# Exploring Research on the Experiences of Persons with Intellectual Disabilities in U.S. Adult Services Programs: Perspectives from Self-Advocates

2023 Social Connectedness Fellowship Program
in Partnership with the Harvard Law School Project on
Disability (HPOD)

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**Social Connectedness Fellows, 2023**
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# EXECUTIVE SUMMARY

Over time, the federal United States government has increasingly encouraged states to spend federal funds to provide services for adults with disabilities in community-based settings. To this end, the U.S. government created Medicaid Home- and Community-Based Services (HCBS) waiver programs in 1981. Before then, most publicly-funded disability services were available only in institutions, which segregate adults with disabilities from society. HCBS waiver program services, in contrast, aim not only to prevent adults with disabilities from living in institutions, but also to support them to live independently in the community. Today, many people with intellectual disabilities in the United States receive the services and supports that they need to be included in their communities through their states' HCBS waiver programs.

Self Advocates Becoming Empowered (SABE) wants to learn more about the experiences of people with intellectual disabilities receiving HCBS waiver services. SABE is preparing for a survey designed and run by self-advocates with intellectual disabilities[1] so that we can learn more about their experiences with their states' HCBS waiver programs.

We are two people with intellectual disabilities in South Carolina and Arizona who either receive or used to receive HCBS waiver services, and we will help SABE with their survey. Thus, this summer we worked to explore the research that has and is being done on this topic to prepare ourselves for SABE's survey project.

We have learned that even though many people with intellectual disabilities receive these important services, and even though HCBS waiver program services help to prevent people with intellectual disabilities from living in institutions, there is limited research on the experiences of people with intellectual disabilities receiving HCBS services. Also, there is even less research on this topic done by people with intellectual disabilities themselves, and so the questions that researchers ask may not always be the questions that are most important to self-advocates.[2] We learned about the available research to identify gaps in what is known about these experiences, that we believe SABE can work to fill through its survey project in the future. We also recommend that researchers interested in this topic work inclusively with self-advocates to expand what is known about the experiences of people like us.

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[1] A "self-advocate" is a person who speaks up about things that are important to them.

[2] As defined by VanReusen et al. (1994), "self-advocacy" is: "An individual's ability to effectively communicate, convey, negotiate or assert his or her own interests, desires, needs and rights. It involves making informed decisions and taking responsibility for those decisions."

## EASY READ SUMMARY

- **We are two self-advocates who have intellectual disabilities, get or have gotten publicly funded services, and wanted to learn more about research on how people like us in the United States get their services.**

- **The services that people with intellectual disabilities get are important because these can help them to be included in the community, and also to be more independent.**

- **We learned that there is not a lot of research on this topic where people with intellectual disabilities are not just the participants but also the researchers.**

- **We think this could mean that researchers may not be asking the questions that are important to self-advocates.**

- **We think that self-advocates should get more involved in research projects and that researchers should do more to make sure they include self-advocates on their research teams, and publish their research in easy read format.**

## 1. INTRODUCTION

In this section, we describe the structure of federally-funded services for adults with intellectual and developmental disabilities (IDD) in the United States, and how these services have shifted from supporting people living in institutions, to people living in the community. We then present the goals and methods of the research we undertook this summer.

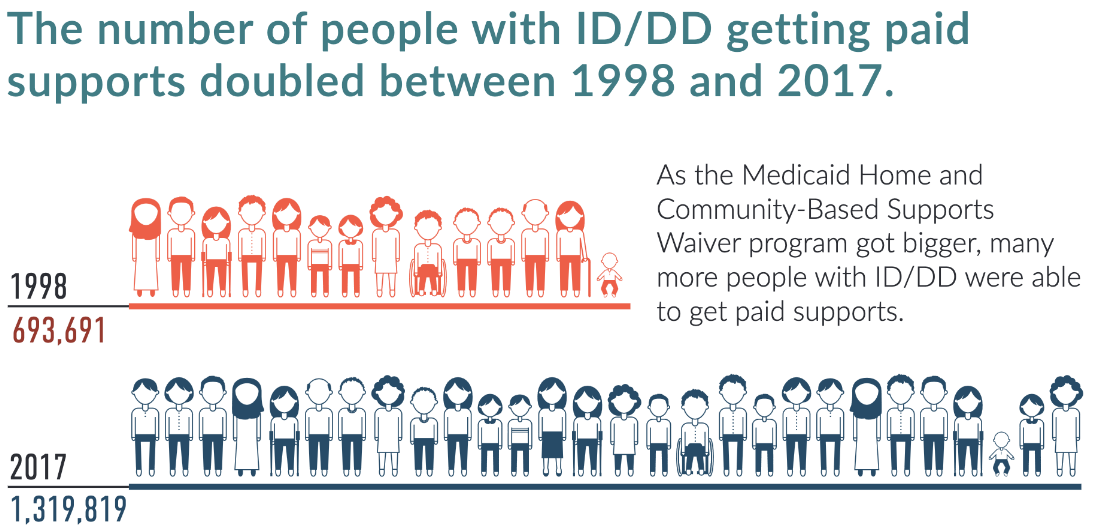
### *1.1 Background*

The United States federal government created the Medicaid program in 1965 to provide health insurance benefits to poor and disabled people. From the beginning, Medicaid funds were distributed to states based on the size of their populations, and the states could decide how to spend those funds. Overtime, the size and popularity of the Medicaid program grew, and states began providing more and more benefits and services to different groups of people, including older adults and people with intellectual, developmental, or physical disabilities, or mental health conditions. In the beginning, the federal government assumed that all adults with IDD who would need Medicaid-funded services lived in institutions. So, the federal government, for a long time, required that states spend Medicaid funds only on services that were provided in large, institutional settings.

As the deinstitutionalization movement in the United States grew stronger, adults with IDD were increasingly living in the community, either on their own, with their families and friends, or in smaller, group settings. In 1981, the U.S. government decided to create Home and Community-Based Services (HCBS) waiver programs, which allowed states to spend Medicaid funds on services for adults with IDD living in the community, and not just in institutional settings.[3] That is why these programs are called "waiver" programs: because the U.S. federal government is "waiving" the requirement that states spend Medicaid funds on services provided in institutional settings.[4]

At first, states could choose whether they wanted to use Medicaid funds on community-based services. Some states were slow to take advantage of the HCBS waiver programs and continued to offer services for adults with IDD either only or mostly in institutions. But that has changed over time.

**Figure 1. Number of People with IDD Getting HCBS Waiver Services in 1998 and 2017[5]**



The number of people with ID/DD getting paid supports doubled between 1998 and 2017.

As the Medicaid Home and Community-Based Supports Waiver program got bigger, many more people with ID/DD were able to get paid supports.

The passage of the Americans with Disabilities Act (ADA) in 1990 made it illegal to discriminate on the basis of disability.[6] The Department of Justice then made an

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[3] National Council on Disability, *Home and Community-Based Services: Creating Systems for Success at Home, at Work and in the Community* (Washington DC, February 2015), 14.

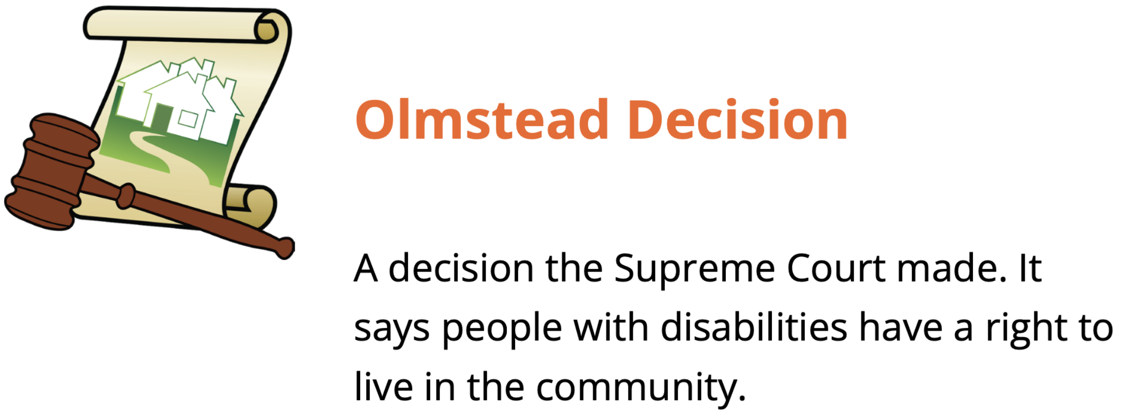
[4] National Council on Disability, *Home and Community-Based Services*, 14.

[5] Sheryl Larson et al., *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2019* (Minneapolis, MN: University of Minnesota, Center on Residential Services and Community Living, Institute on Community Integration/UCEDD, 2022), https://ici.umn.edu/products/AiMjLBqCS8mSwjLmIPPvKg, 17.

[6] Autistic Self Advocacy Network, *Self-Advocate's Guide to the Americans with Disabilities Act* (Washington, DC, 2020), 18,

important rule called the “integration mandate” that specifically required states to provide services for people with disabilities “in the most integrated setting” that can meet their needs.[7] In 1999, the U.S. Supreme Court decided the important case *Olmstead v. L.C.* which said that under the ADA states *must* provide services in community-based settings.[8] Today, all 50 U.S. states have HCBS waiver programs that provide services to adults with IDD in the community.

**Figure 2. Easy Read Summary of *Olmstead v. L.C.*[9]**



**Olmstead Decision**

A decision the Supreme Court made. It says people with disabilities have a right to live in the community.

Alongside these legal developments, the advocacy of the disability rights movement has caused states to invest an increasing amount of their Medicaid and other state and federal funds to provide services to adults with IDD in their communities. In 1987, for example, about 9 of 10 people with IDD who received Medicaid-funded services lived in an institution. But by 2017, the situation had flipped: 9 of 10 people with

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https://autisticadvocacy.org/wp-content/uploads/2020/07/ADA%20Easy%20Read%20Toolkit%20-%20Complete.pdf.

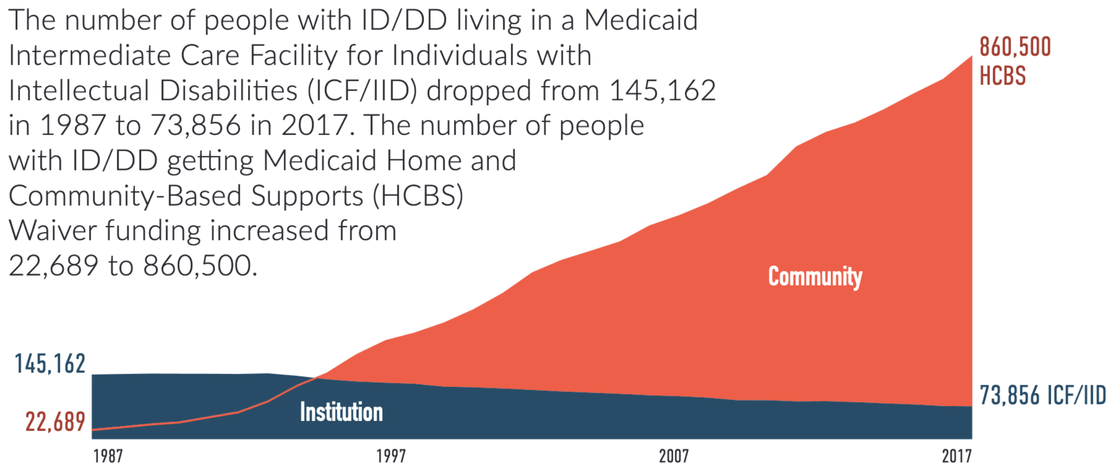
[7] National Council on Disability, *Home and Community-Based Services*, 13.

[8] “Olmstead: Community Integration for Everyone,” U.S. Department of Justice, accessed Aug. 16, 2023, https://archive.ada.gov/olmstead/index.html.

[9] Autistic Self Advocacy Network, *This Rule Rules! The HCBS Settings Rule and You* (Washington, DC, 2019), https://autisticadvocacy.org/wp-content/uploads/2022/11/TRR%20Full%20Toolkit.pdf, 12.

IDD getting Medicaid-funded services lived in the community.[10] Not only did more people with IDD living in the community start getting Medicaid-funded services, but over time, each HCBS waiver program participant received more money. Adjusted for inflation, the average amount of HCBS waiver funded services for people with IDD increased from $4,305 in 1982 to $48,458 in 2019.[11] These are big changes!

**Figure 3. Larson et al. (2021, 21).**



The number of people with ID/DD living in a Medicaid Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) dropped from 145,162 in 1987 to 73,856 in 2017. The number of people with ID/DD getting Medicaid Home and Community-Based Supports (HCBS) Waiver funding increased from 22,689 to 860,500.

In 2017, that number was about 642,000 adults with IDD in the United States receive HCBS waiver services, which is about 3 persons for every 10 adults with IDD.[12] For many of these adults, these services help ensure that they can live in community settings, and not in segregated institutions. In addition to preventing institutionalization, HCBS waiver services also aim to ensure that adults with IDD have meaningful opportunities to be included in their communities. Although there are many ways that HCBS waiver programs can be improved so that adults with IDD get the support they

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[10] Larson et al., *Residential Services*, 21.

[11] Ibid, 62.

[12] Ibid, 21.

need to be fully included in society, for many, community living might not be possible without the services they receive from HCBS waiver programs.

One big challenge is that the line between an institution and a community-based setting is sometimes blurry. Some states spent HCBS waiver program funds on services provided in group living arrangements that in some ways looked like community-based settings, but felt like institutions to the people living there. One self-advocate interviewed by two self-advocate researchers, who participated in the Samuel Centre for Social Connectedness' 2022 summer fellowship program who interviewed group home residents with IDD in Massachusetts about their experiences during the COVID-19 pandemic, said:

> *"I'm only here because I have to be. I lived on my own for twenty years, but my PCAs [personal care assistants] took off on me. The agency said, 'We have to put you in a group home.' I didn't have a choice. I was forced to come here. I had two kitties I had to give away. I don't want to be here, but I have to be here. I've tried everything, but nothing works so far. I've called the hotline and they tried to help me, but they can't find me nowhere. So, I have to stay here. Believe me, I'd rather be somewhere else. I want my life back. This is no life for me."*[13]

Even though this self-advocate was living in a group home that is considered a community-based setting, her description of where she lives does not make it sound like she feels like she is living in the community. In response to many self-advocates' complaints that many people with IDD living in community-based settings did not *feel* like they were living in the community, in 2014 the federal agency in charge of HCBS

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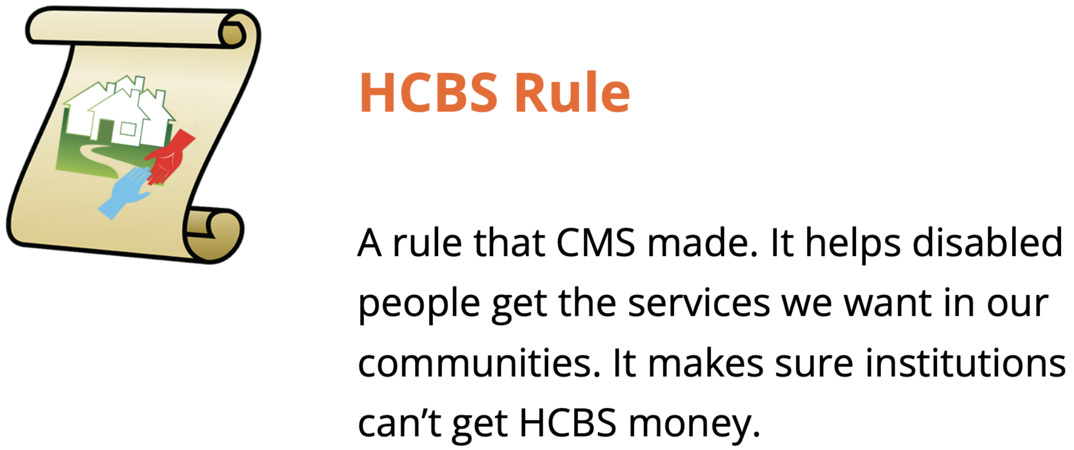
[13] Diana Mairose and Tony Phillips, *The Experiences of Persons with Intellectual Disabilities Living in Massachusetts Group Homes During the COVID-19 Pandemic: A Participatory Action Research Project* (Toronto: Samuel Centre for Social Connectedness, 2022), 34, https://www.socialconnectedness.org/wp-content/uploads/2022/11/Diana-Tony-Final-Report-HPOD.pdf.

waiver programs, the Centers for Medicare and Medicaid Services (CMS), came up with a new rule to make it clearer what community living really means.[14]

**Figure 4. Autistic Self Advocacy Network (2019, 35)**



**HCBS Rule**

A rule that CMS made. It helps disabled people get the services we want in our communities. It makes sure institutions can't get HCBS money.

The rule also clearly says that adults with IDD receiving HCBS waiver services have certain rights that are important for their social inclusion. These rights include 1) the right to choose where we live, 2) to choose where we get services, 3) to have respect and personal privacy from the people providing us services, and 4) to be at the center of our service plans.[15] These rights are intended not only to help us stay and be in the community, but also to really feel like we *belong* in our communities.

These rights are also central to a sense of belonging as described by Kim Samuel. She describes the four dimensions of belonging as 1) people, 2) place, 3) power, and 4) purpose.[16] Our right to respect and privacy helps to make sure that the people who serve and support us recognize our inherent worth. Our right to make our

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[14] National Council on Disability, *Home and Community-Based Services*, 6.
[15] Autistic Self Advocacy Network, *This Rule Rules!*, 87-90.
[16] Kim Samuel, *On Belonging: Finding Connection in an Age of Isolation* (New York: Abrams Press, 2022), 230-240.

own choices about our services is all about making sure that we have power in our relationships with people who serve and support us. Our specific rights to choose where we live and where we get services are about making sure we can live and be in spaces where we are comfortable and feel at home. And our right to be at the center of our service plans preserves our sense of purpose[17], because this right helps us to make sure that our services help us to get where *we* want to go in our lives.

Being at the center of your service plan is called "person-centered planning."[18] Adults with IDD who know their rights can use person-centered service plans not only to have control over the kinds of support they get and how they get those supports but also to strengthen their connections with other people in their lives whom they trust. Chaqueta, for example, wants to be in charge of her own life, but she knows she needs support to make some of her dreams happen. So, she uses her plan to bring together people in her life who can help her turn her dreams into the "real thing." It gives her the opportunity to reach out to others who she knows really care about her and want to support her in making decisions about her life. The process of developing her plan gives her an opportunity to teach others how to support her better. As a result she became more socially connected and had a greater sense of ownership of her own time.

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[17] The Samuel Centre for Social Connectedness, defines belonging as being comprised of 4 P's, people, power, place, and purpose.

[18] Autistic Self Advocacy Network, *This Rule Rules!*, 12-18.

**Figure 5. Easy Read Summary of Person-Centeredness in the HCBS Rule.**[19]

The HCBS Rule says you have a right to get a person-centered plan.

For David, the right to be at the center of his service plan has been very important. “By sitting at the table with service providers and coordinators, you can have an input on and advocate for yourself about your services and what goes into the plan. You can use the plan to realize your dreams and goals by choosing where you live, who comes and goes from your home, and also what money for your services is spent on.” Advocating for the services in your plan can help self-advocates become more socially connected, for example, because they can make their social goals more concrete by writing them into their service plans. This allows them to have support in completing these important social goals and build on them later in the plan.

The deadline for states to make sure that they are fully following the 2014 CMS rule for HCBS waiver programs was March 17, 2023.[20] But there are still many ways that states’ HCBS waiver programs can be improved. Some federal and state policy-makers know this. For example, members of the U.S. Senate and House of Representatives have proposed a new law called the “HCBS Access Act” to expand

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[19] Ibid, 87.

[20] Administration for Community Living, “Joint Statement from the Centers for Medicare & Medicaid Services (CMS) and the Administration for Community Living (ACL): Implementation of the Home and Community-Based Services Settings Regulation,” Mar. 17, 2023, https://acl.gov/news-and-events/announcements/joint-statement-centers-medicare-medicaid-services-cms-and.

access to HCBS waiver programs.[21] And CMS is proposing a new rule called the "Access Rule" to strengthen HCBS waiver programs even more.[22]

Disability rights groups have been asking for laws and policies to strengthen HCBS waiver programs for a long time. As federal policy-makers and regulators act to improve HCBS waiver programs, it is important for their actions to be informed by the experiences of adults with IDD who rely on these programs to live inclusive lives. Over the years, organizations like Self Advocates Becoming Empowered (SABE) have worked to make sure that federal and state policy-makers hear the voices of self-advocates and their supporters who are affected by how states run their HCBS waiver programs.[23]

**Figure 6. Easy Read Summary of Self-Advocates' Advocacy Position.[24]**

We told CMS that HCBS money was getting used by institutions.

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[21] Ai-jen Poo and Nicole Jorwic, "They deserve more: Honor the Americans with Disabilities Act by ensuring access to care," *The Hill*, Aug. 13, 2023, https://thehill.com/opinion/congress-blog/4150718-they-deserve-more-honor-the-americans-with-disabilities-act-by-ensuring-access-to-care.

[22] Administration for Community Living, "Input Needed: CMS Proposes Rule to Improve Access to and Quality of Medicaid Services," Apr. 28, 2023, https://acl.gov/news-and-events/acl-blog/input-needed-cms-proposes-rule-improve-access-and-quality-medicaid.

[23] Autistic Self Advocacy Network, Self Advocates Becoming Empowered, and National Youth Leadership Network, *Keeping the Promise: Self Advocates Defining the Meaning of Community Living* (Washington, DC, 2011), https://autisticadvocacy.org/policy/briefs/keeping-the-promise-self-advocates-defining-the-meaning-of-community-living.

[24] Autistic Self Advocacy Network, *This Rule Rules!*, 56.

Self-advocates know that social connectedness is integral to their movement. For Chaqueta, "Self-advocacy makes me feel good about myself and empowers me to connect with others and build relationships as well as friends who can share their experience with me. We all are able to help one another when we make connections and continue our community connections.  We have to be able to always connect our social networks so that our voices are loud and can be heard by everyone." That's why self-advocates have been so invested in strengthening HCBS waiver programs: in the same way that self-advocacy has helped many people with IDD not only to claim their rights but also to feel less isolated from their communities, they know that HCBS waiver programs can be engines for social connectedness. In parallel with these awareness-raising efforts, SABE, with support from the Harvard Law School Project on Disability (HPOD), has plans to survey self-advocates about their HCBS waiver program experiences, so that SABE can use this information as part of its continued advocacy to improve these programs.

### *1.2 Purpose and Methods*

We are two self-advocates with IDD preparing to do research on HCBS, and we want to see if we can learn information from our peers that could be different from the information that other researchers have already collected. To prepare ourselves for our roles in designing and carrying out SABE's planned survey on self-advocates' experiences with their states' HCBS waiver programs, we wanted to learn about what other research already says on this topic. We also wanted to learn more about the experiences of people with intellectual disabilities in different states who are receiving services through HCBS waiver programs to see what they think about how these programs are working. For example, we want to know if people with intellectual disabilities receiving HCBS waiver services have the opportunity to make decisions about the services they receive. We also wanted to know if researchers who have studied this topic also identified as having IDD or having their own personal experiences receiving HCBS waiver services.

Our main research questions were:

1) **What is the research like on the topic of the experiences of people with IDD participating in HCBS waiver programs?**
2) **What methods have these researchers used?**
3) **What questions have these researchers asked?**
4) **What questions have not been asked that we might want to ask?**
5) **How have people with IDD been involved in this research so far?**

We set about answering these questions in a variety of ways. We started off by learning about an ongoing study by self-advocate researchers exploring this topic in Massachusetts. We then looked at SABE's *GoVoter Survey 2020* report, which gave us a good example of what a survey led by self-advocates looks like.[25] The report itself was written in plain language, the survey focused on questions that self-advocates had decided were important to them, and self-advocates were the ones who analyzed the data that was collected through their survey. David also reached out to staff at the state agency administering Michigan's HCBS waiver program to learn about any research

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[25] Essie Pederson, *SABE GoVoter 2020 Survey Report* (Maineville, OH: Self Advocates Becoming Empowered, 2021), https://www.sabeusa.org/wp-content/uploads/2021/10/SABE-GoVoter-2020-Survey-Report.pdf.

they have done, although we ultimately did not learn much from this outreach, because they only shared their survey questions with us, but not the answers they received to those questions. We then reviewed several research studies published in academic journals on this topic, although we found many of these were not written in ways that were easy for people with IDD to understand. So, we pivoted from academic journals to focus on state reports published by the National Core Indicators® (NCI) project and spoke to researchers who are involved in collecting and analyzing NCI data. One of us also participated in an ongoing study by other researchers on this topic.

We met as a group each week over Zoom to discuss our research and writing assignments and what we had learned with each other, as well as our supporters, Glenda Hyman-Singletary from the Florence County Disabilities & Special Needs Board; Teresa Moore and Alyssa Mills from SABE; and Hezzy Smith and Anne Fracht from our partner organization, HPOD. We recorded our weekly discussions. Notes from those meetings and the recordings are the basis of this report, which we received support in preparing from Hezzy Smith.

## 2. ISSUE EVIDENCE AND KEY FINDINGS

In this section, we describe three main research areas. First we look at how some self-advocate researchers are learning about the experiences of adults with IDD in Massachusetts receiving services through an HCBS waiver program. Then we explore what other researchers have learned about how HCBS waiver programs affect the lives of adults with IDD. Finally we describe the findings of a group of researchers collaborating with state agencies that administer HCBS waiver programs on a joint data collection project called National Core Indicators (NCI)®. We found that there seems to be more research on the *effects* of HCBS waiver programs on the lives of people with IDD than on the *experiences* of people with IDD receiving these services. Also, we found that researchers who are interested in studying this topic seem not to include people with IDD as part of their research teams, and see people with IDD in their research studies only as participants.

### 2.1 What Some Self-Advocate Researchers Are Doing

We spoke to an inclusive group of researchers who were starting a research project on the experiences of people with IDD receiving HCBS services in Massachusetts. They described their approach to how they designed their project, including how they came up with questions for their interviews. We discussed why they chose semi-structured interviews as their study method. For example, an interviewer can explain words that the interviewee doesn't understand. By contrast, a survey tool has to be in "easy read" or plain language because there is not the same opportunity to explain what survey questions mean. They explained even then, different people might interpret the same questions differently. But, a downside of interviews is that they take a lot of time and resources, which means it takes longer to learn about the experiences of people with IDD.

We also reviewed their interview guide and identified many questions that were interesting to us that we might wish to use in a survey with SABE. Some of their questions were:

- What part of your [service plan] is most important to you, and why?
- Before you sign your [service plan], how do you make sure it is the way you want it?

- How much do your [service plan] and [service planning] meetings help you to do what you want to do in your life? Not at all, a little, or a lot?
- What things about the [service planning] process would you change so you can have more control over it or leadership in it?
- What strategies have you used to get what you want out of the [service planning] process?

We felt that one reason their questions were so good was because they were informed by the self-advocate researchers' own experiences with Massachusetts' HCBS waiver program for adults with IDD. These questions also focused on how much say self-advocates have in their service planning process and their perspectives on how well that process works for them, which are different from the questions that other researchers have focused on. As we explore more below, other researchers seem to focus more on the effects of HCBS waiver services on different parts of self-advocates' lives.

### *2.2 What Some Research Studies Say*

Different researchers have studied various ways that HCBS waiver programs have impacted the lives of different groups of people. But most researchers have not focused on how HCBS waiver programs have affected the lives of people with IDD.[26] McLean et al. (2021) created a summary of the research studies that talked about the impacts of HCBS waiver programs on the lives of people with IDD.[27] They started off by finding over 700 published research studies that talked about both HCBS waiver

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[26] Kiley J. McLean, Allison M. Hoekstra, and Lauren Bishop, "United States Medicaid home and community-based services for people with intellectual and developmental disabilities: A scoping review," *Journal of Applied Research in Intellectual Disabilities* 34, no. 3 (2021), 685, https://doi.org/10.1111/jar.12837.
[27] McLean, Hoekstra, and Bishop, "United States Medicaid," 685-686.

programs and people with IDD.[28] Then, the researchers narrowed this big batch of studies down to 7 studies that were the most related to their main research question. Four of them analyzed survey data and three analyzed other kinds of data, such as enrollment data, hospital admission data, or economic data. Together, these studies found that HCBS waiver programs benefit people with IDD in at least three ways:

1) First, HCBS waiver programs reduce unmet healthcare needs, such as the need for psychiatric hospitalization.
2) Second, they increase the likelihood that parents of people with IDD will be able to continue working rather than stay home to provide care.
3) Third, they reduce racial disparities in access to care.[29]

Knowing about the ways that HCBS waiver programs benefit people with IDD is important, but we were more interested in research *on* the experiences of people with IDD receiving services through these programs. That means we were primarily focused on people with IDD's own opinions about their services and their stories. A lot of research on the experiences of people with IDD receiving services seems to focus on the experiences of their parents or caregivers.[30] There seems to be less research on the experiences of people with IDD themselves, although we did find a few.[31]

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[28] Ibid, 686.

[29] Ibid, 692.

[30] Judith M. S. Gross et al., "Examining the Experiences and Decisions of Parents/Guardians: Participant Directing the Supports and Services of Adults With Significant Intellectual and Developmental Disabilities," *Journal of Disability Policy Studies* 24, no. 2 (2012): 88-101, https://doi.org/10.1177/1044207312439102; Heather J. Williamson et al., "Family Caregivers of Individuals with Intellectual and Developmental Disabilities: Experiences with Medicaid Managed Care Long-Term Services and Supports in the United States," J*ournal of Policy and Practice in Intellectual Disabilities* 13, no. 4 (2016): 287-296, https://doi.org/10.1111/jppi.12198; Amy Hewitt et al., "Families of Individuals With Intellectual and Developmental Disabilities: Policy, Funding, Services, and Experiences," *Inclusion* 51, no. 5 (2013): 349-359. https://doi.org/10.1352/1934-9556-51.5.349.

[31] Anne Bowers, Randall Owen, and Tamar Heller, "Care coordination experiences of people with disabilities enrolled in medicaid managed care," *Disability and Rehabilitation* 39, no. 21 (2017): 2207-2214. https://doi.org/10.1080/09638288.2016.1219773; Joseph Caldwell et al., "Experiences of individuals

Bowers, Owen, and Heller (2017) surveyed people with physical disabilities, mental health conditions, and IDD receiving HCBS services in one U.S. state.[32] People with IDD were the smallest of these three groups: of the 442 survey respondents the researchers analyzed, 125 of them were people with IDD.[33] The researchers designed their own scale to measure respondents' satisfaction with their health care services, and they compared those scores to how respondents rated the quality of the care coordination services they received. They found that if people with disabilities said they received quality care coordination services favorably, they were more likely to also say the quality of their health care services was good.[34] They were also more likely to say that they had fewer unmet health care needs.[35] While this approach was interesting to us, the researchers focused on the effects of care coordination services through the HCBS waiver program on the health care people received, but not on other aspects of their lives. Also, people with IDD were not the main focus of this study.

Caldwell et al. was another interesting study that explored how the COVID-19 pandemic affected people's HCBS waiver services.[36] The pandemic caused many states to change their HCBS waiver programs to make it easier for people with IDD to self-direct their services. Self-direction is an option for HCBS waiver program participants that gives them greater flexibility and control of their services. For example, people with IDD who self-direct their services can be in charge of hiring and supervising their staff. They can also have control over how they use funds included in an

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self-directing Medicaid Home and Community-Based Services during COVID-19," Disability and Health Journal 15 (2022): 101313, https://doi.org/10.1016/j.dhjo.2022.101313.

[32] Bowers, Owen, and Heller, "Care coordination experiences," 2209.

[33] Ibid, 2210.

[34] Ibid,  2211.

[35] Ibid, 2212.

[36] Caldwell et al., "Experiences of individuals," 2.

individualized budget to purchase only the services and supports that are important to them. These researchers interviewed 36 people with IDD who were self-directing their services, and they found that the control that self-direction gave them over their services made it easier for them to cope with staffing shortages caused by the pandemic.[37] Self-direction also gave them more options for staying safe from staff transmission of COVID-19.[38] For example, they could choose to hire only staff who followed safety protocols. This was one of the few research studies that we found where the researchers spoke directly to people with IDD about their HCBS waiver services.

After reviewing some of these research studies about people with IDD receiving services through HCBS waiver programs, we decided that a lot of the research was not what we were looking for. Also, most of these research studies were difficult for us to understand as they were not written in plain language.. Instead, we decided to focus on reports made by the National Core Indicators® (NCI) project, because these were easier for us to understand and we were able to dive deeper into how research on this topic is being done.

### *2.3 National Core Indicators® Project*

We spent several weeks focusing on the NCI project, which is a voluntary effort by state developmental disabilities agencies to measure and track their own performance. In the 1980s, when states began implementing HCBS waiver programs, the monitoring and evaluation data that they were required by the U.S. federal government to collect was focused on whether certain processes and protocols were being followed; it did not focus on people with IDD's individual outcomes or

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[37] Ibid, 2-3.
[38] Ibid, 3-4.

experiences.[39] So, in 1997, at a time when the service expectations of people with IDD were rising and when there was increasing pressure on federal and state Medicaid budgets, these agencies decided that they wanted to more effectively track individual outcomes.[40] These agencies, represented by the National Association of State Directors of Developmental Disabilities Systems (NASDDDS), partnered with a human services research organization called Human Services Research Institute (HSRI) to come up with and to use core indicators to collect data that would allow state agencies to assess the outcomes of the services provided in HCBS waiver programs.

The NCI data is collected through in-person surveys of people with IDD receiving HCBS waiver services, and is open access on the NCI project's website. Generally, each state conducts these in-person surveys every two years, but some states choose to do it less frequently because of limited time or resources. Each state report contains easy-to-understand charts describing if people with IDD responded "Yes" or "No" to over 100 different questions. These questions look at the decisions they make, if they are satisfied with their services, how self-determined they are, how included they are in their communities, if their rights are respected, and much more. We did a deep dive into the most recent NCI state reports for Michigan (2020-21) and South Carolina (2018-19), since David used to live in Michigan before moving to Arizona, and Chaqueta is currently living in South Carolina.

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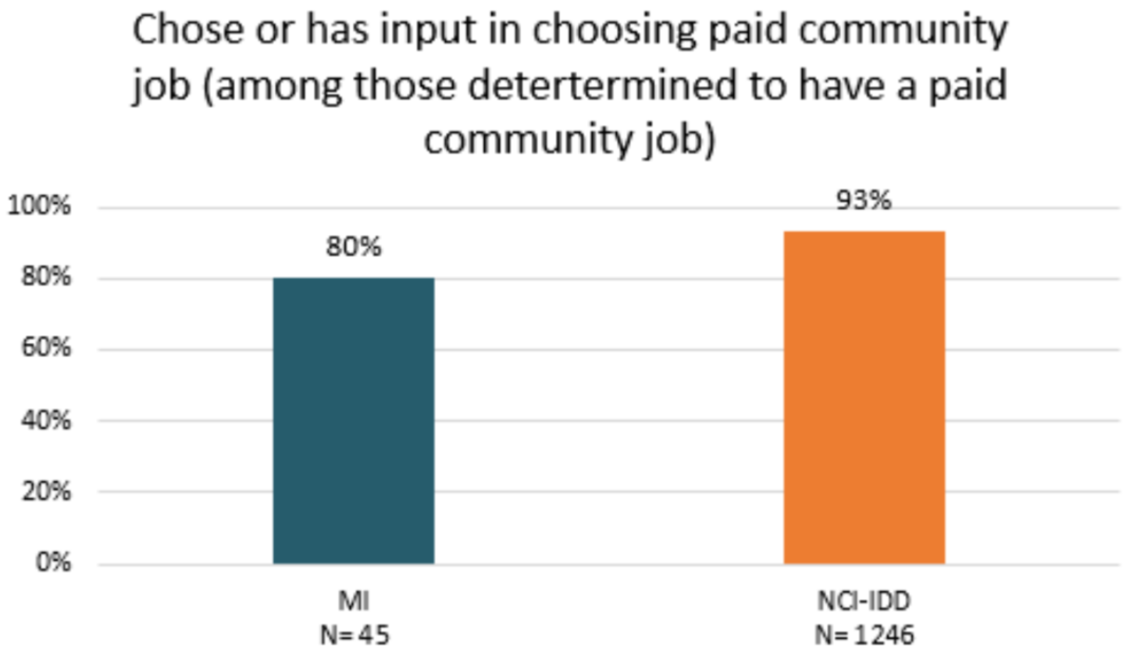
[39] Valerie J. Bradley and Dorothy Hiersteiner, "Quality monitoring of intellectual and developmental disabilities systems in the US: Assessing the utility and applicability of selected National Core Indicators to national and state priorities," *Frontiers in Rehabilitation Sciences* 3 (2022): 960996, https://doi.org/10.3389/fresc.2022.960996.

[40] Valerie J. Bradley and Chas Moseley, "National Core Indicators: Ten Years of Collaborative Performance Measurement," *Intellectual and Developmental Disabilities* 45, no. 5 (2007): 354, https://doi.org/10.1352/0047-6765(2007)45[354:ncityo]2.0.co;2.

For some of the questions, the responses did not match our expectations. In other words, what people said about their services did not resemble what we know through our own experiences and our work about what self-advocates think about their services. For example, in the Michigan state report, 80% of respondents said they had chosen or had input in choosing their paid community job. David, who is from Michigan and has experience with how services are delivered there, was surprised that the percentage of people answering “Yes” was so high. During his experience as a job coach, he encountered many people who wanted to do a particular job but were told they did not have the correct skills and were given a job they did not want.Although the total number of “Yes” respondents was relatively low (n=45), he thought that maybe family members or supporters answered for people with IDD, especially since in the NCI data collection process, it is possible for proxy respondents to answer some questions on behalf of adults with IDD.

**Figure 6. Percentage of HCBS Waiver Recipients in Michigan Who Chose or Had Input in Choosing Where They Work, as Compared to HCBS Waiver Recipients Nationally.**[41]



David learned from his experience working with the Michigan Department of Health and Human Services (MDHHS) to implement a survey based on the Supports Intensity Scale™, how service providers or family members can influence how people with IDD respond to interview questions.[42] For example, they sometimes gave different answers than the people with IDD themselves. In other cases, support staff told David to skip certain questions, or the person with IDD whom he was interviewing was only comfortable answering a question after David asked staff to leave the room.

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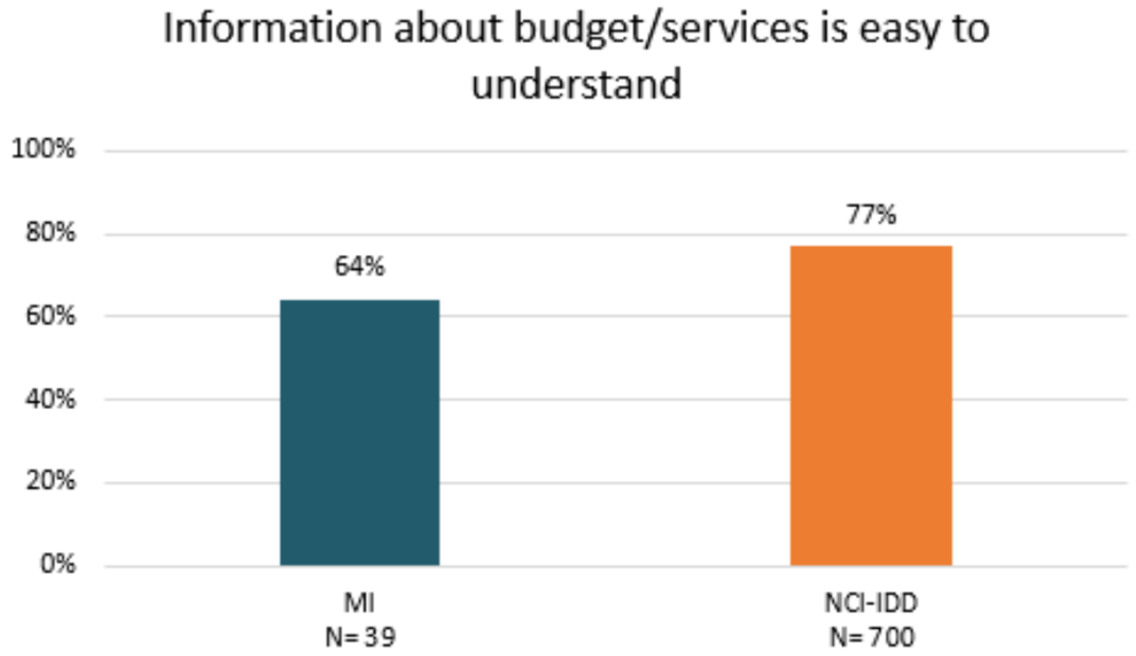
[41] *National Core Indicators™ In Person Survey (IPS) State Report: 2020-21 Michigan Report* (Cambridge, MA: Human Services Research Institute, 2022), 22, https://idd.nationalcoreindicators.org/wp-content/uploads/2022/08/MI-IPS-20-21-State-Report-508.pdf.

[42] *Supports Intensity Scale® - Implementation Manual* (Michigan Department of Health and Human Services, 2021). https://www.michigan.gov/-/media/Project/Websites/mdhhs/Folder2/Folder14/Folder1/Folder114/MDHHS_SIS_Manual_Version22.pdf?rev=fb06d3752acc4ba39e61621cafee1862. This scale was developed by the American Association on Intellectual and Developmental Disabilities.

We identified many questions that we were interested in. For example, the NCI state reports shared information about how many people who were self-directing their services had access to easy-to-understand information about their self-direction budget or services. However, it is unclear if people with IDD were asked this question directly. The reports state that for this question, "Information may have been obtained through state records," which means that people other than the ones responding to this survey may have defined what "easy to understand" means, not people with IDD.[43]

**Figure 7. Percentage of HCBS Waiver Recipients in Michigan Who Perceive Information about Their Services as Easy to Understand, as Compared to HCBS Waiver Recipients Nationally.[44]**



However, there were some questions that we were curious to know people's answers to about their services that were not included in the survey. For example, with regard to service coordinators, the survey asked if people had met or spoken with their coordinator, if the coordinator asks them what they want, if they're able to contact their

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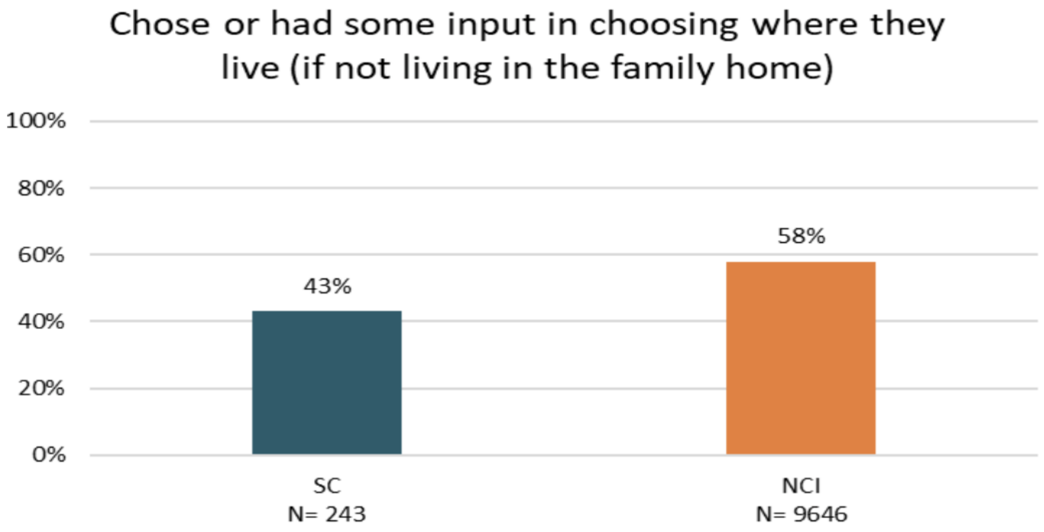
[43] *2020-21 Michigan Report*, 43.

[44] Ibid, 40.

coordinator, and if they can change their coordinator. But the survey did not ask people if they are happy with their coordinator, or if they are happy with their person-centered planning process, or if they are satisfied with how their coordinator does their job. If someone has chosen to change their coordinator, that would give us a clue that the person surveyed may not be happy with their coordinator. However, the survey only asked if someone knew they could change their coordinator,not if they had chosen to do so. It was not clear to us who decided which questions would be included in the survey and which were not, and importantly, if self-advocates were involved in choosing the questions.

For some questions, we did not expect people's responses to be presented in the way they were. In some cases, groups of different people were combined under a single category which was confusing to us. For example, the NCI data presented under the heading, "Chose or had some input in choosing where they live," seem to combine two different situations into the same category. The reports combine both people who chose where they live, and also people who had some input in choosing where they live in the "Yes" column. But in our experiences, there is a big difference between making your own choice and just having input in a choice. We would always rather make our own choices than just have inputs!

**Figure 8. Percentage of HCBS Waiver Recipients in South Carolina Who Chose or Had Some Input in Choosing Where They Live, as Compared to HCBS Waiver Recipients Nationally.**[45]



NCI data presented under another heading, “Chooses or has help deciding what to buy or has set limits on what to buy with their spending money,” seem to combine three different groups of people into the “Yes” category. People who responded “yes” either chose on their own how to spend their money, got help from someone else to decide how to spend their money, or had limits imposed by either themselves or someone else on how they spend their money. These seem like three very different situations that describe very different levels of decision-making that should not necessarily be combined into one category.

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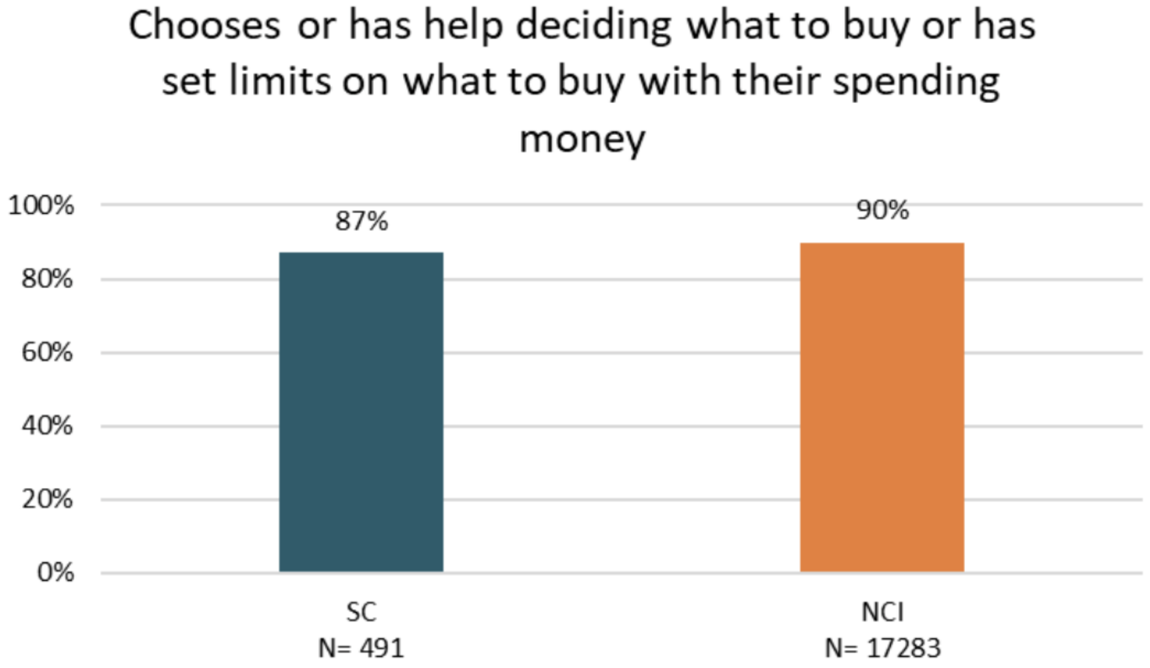
[45] *National Core Indicators™ In Person Survey (IPS) State Report: 2018-19 South Carolina (SC) Report* (Cambridge, MA: Human Services Research Institute, 2022), 22, https://idd.nationalcoreindicators.org/wp-content/uploads/2022/06/SC_IPS_state_508.pdf.

**Figure 9. Percentage of HCBS Waiver Recipients in South Carolina Who Choose or Have Help Deciding or Have Limits on How They Use Their Spending Money, as Compared to HCBS Waiver Recipients Nationally.**[46]



In both cases, we believe that combining these different groups of people in the same category might hide the true extent that people are able to make their own decisions about where they live or how they spend their money.

We shared our observations and spoke with some of the HSRI researchers who work to collect and analyze NCI data. We learned from them that NCI data collection has some limitations. For one, the NCI project is a voluntary data collection project, which means that not all states choose to participate. It also means that states have a say in which questions are asked. So, some states make sure that certain questions are included every year because they think the responses to those questions "make them look good."

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[46] *2018-19 South Carolina (SC) Report*, 24.

Also, we learned that HSRI and NASDDDS had decided to use structured, in-person interviews to collect their data rather than mail-in or online surveys, because they believed that their data was more reliable that way. They worked together to train interviewers on how to use their questionnaire and how to use prompts and paraphrases to make sure that people really understood the questions they were being asked. This way interviewers could also tell if someone was speaking for themselves, rather than a support person just giving their opinion. While this approach was likely more accessible to a broader range of people with IDD, it took a lot more time and resources to collect data this way. In the past, they had received a much higher number of responses for very little cost using mail-in surveys, but they had no way of knowing if respondents had really understood the questions, or if people with IDD had completed the surveys themselves or if someone else had done it for them. They believed that this approach allowed them to involve people with IDD who might be less likely to share their responses through a mail-in or online survey.

Last, they mentioned that some of the interviewers included self-advocates, which we thought was very positive and likely would change how open people felt about answering questions truthfully. However, only a small number of interviewers were self-advocates and only in some of the states that participated in this project.

### *2.4 Participation in a Research Study on HCBS Waiver Programs*

A group of ACL-funded researchers at the Shirley Ryan AbilityLab are working on ways to improve instruments like the National Core Indicators® so that they are more person-centered, which is already a requirement for how states run HCBS waiver programs. These researchers have done a survey of the instruments that researchers have used to explore the experiences of people with IDD participating in HCBS waiver programs.[47] They criticize many instruments used to measure HCBS waiver program participant outcomes for not being person-centered enough.

For example, the instruments that ask people with IDD about outcomes pre-determine which outcomes they will ask about. In other words, researchers ask people with IDD about outcomes that the researchers think are important for people with IDD's lives, but they do not ask if people with IDD also think the same outcomes are important to them. These include the kinds of outcomes reported on in the NCI project, such as, if people choose where they live, where they work, and how they spend their money. But even if we know that a person did not choose where they live, we do not know if that was the choice that was important to that person. Instead, that person might be more concerned about being able to choose their roommate in the place they live. By not asking people with IDD which choices are most important to them, researchers may take for granted that these things are in fact important to the people they are talking to. We think that if people with IDD were more involved in choosing the questions that researchers ask, then the researchers would have a better idea about whether they're asking about things that are important to people with IDD.

How researchers use their instruments also matters. Chaqueta heard about and decided to participate in a research study being run by researchers interviewing adults with IDD about their HCBS waiver program services.[48] They were the same researchers who criticized other instruments for not being person-centered enough. Chaqueta felt

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[47] Lindsay DuBois et al., "Person-centered measures of Home- and Community-Based Services: Identifying approaches to measuring outcomes, services, and supports," medRxiv, 2022 (preprint). https://doi.org/10.1101/2022.12.22.22283875.

[48] "Needed for Research Study: People who use Medicaid-Funded HCBS," Ryan Shirley AbilityLab, accessed Aug. 18, 2023, http://www.advancingstates.org/sites/nasuad/files/SRA_R1_recruitment%20%28003%29.pdf.

the researchers asked her questions that were easy for her to understand. They asked questions like, “How much time do you spend on your own?”, “Do you have privacy?”, “At health care appointments, do doctors talk to you or to your staff?”, “How much time do you spend with your family?”, and “Do you make decisions about your services?” The lead interviewer, even though she was not a self-advocate, also helpfully broke down the questions during the interview.

One limitation of the researchers’ approach, however, was that some of the questions did not seem to apply to Chaqueta. For example, they asked if Chaqueta chose her housemates, but she does not have any housemates. They also asked, “Do you get to spend time in the community?,” even though Chaqueta lives in her own apartment. To Chaqueta, it did not feel right to be asked questions that did not apply to her even after she had told them about where she lived.

Chaqueta also believed that her experience would have been different if a self-advocate had been the one asking her questions instead of a professional. Although it was not clear if self-advocates had been involved in developing the questions they had asked, she felt that being interviewed by a self-advocate would have made a positive difference for her.

### ***2.5 Limitations***

Our research this summer has some limitations. One being that most of the research studies on the topic that we are interested in are not available in plain language or easy read formats. This limited the number of research studies we could review and it also limited how much we could learn from them. One way we tried to address this barrier was to focus on the NCI state reports. These reports contain a series of charts that were easy for us to understand. We felt that we could learn more about how research on this topic is being done if we reviewed and discussed these reports in depth.

Also, there is a lot of research on the topic of HCBS waiver programs. This makes sense, because many people with and without disabilities participate in them and both the U.S. federal and state governments invest a lot of resources in them. But this also means that there may be examples of research studies that we were not able to find. For example, we only learned about DuBois et al. (preprint)'s criticisms of existing tools to learn about the effects of HCBS waiver programs on the lives of people with IDD after Chaqueta had signed up for the Ryan Shirley AbilityLab's research study. Although we came up with our own ideas about the limitations of the NCI state reports, we might have approached our analysis of those reports differently. It was easy to find research studies that addressed the topic of people with IDD and HCBS waiver programs, but we found it challenging to find exactly the kind of information that focused on the experiences of people with IDD participating in HCBS waiver programs.

## 3. IMPLICATIONS AND RECOMMENDATIONS

In this section, we make some recommendations for how self-advocates and researchers should learn from our research and put our findings into practice.

### *3.1 Self-Advocates*

Self-advocates should get more involved in research; "Nothing about us without us" applies to research, too! If self-advocates get involved in research, they can learn things about the way systems work that can help make their advocacy stronger. Getting involved in research can help self-advocates understand why things are the way they are, explore issues that are important to them, and come up with ideas for how to make changes that benefit all people with IDD. Self-advocates may need some training or support to get involved in research projects, but it is important for self-advocates to take the initiative so that they can make an impact. Self-advocates have an important role to play in ensuring research studies focus on issues that are important to self-advocates and that these studies are done in a way that makes it easy for people with IDD to participate fully. Through conversations with self-advocate researchers in Massachusetts, we learned about situations where people without IDD do research and choose questions to ask people with IDD that can make service providers or policy-makers look good. Inclusion in research is about more than just participating in other people's surveys: we need to be included in the development of the surveys themselves so that we can express how it might impact us and our understanding. If self-advocates are not involved in research projects, then they cannot advocate for questions that may focus on gaps and barriers instead.

Also, self-advocates should learn about what research says about people with IDD. A lot of research teams do not include people with IDD, and a lot of research is not written in a way that is easy to understand. But research studies contain important information about why things are the way they are and how this affects the lives of people with IDD. There are different ways of learning about what research studies say about people with IDD. One is by reading research studies, another is by attending conferences where researchers present their research.

Policy-makers pay attention to research when they design laws and policies that affect people with IDD, so self-advocates should become well-informed about the insights and ideas that are described in research studies and use them in their advocacy. Self-advocates should also think about helping other self-advocates to understand research by making some research studies available in plain language or easy read formats. Plain language or easy-read research briefs or summaries can also be useful to share with busy policy-makers, who will also appreciate getting complex information presented to them in ways that are easy to understand.

### *3.2 Researchers*

Researchers should include self-advocates in their research teams. Including self-advocates in the research team will change the kinds of questions that researchers ask. Self-advocates are experts on their own lives and can draw on their experiences to help researchers identify issues that will be important to explore. Self-advocates can also help researchers word their questions in ways that will be easy for people with IDD to understand. Self-advocates can also serve as interviewers; their lived experiences can establish trust with research study participants with IDD in ways that will make participants more comfortable giving honest answers. Self-advocate interviewers are also good, for example, at knowing when staff or supporters are speaking for participants with IDD and giving responses to questions that are different than what the participants with IDD would say without the staff or supporters in the room with them. In other words, self-advocates can help researchers to make sure the answers they receive from participants with IDD are more reliable.

Researchers should also make sure that they present what they learn in plain language and easy-read formats so that people with IDD have an equal opportunity to understand this information. Researchers often write about their studies in ways that are difficult for people with IDD to understand, even though the studies talk about topics that are important to them. In some cases, researchers can and should use technical terms and jargon when writing for audiences other than people with IDD, but they should realize that this kind of language makes their research inaccessible to people with IDD.

Researchers should at least include plain language summaries when they publish their studies. Some academic journals that focus on research about people with IDD already require this, including the *British Journal of Learning Disabilities*, which has required all authors to submit an "easy-to-read" summary of their papers when they submit their manuscripts in addition to traditional research study abstracts. They started requiring "easy-to-read" summaries in 2005, "in the spirit of making research findings more accessible" to people with IDD.[49] The editors also make an important point: these summaries will end up benefiting everyone. They inform their authors, "The editorial board also believe that this will make 'scanning' the Journal contents easier for all readers."[50] These easy-to-read must:

- **Summarise the content of their paper using bullet points (4 or 5 at most),**
- **Express their ideas in this summary using straightforward language, and**
- **State simply why the research is important, and should matter to people with IDD.**[51]

We provide an example of what an "easy-to-read" summary looks like below:

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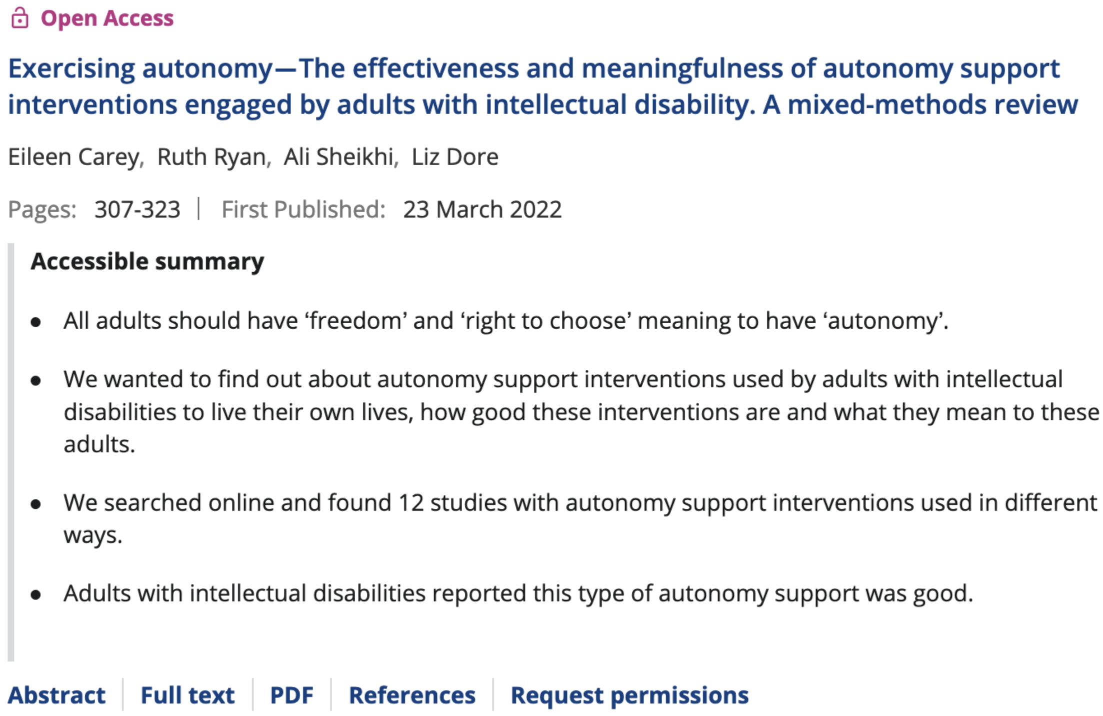
[49] "Author Guidelines," *British Journal on Learning Disabilities*, updated Sept. 2019, accessed Aug. 17, 2023, https://onlinelibrary.wiley.com/page/journal/14683156/homepage/ForAuthors.html.

[50] "Author Guidelines," *British Journal on Learning Disabilities*.

[51] "Author Guidelines," *British Journal on Learning Disabilities*.

**Figure 10. Sample Easy-to-Read Summary of Research Article**[52]



**Exercising autonomy—The effectiveness and meaningfulness of autonomy support interventions engaged by adults with intellectual disability. A mixed-methods review**

Eileen Carey, Ruth Ryan, Ali Sheikhi, Liz Dore

Pages: 307-323 | First Published: 23 March 2022

**Accessible summary**

- All adults should have 'freedom' and 'right to choose' meaning to have 'autonomy'.
- We wanted to find out about autonomy support interventions used by adults with intellectual disabilities to live their own lives, how good these interventions are and what they mean to these adults.
- We searched online and found 12 studies with autonomy support interventions used in different ways.
- Adults with intellectual disabilities reported this type of autonomy support was good.

Other academic journals like *Research in Developmental Disabilities* and the *Developmental Disabilities Network Journal* do this, too. We think this is very positive, and believe that even if researchers are publishing their studies in academic journals that do not have this requirement, they should make "easy-to-read" summaries of their research anyway and publish them online where self-advocates can easily access them. It is not that hard, and as the editors of the *British Journal of Learning Disabilities* point out, these summaries will benefit many more than just people with IDD.

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[52] Eileen Carey et al., "Exercising autonomy—The effectiveness and meaningfulness of autonomy support interventions engaged by adults with intellectual disability. A mixed-methods review," Easy-to-read summary, *British Journal on Learning Disabilities* 51, no. 3 (2023): 307-323.

## 4. IMPACT

Researchers at HPOD have already started to put this idea into action. For example, they recently wrote a brief on the right to political participation of people with IDD around the world for Special Olympics International. Even though Special Olympics International had only asked the HPOD researchers for a traditional policy brief, the HPOD researchers also made sure they provided an “easy-to-read” version.[53] Some of the same researchers also made sure that the *Harvard Law Review*’s blog published an easy read version of their article celebrating the 30th anniversary of the ADA, even though the *Harvard Law Review* had never done something like that before.[54]

Allies like the Samuel Centre for Social Connectedness could also think about ways to make research that fellows produce available in formats that are accessible to a wider audience. For example, the Samuel Centre could think about asking research fellows to include “easy-to-read” summaries in a way that is similar to how the *British Journal on Learning Disabilities* is doing it. And just as the editors of this journal explained, these summaries will likely be useful not just for self-advocates like us but for everyone!

## 5. CONCLUSION

Through our research this summer, we learned that on the topic of the experiences of people with IDD receiving services through states’ HCBS waiver

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[53] “Politics and Persons with Intellectual Disabilities: Challenges and Good Practices from Around the World in Easy Read Format,” Harvard Law School Project on Disability, Nov. 2, 2023, https://hpod.law.harvard.edu/news/entry/politics-intellectual-disabilities.

[54] Hezzy Smith et al., “Supported Decision-Making for Persons with Intellectual and Developmental Disabilities,” *Harvard Law Review* (blog), Aug. 7, 2021, https://harvardlawreview.org/blog/2021/08/supported-decision-making-for-persons-with-intellectual-and-developmental-disabilities.

programs, not much research includes people with IDD; not just as participants but also as researchers. We think this could mean that researchers are not asking the questions that they should be asking or the questions that are important to self-advocates. We think that self-advocates should get more involved in research projects and that researchers should do more to make sure they include self-advocates on their research teams. And everyone should publish their research in plain language or easy-read formats.

As part of an inclusive research project called “Beyond Tokenism,” David and his colleagues explored how people with IDD were included on boards and committees of agencies and organizations that provided services to people with IDD. At the end of that project, David wrote:

> *I know I have a voice that is important to share with the others. I offer a unique perspective of how someone who is receiving services feels about the issues being discussed. I have a voice on how I would like to live my life in my community. I know people (with or without disabilities) can benefit from my voice on these committees, boards, and councils, as I can also learn from them*.[55]

We think this same idea should apply to research about people with IDD. Self-advocates have a voice that is important to share with others and can offer unique perspectives that can benefit the research community.

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[55] David Taylor, “Making Our Voices Heard,” *Inclusion* 4, no. 3 (2016): 159.

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