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"YOU HAVE TO CARE:" PERCEPTIONS OF PROMOTING AUTONOMY IN ADULT SUPPORT SETTINGS

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KEY TAKEAWAYS

* We must consider how paid support services promote autonomy.

* Promoting the autonomy of people with ID can be a challenging endeavor.

* The barriers to promoting autonomy may stem from organizational or policy goals.

SO WHAT IS AUTONOMY?

- self-determination
- self-advocacy
- choice and decision-making.

BUT MORE THAN THAT...

"What makes a life one's own" (Saadah, 2002, p. 979).

Support services should increase autonomy, but they may actually decrease autonomy (Barron, 2001; Stainton, 1994).

"Freedom from both internal and external constraints, to formulate and pursue self-determined plans and purposes (Stainton, 1994, p. 21)."

Autonomy should only be restricted when it leads to greater autonomy (Stainton, 1994).

WHY AUTONOMY?

International Context

"Autonomy, conceived as a basis for participation, is the ultimate aim of rehabilitation" (Cardol, De Jong, & Ward, p. 970).

Need Autonomy

Need Support

Goal of Support

People with disabilities, even sometimes significant disabilities, are capable of self-determination and self-advocacy.

(Source: www.lcdisability.org)

Support workers might not present opportunities for choice.

(Source: www.carp.ca)

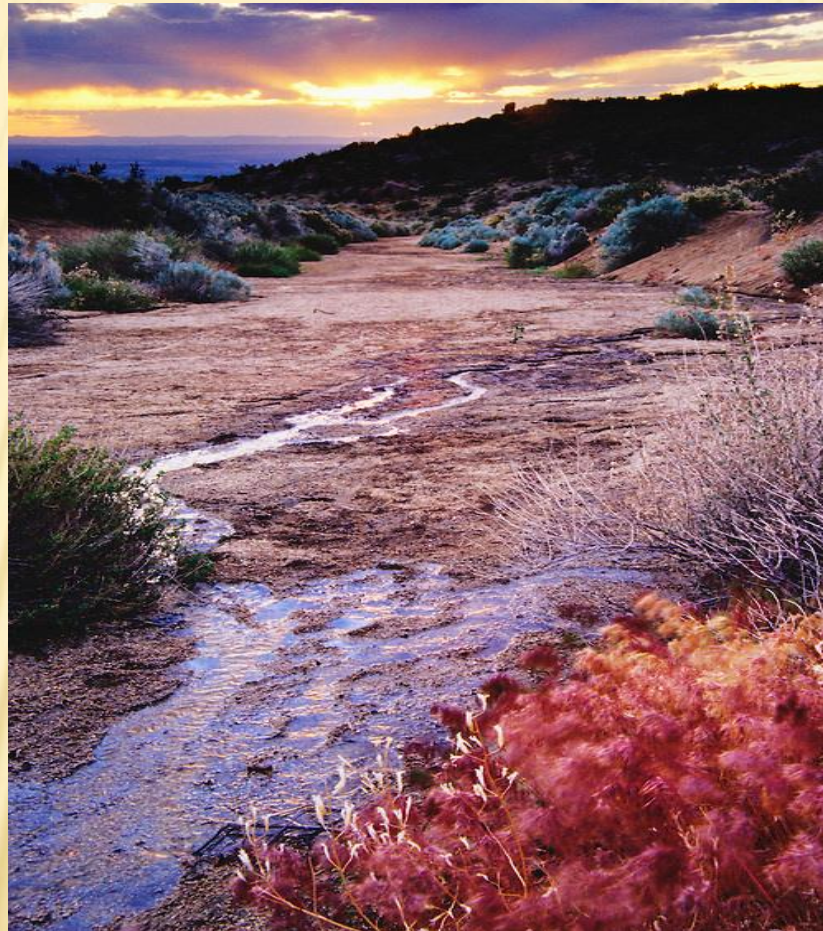# People with more significant disabilities make fewer daily decisions.

(Source: www.lateralfilms.com)

Even efforts to increase choice in paid support situations can sometimes be problematic.

(Source: bloom-parentingkidswithdisabilities.blogspot.com)

NEW MEXICO SUPPORT SYSTEMS

(source: lange-photography.photoshelter.com)

RATIONALE

There is limited published research on how interactions between people with ID and support staff can promote or hinder autonomy, and none examining both perspectives of people with ID and support staff directly about autonomy.

- Healy, McGuire, Evans, & Carley (2009) Sexuality and personal relationships for people with intellectual disability. Part I: Service-user perspectives.
- Bernert (2011) Sexuality and disability in the lives of women with intellectual disabilities.

- Peter (1999) The client role: A help or a hindrance?

- Levinson (2010) Making life work: Freedom and disability in a community group home.

- Nonnemacher & Bambara, 2012"I'm supposed to be in charge": self-advocates' perspectives on their self-determination support needs.

TALKING ABOUT AUTONOMY

- 10 support workers and 10 people with ID
- 20 initial and 6 member checking interviews
- Semi-structured private interviews
- Grounded theory analysis

(Source: http://theclaimsspot.com)

BEING AN AUTONOMOUS PERSON

- Participants with ID were able to articulate their plans, ideals, and values.

- Participants with ID discussed how the advocated for themselves and other people with disabilities

"I wanna do a good I-good things in my life. I wanna get a job. I wanna make money, and when I go to a group home, I wanna be independent"

"I talk up for myself and my roommates. I got a staff, one that wasn't quite right for this home switched to another home."

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SUPPORT... IT'S COMPLICATED

"we do everything... give them their meds, we feed them, we clo-, we help clothe them, we make sure they're safe, if there's health issues, we make sure we contact the nurse. Um we offer friendship, we offer companionship with them"...

"In order to keep the professional line, you know, there's a certain amount of relating that I cannot do with my staff just because we want to keep things professional."

DEMONSTRATING CARE

Both support workers and people with ID discussed how important it is to demonstrate care within their interactions.

''I feel like we're in their homes. We're with them… almost every day and we should be… respecting them… I see staff that come in… and they're just here for a paycheck… This isn't a field for that.''

"Maybe they [support workers] don't intend to lecture me, but they do... if they're too outspoken sometimes they can get really you know... this whole shrinking me 6 sizes kind of thing."

"I felt like an equal with her [a support worker]... I never felt like she was there to do prompts."

"I know we don't supposed to hug or or be friends be friend with em or whatever, and and it's really hard… not to feel some kind of feelings for them… it's so hard not to care. It's just, that's hard."

(Source: www.flickr.com)

CONTROL AND COERCION

''You know like the world view of the staff... their [people with ID] behaviors are controlled in this particular way that has been established over such a long period of time, that it really feels that the staff's world view... is kind of taught to the individuals... The world is filtered through what the staff thinks... they have so many staff too that they get a lot of world views.''

"I tend to tell em 'I'm here to assist you, and you know, now this is your home. This is your home and everything, and I have my home, and I keep mines up to par-tay [clean and orderly], and this is yalls'. And I'm here to assist you in whatever way I can, in helping you to keep, you know to keep your house..."

"That's part of some people's personalities. They like to be organized. They like things clean and tidy. I don't give a rat's butt about stuff like that sometimes."

SUPPORTING CHALLENGING BEHAVIOR

"It's just kind of mentally draining too, just uhm always looking for triggers, and looking for, always observing their behavior to see, you know are they escalating or are they… in a good state?"

Support workers often described supporting people with challenging behavior that made their work difficult.

(Source: www.guystuffcounseling.com)

''I would not want people to be telling me what to do, every single thing... when these guys have some behavior you know I could understand it... if someone did this to me, I'm going to do something else, worse.''

"Maladaptive behavior" might actually be rational behavioral responses to a "maladaptive environment" (Goodley, 2001, p.215).

PROMOTING HEALTH AND SAFETY

A staff member said she weighed "that balance of letting them [the people with ID that she supports] have their lives, but also trying to keep them from hurting themselves or making themselves sick."

Promoting health was important to support workers and seemed to also be in line with organizational and policy goals.

"The policies are structured so we're ensuring the health and safety of the individual."

"Those are restrictions that we don't, you know, like me and you, we don't have. I wanna be a pig and have high cholesterol and high blood pressure, I can. No one's going to restrict me. Them, you know, we try to monitor and keep them under, you know, on a healthy level."

(Source: pizzarules.com)

MANAGING ORGANIZATIONAL CONTROL

Often the issues that prevent DSPs from promoting autonomy stem from issues that are outside of their control.

(Source: mortgagegroup.ca)

"I'm just against how it's [the individual support plan for support services] set up, and like how we have to write the… goals and the outcomes and everything, and it's like everything is turning into this big ole bureaucratic government thing, when it should be… if it's person centered, then it should be person centered."

"it seems ultimately like that's all that anybody cares about, that the outcomes sheet is checked off [a way to monitor that goals are being worked on so that agencies can continue to receive funding]... And it's like well if someone cooks twice a week, is that really them having a meaningful life?"
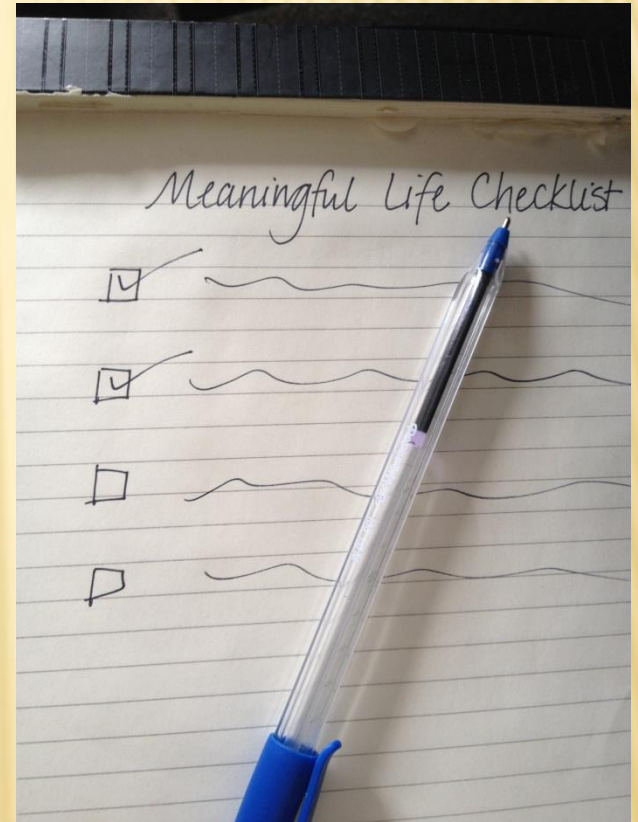
"One day we have art class, so we do art a lot. So I don't do art anymore, and he [a day habilitation support worker] says we have to keep going we have to keep going. That's the goals. We have to keep going and trying to make it up."

(Source: www.fiberarts.com)

ORGANIZATIONAL GOAL PRIORITIZATION

(Source: http://tootiecancook.blogspot.ca/2012/05/what-do-you-do-when-your-day-doesnt-go.html)

Questions/Comments/Conundrums?

Thank You!