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How Persons with Intellectual Disabilities Are Fighting for Decision-Making Rights

CHESTER A. FINN, MATTHEW S. SMITH, AND MICHAEL ASHLEY STEIN

For millennia, societies around the world have deployed labels, devised procedures, and designed schemes to defend and legitimize restrictions on how persons with intellectual disabilities exercise their fundamental human rights. These practices are often justified by paternalistic attitudes about what is in the “best interests” of a person with an intellectual disability. Under this paradigm, societies have long euthanized “invalids,” sterilized “imbeciles,” institutionalized “lunatics,” and disenfranchised “incompetents.”

**Disability
and Equality**

Fifth in a series

That we continue today to hear such terms in casual conversation only illustrates how the world we inhabit has been profoundly shaped by the bias and stigma that forged these terms in the first place. The personal experiences of the lead author of this article, Chester Finn, illustrate how subtle and pervasive these attitudes remain. Chester is an experienced self-advocate—that is, someone who identifies as a person with an intellectual or other disability and is committed to demanding and educating others about their rights. As Chester puts it:

For a long time, people have felt that people with disabilities were incapable of a lot of things. We started to change the narrative and advocated for what we can do, and we showed people that we're capable of things. But still somehow they don't believe it. Even now, you'll see some people that you've

worked with for a long time, they'll still have some of those old-fashioned ideas, like, they'll say, “You can do this, and you can do that,” but then they won't let you do whatever you need to do and help you if you need assistance.

Persons with disabilities have long fought against the paternalism that pervades societies' rules for how they may or may not exercise the myriad rights that people without disabilities take for granted. These include the rights to vote, to have sex, to raise children, to manage money, to consent to health care, and so on.

The first international human rights treaty of the twenty-first century, the Convention on the Rights of Persons with Disabilities (CRPD), which was adopted by the United Nations in 2006 and has since been acceded to by 182 countries and counting, contains important protections for these rights. It is a powerful tool for disability rights advocates to use in the fight against paternalistic rules and attitudes that limit the ability of persons with intellectual disabilities to exercise their rights. Chester says:

When the CRPD was being negotiated, I had an advocate from another country tell me if there was a law to support them, they could justify going up to their government to tell them what their rights are. Because if they spoke up too much, they could lose something—whatever rights they had claimed, they could lose those. In some countries, it's not only about just losing your rights: you might lose your life. In the United States, they don't take us out and shoot us. Instead, they destroy us constructively, with rules and laws and money.

Specifically, the CRPD gives disability rights advocates new ways to combat restrictions on the right to legal capacity. Frequently described as the “right to have rights,” the right to legal capacity

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plays gatekeeper for laws protecting other human rights.

In most countries, the right to legal capacity can be restricted by a judge through a guardianship order or similar determination. In such cases, a judge generally decides both that a person with disability is functionally incapable of exercising legal capacity and that it is therefore in their “best interest” to have another person appointed as their guardian. The judge then transfers many, if not all, of the rights of that person with disability to the guardian, who exercises those rights on their behalf.

Because of this transfer of rights, guardianship has aptly been described as a form of “civil death.” Fundamentally, guardianship is premised on a paradox: removing someone’s rights in order to protect them. As Chester observes:

Why do you have to take someone’s rights away in order to help someone make decisions? It just doesn’t make any sense. Rights protect people. How does taking those away help someone? I think they’re just using the disability against the person. If they didn’t have the disability, they’d say, “These are what your rights are.” What good does it do to say someone is too disabled to have rights? That’s the whole point. What they’re saying is, “You’re disabled, so you shouldn’t have rights.” People don’t come out and say it but in practice that’s what they do.

Restrictions like guardianship take away from persons with intellectual disabilities the opportunity to make important decisions about their lives. Although a guardian generally is required to make decisions that are in the “best interest” of someone in their charge, in practice there are few checks on a guardian’s authority. As a result, a guardian can fall into the habit of making decisions on behalf of a person with intellectual disabilities without consulting them.

Even where a guardian does actively consult with a person in their charge, the law typically gives persons with intellectual disabilities few, if any, means for stopping or undoing actions with which they disagree, creating power imbalances that can become ripe for abuse. The same dynamics that can flow from power imbalances between persons with intellectual disabilities and service providers become amplified in court-created relationships between guardians and their “wards,” as the law often calls the persons with intellectual

disabilities who are in a guardian’s charge. Chester explains how power imbalances can lead to incursions on the smallest of decisions:

People have rights but they’re not followed. Your rights according to whom? It’s what your staff or what your agency thinks. Those are the rights. There’s a person who left a voice message for me. On the message I could hear what was happening. He wanted to go to the bank. But they wanted to take them to a grocery store and get cash. But he said he didn’t want to go to the grocery store because they charge a fee for taking money out. He didn’t want to pay that fee. Even though it wasn’t much, it wasn’t his choice. When you don’t have control over those small things, it can make you dependent on somebody else, and you don’t need that.

DECISION-MAKING AS A HUMAN RIGHT

The CRPD aims to help persons with intellectual disabilities combat decision-making restrictions large and small. Importantly, the CRPD does not only require that states allow persons with disabilities to exercise legal capacity as any person without disability would. Article

12(3) of the CRPD also specifically guarantees all persons with disabilities the right to “the support they may require” to make decisions.

This means that states must avoid relying on stigma and biases about persons with intellectual disabilities in regulating who can exercise legal capacity, and must also affirmatively help them to do so if they need and want assistance.

In other words, the CRPD requires states to look past the threshold question of “Who should exercise legal capacity?” and instead help persons with disabilities to do so. In Chester’s view, this means that instead of sitting in judgment of decisions that persons with disabilities make, we should help them to exercise their rights. For example, he says:

I got a call the other day from an investigator who wanted to know about a situation that I had reported. The person tried to wave off what I reported because they thought it was something that a person with intellectual disability told me. They asked me, “Oh so, the person called you and they told you about it?” And I said, “No. They didn’t have to. I was on the phone with this person talking to them and I heard about the incident myself.” Then the investigator understood and we talked a little bit about it. He tried to say, “Oh, you’re a person with a disability. You

Self-advocates should be at the forefront of reform efforts.

can't possibly know the difference or understand." And my whole thing is, if you can't support me and listen to what I have to say, how are you going to support the people, the hundreds and thousands of people, that you're supposed to be protecting?

In many places, doing away with legal capacity restrictions for persons with intellectual disabilities remains a novel or even extraordinary proposition. At least before the CRPD's adoption, virtually every country had guardianship laws that allowed judges to restrict the legal capacity of persons with intellectual disabilities if they were believed to be unable to make their own decisions.

Although some view guardianship as a benign mechanism that aims to protect a person with disability's interests, it can disempower them by depriving them of opportunities to make important decisions that affect their lives, including where to live, how to spend their money, and whether to marry or start a family. Ultimately, guardianship orders give license not just to guardians but also to others to assume that persons with intellectual disabilities are incapable of making decisions about their lives. That's why Chester urges them to fight these assumptions:

It's hard for people to understand. They think that you need something or someone to help you. And a lot of times you don't. You just ask for help when you need it. You don't want people to think that if they're not around that you can't do something. No one knows why but it's something about human nature: they think that you have to be dependent because of your disability. And they don't get that it's just about letting people be able to make decisions and carry them out, that it's important. It's okay to have people to assist you and help you when it's needed, but not all the time. Because what are you going to do when there's nobody around? In life at certain times people get caught up with the things in their lives and the things they need to do, so you have to learn to be independent and how to make things happen on your own.

Courts' broad grants of legal authority to guardians and affirmations of negative assumptions about the capabilities of persons with intellectual disabilities have had dire, dehumanizing consequences. Legal capacity restrictions have exposed them to forced abortion and sterilization, forced medication, involuntary hospitalization or institutionalization, disenfranchisement, ineligibility for adoption or marriage, termination of parental rights, and financial exploitation, among other human rights violations. We would be remiss not

to mention that people with other kinds of disabilities, such as psychosocial disabilities or disabilities associated with aging, have faced similar treatment.

Despite documented instances of legal capacity restrictions leading to abuse and exploitation, widespread stigma and biases about what persons with intellectual or other disabilities are capable of have allowed institutions like guardianship to persist. Chester puts his finger on the doublespeak that persons with intellectual disabilities frequently hear, which helps to explain how purported protective measures can devolve into struggles for control:

You tell people that you have a right, you have a choice, yet at the same time, you tell them, "These are the decisions that we're making for you. Whether you like it or not, you're depending on us." And that's what it boils down to. It changes the narrative when you have to depend on someone else. And I know that because I'm one of those persons that might need assistance from people. But if I don't get things in the way that I need, I'll find another way. But people who are depending on others to do things for them don't have that opportunity. For them, it's either you do it our way or you're not going to get it done. That's why you should never let people know that you need them too much. If you let them do too much, then they start to control the situation. And you don't want to give the control up.

Popular representations of guardianship, as in *The Girl with the Dragon Tattoo* and Netflix's *I Care a Lot*, dramatize the control inherent in guardianward relationships. Britney Spears' recent, high-profile efforts to restore her rights have highlighted this aspect of guardianship. But the struggles of persons with intellectual disabilities to end their guardianships rarely receive splashy headlines or capture the broader public's imagination. The same stigmas and biases that inform judges' guardianship orders also create barriers to galvanizing broad-based support for systemic changes.

The CRPD has started to turn the tables on these paternalistic patterns. Since the CRPD's adoption, a diverse array of countries, including Peru and Colombia, have either abolished or radically reformed their guardianship laws. Others, such as Ireland and Israel, have adopted new laws to allow persons with disabilities to make arrangements to get decision-making help while avoiding legal capacity restrictions. Still other countries, such as Spain and Germany, have blunted certain effects of guardianship orders by ensuring that

persons with disabilities who have guardians can nevertheless exercise their right to vote in elections.

SUPPORTED DECISION-MAKING

Part of the reason the CRPD has enabled disability rights advocates to successfully challenge legal capacity restrictions is that the CRPD also elevates a guardianship antidote called “supported decision-making.” The idea is that just about everyone at some point in their lives needs or wants help when making some kinds of decisions, and therefore it follows that society should not discriminate against people because their support needs or preferences are different from those of others. The principle is simple: let people have the help they may need to make decisions that are tough for them instead of stopping them from making those decisions altogether. Speaking from experience, Chester states:

Supported decision-making is a way of you making your own decisions with support from those who you choose to help you. It gives you the freedom to make a decision but it also helps you know what’s good about a decision and also the negative things and what could happen in different scenarios. People don’t do that for persons with intellectual disabilities. For them, it’s either you get it, or you don’t.

They don’t ask, “How do you want it?” It’s “You can’t have it,” or “You’re not capable.” They look at your disability and your mental capacity—whether you can handle it or not—and that’s not the right way.

Article 12(3) of the CRPD guarantees all persons with disabilities the right to “the support they may require” to exercise legal capacity, which has sparked initiatives to translate this principle into practice. For example, the Bulgarian Association of Persons with Intellectual Disabilities designed a program for systematically helping people to articulate their life goals and to pair them with support persons to help them realize those goals. Although other countries had individualized service planning processes in place before the CRPD, such a program was novel in Bulgaria. More recently, Costa Rica passed a law in August 2016 creating court-appointed “guarantors” tasked with assisting persons with intellectual disabilities to make their own legally binding decisions. How court-appointed supporters may act differently from guardians remains to be seen.

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Describing novel service delivery systems or court-made legal arrangements in terms of supported decision-making carries risks, however. This is because of the ways that similar systems historically have constrained rather than liberated persons with intellectual disabilities. As Chester has witnessed:

I think that’s where having something like supported decision-making allows you to get people that understand stuff to tell you or point out when other people are trying to control you. There’s a number of ways of controlling people without them even knowing it. You know, we had a hard time advocating to shut down the sheltered workshops. I’m no psychologist but mentally those places work on you. You go to those places every day, you do the same job, you get beat down and then you decide to stop fighting. You stop arguing, you stop doing any of the stuff that you did, because you get tired and it wears on you. And then they look at it as, “They’re not causing no trouble. They’re being nice.” That’s why I like what John Lewis says about “good trouble.” Some people who advocate for themselves get labeled as “trouble-makers” simply because they’re trying to take control of their lives and the service systems can get in the way of that, even though they’re not supposed to. To me, that’s just good trouble.

Even in countries with established service-delivery systems for persons with intellectual disabilities that predated the CRPD, supported decision-making is providing new opportunities for them to reclaim control over their lives. In the United States, for example, organizations like the Supported Decision-Making New York project have piloted programs to assist persons with intellectual disabilities to create written supported decision-making agreements that set expectations for support persons they choose and explain these arrangements to family members, health care and service providers, and others. One person even demonstrated the impact that such documents can have by successfully using his agreement as part of a court proceeding to undo his own guardianship. Chester recalls conversations with a recently deceased friend who believed in the power of these agreements:

When my friend was alive, we talked a lot about supported decision-making agreements. At first I was like, “What do you need that for?” But he explained to me, “I need it for backup. I need it to pick some

different people to support me.” For him, it was all about getting the people to support him, and the agreement is almost like a contract for your life. So, he did that. He put it all down in writing and then he felt better about it. He said, “I’ve got this. If something happens, or something changes, then I know how to make up my mind about a decision.” You know, he didn’t get his own apartment, like he was always striving for, but he did have the notion of having that freedom of having this decision that was important to him. That helped him out. So, for him it was a great thing because that way he got his stuff on paper, in a document. Even though when he talked to his family about it, they discouraged him, he still kept it.

Laws, policies, and practices inspired by supported decision-making will inevitably vary across contexts and continents. They may even be difficult to distinguish in practice from pre-CRPD paradigms. We should be skeptical when service providers present billable schemes that maintain status quo provider–recipient power imbalances as supported decision-making initiatives. Or when nominal supporters in fact exert control or influence over the choices of persons with intellectual disabilities in ways that undercut the spirit of supported decision-making. Or when courts rebrand guardians as “supporters” in half-hearted attempts to align outmoded laws with the CRPD’s requirements. Chester has a litmus test for everyone working on supported decision-making:

I have a question for all of them. Are you able to give people the support to make their own decisions without strings? Because no matter who it is or what it is, people will say, “What we’re giving you is this, look at this,” or, “This is a privilege for you,” and, “You must follow this.” Are you truly letting people decide what they want to do with their lives without putting strings and stipulations on it? I don’t think that supported decision-making comes with strings. It’s just a natural way of life, with supports. You don’t come to your friends offering a friendship with strings. Supporters with strings are like Facebook friends. There are lots of people on there who aren’t really friends, even though that’s what Facebook calls them.

But supported decision-making can also be transformative. It might serve as an impetus for a massive redistribution of decision-making authority from persons without disabilities to those with them. It could also prove to be a means for persons with intellectual disabilities to showcase—and be remunerated for—their lived

expertise in navigating complex systems and hierarchies, as they assist their peers to assert more control over their lives. Peer mentoring programs, like one run by the Michigan Developmental Disabilities Council, are breaking important ground and may signal a path forward.

At a September 2021 US Senate hearing on guardianships prompted by concerns about Britney Spears’ case, numerous persons with intellectual disabilities testified that supported decision-making—whether it takes the form of a written instrument, an organized practice, or a personal conviction—has empowered them to reclaim their rights and emerge from restrictive guardianships. As with so many reforms, though, the ways in which laws, policies, and practices inspired by supported decision-making are implemented will be more decisive than whether they are implemented in the first place.

SELF-ADVOCATES IN THE LEAD

One important criticism of the growing number of supported decision-making efforts is that some are not designed or directed by persons with disabilities themselves, those whom these efforts are supposed to benefit. This reflects the broader, ongoing struggle of the global disability rights movement to ensure that persons with disabilities are involved in all decisions that affect them. The movement’s slogan “Nothing about us without us!” remains as relevant as ever in the context of initiatives that turn on positioning and enabling persons with disabilities to play decision-making roles in their own lives. Recalling Roland Johnson, the pioneering self-advocate and survivor of the abuses at the Pennhurst State School, Chester says:

Part of why people don’t understand is that they don’t listen. Half the battle is listening to what people say. Other people want to get into a conversation and let people with disabilities know, “I’m in charge. I’m the authority.” But early in the 1990s, when Roland Johnson was alive, he did an international conference in Toronto, and he talked about who’s in charge. It should be us: we should be in charge of our own lives. But a lot of us have forgotten that it’s about us. A lot of times, if you listen to people, they talk about “our agency.” They say, “This is what our agency thinks.” But what do you think? What are the points that you want to say? How do you feel about the situation? So that’s why you need people that can support you, but also let you be yourself.

Self-advocates should be at the forefront of supported decision-making efforts. The impact of

initiatives purporting to restore and preserve the decision-making autonomy of persons with disabilities will be limited if they are not led by self-advocates. The moral impetus for self-advocate leadership and direction of supported decision-making efforts should be self-evident. But it is also a question of pragmatism: self-advocates are keenly aware of the barriers to decision-making that they and others face on a daily basis. They often have the deepest understandings of how systems can coerce or control the people they are designed to serve. In other words, self-advocates have a wealth of knowledge and expertise that will inevitably strengthen and improve supported decision-making efforts. We have witnessed this in our own work.

Unfortunately, self-advocate leadership on supported decision-making remains the exception rather than the rule. Chester recently observed one such exception while he was embedded in a self-advocate-directed supported decision-making initiative, during a research fellowship with the Samuel Centre for Social Connectedness:

What Massachusetts Advocates Standing Strong (MASS) is doing is important because no one gave it to them. They came up with the idea that they wanted to be included and they wanted to be a part of making any decision about their lives. They really took “nothing about us without us” to heart. I enjoyed my time working with MASS and what they put together. What was so important to me

was that they put it together themselves. They sat down and thought and had conversations about how this will work for the people with disabilities in their state. It wasn't thinking just about themselves; they were selfless. A lot of people will advocate for issues and when the issue gets resolved, they're done with it. Some advocates and professionals are like, “It's behind us now, we don't have to worry about it. We either won that one or we lost that one.” But it's not about wins or losses for self-advocates. For the individuals who want to make changes in their lives, they're the ones with something to really lose.

To this end, we have tried to model self-advocate leadership in our process of developing this essay. With Chester in the lead, we are helping to inject at least one self-advocate's voice into the kind of forum where self-advocates have rarely had a platform to share their grassroots knowledge and expertise as authors in their own right. By doing so, we hope not only to raise awareness of the potential and pitfalls of supported decision-making as part of the ongoing fight waged by persons with intellectual disabilities for control over their lives. We also seek to inspire others to respond to the CRPD's challenge to put aside the traditional assumptions and exclusionary rules surrounding competency, and instead endeavor to provide the support necessary for persons with intellectual disabilities to assert their autonomy. ■