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GLENN COYLE
HOW TO BE YOUR OWN ADVOCATE
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CAPTIONER: LORRAINE HERMAN, RPR

>> THE SPEAKER: Good afternoon,
everyone. If you could find your
seats, we will get started.

It looks like everyone is
settled in.

Welcome to today's presentation.
The title of today's presentation
is, how to be your own advocate.

So, after listening to me talk,
hopefully you will be better
equipped to serve as an advocate,
either for yourselves or, perhaps,
for another individual.

If you have your presentation
binder in front of you, our
information can be found in Section
8.

I am here today on behalf of the
Center for Independent Living of
Bucks County.

We are a non-profit, disability
service provider, who services all
Bucks County residents who has a
disability, regardless of age or
disability.

My position within the
organization is as an independent
living specialist.

It's a fancy way of saying I am
a case manager.

I provide direct services to our
consumer base, which, again, can be
at any age or any disability.

If you look in your binder,
there is just a couple things
regarding our organization, which
may prove useful to you or someone
you know.

The first flyer gives you a broad overview of who we are and what we do, which I am going to touch a little bit on today and how that relates to being your own advocate.

Our contact information is also listed on that flyer.

If you would, just disregard the contact information listed in Section 10; that's actually our original address.

If you have any questions for us, Section 8 is where you would find that information.

The next couple flyers included give you information about various activities that are offered through our office.

We have monthly peer support and advocacy meetings which can, again, help with advocacy.

They are offered in our office, offered monthly, and they are free to any community member. You do not necessarily need to be a person with a disability.

Any member can attend these activities.

So to touch on who we are and what we do, we at the Center for Independent Living of Bucks County provide four core services which, again, are offered free of charge to any of our consumers.

The first service that we provide is information and referral, which, quite simply, is an individual will call our office with a question, be it general or somewhat complex.

You may just want the number for your local Social Security Office or you might have a question about whether or not you will be eligible for a certain kind of benefit.

If we can give you that information over the phone, we will. In certain cases we may recommend that you meet with a staff member in order to best determine the appropriate way to help you.

That is information and referral.

The second service that we provide is pure support/counseling.

Quite simply, folks will usually come into our office or call into our office and we will talk to them about their current situation and see where the areas of need or if you are having just a bad day and you want someone to talk to who understands what you are going through, the majority of people that we employ are people with disabilities. We are familiar with a lot of different situations that are going on in the community so there's not a lot that you can tell us that will surprise us.

The third service that we provide is advocacy.

Quite simply, for advocacy, if you are attempting to get some form of benefit, as an example, you can come to us for assistance doing that.

You may want to come in and -- let's say you are apprehensive about calling Social Security, we can work with you so that you know the appropriate questions to ask or you know what information not to divulge to those individuals because we don't want you to be disqualified for any benefits you are eligible for.

Sometimes we coach you on the conversation so you are not apprehensive going into the conversation.

Another thing we provide is independent living skills training, which is our bread and butter within our organization.

Individuals will come to us with help, either learning or relearning a skill as a result of a disability.

So this can be something simple, I use the term simple loosely. Money management and budgeting.

It is an essential skill if you want to be independent or at least have that feeling of independence because realistically, not everyone is able to be on their own, completely.

We all need a little bit of help sometimes; that's kind of where our organization can step in and in terms of advocacy, the way I look at it is the first thing that I want someone to tell me, when they come in and they are looking for assistance with advocacy is what are your disability-related concerns?

Do you have a formal diagnosis or have you just been told you have this concern or that concern and you don't have anything on paper?

If you have something on paper, it is going to help you get services in the community, regardless of what it is that you are looking for.

And the second thing on top of what your disability-related concern is is how does that concern affect you?

Does it affect your ability to learn? Does it affect your ability to do certain things in the community?

I, myself, as a person with a disability, I am learning all of the time how my disability affects me.

There are things that I didn't know about until I was getting ready

to transition from high school to college so I am always educating myself about various things related to my disability and other disabilities in the community because we want to know everything that is included when someone says to us, I have Cerebral Palsy or I have bipolar disorder or autism.

We want to know everything that is included in that diagnosis.

Now, once you have determined your diagnosis and how that diagnosis can affect you, you want to go ahead and start to think about, okay, what are some of the things that I want or that I would like to do?

Start to look at action steps to accomplish those goals; that's one of the things that our office can help you with is setting up goals and then figuring out the necessary steps to accomplish those goals.

Now, something like getting a job, it's not as simple as deciding, hey, I want to work. There are a number of steps that you have to take before you can even get to the point where you are working.

Do you have a resume? Have you worked previously? Do you have any experience with interview skills or do you have special skills that may be utilized in an employment situation?

Those are all things that you want to think about as you are getting ready for that transition.

If folks have questions as I am going through this please feel free to raise your hand and hopefully I will address them.

>> AUDIENCE MEMBER: Hi, for the independent living skills training

you mentioned, are those one-on-one classes? Do you have group sessions?

>> THE SPEAKER: Typically they are one-on-one sessions; however, if we do have folks that have a common need that they would like to address, let's say budgeting, that's something we may offer in a group setting.

We understand that everyone learns a little bit differently and that's why we tailor our services to the individual.

We may try several approaches when it comes to teaching an individual skills, depending on how they learn and how to get them to be successful at getting started.

Okay?

Yes?

>> AUDIENCE MEMBER: I don't live in Bucks County. I live in Philadelphia. Do you have an office there?

>> THE SPEAKER: Yes. I should have touched on this earlier. Centers for Independent Living are literally everywhere in the United States and, in fact, the world.

Every county in the United States is covered by a Center for Independent Living, even if you don't have a center in your county.

The center that covers Philadelphia is one of the larger centers in Pennsylvania, it's known as Liberty Resources.

If you folks need their information, contact our office. We have a list of every center in Pennsylvania. We can even go about finding centers in other areas of the country.

Although our service may provide four core services, the other

centers provide additional services on top of the core services.

When you talk to these centers, find out what it is that they provide or specialize in.

There might be something that you can utilize that you don't see on paper. Do a little bit of research before contacting these centers to make sure you understand their services.

Any other questions?

[NO RESPONSE].

>> THE SPEAKER: Okay. Very good. Very good.

Okay. So you have a goal and you have a plan to achieve that goal.

Now you actually have to go out and start that process.

Organizations like ours can be a support system for you during that process.

As you are getting prepared to -- excuse me -- apply for benefits, let's say or you are going to transition to work or transition back to work.

I'm sure you've probably heard terminology throughout the day about that and it is certainly a complicated thing to do.

I have done it myself and I have dealt with the headache, really, of losing my cash benefits but still maintaining the medical benefit.

So it is possible, it's just not necessarily easy, like so many other things.

Our office can make those things seem a little easier or seem a little less daunting.

We are here for people, again, at any stage in their life.

You can even start working with us, and let's say you transition to

employment and you don't necessarily have a need for us at that current time.

If, let's say, six months down the road or even a few years down the road, something happens, you lose that job and you need to consider other options, you can come back to our office.

We don't stop services at any point unless the individual requests it. You can even move and possibly come back into the Bucks County area and we would still work with you or we can help you get connected to that CIL (Center for Independent Living) that you will be entering into.

I am trying to minimize the acronyms because I know there are so many out there.

We actually have a list in our office which contains about 150 acronyms that you come across.

To me, it's kind of like word jumbles with some of these acronyms.

If you get confused with any of this stuff, it doesn't matter if you are outside of Bucks County, you can still call us and, hopefully, we will be able to offer you some direction. Okay?

If you are an individual who lives, let's say, in the upper end of Bucks County, Quakertown, Telford area. We wouldn't ask you to come into our office, we would meet you at a middle ground.

So, really, there are options out there for you but the most important thing is identifying the options and getting in touch with an agency to help you do that.

Doing research on your own is a noble thing to try to do but it can be very difficult.

When I graduated from college, I had no idea about the supports to help a person with a disability find employment.

It was only through pure, dumb-luck, that I was able to find the supports, get connected with an agency like the Center for Independent Living of Bucks County.

I started as a consumer and volunteer and now have transitioned to working for the agency.

I would consider myself to be somewhat of a success story, but I am always striving to do more; that's a key component of advocacy as well.

You want to be striving to do more. You want to understand that there's going to be bumps in the road or road blocks.

The key is to find ways to break through the road blocks or navigate around that, which is another way you're office can help you with that, which is navigating to get those needs addressed.

So, whatever the needs are, most important thing is to come up with -- well, how do I want to address these needs and, as far as being an advocate, being an advocate is not an exact science.

I mean, there are some things where you are going to try to advocate for yourself and you are going to have some success and you may even have some failures, but if that does happen, you need to know, who can I go to to offer that little bit of push that I might need to get what it is that I am trying to get.

Okay?

Any time you have questions, I really think that communication is another key component of advocacy.

Whether you are working with us or working with another organization, you want to be able to communicate your needs and communicate your goals in an appropriate and effective manner.

Again, that is not -- it's not an exact science and that's not an easy thing to do and it does really entitle trial and error.

I went through it. I -- the clients I have worked with have gone through it.

When we first start and we are a little unsure what exactly sure what we are going to do for one another.

Through talking it out we can develop a plan and get started with the process of advocacy.

So it doesn't take a degree or anything to be an advocate. We are all advocates at one time or another regardless of what the issues are.

Being an advocate, when you get to a certain age, is a big component of being independent, which is what our organization is all about, helping you to be as independent as possible.

The way we look at it is, it's whatever the individual wants in order to be independent or their idea of independence.

Even if independent for them is, maybe, living in a group home or with friends or, possibly, with family.

We help them with that transition and getting that plan together.

Any other questions about what I have just gone over?

>> AUDIENCE MEMBER: You just mentioned a group home.

I had a question about independent living as far as -- I

have a young man with me that no longer wants to live at home.

I don't even know where to get started to look for alternative living arrangements.

I am not so sure he can live on his own but what is out there? Maybe semi-structured living arrangements?

>> THE SPEAKER: Depending on the area that you live in, that will dictate what the options are.

You mentioned that you are from Philadelphia so contacting the center that is responsibility for Philadelphia is a big first-step.

They should be able to provide you with options, which is what every center does is she provide you with options.

Whatever the goal is or the need is, we provide you with options.

We, at our office, try to give you a few options, five, maybe ten.

We will not give you a list of a thousand different names or even 100.

We want to make the process as simple as we can for you. When we make a referral, we will refer you to people we have dealt with previously and we know they are reliable and they can help you.

Any other questions?

>> AUDIENCE MEMBER: Yes, I have an adolescent that I am working with that is 17 years old so kind of in that transition age and still a full-time high school student who is looking for a job coach.

All of the job coaching programs that I am aware of, you have to be an adult in order to qualify for.

Is there anything for transition-aged students?

>> THE SPEAKER: Okay. Okay.

Yes, there are -- I can't give you specifics off the top of my head; however, I would recommend getting in touch with us and give us a little bit of time to develop that list of options for you.

There are services available for transitional-aged individuals.

Have you inquired at the school about what the school can do?

>> AUDIENCE MEMBER: The school right now is -- the school has him in a Vo-Tech program and are not doing anything other than that.

>> THE SPEAKER: Okay. Okay.

Most of your schools should be able to provide you with some of that information or direct you in the appropriate direction, at least in theory.

I know that certain schools tend to struggle with that; that's why people come to us as an example.

We do assist with the IEP process or even with the 504 plan.

We can help with transitional plans or if you are preparing for that transition out of high school and into "the real world", we can help you get a feel for what to expect; so that you are not just transitioning and the bottom falls out completely.

Unfortunately, many of the safety nets that are available to folks whether they are in school are not available when you make the transition to adulthood.

We try to make people aware of that because I can speak from experience, I was not aware of that and thankfully I am good at adapting so I saw a problem and was able to get help.

If you have anybody who is interested in vocational

opportunities or, perhaps, maybe going to college at some point, a lot of your colleges are very good when it comes to working with people with disabilities.

I can speak from experience that Temple University is excellent. I was very welcomed when I was there and I felt that they did a very good job of working with me while I was enrolled there.

Definitely, if you see a need at any point, you know, try to come up with the appropriate people to contact.

If you need help with that, you can contact our center or you can contact the center more local to your area.

If you do call us to get that information, we will give you the contact people within that organization, other case managers or perhaps the management within that office. Okay?

We do have good relationships with a lot of the centers, especially in Pennsylvania so, I'm sure that when we make a referral to a center, we have dealt with someone within that office before.

Any other questions?

>> AUDIENCE MEMBER: Hi, there.

I currently work, actually, for the Lehigh Center for Independent Living.

>> THE SPEAKER: Hello.

>> AUDIENCE MEMBER: Hello.

My boss is probably somewhere in another room right now, but what I want to say is what we do is amazing because I think had I known about it myself as an individual with a disability, I would have volunteered with them, I would have done everything I could because it's so

wonderful to know that there are organizations in Pennsylvania in Lehigh County here in Bucks County that work with young people to help them to achieve whatever that next aspect of transition is.

>> THE SPEAKER: I can certainly echo that sentiment.

Had our center been around when I was in college, I certainly would have utilized the services.

Unfortunately, the office was not opened until after I graduated so I didn't have access to a lot of the services that I could have been eligible for, which is why I spend a lot of my time now making sure that folks are connected for services that they should be eligible for.

>> AUDIENCE MEMBER: I am actually only -- even though I am in Bucks County, I am only about 10 minutes from Lehigh County, can you cross county lines or do you have to get services in the county that you reside?

>> THE SPEAKER: Well, we can talk to anyone from any county.

If you want to receive services from a Center for Independent Living, you would want to work with your local center.

So if you are local to the Lehigh Valley CIL I would recommend getting in touch with them.

Like I said, at a minimum they will provide you with the four-core-services and probably some additional services.

It's not listed here, but we are an employment network through Social Security's Ticket to Work Program.

I am not an expert on that program. All I know is that when I was getting ready to find employment, I was approached with

this ticket and I utilized the ticket.

I didn't necessarily see the benefit of it, but I realize everyone's experiences are a little bit different.

It is a very nice initiative that Social Security has made available. We are not experts on Social Security but we feel that we can offer you some very good direction.

It is definitely a very complicated system to deal with and I don't know if that's intentional or not -- [LAUGHTER] -- in a lot of cases you will need the help of a support system to address your needs or get in contact with an organization like Social Security.

They have a lot of wonderful brochures and information available so I definitely recommend talking to them at some point.

If folks have questions and want to, you know, discuss them on an individual basis, you can always call our office or if you happen to be a Bucks County resident, you can stop by and see us.

I will be available during the Meet and Greet session. Once you have will an opportunity to let the information sink in some other things may pop into your head.

A lot of you have been bombarded with information today and can't think of all of the questions that you have; that's certainly understandable.

It's been a long day for everybody so I just hope that the information that's being provided is valuable and useful at some point and as I say, even if you cannot work with our office, contact us and

we will let you know what other offices you might be able to deal with. Okay?

A good way to judge whether or not you are being an effective advocate is giving yourself a timetable to accomplish your goals, which is something that our office will do for our consumers is give them a timetable to accomplish their goals.

At a minimum, we look at goals in six-month intervals. Certain things we understand when talking about independent living, as an example, are not going to be accomplished usually within six months.

So we will want to look at where a person is after six months, see whether they've progressed or not.

If they haven't, can we do anything to help them progress, even if it's a little bit?

Like I said earlier, we don't go away at any point.

Once a person has started working with us, they stay with us.

Your information will stay in our system forever, at least that's the way that I see it. Okay?

When people ask us for our opinion, I ask speak for myself and everyone else that I work with, we will be 100% honest with you. We don't push any one agenda, which I feel is very important.

We let you know what are the options that are best-suited for you.

We don't want to set you up to fail through our office; and that's a key component of advocacy as well, not setting yourself up to fail.

So when you look at what your goals are or what your needs are,

you want to think about them in a very realistic sense.

We have some people who come to us that are very ambitious. They would like to be rocket scientists or a surgeon of some kind and through talking to them, maybe that's a goal that's perhaps a little too ambitious for them.

So we may work with them to find other alternatives.

If it's something they are truly passionate about we can find something closely-related.

We are always willing to be flexible. We hope that the folks we work with are willing to be flexible.

>> AUDIENCE MEMBER: I just had a quick question. I think I am loud enough.

I had a question about -- I work with kids who -- up to the age of 22 who are on ventilators at home.

I have a girl in Montgomery County to start -- she can paint and she wants to do --

>> THE SPEAKER: Using Bucks County, for example, if you are an individual who wants to start their own business, there are resources available.

Small business seems to be an essential component of any community. There are always resources out there.

I would definitely recommend, even if you are outside of Bucks County, getting in touch with your local center and seeing if they can connect you with who is a small business professional within that community.

You can even outreach to some of the small businesses in your community or the Local Chamber of

Commerce.

We have a great relationship with our Chamber of Commerce. They are very helpful to people who are looking at a small business option.

No questions?

[NO RESPONSE].

>> THE SPEAKER: I must be doing a good job.

I could go on forever and, trust me, I have in the past.

At this point, just to summarize everything, advocacy, it is not necessarily a simple thing to do so before you are preparing to advocate for yourself or on behalf of another individual, you really want to do your homework and -- for some of the non-traditional-aged individuals, homework is a difficult term to hear.

You are always going to have homework, regardless of what age you are.

Even if it's something small, making a list or phone call it's still technically considered homework.

We hold our folks accountable for the needs that they are looking to address so if a person is not progressing at a level we feel they should be progressing at, we will have that conversation with them. See if this is something they are truly interested in doing.

There are some people who come into our office, they are very ambitious, they are very gung-hoe. After a while maybe those feelings die down and we just offer encouragement or reinforcement.

Hey, this is what you agreed when we first met. If they decide our agency is not right for them, well, we will want to find out,

okay, where are some other places that they can go so that we assure that they are getting the proper services or are working on those needs and, it seems no matter how many times we tell people to be proactive, there's always people out there who, for whatever reason, are not able to do so.

So if you do find yourself in a situation where you are in need of assistance, even if it's not technically a crisis situation, I recommend asking for help. Okay?

Asking for help is a big part of advocacy. To not be afraid to ask for help.

I myself was apprehensive about asking for help, when I was looking for employment, you know.

A stubborn male, I thought I could do everything on my own; it's not the case.

I wish that it was.

If you are in need of services at any point, make sure you ask.

If you need help, speaking to the right people, get in touch with us or get in touch with your local Center for Independent Living, we provide services to people with disability disabilities; that is what we do; that's what we have been mandated to do since the passage of the Americans With Disabilities Act since 1990.

Our office is a non-profit. We do not charge for the core services that we provide, even for you to call us.

You can call us 100 times a day, if you really feel that is what you need to do. If anything we will talk to you, okay?

We are available Monday through Friday 9 to 5, if you call us after

hours, generally we respond within 24 hours.

What is nice, right now, we don't have a waiting list for services. So if you call us and you come in and meet with us, your enrollment -- you become a consumer right away.

You go through an in-take process, we identify your needs or your goals and we educate you about who we are and what we do.

And then we do our best to develop that plan to help you to provide those services.

Every person has the right to pursue whatever it is their goals are. We help people do that.

I hope that through listening to me talk today, you will get a little bit of a better understanding of advocacy and what goes into being an advocate.

If you need reinforcement at any time, I am readily available so feel free to call me or if you visit our website, you can even e-mail me. Okay?

I am usually available so I would be happy to talk to anybody here about their needs or about their goals. Okay?

You don't have to go through any of this alone. If you do go through it alone it's a very difficult thing to do.

We don't want people going through things alone. Just know that there are always people out there that can help you. Okay?

Any other additional questions at this point?

[NO RESPONSE].

>> THE SPEAKER: Okay. Again, I will be available at the 3:00 meet-and-greet.

Just a reminder about the survey. If you would please fill out the survey, which is in the back of Section 8, I'm sure the folks here want to know how these presentations went and I essential appreciate your feedback as well. So if you see me walking around here and you have any suggestions for me or any questions for me, let me know. Okay?

I take criticism very well. If you have any -- I hope I didn't speak too quickly and didn't use any terminology that is above anybody's head.

I try to speak simple terms at all times.

Again, thank you very much for participating.

[APPLAUSE].

>> THE SPEAKER: If you just want to hand your surveys to me on the way out, I will collect them.