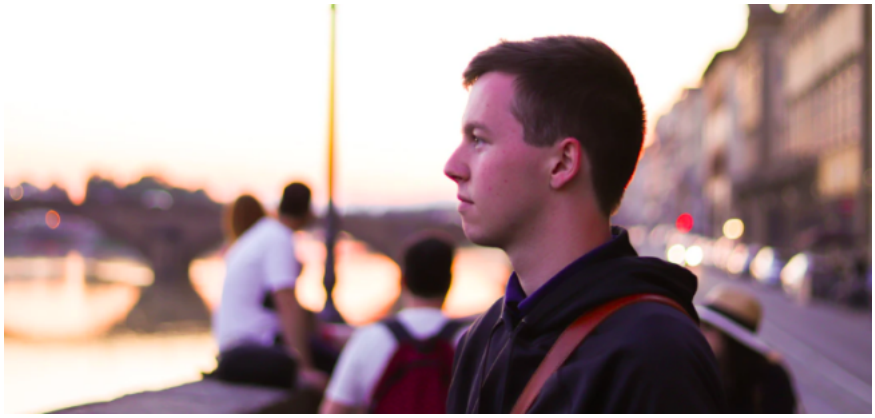
Disability Identity: A Conversation with AUCD's Andy Imparato and Rylin Rodgers

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Recently, PolicyLab team members had the pleasure of engaging in a thought-provoking discussion led by Andy Imparato, JD, executive director of the Association of University Centers on Disabilities (AUCD), and Rylin Rodgers, director of public policy at AUCD, on disability-identity development in children and youth. This topic is of great interest to me—I continue to advocate for policies to help Philadelphia families access services for their children with autism and other disabilities, and I also have a great interest in the link between a caregiver's mental health and having a child with a developmental disability. I wanted to continue this conversation around disability identity and learn how PolicyLab can incorporate the voice of parents and individuals with disability into the work that we do, and Andy and Rylin were generous to participate in a Q&A. I hope you find their answers as informative as I did for understanding the future of the disability rights movement and the well-being of youth living with disability.

Thank you so much for your recent visit to talk with our faculty and staff at PolicyLab about disability identity. To continue the conversation, can you start by defining "disability identity?" When you use the term "disability" are you referring to a specific set of conditions, or do you use a definition related to an individual's experiences or adaptive skills?

Rylin and Andy: Disability gets defined in different ways for different purposes. For example, the Social Security Act defines disability narrowly for purposes of a cash retirement program, and the Americans with Disabilities Act (ADA) defines disability broadly to include the range of people who may experience discrimination based on physical or mental characteristics or conditions. In social and daily interactions, we prefer to defer to the disabled individual's definition and identity frame, which can vary widely and include a medical or clinical diagnosis or category or reflect how they may encounter barriers interacting with their environment. Most of the young people who utilize children's hospitals are likely to grow up with long-term conditions that qualify for protections under the ADA. We believe it is valuable to introduce them to the idea that their disabilities and chronic health conditions are a natural part of the human experience and should not

prevent them from achieving what they want to achieve as children, teens and adults. As individuals with disabilities and family members of people with visible and non-apparent disabilities, we have both seen the value of viewing our disabilities as a natural part of human diversity.

When thinking about definitions in terms of policy or sharing an identity lens with an individual or family newly experiencing disability, often we prefer a civil rights frame, which looks at the ways you may be subject to discrimination related to disability. The ADA frames disability as a legal, not medical, term, and thus it includes a person who has a physical or mental impairment that substantially limits one or more major life activities, a person with a history of such an impairment, or a person who is regarded or perceived as having such an impairment. Yet, we challenge professionals to move and think about disability beyond the medical and legal frameworks of disability and approach it as a human condition—not to be fixed or as devastating. Tobin Siebers, author and former co-chair of the Initiative on Disability Studies at the University of Michigan, says it best, “What difference to human rights would it make if we were to treat fragility, vulnerability and disability as central to the human condition, if we were to see disability as a positive, critical concept useful to define the shared need among all people for the protection of human rights?”

Why is it important to embrace and use the term “disability?”

R&A: Disability is a political word that connects individuals to a diverse and vibrant movement. There is power in claiming an individual’s full identity—we see and acknowledge that gender, race, sexual orientation and religion are parts of our whole selves and remain traits that can lead to discrimination or marginalization. In many settings, we now operate in a way that encourages individuals to bring and share their whole selves and with an understanding that all aspects of who we are contribute to our strengths and gifts. The same is true of disability: claiming the term is part of claiming your whole identity. Importantly, it is also about addressing the bias that has often followed the term. Asserting a pride in disability identity is part of the ongoing work to address ableism. As disabled people are able to claim our oppression, transform and be emancipated from the stigma of disability, we can better address the stereotypes and challenge paternalism, segregation and exclusion when we encounter it.

Our researchers do a lot of work to understand the social determinants of health: factors such as poverty, unstable housing and adverse childhood experiences. Individuals with these social concerns may overlap and/or share many risks with individuals with disabilities. Is there a role for using the term “disability” to include individuals with social risk factors?

R&A: When trying to understand factors related to both public health and individual health, attending to the disability status both for the individual and within a family unit may be of value. Disability is often interrelated to many other social determinants of health—the cost associated with disability, the barriers to workforce participation and the income-level limits associated with our current disability benefit systems that too often are connected to disability create a strong (negative) relationship between disability and quality of life.

While disability is interrelated to the social determinants of health, we should take caution in using disability to include individuals with social risk factors. As risk factors are considered to be a condition that influences the health of people and communities, this results in an implication that “if you are disabled, you therefore are not healthy.” Again, if we start with the proposition that disability is natural and help people from multiple marginalized identities see the connection between the various forms of discrimination that they may experience, our hope is that we can help individuals and families fight for more equity and more justice for themselves and for their communities.

Many of us here at PolicyLab conduct research on young children and youths with disabilities. What recommendations can you offer to help us better incorporate the voice of parents and individuals who will most be impacted by our work?

R&A: A mantra of the disability movement is “*nothing about us without us.”* This frame is instructive to the work of researchers. Including the voices of people with disabilities at all levels of research can transform and enhance the quality of the research foundationally. It can guide us to ask better questions to research the issues that matter most. When developing a research budget, please include funds to hire and compensate

those who inform, advise and design our research. In research related to children with disabilities, it is important to provide room for the difference in experience and perspective between the child with a disability and their parent/caregiver. Too often the parent perspective is used as proxy for both—asking and including the voice of the child from a very young age strengthens our work and supports self-determination and effective self-advocacy for the child. Researchers must always be asking, “Whose bodies, whose voices are being left out?”

How do you think that having more families and individuals embrace the term “disability” would affect policymakers and future policy decisions?

R&A: One in five Americans experience disability, and in many cases their needs related to effective policy are interrelated across the disability experience. Yet as a group, people with disabilities are not seen as a political constituency and are often not represented by disabled people. A move toward disability identity across the life course and across disability categories is a path to political influence and power. There are examples across the civil rights landscape where collective identity yields positive policy outcomes, and in many ways, disability is the marginalized group that is both most in need of greater political influence and most poised to move to a different level of collective power. Ideally, we would love if youth with disabilities, their families and the clinicians who work with them all see themselves as part of a “disability vote” that can hold policymakers accountable for making better decisions that affect this community.

As advocates, clinicians and researchers, what can we do to demystify the term “disabled” to allow parents, people with disabilities and society see the possibilities of what individuals with disabilities can attain?

R&A: Connections and relationships can be critical to shifting understanding of disability. Engaging with leaders who have disabilities is a way to expand your knowledge and establish disabled mentors in your life. Learning about the rich history of disability rights can help empower families around what is possible and their place in the world. Rylin made a point of connecting her children with disabilities with adults who had a similar lived experience so they could see from an early age what life might look like for them as adults. Clinicians and researchers must recognize their power in shaping a person’s disability identity. Parents and newly diagnosed individuals receptively form their first disability identity through the interactions of these professionals. Critical thought and action must be taken in this process, as well as being aware of the implications it will have on an individual’s identity formation.

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