logs onto the Build Your Plan™ tool the following Saturday. Lyn suggests they tackle the Supporting Daily & Major Life Decisions portion because she knows that just like everyone else, her life involves making thousands, if not millions, of daily and significant life decisions, and she wants to make sure she is going to have the support she needs to make good decisions. Some decisions are small, like what she wants to wear or what to eat

for dinner; others are large, like managing a monthly budget or speaking with her doctor about whether to get another round of shots for her allergies.

Let's listen in on their conversation to see how this can work for your family:

Janet says: "Hmm...the Center for Future Planning® recommends we begin by identifying a trusted family member, friend or a professional who will play a role in decision-making and who will respect Lyn's wishes."

"Oh, look here," said Dad, as he scrolls down the website. "To help us get started, The Center provides us with a list of some ways that Lyn could receive support in making decisions: representative payee, dual power of attorney for financial decisions/health care, authorized health care representative, supported decision-making or guardianship."

"So there's a way to ensure that Lyn can make her own decisions, yet have supports in place for those times when she would like a little guidance?" Janet queried. "When we started this process, we all agreed we would keep the plan person-centered and focused on Lyn and her strengths and goals."

Mom says, "You're right, Janet. We all need advice from each other when we make decisions, and here we are just setting up a more formal arrangement for Lyn to get that advice. In the past, some people assumed that just because someone had a disability they needed a guardian to make decisions for them. That's just not true. We've always let Lyn make decisions and take risks, just like we let you, and we tried to talk to both of you about how to make good decisions and what to do if you made a bad one. Now we should ask Lyn whom she trusts to give her advice. On some things it may be you, Janet, but she may want to talk to rely on advice from other people on some issues."

Lyn jumped in, "That's right. Janet, you faint at the sight of blood so I don't want your advice about my health care. No offense, but I'd rather talk those things through with our cousin Jamie."

"None taken," said Janet, "now let's talk about how formal we think these supports should be. Maybe you should put a power of attorney in place – I think we all agree that with good support you can make your own decisions. Mom and Dad, I am so glad you helped us learn how to think through how to make a good decision."

Years have passed since the Locke family first gathered around their kitchen table and started developing a future plan. In that time, Lyn expanded her self-advocacy skills, gained new skills and made new friends. The family completed the other sections of the Build Your Plan™ tool and updated the plan each year. Lyn's parents retired, and Lyn moved out of their house and into an apartment with a roommate. This was a big transition, but the family

knew that they had thought things through and had a plan built on Lyn's strengths and abilities.

And your family can have that assurance, as well. Visit the Center for Future Planning® and explore the Build Your Plan™ tool [today](#).

The family depicted in this blog is fictitious, but this story demonstrates how family members can work together to build a person-centered plan for the future of a family member with intellectual/developmental disabilities, using the information and resources available on The Arc's Center for Future Planning®.

The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes. The Special Needs Alliance is collaborating with The Arc to provide educational resources, build public awareness and advocate for policies on behalf of people with intellectual/developmental disabilities and their families.

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