

## You First Podcast - Episode 16: Navigating Facility Transition

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**Announcer:** Welcome to "You First", the Disability Rights Florida podcast.

**Keith Casebonne:** I'm Keith Casebonne. Welcome to this episode of You First.

In early May, Bellwether Behavioral Health, a private company that operated the Carlton Palms Education Center and two smaller group homes in Florida announced that it was ending its operations in the state.

Over the last few years, Carlton Palms was under scrutiny for the deaths of two residents and for not complying with abuse and neglect reporting requirements, filing misleading reports of abuse and neglect, failing to comply with residents' behavior plans and much more.

Now that the facilities are closing, residents need to be safely transitioned into other settings, which will take place over the next few months.

This process can be tricky to navigate and can be extremely stressful for the residents and their families. We hope that in this episode of You First we can provide you with some information that can help you with this process.

Today, we have a panel of three guests that will give us some insight and share their stories.

We'll start with Deborah Linton, Chief Executive Officer of the Arc of Florida, who will give us an overview of issues regarding transition and provide some helpful resources.

Next, Bonnie Carr, who -- with her daughter, Sara -- went through the process of transitioning from one facility to another, will tell us her story.

We'll wrap up with Kathy Clinton, who -- with her son, Tristan -- also experienced the process of transitioning to a new facility.

Thank you all for being here today. I'll turn it over to you, Deborah.

**Deborah Linton:** Thank you, Keith. Good morning. I've worked in this field for about 34 years. I've found that, through the years, transition is difficult. Even when the individual and the family are choosing to move but, obviously, much more difficult when the facility's closing and you're really forced to leave.

I want to talk today about some administrative-type issues you can look at as you get ready to move your family member or if you're the individual that's moving, some things that may be of interest to you. The other ladies on the call are going to give a more personal view from the family view. These are just some administrative issues I'd like to bring up.

First, if you are considering transferring to an Intermediate Care Facility for the Developmentally Disabled, or what we call ICF/DDs in this system, the Agency for Health Care Administration -- we call it AHCA -- has a website where you can go and look up the reviews of the various ICF/DDs around the state.

Keith, I believe, is going to post this website link up on the podcast link on the Disability Rights Florida website. You can go up there and find it and be able to link.

When you go on that weblink, it'll bring you up and you'll see a button that will say "Search by facility type." When it takes you to the next page, there's a dropdown list of all the types of facilities that the Agency for Health Care Administration licenses.

You'd want to click on Intermediate Care Facility for the Developmentally Disabled. When you do that, immediately, this very large spreadsheet of every ICF/DD in the state will come up. You can search for the ones near you, or you could actually search for one that you've had your eye on, and that you're considering.

When bureaucracies are monitoring these facilities, they're looking at a variety of issues. Honestly, not all of them are going to be important to you as a family member or an individual.

I would think that, first and foremost, you're most concerned with the health and safety issues. You can go on there and I would click on the "More recent years." There's a long history of reviews for the facilities that there are.

I would click on "Complaints" because, generally, those are generated by their staff or the families. You can see how a facility has responded. Many times, there'll be no finding that the complaint was true but sometimes there is.

When you see something, those facilities have to respond with a plan of corrective action. I would look in their next reviews to see, did they really correct the issues that they have been cited on? That's a good resource if you're considering ICF/DD placement.

There's a second website that you can go to if you're looking at community group homes or residential facilities. These are, obviously, operated through the Agency for Persons with Disabilities, or APD as we call it.

APD has a quality assurance provider that goes in and reviews the homes for them. Keith is also going to post this website on the Disability Rights Florida podcast section of their page.

You can go on there and when you click that website, immediately, a screen comes up. You can search by just typing in the name of the group home perhaps you want to go to or the provider organization that operates it because many organizations operate multiple group homes.

Or you can do it by area of the state and it'll bring up all the group homes in that area. It will have the review results for these quality assurance monitorings that have taken place.

Again, bureaucracies have all kinds of thing that are important to them like paperwork and things that may not be as important to families. If I were a family member, what I would really want to look at would be background screening.

You'll see background screening up there and it'll say, "Four of four," or "Four of five." That means four out of four files they reviewed, 100 percent of the files they may have reviewed at that home had their background screening.

If you see "Three of six," that means only three of the staff members working would have had their background screening. Obviously, that's not allowable. That would be of concern.

There's also a health and safety score up there. The review section for these reviewers on health and safety are things like locking up medications, fire issues. It could be, are they prepared for hurricanes? Those sorts of things are important to families.

Again, you'll see their scoring will be six out of six or four out of six. It will tell you the number of times that, every time they've reviewed a single health and safety item, how that provider scored.

This is a good place to begin. I know the other ladies on the phone today are going to tell you more about other ways to look at facilities when you're considering.

Just two more things I want to bring up real quickly. One would be, I always say, "We all have non-negotiables." Those non-negotiables, like for me, is a cup of coffee in the morning. I'm going to have a better day when I have that.

Your family member or if you're the individual, has a non-negotiable in your life, maybe a couple of them.

It's important that those are communicated to the receiving facilities in group homes. They need to know that. Sometimes, when they don't, they don't know how important it is for that person to have that teddy bear within their eyesight or they're going to get very upset.

Communication is key there. If we can ever be of assistance, just let us know. Keith?

**Keith:** Thank you so much. That's very helpful. Bonnie, we'll turn it over to you. Tell us a little bit about your story with Sara.

**Bonnie Carr:** My daughter, Sara, is physically impaired. That is her major disability. She had been living in an ICF for nine years when I was ready to move to another area. It was time to move her closer. I didn't want to be two hours away.

I wanted to look for something that was less restrictive. Even though the physical part of Sara's life is very important, I had to consider that Sara is an extremely social and verbal young lady. That's what's most important to her.

She needs people that she can communicate with. She needs to be in an environment where there are plenty of activities and lots of choices. That's how she stays happy.

We looked around. I did actually look at some ICFs near where we had moved and did not find any that were appropriate. They didn't have enough residents that were able to carry on a conversation with Sara. They did not appear with the limitations of those living in the house.

I knew she would not get out and about like Sara likes to. Fortunately, we found a home that met all of those needs. In the ICF, she had 24-hour nursing. She had a PTOT. A lot of those concerns, I didn't have to worry about.

Now, she's in a different situation and those are things I have to be more aware of myself. I have lost some things by moving her over there where I need to be more concerned about the wheelchair and doing the calling myself to get things fixed.

She isn't being put in positions like she was in the ICF. They were very regimented about her getting out of her chair a certain amount of time in different positions, which is great. Sara hated it but it was good for her body.

We have lost some things but in the long run, I think that this is a much better situation for Sara. I was very fortunate to have found the place that we did.

**Deborah:** Bonnie, this is Deborah. One of the things that seems like it's really important for these families to check out is the availability of therapists, or it could be medical providers where they're being moved to, what their relationships are with those facilities and their access to them.

**Bonnie:** Sure. This has left me in a position where I have to be a bit more active in making sure these things happen for her than I did in the ICF. That was already taken care of.

On the other end, the social aspect, which is very important to Sara, is being taken care of. She's closer so it's working well.

You have to look at both sides and be aware of, for your loved one, what is going to be more important in the long run to them. I feel real good about where she is now.

It was actually a much smoother transition than I thought that it would be. It happened a lot faster than I thought we were going to be able to do. All in all, it was a very good experience.

**Keith:** Thank you so much for sharing your story, Bonnie. Kathy, tell us a little bit about your experiences.

**Kathy Clinton:** I will. Our son, Tristan, was moved to a group home when he was 13. He had very severe seizures. It was just impossible for us to watch him 24 hours a day. We moved him at the age of 13.

Over the course of his life, he lived in four group homes. We have quite a bit of experience in investigating new placements for him and the challenges that go along with that.

At one time, we did go to Carlton Palms and look at that as a possible placement for him. We decided that was not the right placement for him. Even at one point, we could not find placement and we had to move him home for nine weeks.

I certainly feel your pain and know what all of you are going through right now. I thought I'd share a few of the things that we learned along the way that might be of help, might be of things that you've thought of or maybe not.

My first suggestion is that you make sure that you have a really good waiver support coordinator who is well versed on group homes and actually has other clients in group homes.

Those waiver support coordinators are going to know the ins and outs, the good, the bad, and the ugly about the local group homes. I would highly suggest that you look for a good support coordinator if you don't already have one.

The second thing -- Bonnie already talked about -- was the access to medical care. If your loved one is medically fragile, you'll want to make sure that you're close to a hospital or the type of specialist that you might need. That would be important.

The third thing is, I think it's important to understand the dynamics of the residents in the home that you're looking at. Are they verbal? Are they ambulatory? Are they medically involved? Are they behaviorally challenged?

Based on the needs of your family member, what's a good fit for you? That's going to be different for each one of us. Ask those questions as you're investigating.

The fourth thing is talk to the residents. Now, some of the residents may or all the residents may not be verbal. You may not be able to do this.

If you do find that there are residents in a home you're looking at who are verbal, just sit down and talk with them.

Ask them, "What did you do yesterday? What'd you do last night? What do you do for fun? Do you get choices about what you get to eat or where you get to go? Do you like the staff? Are you happy?"

Don't ever hesitate to ask them something that might give you good information because they are very honest. You'll find out a lot of good things.

The next thing is, talk to staff. There will be staff there that you can get to know and pick their brains.

How long have they been there? What's their favorite part of their job? If they can't think of anything that they really like then maybe they don't like being there. Is there a turnover of staff? Have these people been here for a while?

Do they have backups for call-outs? People that get sick, what do they do about overnight staff? All those things are very important.

Then the next thing is, look. Look at everything. Do not be shy. Open the refrigerator. Look and see if there's food there. Look in the freezer. Look in the bedrooms. Make sure the sheets are clean.

Look at the meal plan that's on the refrigerator door. Look and see if there's an activity schedule. Look at the bathroom. Is it accessible for your family member? All these things are very important.

Then, the last thing that I suggest is something that we did for any time Tristan was ever in a different situation -- whether it'd been a babysitter, a new caregiver or going to the hospital.

I made up a one-page sheet that said, "All about Tristan." It told them all the things that were just things that somebody taking care of him would probably not know just looking at him.

For instance, he liked to sleep with the covers pulled over his head. Nobody would've known that. That made him comfortable. It made them not fear that something was wrong with him.

Deborah was talking about those non-negotiables. You want to put those things on there or any things that "This is how he gets to sleep easier," or, "He likes to eat his food in this order." Just anything that would make their life easier.

Those would be my suggestions from someone who's been through it a couple of times.

**Deborah:** This is Deborah. Kathy, I'm guessing you're saying really be present in that home. Know what's going on. Get to know the other residents. Know that environment and that staff, right?

**Kathy:** Definitely. I'll tell you one of the tricks that I used to use when I used to go visit Tristan when he was in a group home.

I'd drive up and I wouldn't park in the driveway. I'd go stand at the front door. I'd listen for a little while [laughs] and see what was going on in that house before I rang the doorbell.

You need to be present. They need to know that you are there and you are around and you care.

**Deborah:** One of the things you talked about -- we haven't exactly gone further into this -- but that, if it's a home where there are going to be two people in a bedroom.

Many homes, now, only have one person a bedroom, which is really a good situation. If they're going to have a roommate, you have really got to get to know that person.

Now, you will not have access to that person's personal information such as their behavioral plan, if they've had some criminal charges against them or something.

You're not going to have access to that. If you have a vulnerable family member, that pairing of the roommates is so very important. I would just stress that that's someone you really do want to get to know if at all possible.

**Keith:** Very helpful information. Thank you guys so much. It sounds like there is no one typical way that this process plays out. It sounds like it's different for everyone involved.

The best thing to do is to stay vigilant and on top of things. I love the idea of putting together a little one-pager about your child and the uniqueness of who they are and the things that they need. Those are wonderful tips.

Deborah, Bonnie, and Kathy thank you again for being our guests today. This has been very informative and interesting.

**Bonnie:** Thank you, Keith.

**Deborah:** Thank you, Keith, for the opportunity.

**Keith:** You can also get more information about transitioning and much more at the Arc of Florida's website, [www.arcflorida.org](http://www.arcflorida.org).

You can also access the links to the provider search engines that Deborah referenced in the description of this podcast at [disabilityrightsflorida.org/podcast](http://disabilityrightsflorida.org/podcast).

If you would like assistance in navigating the transition process, please feel free to contact Disability Rights Florida, toll-free at 1-800-342-0823 or online at [disabilityrightsflorida.org/intake](http://disabilityrightsflorida.org/intake).

Thank you to everyone for listening to the You First podcast or reading the transcript online. Please, email any feedback about the show to Podcast at [disabilityrightsflorida.org](http://disabilityrightsflorida.org).

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