

FASD DIGNITY: MY AGENCY... JUST LET ME TRY IT

Marleny Bonnycastle, Ph.D.

So, you know...?

...There is a risk of overprotecting individuals with FASD while we support them in a way that they cannot exercise their autonomy and making decisions about their lives. Unintentionally, healthcare, education, social services, family, friend, community might contribute to reinforce dominant FASD narratives that led to the dismissal of their capabilities and control.

1. How do societal attitudes and perceptions towards individuals with FASD influence their sense of agency and self-efficacy?
2. How do support systems and interventions empower individuals with FASD to have agency and advocate for themselves and pursue their goals?

Overprotection may undermine individuals' agency leading to feelings of inadequacy and might contribute to stigma in FASD...

"I'm not saying that we should push people to go beyond their capacity but there are people who are willing and able to go beyond. And there needs to be some acknowledgement of people who want to take those opportunities."

Lack of space to take risk

Lack of understanding

"...with a woman who is using substances in pregnancy... we might not have that full understanding of what her life is like... I hate that term 'at risk' or 'risky decision', or 'risky person', I don't like that."

Underestimate their capabilities

Overemphasize disability

Lack of space for freedom

"...with stigma and dignity, I guess I treat myself terrible when it comes to [having an opinion], because I don't really show who I am..."

"I think one of the other things that come to mind, people with the diagnosis are often imposed with limitations, we don't expect them to aspire to anything beyond an average accomplishment and that's false."

"Frustration as we know is the on-set of a lot of negative things like anger, resentment... if we can avoid that and working with them in bite-size chunks, breaking it down, compartmentalizing some things... everybody needs that dignity. Everybody's got to be able to have some form of control of their life..."

*Let's talk more about... dignity

"I think essence of agency is important to understanding dignity. So the ability to make free choices and of course understanding with dynamics of marginalization and other forces of I guess power and lack of power in society, free choice isn't always free choice."

Agency

Giving space to make decisions

"When you're planning for somebody... where do they want to go to school? Where do they want to live? What kind of programs do they want to take? Instead of making the decisions for them, have whoever you're working with be an active participant in their life..."

Power to make decision

"We can't prevent people from taking a risk... or making a decision in their lives that we might see... oh that's not what I would do. But who are we to say?... So, allowing people to say,... you understand it better than anyone else, I can't presume to understand why you might be doing a thing that you're doing, or the different things at play there."

"...empowering them to come up with and respect the choices that they've made, and support them in that provider that is not harmful, but beyond that to say OK that's a yes, that's how you feel you can best deal with this then now what can we do?"

Empowerment

"In relation to people with FASD, I think with dignity... is to allow them that freedom to make choices, to explore, to find what else is out there..."

Freedom