SIERRA ROYSTER: Yeah.

So, Kings is getting ready to talk a lot about parent involvement.

When parents come to the table, they've been talking about their child for years, right?

They know all their favorite foods.

They know where they want to go on their travel destinations.

They know those things.

But what about the new dreams and ideas where they're like I don't know.

Or that's something new I've never heard my youth say before.

Those squeegldoors and those shumalakas.

Who can talk best about that?

You can talk best about that.

We have to be able to listen and hear what the other person is saying.

And for a lot of you that was taking notes about a complete stranger and making sure you heard all of that.

And we really want to encourage you guys as you're working with parents and youth to do that, of course.

We should always do that.

But also encourage parents to do that when they're listening to their young person.

Let them actually hear what they want to say.

And then vice versa.

Sometimes our youth need to hear where the parent is coming from, too.

That wisdom piece that we were talking about yesterday.

Doesn't mean they have to follow it, but they can hear it.

Really kind of working together.

But it all breaks down to that communication.

And we feel warm and comfortable and cozy when talking about something we know.

And then when it starts to get uncomfortable is when it gets good.

That's the good stuff.

You want to be in the uncomfortable spot.

KINGS FLOYD: There's also a willingness to understand that comes with listening.

Are you willing to understand something that you don't yet understand.

So keeping that in mind when talking to parents, keeping that in mind when talking about youth.

SIERRA ROYSTER: Perfect.

All right.

If you need to go back, I will make you unsqueegle your doors.

KINGS FLOYD: All right, guys, we're crunched for time.

Please let me know if need to slow down.

We are going to wham bam thank you ma'am through parents and youth transition.

So I was tasked with coming up for the secret allies of youth transition.

Because that is what I believe parents are.

So first, we need to recognize this, and I need to say it because I am a youth, but it's also really important for you guys to know.

This presentation is meant to provide you with an added resource for youth with disabilities in IL.

It is not to make you forget that there is power in the youth.

There is power in the youth movement, and they are their own advocates first and foremost.

They are also, parents are also not a consumer.

They're a resource for your consumers and they might be consumers if they are parents but keep in mind who you're focusing on when you're providing these services.

This is a quote directly taken from the NCIL website that said independent living means that we demand the same choices and control in our everyday lives.

Parents are not necessarily going to make those choices for our youth, and it's important to keep in mind the balance of that.

So, getting in the door.

Parents may provide potential transportation for their children, they may provide permission slips for centers if they are under 18, getting into schools, working with other organizations, and they also might provide detailed notes about their child's strengths, their weaknesses, their disability.

They also might not provide that.

You have so many different levels of parent engagement.

So parents don't necessarily provide a warm and supportive, accepting environment for their child.

They may want nothing to do with their child or their disability.

They may not have definitions for their children's disability or goals.

You should not let a parent completely define your consumer's goal if that consumer is a youth or an adult, but specifically someone who is trying to make their way and create their own identity.

They're also not going to provide a step-by-step instruction on how to make their child independent.

Some parents, if they are a helicopter parent, may try and make that step-by-step instructional guide.

You should not let them.

Make sure you are always involving the youth while you are involving the parents.

So some parents may come into your office and say, we have so much information.

We're so well informed.

We need this this and this from your center.

That's it.

Reality of that happening?

Probably slim.

Here are some of the things they are probably going to want to know.

They may be coming to you first.

They may be coming to you last, but it's still good for you to have the information on hand so you can share with them.

What is an IEP?

What does it involve?

How do I get one for my child?

What is IL?

How can they support their child in the IL philosophy?

What is the IL philosophy?

What are other resources such as voc rehab and other community supports?

How can I support my child as they transition out of school?

What are the things that I can be doing as a parent proactively to help support my child?

What is disability pride?

How can I encourage this?

How can I make my child feel loved and special but also proud of who they are and proud of their identity?

They are probably going to want to know about internship programs and employment programs.

Adaptive driving programs, if that's one of their goals.

Other transportation options.

Also, the dignity of risk and loss.

This has been mentioned a couple of times today, but parents don't naturally want to see their child fail.

That is still a great teaching technique.

And so you need to make sure that parents understand that this is a learning experience not only for them, but for the youth as well.

So, how do we reach parents?

How do you reach parents to reach youth?

Some suggestions are getting in touch by talking to your schools, getting on to their website.

If they're under 18, uploading a permission slip so they can come to your center so you can talk with them.

So if they need to go offsite for a driving evaluation or something, you have permission from the parents for that.

Getting in the newsletter.

Reaching parents through, you know, e-mails through the school or e-mails through other community oriented events.

Speaking with the parent teacher association.

Great, off the bat.

Say hey, we'd love to present at one of your meetings.

When's the next one?

Can we do that?

Outside of school, contact community centers with parent groups, YMCA.

If you have different community centers, different youth groups, church groups was mentioned before.

And reaching out to disability organizations that CILs / SILCS have ties with.

If I am not saying anything right now and you have a tie with a business or local organization in your area, reach out to them.

How to support parents who in turn support their youth?

Talking to them about the IL philosophy.

What is IL?

What are you providing?

What are the goals?

What is the whole power behind the movement?

Many parents have concern for their child's success.

So remind them of the growing and changing terminology.

Many people prefer different things in terms of regarding relating to their disability.

So what does their child prefer?

Create a parent peer-to-peer support group so that other parents of children with disabilities can be a resource to each other.

Some parents, especially if their child's disability is relatively new, or they don't know how to understand that, find great value in talking to other parents who have children even with completely different disabilities, about how they're handling it, about how they're coping, and cool tips and tricks.

How do you, like, you know, where do you buy equipment?

Where do you get services?

Little things to big things can add up and they really find value in this.

The same way you reach out to your consumers, tailor your style of communication to parents.

Some parents are going to have absolutely no idea about the terminology such as IEP, such as OVR, you know, pre-transition employment services.

So what does that look like in tailoring your language and your tailoring you communication style?

Everyone is going to have a different communication style.

Creating space where they feel their child is comfortable and getting help and resources.

This is especially important for parents whose youth are still under age.

Are they comfortable in your center?

Are they comfortable with you providing their services?

Referring them to school resources such as guidance counselors, special Ed coordinators, local colleges programs and campuses.

One of the best things my parents did for me, my parents are wonderful by the way, shout out to mom and dad.

About getting me involved was, getting me involved with older people with disabilities in my area.

That is incredible.

My parents wouldn't have known that if they didn't reach out to the disabled community and say, hey, what can we do?

That's really important for you to provide, even just like ideas or suggestions for parents.

Resources that you can use specifically are the peer support groups, like I mentioned.

Try to include the IL philosophy in these events versus special needs parents.

That is not the IL movement.

That is not the IL way.

We are not looking to provide, you know, inspiration porn.

We are looking to provide support and services.

So parent engagement centers and family engagement centers, those are kind of region by region.

Some of them are in your area, some of them may not be but it's an added resource.

Most states have a family engagement news and contributions form.

And what it is, is it allows parents and different organizations to upload basically an online newsletter to talk about what services are in the area, what activities are going on.

That's super tailored to location, and a good way for parents and for CILs to get involved.

Potential mentoring with a similar disability in your CIL and SILC.

If you have a young person that comes in and says I have XYZ disability and I'm a little bit lost, setting them up as a youth and then the parent as well with a possible mentor in your area that says okay, they have similar struggles.

It would be a great opportunity for them to have a positive influence.

So my mini equation for success is engaging schools, engaging parents, engaging youth or students, and IL services equal youth transition.

KINGS FLOYD: Thank you.

I can have questions.

Does anyone have any questions?

AUDIENCE MEMBER: My name is Sue Fager, and I work for the Colorado Developmental Disabilities Council.

I've had my foot in two worlds for a very long time.

One world is parent trainer and sibling of a big brother who lives with a significant disability.

The other world is independent living.

And I was a little disappointed, frankly, to see the slide that talked about what parents don't offer in terms of support for their young people.

That might be true for some families, but I don't think it's true for a lot, though.

So I really encourage you as you begin thinking about reaching out to families if you're not already doing it to engage families one-on-one and find out their special education journey.

And think about what special education teaches families.

It's not a strength based provision of service.

It's deficit.

So families grow up thinking about their young people in the medical model.

These kids are broken and we have an IEP to fix them.

Families spend a lot of time advocating for their young people, and in that way, I think center staff and families are similar.

They've got that advocacy journey down.

So I encourage you to reach out to families and talk with them and ask them to share their stories like Rick was talking about so eloquently at lunch today.

There are stories out there and I really want to see CILs and families collaborate better than we have in the past and to move away from this we're hitting heads.

Families won't let their kids be self-determined.

They just don't know how.

That's the beautiful thing I think independent living centers can bring to families is we've got the resource that you need.

We've got adults living with disabilities and families need to know how to dream and advocate for that.

Okay.

I could go on, but I'm not going to.

So thanks, everybody.

AUDIENCE MEMBER: We've run into a few parents who are completely disengaged at this point.

If anybody has tips about how to get them re-involved, it's, I can give a real quick example of a mother and her daughter and the mother was on the phone texting not wanting to be involved.

It was just a discussion.

It wasn't an IEP meeting.

KINGS FLOYD: Does anybody want to respond to that?

AUDIENCE MEMBER: Was this a discussion at the school?

How old was the daughter, if you don't mind me asking?

She was about 16.

So I'm just wondering if maybe that was just the parent's way of trying to let her be, you know, more independent?

I don't know.

JOE MICHNER: I think we've all had experiences like that.

JI remember a parent telling us I've taken care of my son for the last 20 years.

Now it's your turn.

It's sometimes a thing we face and the best thing we can do is support the consumer, right?

Support that young adult in the best way we can and maybe provide other resources.

It's heartbreaking but at the same time, I think it's a reality we've probably all faced.

AUDIENCE MEMBER: I have had similar conversations with families, and I think I try to operate from the place of assuming that anyone I come in contact with at any given moment is doing the best they can do in that moment, so to reserve the judgment and reserve how I might handle the situation or how I assume they should be handling and advocating for their child, because I don't know all of the steps that they have walked in their process with the child.

In that situation, perhaps following the meeting I would outreach to the parent and connect them to support resources and see if there is anything in their particular life that they need support for.

Because a lot of our families, parents have disabilities themselves that are not, they're not receiving any types of support for those, things that would make their life easier and make them more successful.

I think to try really hard to reserve judgment when it would be really easy to be like, what are you doing?

Get off your phone! AUDIENCE MEMBER: I very much appreciate the last comments that you just made.

Thank you.

As a parent of a child with a disability who's 26, I entered the IL movement when she was 13, actually 12.

I kept hearing the word "transition.

" I had no idea what it meant and I kept hearing it from every single person who was in her life at that time in the school system.

I went to the special ed director and I said tell me about transition, I need to learn.

Tell me, I didn't know.

And she proceeded to reach up on to her top shelf, dusted off a three-ring binder and handed to me a thick three-ring binder.

Handed it to me and told me to go home and read it.

That was my education.

I passed the Freedom Resource Center, which is the center that I now work at, and I'm like I got to stop there because I knew a person who worked there, did not know what it was.

And I cried for two hours.

That was my introduction.

So without a center for independent living, I don't know where she would be here today.

I'm going to stop because I'm going to start to cry.

But parents don't have the education they need, and we're here to give it to them and the support.

So no passing judgment.

Appreciate that.

Thank you.

AUDIENCE MEMBER: With working with parents, one of the issues I've ran into at my particular center is we've got some referrals of young folks who have turned 18 and they've been placed under full guardianships, and their relationship with their guardian is very combative.

The guardian and the consumer completely disagree about what they want for their lives.

As much as possible, as an advocate, I want to try to resolve that without someone losing their natural supports but at the same time I feel very limited as an advocate in some ways with the way those rights have been removed under the guardianship and I don't know if anyone had any advice.

I always try to give the guardian the benefit of the doubt and things like that.

But still, it's so difficult to work through those situations, and I haven't had much success.

TIM FUCHS: Time for one or two more comments or questions.

AUDIENCE MEMBER: I wanted to respond to the earlier comment about a parent that was texting during a discussion, and having been in the IL movement from way back when, a lot of parents have had to fight with the school system for access for their children and I just wonder if maybe at some point they're so alone and so exhausted that it was maybe a cry for help, too, in kind of an odd way, but just they didn't have any more ideas or any more resources and were hoping for some support and help.

TIM FUCHS: I saw two hands at the same time.

Here.

AUDIENCE MEMBER: I was just going to say that I know sometimes I'm on my phone when I'm trying to think, or sometimes when I don't want to look at the person I'm talking to.

So maybe it's more of a coping mechanism than actually that they don't want to be part of the conversation.

AUDIENCE MEMBER: I work with parents all the time.

I have a support group for parents, and a lot of times they just have battled the school systems and they get to a point where they just feel like it doesn't matter.

And like an IEP is just not valuable and they're not actually being heard and nothing is going to happen and the kid has had the same goals forever, and so they, I can see where somebody might tap out and be like this isn't going to matter anyway.

They're not going to listen to what I say.

They've never listened.

Maybe.

TIM FUCHS: Great discussion.

I see some hands.

We're going to have to move on.

This reminds me so much of some of the conversations with the aging community, right.

That a lot of us are dealing with the same issues and there's real chasms in terms of language and sometimes even philosophies.

We need to remember what our values are and not sway from that.

But I think it's important to give people a lot of leeway in terms of where they are and what language they might use.

And sharing our philosophy and our perspective, because that might be all it is, having that conversation, finding that common ground and going from there.