



## IACC Member Questions for Social Security Administration from IACC Meeting January 19, 2022

### IACC Member: Craig Johnson

- How often does fraud occur in Social Security benefits claims?
- Does fraud make a significant impact on caseloads, human resources, and available funding for individuals who really need these benefits?
- What is done to prevent fraud?
- Is there anything that can be done at various systems levels to improve fraud prevention so that those who are genuinely in need can receive benefits more efficiently and effectively?

### IACC Member: Dena Gassner

#### Background

Research reflects that the process for apply to and utilize social security benefits is fraught with administrative burden. Further, administrative burden presents three primary negative factors including an undue *burden to identify, solicit and seek resources; costs associated with time, cognitive effort* and executing tasks (such as seeking diagnoses and records); and *dealing with assigned stigma* when associated with SSA as, despite a lack of evidence, the idea that folk “cheat the system” and consumers “work the system” creates huge emotional burdens (Herd and Moynihan, 2020).

We also know that the implications of administrative burden is “distributive” meaning those already marginalized by failures of multiple systems (education, poverty, housing, race, color, gender) with less *human capital* experience administrative burden with steeper, more costly implications that those without such inherent social justice challenges (Christensen et al., 2019; p. 127; Herd and Moynihan, 2020).

Based on my practice experience with hundreds of autistic persons navigating SSA, they’re often in one of the darkest, most cognitively repressed states of being they’ve experienced in their adult lives enduring feelings of burnout, disempowerment, worthlessness, loss of autonomy and generalized stress/anxiety (Christensen, et al., p. 120; 2020; Higgins et al, 2021; Phung et al., 2021; Raymaker et al, 2020). I myself, and many clients report (anecdotally) being treated harshly, abusively and with insensitivity in the offices by personnel.

Lastly, while the burden of proof of disability has been thrust to the forefront for those with “invisible disabilities” with Covid-19, the autistic community has struggled with this burden for generations. “Those whose disabilities are invisible may also have to convince other people that they really are *disabled*, not seeking some special—unfair—advantage: thus, what they must do is meet a burden of proof. They face a double bind: either they forgo the assistance or accommodation they need—and thus suffer the consequences of attempting to do things they may not be able to do safely by themselves—or



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they endure the discomfort of subjecting themselves to strangers' interrogations" (Davis, 2005; p. 153-154).

This has resulted in very negative experiences for myself and my clients. And the catch-22 of being asked to use cognitive skills that in themselves, are representative characteristics of the disability itself, while being in a state of cognitive depletion is more than ironic. Yet, the word "accommodation" or resources to execute obtaining direct support, sensory friendly wait rooms, patient and kind case workers does not even appear in the Red Book.

For families, this is equally challenging; they are busy with the multi-layered business of navigating systems and parenting persons with various support needs so any burden presented while using the SSA systems is undue for them. Meanwhile, our constituents languish in poverty, without healthcare, expediting their decline.

### **Accessibility Questions**

With this as the foundation for my questions, I would like to ask a few questions.

Due to Covid-19 and inherent systems issues that have long taxed SSA, how will you address the following:

- lack of funding
- increased office closures
- failure of personnel to respond to requests for contact
- providing a mechanism for delivery of evidentiary documents
- reducing the wait times
- lack of training of personnel about autism, how it's expressed and how to aid autistic individuals in utilizing the SSA offices and services
- can SSA coordinate with autistic persons to identify and provide accommodations to make the system more accessible?

### **In regard to IACC and our focus on research**

- As a disabled researcher, I find the costs associated with securing data from SSA inordinately costly under FOIA
- Also, I have found the determinations of worthiness of such research as "informing the SSA systems" to be rigid and ill-informed



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How can SSA reduce the costs of us securing critically needed information for research and for this body including questions such as:

- In 2021 (2020), how many autistic individuals (with and without co-occurring ID) applied for SSI? SSDI?
- How many were denied at each level?
- How many dropped out at each level?
- What was the timeline and tier when those who persevered were finally approved?
- Are all autistic applicants evaluated (when required) by MDs with expertise in autism? (I was evaluated by a pulmonologist)
- Is there any plan for staff training, the ALJs and staff evaluations for the care and treatment of applicants?
- Would SSA consider the collaboration of autistic persons in considering the service needs and accommodation supports that could make this easier?
- Can you simplify the language, system and access such that the use of legal representation is not considered automatic, at a cost to the clients?
- Can you get ALJs to allow support persons to attend hearings