

WHY RETURN TO WORK?

Consumer Perspectives from the SGA Qualitative Study

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OVERVIEW - SGA QUALITATIVE STUDY

- **Follow-along study** to the SGA Model Demonstration Project
- **Purpose:**
 - Gather experiences and perspectives of VR customers who are SSDI beneficiaries
 - Understand how these customers make decisions about employment

OVERVIEW - SGA PROJECT

- Funded by the Rehabilitation Services Administration (RSA)
- Model Demonstration – MN/KY VR
 - ↑ Pacing, Benefits/Financial Counseling, Job Placement, Coordinated Team Approach
 - RCT – split by VR office
- Sample
 - ~2300 SSDI disabled worker beneficiaries (non-blind), VR customers, 18-64

Learn more: **“Helping VR SSDI Recipients Achieve Success”**
tomorrow, 1:00-2:30, in the Winnebago Room

RECRUITMENT, SAMPLE, & METHODS

Recruitment:

- Recruitment packets mailed by state VR agencies

Sample:

- 48 VR customers (25 from KY, 23 from MN)

Method:

- 1-3 Qualitative interviews

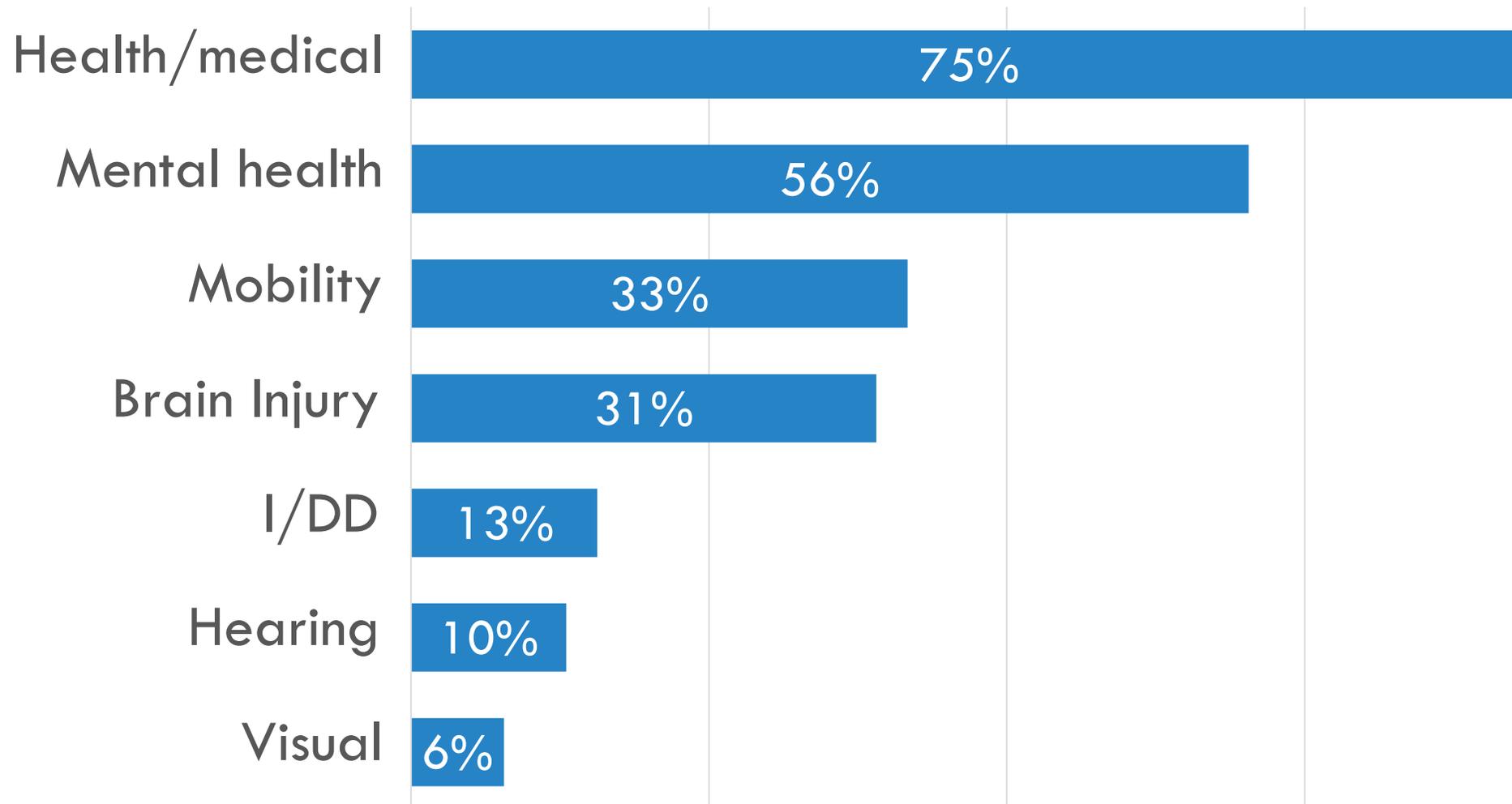
INTERVIEWS CONDUCTED

	1 st Interviews	2 nd Interviews	3 rd Interviews	Total interviews
MN	23	20	10	53
KY	25	20	9	54
TOTAL	48	40	19	107

PARTICIPANT DEMOGRAPHICS

- **GENDER: 60% Female, 40% Male**
- **AGE: Range 26-65, Median 51**
- **RACE: 21% Black, 77% White, 2% Latino**

PARTICIPANTS: DISABILITIES



PARTICIPANTS: FAMILY/LIVING SITUATION

- 25% Married
33% Divorced/Separated
42% Single
- 17% Have Kids under 18 at Home
- 46% Live Alone

RESEARCH QUESTIONS

- What are the experiences and perspectives of VR customers with SSDI?
- How do they make decisions about working?

SSDI & other Benefits

Family



Transportation

DECISIONS
ABOUT
WORKING



Disabilities

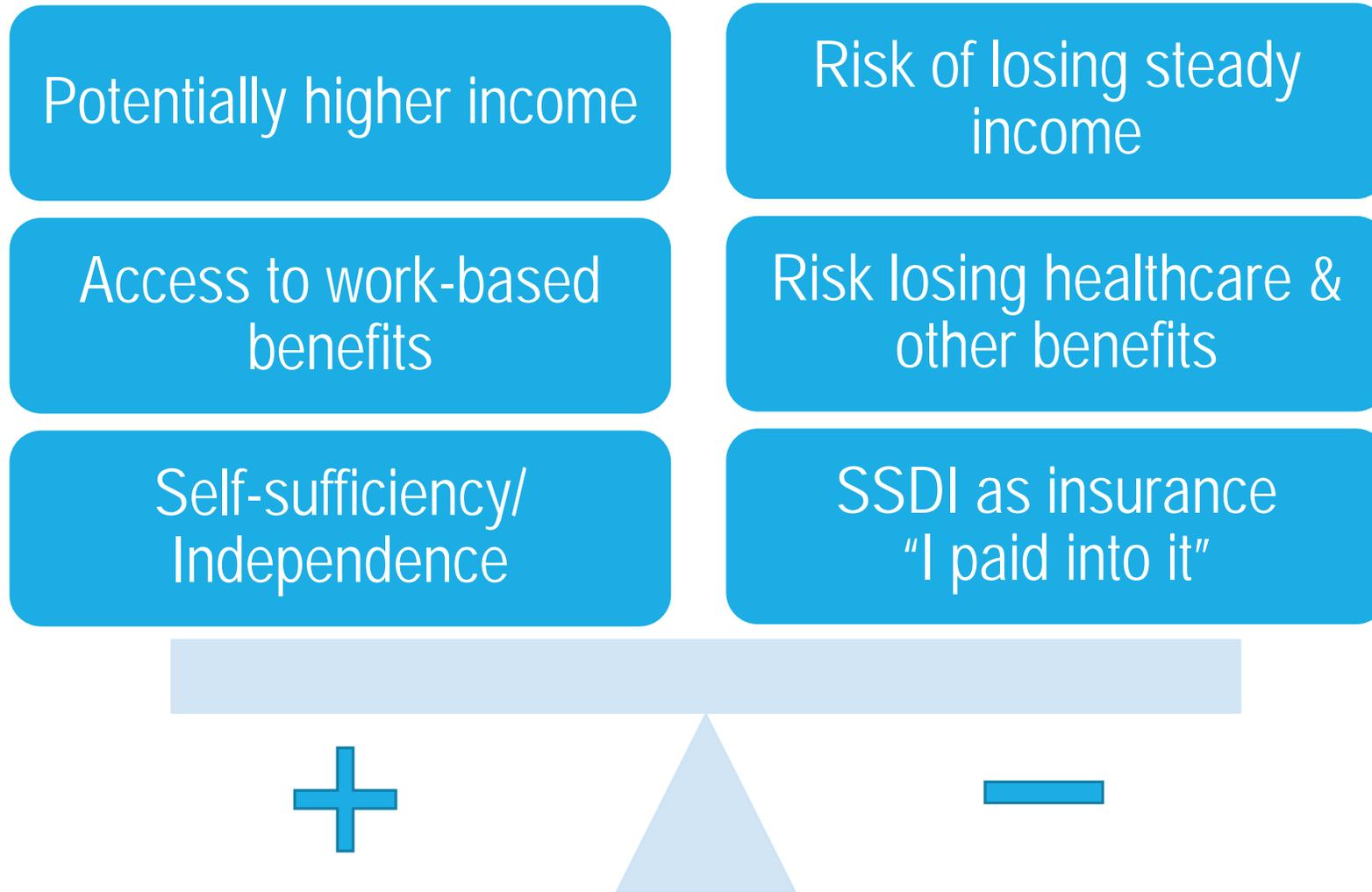
Being Active
/Social



Meaning of Work



DECIDING TO WORK: SSDI/OTHER BENEFITS





DECIDING TO WORK: DISABILITIES

Improving, in remission,
or better managed

Unpredictable/frequent
relapses, med appts

Belief that working
improves mental health

Fear that working too
much will damage health

Wanting to be more than
a "disabled" person

Stigma/discrimination,
fear of disclosure



F, 60s (KY): “FEELING GOOD ABOUT YOURSELF”



“When you’re disabled, it’s nice to think that **you’re still capable of doing work** and feeling good about yourself by helping a company or helping a doctor’s office or running a register and just greeting people, just talking to people. It makes a disabled person **feel good about themselves**, and it gets them to **forget about their disability for a while.**”



F, 40s (MN) “IF I HAVE A BAD DAY”

Unpredictability: “Really, my main concern is if I have a bad day--I get really bad days--can't get out of bed or do anything. And I'm really afraid that if that happens, what my consequences might be.

Disclosure: “I'm a little afraid to tell them that I'm on disability. But then again, **would they make any exceptions** if they did know and I had one of my bad days or something like that?”

Accommodations: “The good part about it is that I'm going to be at home in my home office and don't have to worry about going anywhere in particular, but it's still a job that **I want to be good at and reliable.**”



DECIDING TO WORK: TRANSPORTATION

\$ for gas, maintenance,
purchase new vehicle

Cost of getting to
interviews, work

Safety, security, & health

Limited public
transportation

Independence

Inability to drive, no license

Family & community
engagement

Lack of access to vehicle





F, 50s (KY): “SAFETY ISSUES AND MY HEALTH”

Safety, Security, and Health:

“I’ve got a car payment and insurance. And I can’t help that because **with my disability, I can’t walk like I used to.**”

“And then it’s not me, **safety reasons, kids on the bus stop,** and that’s not a good thing. I’ve been on a couple of buses where the guy pulled out a 9mm and joking around and playing and pointing it at his friends. And I just rang the bell and politely got off, and it made me late for work, made the kids late for school....”

“So it’s just—in **between safety issues and my health, I have to keep some type of transportation right now.**”



F, 50s (KY): “TOOK AWAY MY INDEPENDENCE”

Independence and Health:

“Once I got sick, **I couldn’t work**, so that took away my **financial independence**. And then when **I lost my car**, it took away my **mobility independence**. [Before I got sick], I could do whatever I wanted to do. I had the money to do it and I had a car to do it in, but now I don’t have either one of those. So it’s been hard. It’s been a big transition for me. I went through a big depression because it was just devastating.”



M, 50s (KY): “I MISS MY FAMILY TO DEATH”

Family Engagement:

“[Having a job] helps me with all my free time. I don’t have to sit there 24 hours a day just watching the TV. **I can go see my family now**, which back in the day **I didn’t have the money** to go see them half the time, and now I can see them at least once or twice a week. **And that’s been great because I miss my family to death.** They live about 50 miles away from me, so it’s kind of hard sometimes with no money. So now I can go see them constant whenever I want to.”



DECIDING TO WORK: FAMILY

Providing for basic needs,
improving family circumstances

Helping adult family members

Role in family

Visiting, going to family outings,
buying gifts

Worry about providing for family
if lose SSDI

SSDI and other benefits to
children

Caregiving responsibilities

Less time to spend with family





F, 50s (KY): “I NEED TO...BE A PARENT”

Caregiving responsibilities:

“I have to go to temp services because it's **flexible.... I need to...be able to work and then be able to be a parent**, like with homework, stuff like this.”

Being a role model:

“I'm trying to be as **self-sufficient** as I can **because I have children**, and I **want to be a good example.**”

Providing for basic needs:

“I'm divorced and in a situation with these two children. I just try to **work as much as I can so we can be able to make it** and be able to handle it, because just on this Social Security, on my own now, I'm **struggling.** It's hard.”

F, 30s (MN): “IF WE CAN PLAN IT JUST RIGHT”

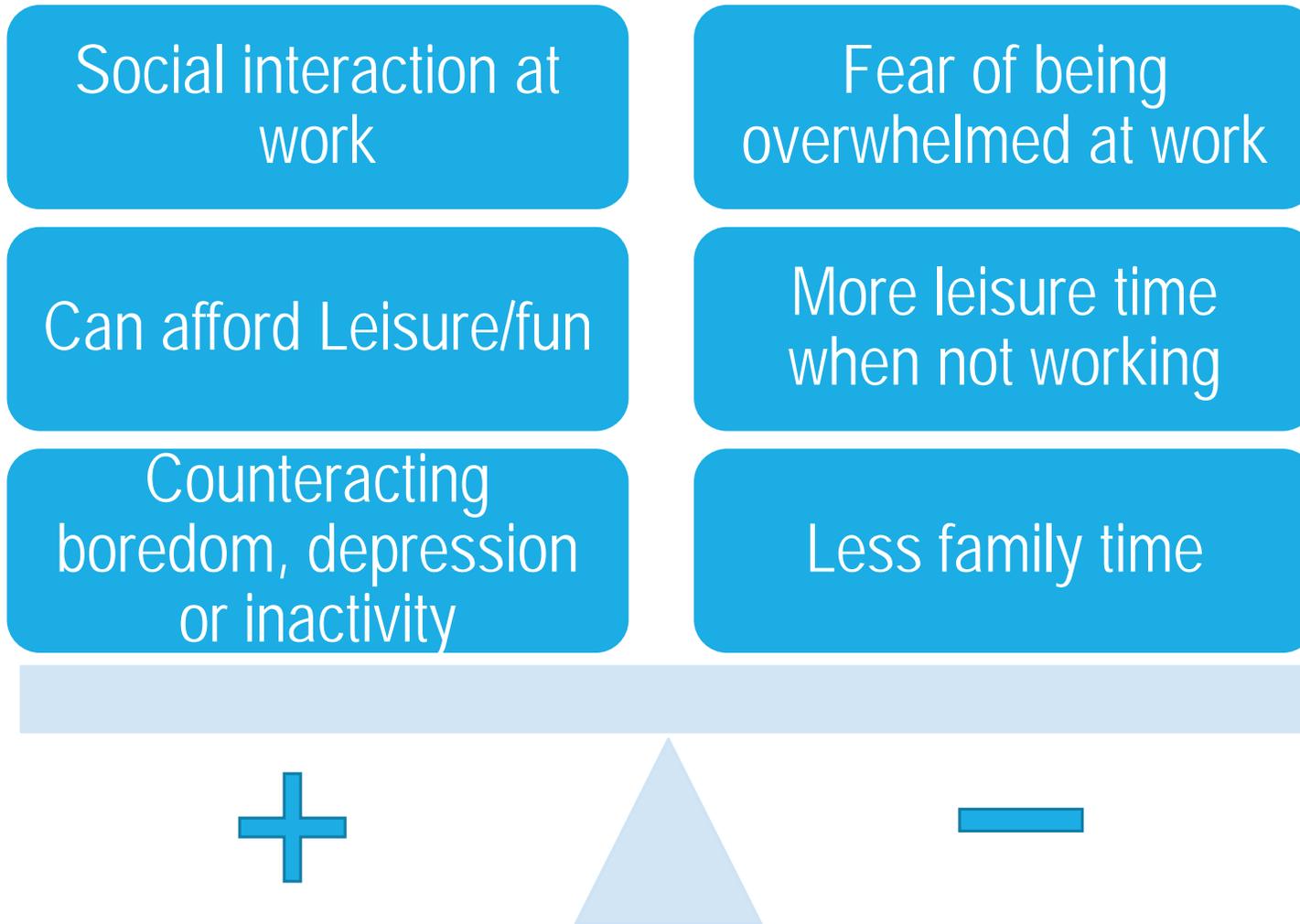


Improving family circumstances, role in family:

“I thought that I would always have to be the stay-at-home, disabled wife. I didn’t think that I could ever contribute significantly to our family. I thought we’d probably always have to live in an apartment because of the cost of my care is so high. So the fact that there’s a possibility that I could be contributing an actual equal income is amazing.”



DECIDING TO WORK: BEING ACTIVE/SOCIAL





F, 50s (KY): “A REASON TO GET OUT OF BED”

Counteracting boredom/inactivity:

To me the **socialization is important**. And...I guess basically a **reason to get out of the bed, get showered and get out of the house every day**.

Social interactions at work:

I moved up here and my parents were gone for three months in [another state]. They just got back a couple days ago, and I really don't have any friends--I mean I have friends, but we don't socialize; we'll talk on the phone. And it's very, very **lonely and isolating**. And even at work, it's just me with one patient. But it's **better than sitting here by myself and watching TV**.



F, 30s (MN): “I WANT TO DO BETTER”

“I have **too much time on my hands** right now, and the more time I have in my hands the more time **I get to thinking about stuff**. But then I get to thinking back to conversations that me and my best friend had. Because [she] was my backbone. She was trying to help me go back to work. You know what I’m saying?

...

“I’m tired of not doing nothing. I’d like to at least act like I’m sane and halfway productive in this world instead of just sitting here withering away time. I want to do better. I want to feel better.”



F, 40s (MN): “I LOVED WORKING”

I’ve been on disability for, gosh, it’s been, I want to say, six years. So I’ve basically been **stuck in this house...** and I’m **going crazy**. I used to work a lot of hours. Prior to being disabled, I worked almost 50 hours a week and made a wonderful income off of that. And **I miss it**. I miss it. I really just **want to get back to work, meeting new people. I loved working**. I don’t like being at home. I mean I can say maybe the first month or so was kind of nice to get a break, but it’s not what I wanted.

DECIDING TO WORK: MEANING OF WORK

Being a role model

Contributing to society

Social belonging

Self-esteem

Achieving personal goals

Being productive

Self-identity as worker



M, 50s (MN): “CONTRIBUTING MEMBER TO SOCIETY”



Being a role model:

“Being unemployed has been very helpful in terms of me being able to **do things with my kids** and getting them places where they need to go, for them, which is really good. Because if I was working, that would be a lot more challenging... So certainly that’s kind of a plus side to all of this, but on the other hand...**they know their dad doesn’t work**. And I’m sure on some level, that’s got to be hard for them in terms of sharing with their friends...”

Contributing to society:

“I just want to feel like a contributing member to society in some form or fasion, rather than just sitting back and collecting a disability check.”

“But I mean I think for me, just again, [I want] to feel **productive, feel like I’m doing something.**”



F, 40s (KY): “PART OF THE SOCIETY”

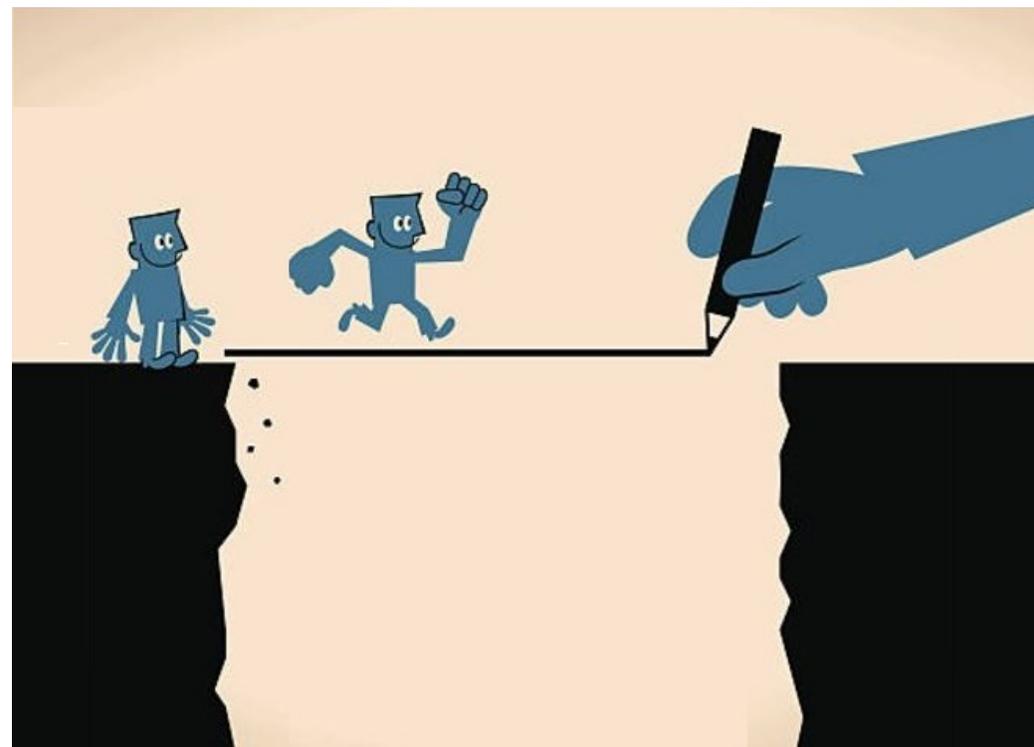
Self-esteem, social belonging:

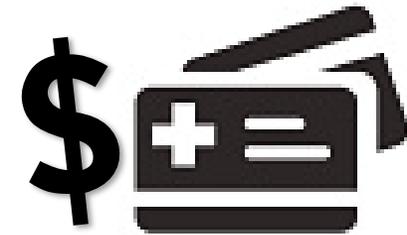
[Q: And what do you think it would be like to work and go off disability?] “Well, for one, my **self-esteem** would be built because I know that I would be doing something to help other people and that **I belong somewhere, that I'm needed somewhere.** And the feeling to be needed, that goes a long, long way. ...**I want to feel like I belong.** I want to feel like I'm **part of the society.** And **when you're on disability, you're this little group over here outside the circle with the rest of the world.**”

Achieving personal goals, being a role model:

[Q: Does going to school help you feel like you're part of the society?] “Oh yeah, because none of them kids know that I'm on disability. I got a 4.0; I got straight ‘A’s... Those students, when they find out the grades that I have, they come to me and ask me to help them. That makes me feel so good to know that **them kids are looking up to me** for something. It makes me feel **part of the society.**”

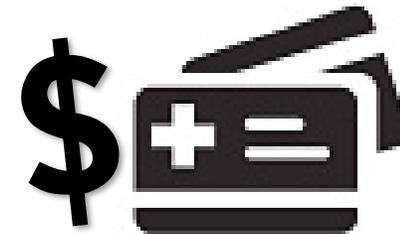
GOING OFF SSDI: TAKING THE LEAP





GOING OFF SSDI: TAKING THE LEAP

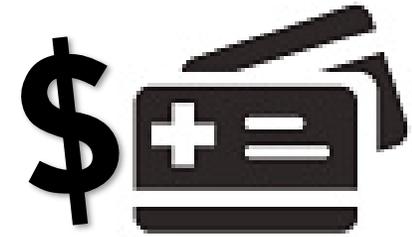
“I need to go part-time. I just feel I **don't want to jump in over my head and drown.** I've got a daughter. I'm not going to drown.” *(F, 30s, KY)*



M, 30s (KY): “THE FEAR OF NOT KNOWING”

“I was 26-ish when I first started thinking about getting back to work... Even **the fear of losing the little I was getting**, the fear of not knowing....

I didn't know if...I could do a full day of work....
Everything was just so uncertain. **It would have been really nice to have a little bit of certainty**
in...understanding what happens with SSI and SSDI and Medicare or Medicaid when you start working....”



M, 30s (KY): “MY WINDOW IS A BIG JUMP”

The **financial planning** lady, she had a very thorough discovery of what all of my benefits are, what all my income sources are, what they could be in the future...and whether it was worth it for me.

...One of the **biggest worries** with me at the very beginning was, “If you work too much, **you're going to lose these benefits.**”... **It gave me confidence that, yeah, here's my window.** ...With me, my window is a **big jump.** ...[The work incentives program] is a comfort. I think it's a great thing to have in place because it actually motivates--**it allows people in my situation to make a plan like this and be comfortable moving on the plan.**

A FEW FINAL NOTES

Main points:

- Our study participants want to work, but going off SSDI is a risk.
- Ambivalence is common, decisions complex.
- VR helps people make informed decisions.
- Microeconomic or quantitative analysis not enough; qualitative research explains whys and hows.

For future research:

- Family/household, incl. interviews w/family members
- Longer-term f/u – entire employment process (find, get, keep)

Questions/Comments?