

# CONNECTICUT PUBLIC INTEREST LAW JOURNAL

---

VOLUME 24

2024–2025

Number 2

---

## If Billboards Could Talk: Re-Imagining Urban Spaces as Sites of Individual Expression

KATYA ASSAF-ZAKHAROV & TIM SCHNETGÖKE\*



*Imagine a city where . . . everybody could draw whatever they liked. Where every street was awash with a million colours and little phrases. Where standing at a bus stop was never boring. A city that felt like a party where everyone was invited, not just the estate agents and barons of big business.*

BANKSY, WALL AND PIECE (2005)

---

\* Katya Assaf-Zakharov is a Visiting Professor at the Peter A. Allard School of Law of the University of British Columbia and a Senior Lecturer at the Law School and the DAAD Center for German Studies of the Hebrew University of Jerusalem. Tim Schnetgöke is a professional photographer and a connoisseur of vandalism, specializing in urban photography and extensively documenting graffiti and other urban interventions. We would like to thank Netta Barak-Corren, Avner De Shalit, Deborah R. Gerhardt, Daphna Lewinsohn-Zamir, Eva Illouz, Noam Shoval, Eyal Zamir, the participants of the international conference “Who Owns the City” and the participants of the “Law and Cities” event at the UBC for their invaluable insights, comments, and suggestions. We would like to express our gratitude to Wall GmbH and the Hebrew University of Jerusalem for sponsoring the experiment described in this paper. Our special thanks go to Frauke Bank from Wall GmbH for her guidance, patience and support. We are also very grateful to Svenja Arndt, Stefanie Menschner, Max Mundhenke, and Janka Haverbeck for supporting our project in media-related aspects.

## INTRODUCTION

Imagine a city that gives all its residents a chance to become visible by adding content of their own to the urban landscape. What kind of content would people share with their co-residents once given the chance to do so? How would this make them feel? How would the others react to individual expressions in city streets?

In this paper, we present the findings of a real-life urban experiment (living lab) we conducted in the public space of Berlin, Germany, during March–August 2022. With this experiment, we wanted to test a novel tool of democratic and urban participation — one that would allow individual expression in urban public spaces.

We hypothesized that the tested participatory tool could ameliorate three distinct, but correlated phenomena. The first is democratic deficit resulting from the polarization of public discourse and inability of political rivals to communicate with each other. Scholars have suggested different measures of “mending democracy” and restoring the common basis for social communication. Many of these proposals advocate democratic deliberation to achieve greater understanding on disputed political issues. Others take the opposite direction, pointing out that the social discourse is oversaturated with politics and suggesting to introduce collective endeavors where politics is beside the point.

Our idea is trying a different method of de-polarizing the public discourse: providing space for individual speech. We suggest allowing individuals to place contributions of their choice in spaces that would reach a broad and diverse audience. In our experiment, we wanted to test this idea, exploring what kind of content people would share with the public if asked to make their choice without any pre-given topics and knowing that there will be no selection process, but, naturally, while remaining in the framework of the existing legal regulations. In this way, we sought to get a sense of how the social discourse would look if some spaces were given to free individual — rather than collective or channeled — speech.

The second concern our proposal seeks to address is the anonymity of urban public spaces. Although these spaces belong to the public and are legally recognized as “public fora,” practically, they are shaped and controlled by a small number of public and private entities. City residents are left with the passive role of consumers rather than co-creators of their shared visual environment. Our proposal is to create tools that would allow residents to actively co-design their city, in a simple and low-threshold way. Our experiment sought to explore whether many people would take the opportunity to “personalize” public spaces and, if so, what they would like to present there, what their motivations would be, and what they would like to communicate with their contributions.

Finally, our proposal touches upon the topic of public art. The highly exclusionary nature of art in today’s western societies is well-illustrated by the quote: “If it is art, it is not for all. If it is for all, it is not

art.”<sup>1</sup> Scholars repeatedly criticized the hegemonic position of art, arguing that “cultural democracy” — where everyone is encouraged to contribute one’s creativity to the shared culture — is indispensable for a true political democracy.<sup>2</sup> Our proposal joins these voices. One of the goals of our experiment was to sense whether such democratization of culture is a feasible idea. We wanted to discover what would happen if people had an opportunity to add their contributions to the shared visual environment; would many of them use this opportunity to share their artworks? Another interesting question was how other people would react to art that is shared without any selection process. Finally, it was interesting to see how important it would be for participants to receive reactions to their artworks. These findings could provide initial reference points as to how the ideas of cultural democracy might function in real life.

In March 2022, we invited people in Berlin to use the project’s website to upload contributions they wished to present on a billboard in urban public space. In August 2022, these contributions appeared on 1500 large billboards — city-light posters, 175x118 cm, which were kindly provided by Wall GmbH — throughout Berlin. We analyzed the submitted contributions, as well as other information the participants provided, such as comments and demographic data. In addition, we conducted a survey among the participants. In this paper, we will present the results we obtained and assess how far they support the feasibility of our idea of individual speech as a meaningful tool.

The paper proceeds as follows: Parts I–III discuss the three abovementioned phenomena: political polarization, anonymity of public spaces, and the exclusionary nature of public art. We explain how the envisioned participatory tool could help ameliorate each of these phenomena. Part IV describes the conditions of our experiment, and how it proceeded. Part V lays down our research questions, and discusses the methods we used to collect and analyze data. Part VI presents and discusses the results obtained from the experiment. Finally, Part VII concludes the discussion.

## I. POLITICAL POLARIZATION

The current crisis of western democracies caused by political polarization has been the subject of some of the most intensive academic discussions.<sup>3</sup> Empirical data reveals a growing hostility between political opponents, who tend to hold highly unfavorable views of each

---

<sup>1</sup> A regularly employed phrase accredited to Arnold Schoenberg; see, e.g., Harlow Robinson, Schoenberg in Hollywood: *An Operatic Tale of Artistic Integrity and Identity*, S.F. CLASSICAL VOICE (May 20, 2025), <https://www.sfcv.org/articles/review/schoenberg-hollywood-operatic-tale-artistic-integrity-and-identity>.

<sup>2</sup> See e.g., Jack M. Balkin, *Cultural Democracy and the First Amendment*, 110 Nw. U.L. Rev. 1053 (2016); NICK C. WILSON, JONATHAN D. GROSS & ANNA L. BULL, TOWARDS CULTURAL DEMOCRACY: PROMOTING CULTURAL CAPABILITIES FOR EVERYONE (2017).

<sup>3</sup> CRAIG A. HARPER & DEAN FIDO, THE ROLE OF COGNITIVE EMPATHY IN REDUCING POLITICAL OUTGROUP AVOIDANCE 3 (2018) (“Polarization has become one of the most-studied topics in political psychology in the last decade, with scientists examining the roots, manifestations, and effects of these processes.”).

other. People increasingly perceive their political rivals as unintelligent, immoral, irrational, dishonest, and even mentally ill. They typically avoid discussions with individuals holding different political views, perceiving their beliefs as unsubstantiated and therefore not worth engaging with.<sup>4</sup> This “affective polarization” divides western societies into competing “political tribes,” whose members often seek to avoid any contact with members of other tribes.<sup>5</sup>

Interactions with like-minded individuals tend to amplify one’s political views, and hence, political tribalism expands the ideological gap between the opposing groups.<sup>6</sup> Social media also play a significant role in this process; instead of exposing their users to diverse views, their algorithms deliver content that affirms previously held opinions, thus enclosing the users in separate informational universes and deepening political polarization.<sup>7</sup>

Affective polarization creates an atmosphere of distrust and undermines mutual respect, which is a pre-condition for a genuine dialogue, coordination, and compromise.<sup>8</sup> Indeed, empirical data shows that people tend to perceive rival political ideas as not only wrong, but also as a significant threat to the well-being of society.<sup>9</sup> Hence, unsurprisingly, they tend to meet rival political leadership with mistrust and may even question its legitimacy. Political polarizations thus lead to a policy deadlock and paralyze democracy.<sup>10</sup>

This troubling situation has provided a rich ground for scholarly and political proposals as to how to restore a common basis for a democratic exchange and cooperation. A great number of these proposals take the direction of remodeling the political sphere to create greater room for deliberation.<sup>11</sup> Echoing Jürgen Habermas’s concept of

---

<sup>4</sup> ROBERT B. TALISSE, *OVERDOING DEMOCRACY: WHY WE MUST PUT POLITICS IN ITS PLACE* 4 (2019) (explaining how the increasing divide between the political opponents leads both sides to conclude that the ideas and arguments of their political rivals are without merit and thus not worth engaging with).

<sup>5</sup> Harper & Fido, *supra* note 3, at 3 (“[P]olitical partisans increasingly dislike each other, sort themselves into distinct neighborhoods, and avoid each other’s viewpoints.” (citations omitted)); James Fishkin, Alice Siu, Larry Diamond & Norman Bradburn, *Is Deliberation an Antidote to Extreme Partisan Polarization? Reflections on “America in One Room,”* 115 AM. POL. SCI. REV. 1464, 1464 (2021) (“Our division into competing political tribes has led to a tribalism of social separation.”).

<sup>6</sup> TALISSE, *supra* note 4, at ch. 4 (describing experiments that demonstrate that discussion among likeminded people amplifies the members’ pre-discussion political tendencies).

<sup>7</sup> ELI PARISER, *THE FILTER BUBBLE: HOW THE NEW PERSONALIZED WEB IS CHANGING WHAT WE READ AND HOW WE THINK* (2012); CASS R. SUNSTEIN, *#REPUBLIC: DIVIDED DEMOCRACY IN THE AGE OF SOCIAL MEDIA* (2017) (both discussing how the social media algorithms divide society into separate informational universes and how the social and political effects of this division).

<sup>8</sup> MARK J. HETHERINGTON & THOMAS J. RUDOLPH, *WHY WASHINGTON WON’T WORK: POLARIZATION, POLITICAL TRUST, AND THE GOVERNING CRISIS* 15–26 (2015) (explaining how affective polarization creates and deepens political distrust).

<sup>9</sup> TALISSE, *supra* note 4, at ch. 4 (describing experiments that generated this data).

<sup>10</sup> HETHERINGTON & RUDOLPH, *supra* note 8, at 39–42.

<sup>11</sup> See, e.g., AMY GUTMANN & DENNIS A. THOMPSON, *DEMOCRACY AND DISAGREEMENT* 199–230 (1996); see also Lynn M. Sanders, *Against Deliberation*, 25 POL. THEORY 347, 347 (1997) (“When democratic theorists suggest remodeling our politics, it is in the direction of making them more deliberative.”).

an “ideal speech situation,”<sup>12</sup> scholars and politicians suggest creating citizens’ fora, where small groups of participants representing diverse views would have a genuine opportunity to discuss specific topics.<sup>13</sup>

Deliberation consists of a civil discussion, where all the participants have correct and comprehensive information, as well as an equal opportunity to speak. Deliberators put forward arguments based on reason, discuss and criticize them, and attempt to reach a consensus.<sup>14</sup> Experiments demonstrate that deliberation can narrow the differences between initially polarized groups.<sup>15</sup> Many small-scale deliberative citizen fora have been introduced across the globe; scholars propose to institutionalize these practices as an integral part of political processes.<sup>16</sup>

A further line of writing has pointed out that focusing on the spoken word and reasoned argumentation, the ideal of deliberative democracy, excludes other important media of political expression.<sup>17</sup> Focusing on rational and assertive argumentation favors formally educated and self-confident individuals, who often belong to privileged social groups.<sup>18</sup> Emotional or experience-based expression, more typical for marginalized groups, is thereby devalued and excluded.<sup>19</sup> Scholars have suggested expanding the range of democratic communication to include such tools as visual art, sounds, dance, performance, humor, poetry, rhetoric, storytelling, testimony, compliments, and greetings.<sup>20</sup> Fostering

<sup>12</sup> JÜRGEN HABERMAS, *THE STRUCTURAL TRANSFORMATION OF THE PUBLIC SPHERE: AN INQUIRY INTO A CATEGORY OF BOURGEOIS SOCIETY* 34 (Thomas Burger & Frederick Lawrence trans., 1989) (1962).

<sup>13</sup> E.g., Fishkin, Siu, Diamond & Bradburn *supra* note 5, at 1479 (suggesting to foster opportunities for many more people to deliberate); Joshua Cohen, *Deliberation and Democratic Legitimacy*, in *DELIBERATIVE DEMOCRACY: ESSAYS ON REASON AND POLITICS* 67 (James Bohman & William Rehg eds., 1997) (proposing ways to institutionalize deliberative practices into democratic decision-making processes).

<sup>14</sup> Robert E. Goodin, *Democratic Deliberation Within*, 29 *Phil. & Pub. Affs* 81, 81 (2000) (“Deliberation consists in the weighing of reasons for and against a course of action.”).

<sup>15</sup> E.g., Fishkin, Siu, Diamond & Bradburn, *supra* note 5, at 1478.

<sup>16</sup> E.g., *THE DELIBERATIVE DEMOCRACY HANDBOOK: STRATEGIES FOR EFFECTIVE CIVIC ENGAGEMENT IN THE TWENTY-FIRST CENTURY* (John Gastil & Peter Levine, eds., 2005); *DELIBERATIVE MINI-PUBLICS: INVOLVING CITIZENS IN THE DEMOCRATIC PROCESS* (Kimmo Grönlund, André Bächtiger & Maija Setälä, eds., 2014). See also CAROLYN M. HENDRIKS, SELEN A. ERCAN, JOHN BOSWELL, *MENDING DEMOCRACY: DEMOCRATIC REPAIR IN DISCONNECTED TIMES*, ch. 8 (2020) (briefly overviewing such initiatives).

<sup>17</sup> Ricardo Fabrino Mendonça, Selen A. Ercan & Hans Asenbaum, *More Than Words: A Multidimensional Approach to Deliberative Democracy*, 70 *POL. STUD.* 153, 157–68 (2022) (criticizing the “talk-centric” nature of deliberation and suggesting to conceptualize deliberative democracy in multidimensional terms, so as to include visuals, sounds and presence); ANDRÉ BÄCHTIGER & JOHN PARKINSON, *MAPPING AND MEASURING DELIBERATION: TOWARDS A NEW DELIBERATIVE QUALITY* 25 (2019) (explaining the relevance of theatre plays or dance performances for deliberative processes).

<sup>18</sup> Iris Marion Young, *Communication and the Other: Beyond Deliberative Democracy*, in *DEMOCRACY AND DIFFERENCE: CONTESTING THE BOUNDARIES OF THE POLITICAL* 120, 123–24 (Seyla Benhabib ed., 1996) (explaining that the rules of deliberative discourse privilege males over females, and better-educated, white, middle-class people over other social groups).

<sup>19</sup> *Id.* at 123–25 (explaining how deliberation privileges certain types and styles of speech while devaluing and excluding others).

<sup>20</sup> *Id.* at 130 (discussing greetings and compliments); IRIS MARION YOUNG, *INCLUSION AND DEMOCRACY* 75 (2000) (making the case for storytelling and rhetoric); Lincoln Dahlberg, *The Habermasian Public Sphere: Taking Difference Seriously?*, 34 *THEORY & SOC’Y* 111, 113–14 (2005) (suggesting including humor, poetry, theatre, and ceremony in the range of deliberative practices); Sanders, *supra* note 11, at 351 (referring to testimony); Vid Simoniti, *Art as Political*

imagination and creating empathy instead of employing logical argumentation can help to overcome the difficulty of attending and appreciating perspectives that contradict one's political views. This, in turn, could help in restoring the basis for a genuine democratic discourse.<sup>21</sup>

Other scholars are less optimistic about the opportunities of deliberation. They point out that polarization has much more to do with group affiliation than with independent thought. Most citizens choose a group they wish to belong to, and base their political views on group identity — “us” vs. “them” — rather than on rational arguments or the desire to protect one's interests.<sup>22</sup> Members of “political tribes” hold predictable views on a wide range of topics, and are inclined to support whatever policy they believe is backed by their political party.<sup>23</sup> Moreover, people even tend to deny objective facts presented to them if they contradict their party's views.<sup>24</sup> All this leaves little hope for the possibility of reaching understanding, agreement and compromise by the means of rational argumentation.<sup>25</sup>

Hence, scholars have suggested moving away from deliberative discussions and discovering new ways to create solidarity and trust, thereby restoring the basis for social communication and political discourse.<sup>26</sup> Others have gone further to suggest that to save democracy, we should have less, rather than more, politics in our lives.<sup>27</sup> Such scholars argue that engagement with politics makes people biased,

---

*Discourse*, 61 BRIT. J. AESTHETICS 559, 570 (2021) (discussing the role of art in democratic deliberation).

<sup>21</sup> Harper & Fido, *supra* note 3 (describing an experiment whose results demonstrated correlation between empathy and reduced levels of outgroup avoidance); Michael Hannon, *Empathetic Understanding and Deliberative Democracy*, 101 PHIL. & PHENOMENOLOGICAL RSCH. 591, 607 (2020) (“[D]emocratic deliberation can be said to have epistemic value when it fosters empathetic understanding.”); Hannah Read, *Empathy and Common Ground*, 24 ETHICAL THEORY & MORAL PRAC. 459, 467 (2021) (“[E]xperiencing common ground through empathy may play a crucial role in helping antagonistic moral opponents recognize and appreciate their common ground as such.”).

<sup>22</sup> MICHAEL HANNON, THE ILLUSION OF POLITICAL DISAGREEMENT 17 (2023), <https://static1.squarespace.com/static/551587e0e4b0ce927f09707f/t/5d45982ef352bf00011fb285/1564842036109/The+Illusion+of+Political+Disagreement.pdf> (“Citizens do not choose to support a policy on the basis of their own preferences; they instead alter their ‘reasons’ to support a party according to whichever party they support.”).

<sup>23</sup> HRISHIKESH JOSHI, WHY IT'S OK TO SPEAK YOUR MIND 131 (2021) (“[A] good member of either political tribe today, in the United States, has prescribed and predictable views on immigration, minimum wages, crime and policing, abortion, environmental policy . . . . Political tribes are not hospitable locations for independent thinkers.”); Michael Hannon, *Is There a Duty to Speak Your Mind?*, SOC. EPISTEMOLOGY 274, 279 (2022) (“[Political parties] encourage us to adopt views with little reflection, to let our leaders do our thinking for us, and to support whatever our ‘team’ supports.” (discussing Joshi's book)); Geoffrey L. Cohen, *Party Over Policy: The Dominating Impact of Group Influence on Political Beliefs*, 85 J. PERSONALITY & SOC. PSYCH. 808, 814 (2003) (asserting that people will support whatever policy or platform they think is backed by their party).

<sup>24</sup> Hannon, *supra* note 22 (“[T]he facts play no substantive role in shaping our political attitudes or beliefs.”).

<sup>25</sup> *Id.* (“[A]ttempting to resolve political disagreement by closing partisan gaps on policy issues is misguided. This is a problem for deliberative democracy. If our disagreements are not based on genuine reasons or arguments, then we cannot engage with each other's views.”).

<sup>26</sup> *E.g.*, HENDRIKS, ERCAN, AND BOSWELL, *supra* note 16, at 2–10 (2020) (discussing activities, such as knitting protests, that bring people together and create new bonds of solidarity).

<sup>27</sup> TALISSE, *supra* note 4; JASON BRENNAN, AGAINST DEMOCRACY 203 (2016).

irrational, polarized, and unable to think independently.<sup>28</sup> Interestingly, empirical data demonstrates that exposure to diverse perspectives makes people ambivalent about their political views and less likely to participate in politics. Conversely, spending time in one's "echo chamber" makes people more politically engaged, but also less open-minded.<sup>29</sup>

In his book *Overdoing Democracy*, Robert Talisse points out that our shared social environment is oversaturated with politics.<sup>30</sup> Our workplaces, neighborhoods, places of worship, and many other sites of socialization increasingly turn into spaces of interaction against the background of political homogeneity. We surround ourselves ever more by people with similar political views, thus making politics omnipresent, inescapable, and universally relevant.<sup>31</sup> We increasingly perceive others through the prism of their political affiliation, and distrust the capacities of our political opponents in fields that have nothing to do with politics.<sup>32</sup> Talisse suggests taking steps to desaturate our social environment of politics by initiating collective endeavors, in which politics would be beside the point.<sup>33</sup> Regaining the ability to regard our co-citizens as people with valuable aspirations and pursuits that lie beyond politics would help to restore the basis for understanding and cooperation.<sup>34</sup>

In addition to making specific proposals, scholars have repeatedly pointed out the general need to experiment with new tools of democratic participation.<sup>35</sup> In a way, our current project is an attempt to test one such novel democratic tool.

Our idea is to create a space where people could express themselves in a way that reaches an audience. Our proposal is to explore the medium of *individual* speech. Today, most occasions people have to speak publicly involve some collective dimension. For instance, demonstrations are organized around shared ideas, interests or identities; social media encloses their users in "filter bubbles," bringing forward the common basis between groups. Yet, collective speech is, to a certain

---

<sup>28</sup> Hannon, *supra* note 23, at 279 ("If we pay too much attention to politics, we lose our ability to think freely."); TALISSE, *supra* note 4, at ch. 1 (arguing that engagement with politics makes people irrational and biased).

<sup>29</sup> Diana C. Mutz, *The Consequences of Cross-Cutting Networks for Political Participation*, 46 AM. J. POL. SCI. 838, 845 (2002) (reporting experiments that yielded these results).

<sup>30</sup> TALISSE, *supra* note 4, at ch. 2 (discussing the expanding reach of politics and describing how it infiltrates and saturates our shared social environment).

<sup>31</sup> *Id.* at 22 ("[O]ur workplaces, neighborhoods, places of worship, households, and shared public spaces have become both more politically homogeneous and more politically intoned.").

<sup>32</sup> *Id.* at 120 ("[W]e tend to exhibit distrust in the general capacities of those who do not share our politics, even when it comes to those who are experts in tasks that do not involve political judgment.").

<sup>33</sup> *Id.* at ch. 1 ("We need to devise cooperative endeavors in which politics is not surmounted, but beside the point.") and ch. 6 (making several specific proposals of such endeavors). See also JASON BRENNAN, AGAINST DEMOCRACY 142 (2016) (suggesting that less participation in politics may make us better off).

<sup>34</sup> TALISSE, *supra* note 4, at ch. 5 (explaining how such "civic friendship" will help to restore the basis for social cooperation).

<sup>35</sup> *Id.* (explaining that there is no pre-given list of tools to create non-political spaces of democratic participation, and that this field needs experimentation); HENDRIKS, ERCAN, AND BOSWELL, *supra* note 16, at ch. 8 (calling to experiment with new ways of mending democracy: to take risks, push boundaries, and try new things).

extent, “one-dimensional”: it is always reduced to a common idea, interest or message. As such, it lacks the nuance, complexity, ambivalence, and richness individual speech may have.

In addition, since the current political polarization is strongly connected to group identities, it might be reasonable to speculate that creating space for *individual* expression within public discourse might alleviate this detrimental condition. In other words, if our social sphere is saturated with politics and largely reduced to two opposing collective voices, opening it up for independent individual expression might add some polyphonic elements to this brawly duo.

Unlike previous suggestions, we propose to avoid the choice between political and non-political themes, between rational arguments and artistic speech, between greetings and poetry. Instead, we suggest assuming an *agnostic* position as to the question what public discourse should consist of, and letting people decide on this question individually. In other words, our proposal is to democratize the very question of what kind of themes and ways of expression should belong in the social sphere.

In our experiment, we sought to explore what people — and not only scholars theorizing on the subject — feel appropriate to share with others, to contribute to the social discourse. In this sense, the experiment goes in the opposite direction than the proposals made so far: instead of looking for novel ways to find common grounds for connections between people, we wanted to allow some space for individuality. At the same time, we did anticipate that our experiment would generate feelings of social connectedness, community, and belonging. Our assumption was that these feelings might emerge not only in the context of commonality, but also in a framework of diversity.

## II. ANONYMITY OF PUBLIC SPACES

The second field that our project touches upon is public spaces. City life happens in these spaces; this is where the spirit of the city emerges and evolves. Scholars point out that public spaces should function as sites of social exchange and discourse, which are indispensable for a functioning democracy. Similarly, courts identify these spaces as quintessential “public fora.”<sup>36</sup> Indeed, since public spaces are used by everyone and cannot be avoided, they provide the best opportunities for social encounter and exchange. This is apparently how public spaces functioned in medieval cities.<sup>37</sup>

By contrast, one can hardly say that public spaces in modern western cities serve as sites of vivid interpersonal interactions between strangers. Starting a conversation with an unknown individual is

<sup>36</sup> *E.g.*, *United States v. Grace*, 461 U.S. 171, 177 (1983) (recognizing urban public spaces as quintessential public fora); *United States v. Marcavage*, 609 F.3d 264, 274–75 (3d Cir. 2010) (holding that parks and sidewalks are “traditional public fora”).

<sup>37</sup> Andrzej Zieleniec, *The Right to Write the City: Lefebvre and Graffiti*, 10 ENVIRONNEMENT URBAIN / URB. ENV'T 1, 7–8 (2008) (“[Ancient and medieval cities] grew and developed according to the needs of their inhabitants who prioritised social and public spaces . . . as a key feature and element of collective belonging and the shared experience of the town and the city.”).



regarded as awkward and even intrusive behavior.<sup>38</sup> Moreover, scholars note that public spaces are increasingly commercialized and privatized.<sup>39</sup> This trend redefines the shared spaces as sites primarily designed for consumption, and reduces social participation in the public sphere to the liberty to consume, driving away any chance for spontaneity and creativity. As Bradley Garrett puts it, “the potential range of spatial engagement [in commercialized public spaces] can fit in a coffee cup.”<sup>40</sup>

Public spaces turn us into consumers in another sense: most of us passively consume urban semantics most of the time. The visual design of cityscapes is highly expressive. Cityscapes tell us stories — of wealth and poverty, of power and weakness, of social acceptance and rejection, of winners and losers. The high fences around private homes emphasize the power of wealth;<sup>41</sup> advertising billboards teach us about the central role of consumption in our lives;<sup>42</sup> and whitewashed graffiti signifies that personal messages are out of place in public space.<sup>43</sup> Persistent, but barely noticed, cityscapes educate us about what is socially acceptable, what is important, and what the right order of things in society is.<sup>44</sup>

Although public spaces are defined as “quintessential public fora,” this status has practical significance only in the field of temporal speech, such as demonstrations, rallies, and the distribution of handbills.<sup>45</sup> Adding new expressive elements to the cityscapes or altering the existing ones is forbidden.<sup>46</sup> Thus, while everyone may access public spaces, cityscapes are created by a limited social group, consisting predominantly of urban planners, property owners, and commercial enterprises.<sup>47</sup> This defines most citizens as mere consumers, rather than co-creators of urban semantics.

Scholars have pointed out how commercialized cityscapes police social behavior, colonize daily experiences, impose values of consumer culture on city residents, and exclude groups that do not fit into

---

<sup>38</sup> Luca M. Visconti, John F. Sherry, Jr., Stefania Borghini, & Laurel Anderson, *Street Art, Sweet Art? Reclaiming the “Public” in Public Place*, 37 J. CONSUMER RSCH. 511, 522 (2010).

<sup>39</sup> E.g., Bradley L. Garrett, *Squares for Sale! Cashing Out on Public Space*, in THE RIGHT TO THE CITY: A VERSO REPORT 39, 40–41 (2017) (ebook).

<sup>40</sup> *Id.* at 42.

<sup>41</sup> Mojtaba Valibeigi & Faezeh Ashuri, *Deconstruction and Fractalization of Urban Identity*, 7 J. URB. SOC’Y’S ARTS 1, 4 (2020).

<sup>42</sup> See Katya Assaf, *The Dilution of Culture and the Law of Trademarks*, 49 IDEA 1, 80–81 (2008).

<sup>43</sup> Rachel Heidenry, *The Murals of El Salvador: Reconstruction, Historical Memory and Whitewashing*, 4 PUB. ART DIALOGUE 122, 135–136, 139–41 (2014).

<sup>44</sup> See, e.g., JANE JACOBS, *THE DEATH AND LIFE OF GREAT AMERICAN CITIES* (Vintage Books 1992) (1961); CLARE C. COOPER, *EASTER HILL VILLAGE: SOME SOCIAL IMPLICATIONS OF DESIGN*, 198–201 (1975).

<sup>45</sup> William M. Howard, Annotation, *Constitutionality of Restricting Public Speech in Street, Sidewalk, Park, or other Public Forum—Characteristics of Forum*, 70 AM. L. REPS. 6th 513 (2011, updated 2023). See also, e.g., *City of Cincinnati v. Discovery Network, Inc.*, 507 U.S. 410, 428–30 (1993) (invalidating city’s ban on the distribution of commercial handbills in public spaces).

<sup>46</sup> E.g., D.C. CODE § 22–3312.01 (2025) (defining such behavior as a crime); CAL. PENAL CODE § 594 (West 2024) (same).

<sup>47</sup> Katya Assaf-Zakharov & Tim Schnetgöke, *(Un)Official Cityscapes: The Battle Over Urban Narratives*, 57 HARV. C.R.-C.L. L. REV. 177, 179 (2022).

commercial playgrounds.<sup>48</sup> Perhaps one of the most striking features of urban landscapes shaped by strategies of capital is their gravitation towards homogeneity.<sup>49</sup> Store signs and billboards of global brands lighten cities across the globe with their neon sameness. In London and Berlin, New York and Singapore, streets greet people with H&M, Starbucks and Adidas, making it sometimes almost hard to tell cities apart. What makes cities truly unique are people, but their individuality remains largely invisible in the fabric of urban semantics.

A notable exception in this theatre of anonymity is graffiti. The practice of non-commissioned writing and painting on various visible urban surfaces relentlessly challenges the hegemonic power of property, commerce, and politics that shape our visual environment.<sup>50</sup> Using various urban surfaces as canvases, graffiti “disrupts the aesthetic fabric of the urban environment,” demonstrating that an alternative vision of public space is possible and making its own claim over urban semantics.<sup>51</sup> Graffiti writers are driven by numerous motivations, such as exercising their artistic skills, experiencing creative freedom, enjoying the thrill of risk, marking their presence, greeting the passerby, gaining recognition within the graffiti community, expressing themselves, awakening public consciousness on a social issue, making art accessible for everyone, and beautifying their city.<sup>52</sup> Yet, graffiti is an illegal and risky endeavor, which naturally makes the circle of its creators rather exclusive.<sup>53</sup>

In our experiment, we wanted to explore what would happen if people have an opportunity to emblazon public spaces with their personal messages in a legal way. This line of thought connects to the discourse on “the right to the city.” A term coined by Henri Lefebvre, the right to the city entails the right of the residents to actively engage in

---

<sup>48</sup> Zieleniec, *supra* note 37, at 6 (“Hegemonic values and meanings are imposed on those who live in cities through dominant representations. . . . Instead of being able to inhabit and use social, public or collective space freely we are forced to endure a habitat created by and for the needs of capital.”); Visconti, Sherry, Borghini & Anderson, *supra* note 38, at 513 (pointing out that urban public spaces are increasingly conceptualized as commercial “playgrounds” that “inevitably exclude[] some social groups”).

<sup>49</sup> Zieleniec, *supra* note 37, at 7 (“As neo-liberal global capitalism colonises more of the world so more towns and cities . . . are subject to the planning and design strategies of capital that mould and shape their form to meet their own ends. . . . What is produced as urban landscapes is a perpetual sameness . . .”).

<sup>50</sup> Stefano Bloch, *Challenging the Defense of Graffiti*, in *Defense of Graffiti*, in ROUTLEDGE HANDBOOK OF GRAFFITI AND STREET ART 440, 443–45 (Jeffrey Ian Ross ed., 2016) (describing graffiti as a practice of symbolic resistance); Jamison Davies, *Art Crimes?: Theoretical Perspectives on Copyright Protection for Illegally-Created Graffiti Art*, 65 ME. L. REV. 27, 47–48 (2012) (discussing the message of opposition to property and commerce embedded in graffiti).

<sup>51</sup> Cameron McAuliffe & Kurt Iveson, *Art and Crime (and Other Things Besides . . . )*: *Conceptualising Graffiti in the City*, 5 GEOGRAPHY COMPASS 128, 140 (2011); *see generally* Renia Ehrenfeucht, *Art, Public Spaces, and Private Property Along the Streets of New Orleans*, 33 URB. GEOGRAPHY 965, 976 (2014).

<sup>52</sup> McAuliffe & Iveson, *supra* note 51, at 135 (discussing the various motivations of graffiti writers); Ana Christina DaSilva Iddings, Steven G. McCafferty & Maria Lucia Teixeira da Silva, *Conscientização Through Graffiti Literacies in the Streets of a São Paulo Neighborhood: An Ecosocial Semiotic Perspective*, 46 READING RSCH Q. 5, 6 (2011) (same).

<sup>53</sup> Ricardo Campos, *Graffiti Writer as Superhero*, 16 EUR. J. CULTURAL STUD. 155, 163 (2012) (explaining the risks associated with graffiti and how they function as a mechanism of exclusion).

the creation and recreation of their shared spaces.<sup>54</sup> We were curious to discover if many people would take the opportunity to “personalize” city streets — in this case, one could argue that graffiti is only a symptom of a larger phenomenon of people wishing to leave a personal mark in the public space. Consequently, developing tools to allow this kind of expression could meaningfully advance their “right to the city,” and fill in this vague theoretical concept with specific content.

Indeed, although many projects have advanced the idea of urban placemaking in various forms, they have always entailed some sort of selective criteria. For instance, some of them conducted competitions, others prescribed specific topics, others still focused on particular social groups.<sup>55</sup> Yet, no attempt has been undertaken so far to discover what people would share in urban public spaces once they have an opportunity to do so freely, without given topics or quality judgements. In this sense, our experiment tests an entirely novel idea.

### III. EXCLUSIONARY PUBLIC ART

The third context our experiment touches upon is public art. In addition to commercial messages and graffiti, official public art — including commissioned street art — constitutes a conspicuous expressive element of the cityscapes. City planners and real estate developers in many western cities increasingly work to incorporate artistic elements in urban design.<sup>56</sup> Scholars criticize this tendency, pointing out that public art often causes gentrification of neighborhoods, resulting in demographic displacement.<sup>57</sup> Others suggest that although seemingly apolitical, public art reinforces the existing division of social power, creating the appearance of harmony and glossing over inequality, suppression, and injustice.<sup>58</sup> Interestingly, even art with critical content may act to suppress the very voice it articulates by aestheticizing, and thus taming, its subversive message. Consider, for example, the meaning of anti-consumerist messages decorating Nike and Sony stores, or an artwork depicting the evil face of capital adorning the headquarters of the European Central Bank.<sup>59</sup>

---

<sup>54</sup> HENRI LEFEBVRE, *The Right to the City*, in WRITINGS ON CITIES 63, 63–183 (Eleonore Kofman & Elizabeth Lebas eds. & trans., 1996); see also David Harvey, *The Right to the City*, 27 INT’L J. URB. & REG’L RSCH. 939, 941 (2003); Mark Purcell, *Possible Worlds: Henri Lefebvre and the Right to the City*, 36 J. URB. AFF. 141, 149 (2014).

<sup>55</sup> E.g., DaSilva Iddings, McCafferty & Teixeira da Silva, *supra* note 52, at 9 (explaining their project which involved both pre-given topics and competition among the participants); Alison Mary Baker, *Constructing Citizenship at the Margins: The Case of Young Graffiti Writers in Melbourne*, 18 J. YOUTH STUD. 997, 1002 (2015) (explaining their project which focused on the group of young graffiti writers).

<sup>56</sup> Joanne Sharp, Venda Pollock & Ronan Paddison, *Just Art for a Just City: Public Art and Social Inclusion in Urban Regeneration*, 42 URB. STUD. 1001, 1004 (2005) (“In the UK, as in many other contemporary Western countries, public art appears to have an increasingly prominent role in urban design.”).

<sup>57</sup> Stuart Cameron & Jon Coaffee, *Art, Gentrification and Regeneration — From Artist as Pioneer to Public Arts*, 5 EUR. J. HOUS. POL’Y 39, 51 (2005).

<sup>58</sup> Sharp, Pollock & Paddison, *supra* note 56, at 1018.

<sup>59</sup> See Andrea Mubi Brighenti, *Graffiti, Street Art and the Divergent Synthesis of Place Valorization*, in ROUTLEDGE HANDBOOK OF GRAFFITI AND STREET ART 158–67, 162–63 (Jeffrey Ian Ross ed., 2016).

Making public art more independent, inclusive, and multi-voiced is a hotly-debated topic in academic literature, urban planning, and the artistic world.<sup>60</sup> Indeed, numerous projects that involved local residents in the process of decisions about and the active co-creation of art in their communities reported enhanced feelings of belonging, visibility, and cohesion.<sup>61</sup> Some scholars oppose this trend, arguing that the role of public art is not to enhance the sense of community and belonging (and thereby soothing conflicts), but rather to create “dissensus” and sustain and amplify contradictory voices representing the diversity of people using public spaces.<sup>62</sup> Others worry that art created by communities tends to be devalued, perceived as “not real art,” imposing another criterion of exclusion to already marginalized communities.<sup>63</sup>

This corresponds with broader discourses about what art is, and about its proper role in a democratic society. The contemporary perception of art is indeed unique in its combination of wide-open and restrictive elements. On the one hand, the concept of art has undergone significant liberalization, perhaps reaching the ideal of being “unbound to any form,” akin to an idea envisioned by Kazimir Malevich as he described “in the year 1913, in my desperate attempt to free art from the ballast of objectivity, I took refuge in the square form.”<sup>64</sup> Modern art is largely limitless in form, encompassing a toilet sink, as in the famous Marcel Duchamp’s sculpture, and dissected human and animal bodies, as in Gunther von Hagens’s exposition “Body Worlds.” Any object may become a work of art when an artist decides to designate it as such.<sup>65</sup>

This highly inclusive attitude toward art, however, is confronted by another social tendency: to perceive only those few individuals who have been singled out by art experts and/or market demand as “artists,” and to regard only works created by these individuals as “genuine” art. This results in a very small group of individuals being perceived as artists, to the exclusion of all other people who create artistic works. The coexistence of these two opposing trends, the ultra-open one and the closed tight-as-a-drum one, leaves many people quite confused and

---

<sup>60</sup> Ann Markusen, *Creative Cities: A 10-Year Research Agenda*, 36 J. URB. AFF. 567, 575–82 (2014) (making an overview of these debates); Sharp, Pollock & Paddison, *supra* note 56, at 1003 (“[P]ublic art should be able to generate a sense of ownership forging the connection between citizens, city spaces and their meaning as places through which subjectivity is constructed.”).

<sup>61</sup> E.g., DaSilva Iddings, McCafferty & Teixeira de Silva, *supra* note 52, at 8.

<sup>62</sup> ROSALYN DEUTSCHE, EVICTIONS: ART AND SPATIAL POLITICS, 270 (1996) (arguing that those who see public art as enhancing community miss the point in that they “presume that the task of democracy is to settle, rather than sustain, conflict”); Chantal Mouffe, *Art as an Agnostic Intervention in Public Space*, 14 OPEN 6, 12 (2008) (“[C]ritical art is art that foments dissensus, that makes visible what the dominant consensus tends to obscure and obliterate.”).

<sup>63</sup> E.g., Mae Shaw & Rosie Meade, *Community Development and the Arts: Towards a More Creative Reciprocity*, in LEARNING WITH ADULTS: INT’L ISSUES IN ADULT EDUC., 195, 201 (Peter Mayo ed., 2013).

<sup>64</sup> GERRY SOUTER, MALEVICH: JOURNEY TO INFINITY 110 (2008) (quoting KAZIMIR MALEVICH, SUPREMATIST MANIFESTO (1915)).

<sup>65</sup> Nan Rosenthal, *Marcel Duchamp (1887–1968)*, THE MET: HEILBRUNN TIMELINE OF ART HISTORY (Oct. 2004), [http://www.metmuseum.org/toah/hd/duch/hd\\_duch.htm](http://www.metmuseum.org/toah/hd/duch/hd_duch.htm).

dubious of their capacity to judge any artwork at all.<sup>66</sup> Meanwhile, cultural gatekeepers often define art in exclusionary terms, holding the view that only a small minority of people are able to appreciate art. As Arnold Schoenberg put it: “If it is art, it is not for all. If it is for all, it is not art.”<sup>67</sup> This has led several scholars to argue that identifying what is and what is not art often serves to preserve status and power rather than to determine quality.<sup>68</sup>

Some politicians and scholars advocate moving away from expert-dominated toward a market-based perception: art should be defined as creative works that enjoy sufficient demand.<sup>69</sup> Notwithstanding its more egalitarian appeal, this perception is also highly exclusive, since it demands fame, which only a very small group of artists achieve. In practice, these two perceptions of art — expert-based and market-based — coexist and are interconnected: expert support helps an artist to gain fame, and fame helps get the experts’ approval.<sup>70</sup>

One may wonder why it is important to define art. The main importance of this definition naturally lies in the fields that involve judgement of artworks, such as competitions for public funding, selection of works for museums, and — more to the point of our discussion — for display in public spaces. In fact, people identified as artists are the only ones who have meaningful opportunities for *individual* expression in public: whereas politicians speak for the groups they represent and copywriters speak for their corporations, artists are expected to speak for themselves. In other words, the title of “real art” is associated with tangible privileges. Unsurprisingly, many voices call for democratization of processes that grant this valuable title.<sup>71</sup> Suggestions as to how democratization of art should occur include expanding the category of “art” to embrace practices many people understand and

---

<sup>66</sup> Angelina Hawley-Dolan & Ellen Winner, *Seeing the Mind Behind the Art: People Can Distinguish Abstract Expressionist Paintings from Highly Similar Paintings by Children, Chimps, Monkeys, and Elephants*, 22 PSYCH. SCI. 435 (2011) (describing an experiment in which participants were able to distinguish paintings made by well-known modern artists from creations of toddlers, chimpanzees, and elephants at a rate only slightly above chance); see also Axel Cleeremans, Victor Ginsburgh, Olivier Klein & Abdul Noury, *What’s in a Name? The Effect of an Artist’s Name on Aesthetic Judgments*, 34 Empirical Stud. Arts 126 (2015) (explaining that when a certain picture was painted by a famous artist, people tended to evaluate it much more favorably).

<sup>67</sup> ARNOLD SCHOENBERG, *New Music, Outmoded Music, Style and Idea*, in STYLE AND IDEA, 113, 122 (Leonard Stein ed., Leo Black, trans., 1984); see also JOHN HOLDEN, DEMOCRATIC CULTURE: OPENING UP THE ARTS TO EVERYONE 18 (2008) (“[T]he cultural gatekeepers of the avant-garde go so far as to *define* art in terms of exclusivity.”).

<sup>68</sup> HOLDEN, *supra* note 67, at 14 (“[I]n the cultural field, sometimes people are ‘pretending to maintain standards but really just preserving status’; we must beware of ‘taste as power pretending to be common sense.’”).

<sup>69</sup> LAMBERT ZUIDERVAART, *ART IN PUBLIC: POLITICS, ECONOMICS, AND A DEMOCRATIC CULTURE* 6–7 (2011).

<sup>70</sup> Alain Quemin, *The Superstars of Contemporary Art: A Sociological Analysis of Fame and Consecration in the Visual Arts through Indigenous Rankings of the “Top Artists in the World,”* 66 REVISTA DO INSTITUTO DE ESTUDOS BRASILEIROS 18, 45 (2017).

<sup>71</sup> ZUIDERVAART, *supra* note 69, at 278 (“[L]iberal representative democracies . . . not only exclude many people from the channels of governance but also restrict the scope of democracy to the political arena, leaving economic and cultural orders as exploitative and hegemonic as ever.”).

enjoy;<sup>72</sup> including diverse public voices in decisions about art,<sup>73</sup> and supporting artistic practices that challenge hegemonic values and social structures.<sup>74</sup>

Another line of writing focuses on art creators rather than on its addressees. Scholars propose allowing access and opportunities for everyone to engage in the creation of the shared culture, so that everyone has a chance to become a co-creator rather than a mere consumer of art.<sup>75</sup> In this view, such “cultural democracy” — where everyone is encouraged to contribute one’s creativity to the shared culture — is indispensable for a true political democracy.<sup>76</sup> Somewhat similarly, Marxist and feminist voices have long challenged the narrow focus of modern democracies on politics, to the exclusion of culture.<sup>77</sup>

Our proposal joins these voices. One of the goals of our experiment was to sense whether democratization of culture (letting anyone interested to create and present art) is a feasible idea. Specifically, we wanted to discover what would happen if people had an opportunity to add their contributions to the shared visual environment. Would many of them use this opportunity to share their creative works? Another interesting question was how other people would react to art that is shared without any selection process, art that was neither defined as such by experts nor created by famous artists. These findings could provide initial reference points as to how the ideas of cultural democracy might function in real life.

#### IV. THE EXPERIMENT: THEORETICAL IDEA MEETS REAL LIFE

Most visible surfaces that shape the cityscapes are private or public property. Hence, an experiment that intends to let people place expressive messages of their choice on such surfaces inevitably requires cooperation of entities that control them. We were fortunate to receive the generous sponsorship of Wall GmbH that provided 1500 places on billboards (city-light posters, 175x118 cm) throughout Berlin for our experiment. We used these spaces to present individual contributions.

We called the project “Du bist am Zug,” which can be translated as “it’s your move” (in a game), but also “it’s your turn” (to act, to do

<sup>72</sup> Markusen, *supra* note 60, at 579.

<sup>73</sup> HOLDEN, *supra* note 67, at 23 (“Questions of cultural excellence cannot and should not be determined solely by a group of peers . . . . It is essential that the many competing voices of the public are admitted into the debate as well.”); François Matarasso, *Whose Excellence?*, 171 ARTS PRO. 2, 8 (2008) (“[W]hat really needs to be excellent is the conversation we have about culture . . . . And a rich, generous and democratic debate about culture is entirely achievable—if we want it.”).

<sup>74</sup> DAVID SCHWARTZ, ART, EDUCATION, AND THE DEMOCRATIC COMMITMENT: A DEFENSE OF STATE SUPPORT FOR THE ARTS, 50–56 (2000).

<sup>75</sup> HOLDEN, *supra* note 67, at 26 (“The goal [should] be for everyone to have physical, intellectual and social access to cultural life, and to have the ability and confidence to take part in and fashion the culture of today.”); *Id.* at 32 (“Culture should be something that we all own and make, not something that is ‘given’, ‘offered’ or ‘delivered’ by one section of ‘us’ to another.”).

<sup>76</sup> *Id.* at 34 (“It is only when we have a cultural democracy, where everyone has the same capacity and opportunity to take part in cultural life, that we will have a chance of attaining a true political democracy.”).

<sup>77</sup> See ZUIDERVAART, *supra* note 69, at ch. 9.

something). It operated via a website, on which people could upload contributions — either in the form of a text or an image — they wished to present on billboards in Berlin. Participants could submit one contribution in their own name and two additional contributions in their children's names.<sup>78</sup> To make sure that no bots take part in our experiment, we required an e-mail verification to complete the submission. The website explained that there are no given topics and that no competition will take place. Should we have received more than 1,500 contributions, we would raffle off the places on billboards among the participants.<sup>79</sup>

Our real-life experiment could not allow unlimited freedom of expression. Placing a message on a billboard in Berlin is subject to legal regulations of speech — such as copyright, privacy protection, as well as laws banning libel, incitement, and pornography. We referred to these restrictions on the project's website, which certainly could have affected the choices of the participants as to the content of their contributions. In addition, Wall GmbH has its own rules regulating the content of its billboards. Since we did not have deep knowledge of these rules, we only stated on the website that we reserve the right to exclude contributions that could be harmful to our sponsor. We do not expect this general statement to have affected the participants' behavior. Additional types of speech we excluded were advertising, links to websites, usernames in social media, and identical contributions submitted by several persons. This is because our idea was to create a medium for individual speech.

We wanted to collect some data about the participants, such as age, gender, place of birth, and occupation. However, lengthy forms could jeopardize our idea of allowing an easy and low-threshold participation. Hence, we decided to make sharing of the additional data non-mandatory. Similarly, our website encouraged the participants to tell more about their contributions by leaving comments.

The project's website opened for submissions in the last week of April 2022, and closed in the first week of June, so we had six weeks to collect the contributions. To be successful, *Du bist am Zug* needed visibility. Hence, we used various ways to advertise it: it had its own social media;<sup>80</sup> we posted information about it in relevant Facebook groups, and used paid advertising on Instagram and Facebook. In addition, we made an effort to get a good coverage in the local press,<sup>81</sup>

<sup>78</sup> We invited people with more than two children to contact us in order to submit additional contributions in the names of their children, but no one made use of this suggestion.

<sup>79</sup> Katya Assaf-Zakharov & Tim Schnetgöke, Notes from Telephone Call, on file with the authors.

<sup>80</sup> *Du bist am Zug*, FACEBOOK (last visited Feb. 2, 2025), <https://www.facebook.com/dubistamzugberlin>; *Du bist am Zug* (@dubistamzugberlin), INSTAGRAM (last visited Feb. 2, 2025), <https://www.instagram.com/dubistamzugberlin/>.

<sup>81</sup> *Ein "instagram" fürs sommerliche Straßenbild*, BERLINER ABENDBLATT (May 16, 2022), <https://berliner-abendblatt.de/berlin-news/du-bist-am-zugplakatreihen-fuer-jedermann-id155731>;

*Aktion "Du bist am Zug" bringt Sie auf Plakatwänden groß raus*, B.Z. (May 17, 2022), <https://www.bz-berlin.de/ich-und-berlin/aktiondu-bist-am-zug-bringt-sie-auf-plakatwaenden-gross-raus>; see Dirk Jericho, *Die Stadt Wird zur Bürgergalerie*, BERLINER WOCHEN (May 20, 2022, 6:00 AM), <https://www.berliner-woche.de/mitte/c-kultur/im-rahmen-des-projekts-du-bist-am-zug>

on the radio<sup>82</sup> and television,<sup>83</sup> as well as in popular social media channels, including the official channel of the city of Berlin. Finally, we employed our personal contacts to spread the word.

To be sure, our contacts and our abilities — for instance, the languages we speak — must have influenced the identity of the participants. Yet, any experiment of this kind is deemed to have some “subjective” factors. We made significant efforts to embrace a possibly broad audience, reaching out to diverse groups and institutions — including schools, universities, and colleges, as well as the Turkish, Kurdish, Israeli, Arabic, Russian, and Ukrainian communities in Berlin. We did not have a strict requirement that participants should be located in Berlin, but all our communication channels addressed primarily people in Berlin and, accordingly, a prevailing majority of the participants were located in Berlin.

We received 771 contributions, 666 of which withstood our submission criteria.<sup>84</sup> Since we had 1500 billboards at our disposal, we could present all the contributions twice, some of them three times, and we raffled off the places for the third presentation. Thus, in August 2022, personal messages appeared on 1500 billboards throughout Berlin. Wall GmbH provided us with information about the location of the billboards with *Du bist am Zug*’s contributions, but we did not know which contribution appears on which billboard because it would have been enormously complicated for Wall’s workers to keep track of it. Since the posters were supposed to hang for only a couple of weeks, Berlin is a big city, and we were a very small research team, we did not have enough time to visit all the locations, and discover which posters hang on which spot.

We were not aware of these circumstances when we started the project, so we had to find an instant solution to help the participants find their contributions in the streets of Berlin. Once again, we used all the available communication channels to invite the project’s participants — as well as non-participants — to join us in this “Easter egg hunt,” and publish the posters they find on social media with their location and the hashtag #dubistamzug.<sup>85</sup> All the project’s posters were also provided with text asking those who discover them to share their location on social media.

---

kann-jeder-fotos-gedichte-und-zeichnungen-einreichen\_a346331; Dirk Jericho, *Private Botschaften auf Werbewänden: Kunstprojekt „Du Bist am Zug“ Bringt Bürgerbilder Groß Raus*, BERLINER WOCHE (July 24, 2022, 2:00 PM), [https://www.berliner-woche.de/mitte/c-kultur/kunstprojekt-du-bist-am-zug-bringt-buergerbilder-gross-raus\\_a353093](https://www.berliner-woche.de/mitte/c-kultur/kunstprojekt-du-bist-am-zug-bringt-buergerbilder-gross-raus_a353093); Redaktion, *Projekt „Du bist am Zug“ gestartet [Project “It’s your turn” launched]*, BLICKPUNKT BRANDENBURG (May 27, 2022), <https://blickpunkt-brandenburg.de/nachrichten/artikel/projekt-du-bist-am-zug-gestartet>; Fotomagazin, May 27, 2022.

<sup>82</sup> We got to speak about the project at RBB-Kultur, radio eins, Radio Paradiso, RBB-88.8 and Cosmo po-russki. COSMO po-russki, *Ispol’zuñ vozmozhnost’ sdelat’ Berlin krasivee* [Take the Opportunity to Make Berlin More Beautiful], WDR, at 0:10 (May 5, 2025), <https://www1.wdr.de/radio/cosmo/programm/sendungen/radio-po-russki/gesellschaft/dubistamzug-106.html>.

<sup>83</sup> The project was covered in the television program *Abendschau* on July 26, 2022.

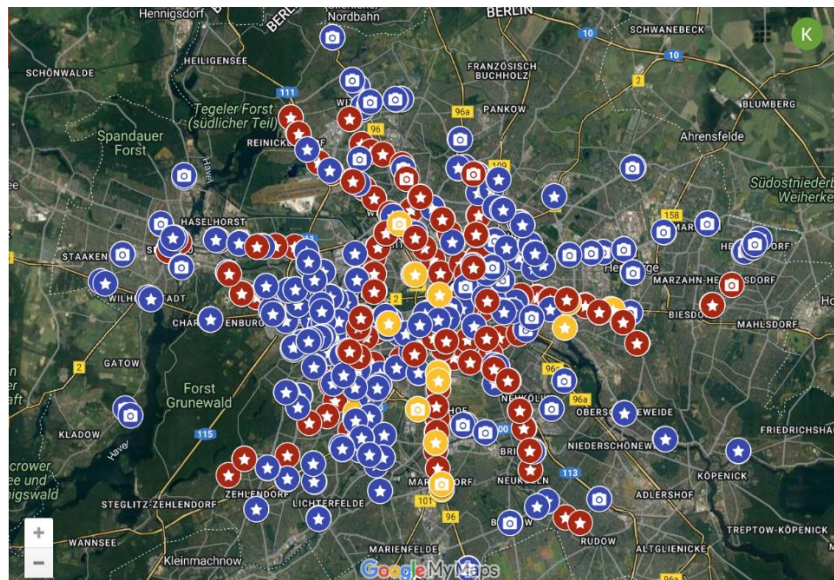
<sup>84</sup> Katya Assaf-Zakharov & Tim Schnetgöke, Notes from Telephone Call, on file with the authors.

<sup>85</sup> Du bist am Zug (@dubistamzugberlin), INSTAGRAM, (July 29, 2022) <https://www.instagram.com/p/CglueOSM8Cj/>.



Some participants responded enthusiastically to our call and actively looked for billboards with *Du bist am Zug*'s contributions; others followed the hashtag in hope that someone would discover their poster (some even promised a prize to the finder); others still (participants and non-participants) accidentally discovered the individual messages in the public space. This unplanned turn added a playful element to the project and created a vivid online dynamic around it.

The intensive online sharing of posters discovered in various locations in Berlin resulted in a huge amount of sporadic information.<sup>86</sup> We were lucky to receive an offer from one of the project's participants to build a "treasure map," where the participants could easily find their contributions by typing in their names in the search function.<sup>87</sup> This allowed an absolute majority of the participants to discover their posters.



Blue points indicate posters at subway stations, the red – posters on columns, and the yellow – posters that we were unable to allocate. Stars indicate that the posters were found.

*Du bist am Zug* was by no means a typical scientific experiment. It was a pilot project implementing a conceptual idea — creating space for individual expression in public discourse — in one particular way. It took place in Berlin during the summer of 2022, in the midst of the war in Ukraine and two years after the outbreak of the Covid-19 pandemic.

<sup>86</sup>See *Du bist am Zug* (@dubistamzugberlin), *Gefunden!*, INSTAGRAM, <https://www.instagram.com/stories/highlights/18005349985455426/> (last visited Feb. 7, 2025); *Du Bist Am zug* (@dubistamzug), INSTAGRAM, (last visited Jan. 28, 2025), <https://www.instagram.com/stories/highlights/17921731796382876/>; *Du Bist Am zug* (@dubistamzug), INSTAGRAM, (last visited Feb. 22, 2025), <https://www.instagram.com/stories/highlights/17969053375639897/>.

<sup>87</sup>*The Treasure Map!*, DU BIST AM ZUG, (Jul. 30, 2022), <https://web.archive.org/web/20220808063738/https://dubistamzug.net/die-schatzkarte/>; *Dubistamzug, The Treasure Map Vol.2*, DU BIST AM ZUG (Aug. 18, 2022), <https://dubistamzug.net/die-schatzkarte-vol-2/>. We are deeply grateful to Svenja Arndt.

Its course was somewhat influenced by our personal factors and its own specific circumstances and dynamics. Yet, we believe that in spite of its specificity, our experiment delivered widely applicable insights, as will be explained below.

## V. RESEARCH QUESTIONS, DATA COLLECTION AND ANALYSIS

Most of the questions our experiment sought to answer are of an exploratory nature, *i.e.*, without specific assumptions that the empirical data could confirm or refute. Broadly speaking, we wanted to discover what would happen if people are given the opportunity to place expressive messages of their choice in the public space. We broke down this general question into several specific points:

1. How many people will take part in *Du bist am Zug*?
2. Who will take part in the project — in terms of age, gender, origin, and occupation?
3. What kind of content will people share?
4. What will be their motivation for taking part in the project?
5. What will the participants wish to communicate with their messages?
6. What kind of reactions will the personal contributions trigger?
7. What will people think about the idea of allowing everyone to share visual messages in urban public space?

The first stage — submissions via the website — delivered data in form of the individual contributions themselves and demographic data about the participants: more than half of them (344 persons) answered all the demographic questions while making their submission, although they were optional. In addition, 313 participants left comments while submitting their contributions, providing information about the content and the background of the contributions, as well as about their motivation for taking part in the project. To gather further information, we conducted a survey after the project had been completed. In total, 131 persons took part in this survey.<sup>88</sup>

We used simple digital methods of data analysis to analyze the quantitative data, such as age, gender, and survey questions with numerical evaluations. However, we did not use any digitalized methods to analyze the qualitative data, since its volume allowed us to make an in-depth, qualitative text and image analysis. Specifically, we used the method of grounded theory,<sup>89</sup> to create, complement, and amend the categorization of the obtained data. Let us illustrate how this functioned: in order to sort the submitted contributions into categories, we started

---

<sup>88</sup> German survey results, <https://docs.google.com/spreadsheets/d/1IH6t3ggU6sBJV91e3unlQDviTaEovgvr0xeqxsvhJm8/edit?usp=sharing> (last visited Feb. 7, 2025); English survey results <https://docs.google.com/spreadsheets/d/1ZnhgLLA4iojSTTTw205HYJZ0CLbG7hSYke3ZywhP4AM/edit?usp=sharing> (last visited Feb. 7, 2025).

<sup>89</sup> JULIET CORBIN & ANSELM STRAUSS, *BASICS OF QUALITATIVE RESEARCH: TECHNIQUES AND PROCEDURES FOR DEVELOPING GROUNDED THEORY* (4th ed. 2014).

observing them, trying to identify characteristics that some of them have in common. For instance, consider the following three pictures:



Image 1



Image 2



Image 3

These are three photographs, but it is not entirely clear — at least at first glance — what kind of an image each of them shows. If so, they may fit together into a category of photographs displaying not immediately discernable images. Yet, the authors of the three contributions left comments that shed light on the content of their pictures:

Image 1: "With my picture of the back of a friend's head, I wanted to surprise him. Also, his hairstyle looked like the yin & yang sign because of his swirl." (here and below, all the translations of the experiment's results are our own)

Image 2: "The photo shows a Berlin ice creature . . . so to speak from the underworld. Taken on the frozen canal in Neukölln [a neighborhood in Berlin]."

Image 3: “I am a mathematician at the Technical University of Berlin and work, among other things, on conformal mappings and their discretization. The picture shows a conformal mapping of a chrysanthemum and combines mathematics and art in an impressive way.”

Given this additional information, we could assign each of these pictures to further categories. Thus, image 1 may fit into the category “photos of oneself, one’s family, and friends;” image 2 fits into the categories “photos of nature” and “contributions about Berlin;” and image 3 into the category “contributions allowing insights into one’s professional life.” Note that the assignment to a category is not exclusive, that is, one contribution may belong to several categories.

As our analysis proceeded, we redefined the already created categories to make them more precise, broke some of them down, merged others, and added new ones. We used a similar method to analyze additional qualitative data: the participants’ comments and answers to open questions in the survey.

Naturally, unlike machine-made analysis, our method involved some subjective elements: other researchers might have sorted our qualitative data differently. The advantage of the method we chose is the possibility to create categories relevant for our analysis. To give one example, no AI-based method could identify the similarity between the two following images:



Image 3



Image 4

Since image 4 shows the participant at his work, we classified both pictures as “contributions allowing insights into one’s professional life” — a category that is meaningful for our discussion, but which would have been missed in a digitalized analysis. On the other hand, AI is likely to find similarities such as stripes, dots or the prevalence of a certain color that do not add much to our understanding of what kind of content the participants chose to share. Therefore, despite the fact that an in-

depth text and image analysis inevitably involves some subjectivity, we believe that it was an adequate method to deal with our qualitative data.

## VI. RESULTS AND DISCUSSION

To hold this paper within a reasonable scope, we will focus on the major results of our study rather than presenting them in their entirety. We will present results on the first five research questions stated above, and refer briefly to the remaining two questions.

### *A. How Many People Took Part in Du bist am Zug?*

The submission period started on April 21 and concluded on June 5, 2022. During these six weeks, we received 771 complete contributions, and 86 additional ones that were submitted but not verified via e-mail. Considering the short period of the project, we regard this number as substantial. We believe that this number of participants may serve as a solid proof that the opportunity to place individual expressions in the public space meets significant demand. We have no particular reason to assume that this result is site- or time-specific.

This finding has significant policy implications: if many people wish to express themselves publicly and “personalize” city streets with their individual messages, then developing tools to allow such expression would meaningfully advance both freedom of speech and the “right to the city.”

### *B. Who Took Part in the Project?*

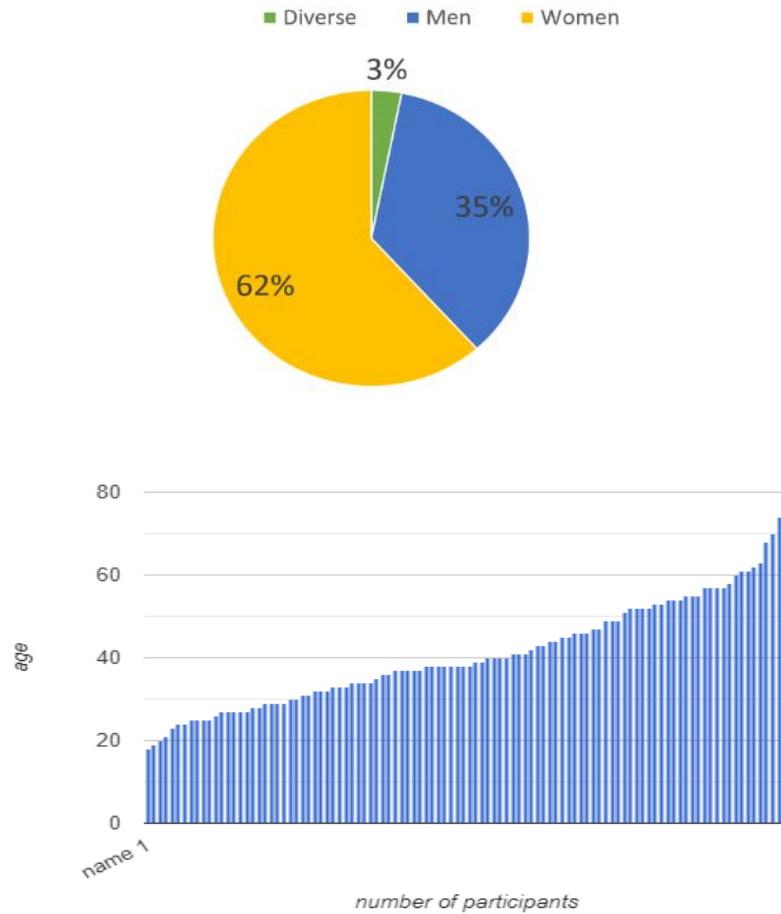
According to the demographic data supplied by the participants at the time of submission, roughly one third of the participants were men, two thirds were women, and three percent were of diverse gender. The percentage of people with diverse gender largely corresponds with their percentage in the general population.<sup>90</sup> The higher participation of women is a factor to which we do not have a clear explanation. Yet, since women’s voices are underrepresented in many contexts, the tested avenue of expression might have the benefit of increasing female presence. Yet, this result should be checked in additional experiments and on other locations to inquire whether it repeats itself.

In terms of age, the data shows a broad diversity — from 18 (which was the minimal participation age) to 77 (average 41.27). In addition, we had 32 contributions made in the name of the participants’ children, whose ages ranged from 1 to 17. As one can see in the graph below, the participation rate was quite even among the different age groups, except for people older than 60, who had a somewhat lower participation rate. This leads us to the conclusion that in future projects, one should pay special attention to the ways of involving older people and making participation more accessible to them.

---

<sup>90</sup> Martin Orth, *The Varied Republic of Germany*, DEUTSCHLAND.DE (June 21, 2024), <https://www.deutschland.de/en/topic/life/diversity-in-germany-facts-and-figures>.





In terms of origin, most participants were born in Berlin and a significant further number in other German cities: overall, about three quarters of participants were of German origin. Another notable group were people from Ukraine: about five percent. We also had participants from other places, such as Austria, Switzerland, France, Italy, the Netherlands, Sweden, the United Kingdom, Russia, Romania, Lithuania, Moldova, the United States of America, Canada, Brazil, Mexico, Columbia, Afghanistan, China, Vietnam, Turkey, Israel, Palestine, Syria, and Rwanda.

In contrast to people from Ukraine, other minority groups living in Berlin — such as people of Turkish, Syrian, and African origin — were not sufficiently represented among the participants, although we did attempt to reach out to the respective communities. To make another comparison, the LGBT community presumably did have a significant representation — as will be shown below, equality for LGBT people was a prominent topic of the contributions. We can cautiously assume that most people behind these contributions belong to the LGBT community. These different degrees of involvement in the project appear to mirror the participation of the respective groups in the public discourse more generally. Our conclusion is that creating an opportunity for expression

does not suffice to involve the less vocal social groups. For future projects, one must consider more effective ways of reaching out to such groups.

About twenty percent of the participants indicated occupations that have to do with expression and creativity, such as artist, visual artist, designer, web designer, graphic designer, textile designer, photographer, copywriter, illustrator, journalist, and poet. Some participants indicated that this is not their main profession (e.g. “I am an amateur photographer.”). The notable number of participants, who are engaged in creative and expressive activities in their everyday lives probably has to do with the fact that such people can relatively easily decide what they would like to share publicly when given the opportunity to do so.

Apart from the remarkable participation of the various artists, people of a wide range of occupations — such as physicians, schoolteachers, salespersons, scientists, university professors, students, managers, engineers, waiters, as well as retired and unemployed persons — took part in *Du bist am Zug*. This result indicates that the desire to express oneself and be seen and heard is quite widespread and is by no means exclusive to people who have a prominent tendency towards creative activity in their everyday lives.

To sum up, our experiment has revealed a significant demand for opportunities to express oneself in urban public spaces. This demand exists among people of different age, gender, origin, and occupation. We believe that this finding is not time- or place-specific, and is likely to repeat itself in subsequent experiments.

### *C. What Kind of Content did People Share?*

Perhaps the most interesting — and at the same time, the most worrisome — aspect of our experiment was the question what people would share once given the freedom to submit contributions of their choice. Many of our colleagues, along with potential sponsors, had expressed the concern that our website — in spite of the notice that we will not publish contributions violating German laws — would be overflowed with hate speech, pornography, or simply meaningless content.

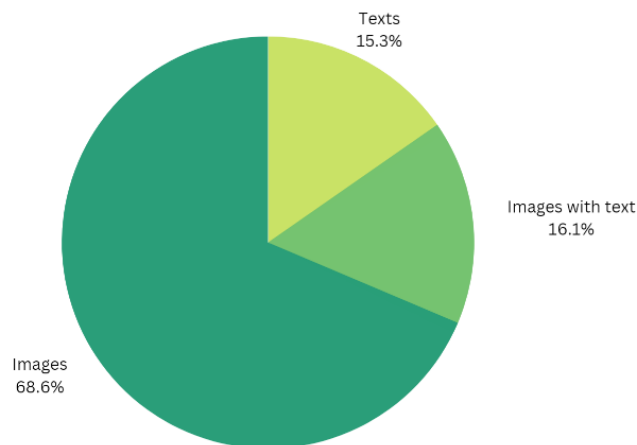
This concern has revealed itself as absolutely unfounded. Although we did have to exclude some contributions because they violated project rules (e.g. no social media usernames or no advertising) we only had one case where we had to exclude a contribution because of its objectionable content. In this case, a Ukrainian artist submitted a picture showing a doll called (in Russian) “a hero’s wife.” The doll had accessories stained with blood, and the text on the box informed that the hero’s wife can talk. The doll’s texts referred to rape and robbery of the Ukrainians by Russian soldiers, whereas one of the phrases stated: “What kind of a Russian guy would not steal anything, are you out of your mind?” This expression defamed Russian people in a way that is forbidden by the

German law.<sup>91</sup> Accordingly, we excluded the contribution from participation in *Du bist am Zug*.



Although it is difficult to measure meaningfulness and quality in rigorous terms, we can share our feeling that the overwhelming majority of contributions were well thought-out and gave the impression that the participants made an effort to present something valuable and significant. This was the case even with the Russian doll contribution; it just went too far and crossed the line of the allowed criticism in Germany.

In terms of form, our website allowed submitting either images or texts, and 85% of the participants chose the image option. Yet, some images contained text as well, and these combined image-text contributions comprised 16% of submissions. Thus, 69% of the contributions were images without any text:

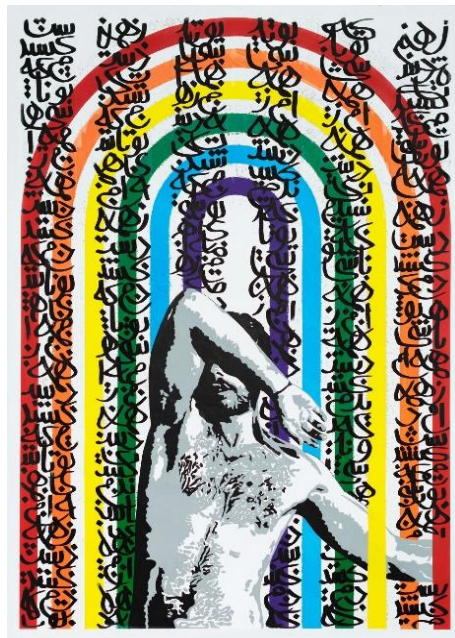


<sup>91</sup> E.g., BVerfGE 93, 266 - *Soldaten sind Mörder*.



This finding is significant for the question of how an open democratic discourse could look if more places were given to individual speech. We can see that an absolute majority of the participants chose to use images to express themselves, and a majority chose not to use any text at all. This lends support to voices questioning the logocentric nature of the current public discourse. Indeed, given the freedom to express themselves in public spaces, most participants gave up words altogether.

A curious fact about the texts is that they were not only in German or English — languages that the participants could expect that most passersby in Berlin understand — but also in Ukrainian, Russian, Chinese, Vietnamese, Georgian, Kurdish, Hebrew, French, and even medieval Persian:



*This contribution incorporates a love poem by Saadi Shīrāzī, a Persian poet of the medieval period: “I gave up on everyone so that you are all me.” The poem is written in calligraphy; it repeats many times.<sup>92</sup>*

One might speculate that sometimes, the aspect of self-expression and presence is more significant than the perception by others — at least in the context of expression in public spaces. We will return to this point later.

In terms of the topics the contributions touched upon, we will present here the six largest categories that we identified: (a) creativity;

---

<sup>92</sup> We are thankful to Fati Masjedi for the identification of the poem and its translation.

(b) photographs of nature, animals, and cityscapes; (c) political messages; (d) glimpses into personal worlds; (e) Berlin, and; (f) inspiration, greetings, compliments, and advice. Almost all the submitted contributions fall at least under one of the six categories. As mentioned above, these categories are non-exclusive.

### *a. Creativity*

In this category, we included contributions that reveal the participants' creativity: drawings and paintings made in various techniques, collages of various kinds, art installations, digital artworks, sculptures, poems, self-made designs and a self-made costume, as well as photographs showing the participants dancing, signing, playing musical instruments or performing. This category is by far the largest of all, comprising 425 contributions, roughly two thirds of all. Here are several examples of how these contributions looked as posters:



Tobias Lück

#DUBISTAMZUG  
WALL



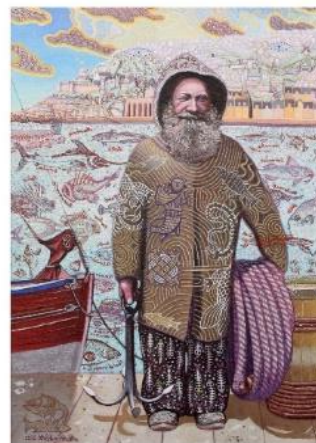
Jochen Schlick

#DUBISTAMZUG  
WALL



Helga Wimmer

#DUBISTAMZUG  
WALL



nobilitate.M a(n)A

#DUBISTAMZUG  
WALL



Maik Zehrfeld

Die Kunst der Dunkelheit ist, die Dunkelheit zu lieben und sie zu nutzen. In der Dunkelheit kann man die Welt anders sehen. In der Dunkelheit kann man die Welt anders fühlen. In der Dunkelheit kann man die Welt anders verstehen. In der Dunkelheit kann man die Welt anders lieben. In der Dunkelheit kann man die Welt anders sein.

#DUBISTAMZUG



Ligia Fascioni

Die Kunst der Dunkelheit ist, die Dunkelheit zu lieben und sie zu nutzen. In der Dunkelheit kann man die Welt anders sehen. In der Dunkelheit kann man die Welt anders fühlen. In der Dunkelheit kann man die Welt anders verstehen. In der Dunkelheit kann man die Welt anders lieben. In der Dunkelheit kann man die Welt anders sein.

#DUBISTAMZUG



### *b. Photographs of nature, animals, and cityscapes*

Photographs of landscapes, cityscapes, and animals comprise the second-largest category, along with political messages of various kinds. Both categories consist of 132 contributions, that is, each comprises about a fifth of all contributions.

We received pictures of trees, flowers and other plants, along with various landscapes – mountains, forests, fields, lakes, rivers and seas. Some participants sent pictures of birds: doves, a robin, a duck, a heron, and a peacock. Others submitted photos of animals, among them a raccoon, a squirrel, a grasshopper, and, unsurprisingly, many cats and dogs. We also received pictures of cityscapes, most of them of German cities.



Anja Beyer

Die Kunst der Dunkelheit ist, die Dunkelheit zu lieben und sie zu nutzen. In der Dunkelheit kann man die Welt anders sehen. In der Dunkelheit kann man die Welt anders fühlen. In der Dunkelheit kann man die Welt anders verstehen. In der Dunkelheit kann man die Welt anders lieben. In der Dunkelheit kann man die Welt anders sein.

#DUBISTAMZUG



Jana Erwig

Die Kunst der Dunkelheit ist, die Dunkelheit zu lieben und sie zu nutzen. In der Dunkelheit kann man die Welt anders sehen. In der Dunkelheit kann man die Welt anders fühlen. In der Dunkelheit kann man die Welt anders verstehen. In der Dunkelheit kann man die Welt anders lieben. In der Dunkelheit kann man die Welt anders sein.

#DUBISTAMZUG







Simon Lüttmann



Michael Jespersen

#DUBISTAMZUG



#DUBISTAMZUG



Alexander Rieck

#DUBISTAMZUG



Britta Lafleur

#DUBISTAMZUG



### c. Political messages

This category also included 132 contributions. A significant number of political messages promoted equality in general or objected to specific types of discrimination — most notably, the discrimination of LGBT people, but also of women, as well as sick, disabled, mentally ill, introverted, and overweight persons. In addition, we received contributions aiming to make specific illnesses — such as diabetes and depression — more visible. We had an especially remarkable number of

people suffering from an illness called ME/CFS,<sup>93</sup> who are a rather well-organized group fighting for prominence and recognition.

**90%  
of people  
are biased  
against  
women**

You need to be taller

Gender Social Science Index 2020 / Sozialer Status Index (SSI)

Silke Schwarz



**DIE WÜRDE DES MENSCHEN  
IST UNANTASTBAR. DA STEHT  
NIX VON NUR BIS GRÖSSE M.**

Natalie Rosnke

Die hier gezeigten Ergebnisse sind nur eine grobe Schätzung und können von der tatsächlichen Situation abweichen. Die Ergebnisse sind nicht als Grundlage für politische Entscheidungen zu verwenden.

**#DUBISTAMZUG**

Die hier gezeigten Ergebnisse sind nur eine grobe Schätzung und können von der tatsächlichen Situation abweichen. Die Ergebnisse sind nicht als Grundlage für politische Entscheidungen zu verwenden.

**Wall**

Die hier gezeigten Ergebnisse sind nur eine grobe Schätzung und können von der tatsächlichen Situation abweichen. Die Ergebnisse sind nicht als Grundlage für politische Entscheidungen zu verwenden.

**#DUBISTAMZUG**

Die hier gezeigten Ergebnisse sind nur eine grobe Schätzung und können von der tatsächlichen Situation abweichen. Die Ergebnisse sind nicht als Grundlage für politische Entscheidungen zu verwenden.

**Wall**

*Human dignity is  
inviolable.  
Nowhere is stated  
“up to size M.”*

STELL DIR VOR, DEIN LEBEN IST VORBEI.  
ABER DU BIST NOCH DA.



Die hier gezeigten Ergebnisse sind nur eine grobe Schätzung und können von der tatsächlichen Situation abweichen. Die Ergebnisse sind nicht als Grundlage für politische Entscheidungen zu verwenden.

**#DUBISTAMZUG**

Die hier gezeigten Ergebnisse sind nur eine grobe Schätzung und können von der tatsächlichen Situation abweichen. Die Ergebnisse sind nicht als Grundlage für politische Entscheidungen zu verwenden.

**Wall**

*Imagine your life is  
over. But you are still  
around.*

<sup>93</sup> See *ME/CFS Basics*, CDC, <https://www.cdc.gov/me-cfs/index.html> (last visited May 10, 2024).

Additional prominent topics included environmental protection and animal rights, as well as anti-war messages — some objecting war and promoting peace generally, but most referring specifically to the war in Ukraine.



*One heart for all creatures*

*I can see into  
the future! ...  
but there is no  
future!*



*We will always be free*

*d. Glimpses into personal worlds*

In this category, we included contributions allowing a glimpse into the personal worlds of the participants. This category is almost as large as the previous two, totaling 125 contributions. We received pictures of the participants, their families, friends, and pets, as well as pictures of intimate domestic environments — for instance, showing children’s toys or baby’s hands and dog’s paws. Some participants sent in personal stories — among them stories of illnesses, sexual abuse, experiences of war and refuge, but also positive experiences, such as finding love or a new home. Others sent messages to specific persons, for instance, a message expressing gratitude to a relative who had influenced the participant’s path of life, encouragement for the participant’s disabled daughter, a poem in memory of the participant’s deceased grandmother, and two marriage proposals. In addition, many participants shared paintings and other artworks of their children.



Cloud Cakloo

#DUBISTAMZUG



Dirk Jericho

#DUBISTAMZUG



Giulmaz Sagitova

#DUBISTAMZUG



Rajsh 12

#DUBISTAMZUG





*Laubi, will you marry me?*

A notable group of contributions incorporated both, glimpses into one's personal world and political messages:



*My name is Sandra. I suffer  
from the severe disease  
Myalgic Enzophamomyitis -  
#mecfs. I am a mom of  
three sick children. We are  
in desperate need of  
research. Please help us  
publicize the disease. It is a  
neuroimmunological  
multisystem disease.*

*I am an artist in exile and  
cannot work here!*



Я заснула 24 лютого і не  
можу прокинутись. Це  
найстрашніший сон з усіх, що  
я бачила. Допоможіть

Viktoria Korotko



*I fell asleep on  
February 24 and  
can't wake up. This  
is the worst dream  
I've ever had. Please  
help.*

*e. Berlin*

The fifth category consists of 61 contributions dedicated to the city of Berlin, which make about 10% of all contributions. We received pictures of different places and from various historical periods of Berlin, along with collages on the topic (mostly incorporating the famous TV Tower). Participants also shared poems dedicated to Berlin, texts about their love to this city, about how it connects people, makes everyone feel at home, as well as about how diverse, unconventional, and inclusive it is.



Thomas Bulgrin



Julia Zakharov





pickle cucumbers. In this category, we also included inspirational quotes, such as “Do not be afraid of the stupid who know nothing, be afraid of the smart who feel nothing” (Erich Kästner) and “One sees clearly only with the heart. Anything essential is invisible to the eyes.” (Antoine de Saint-Exupéry).



Nod Eto

#DUBISTAMZUG



#DUBISTAMZUG



*Time is always there.  
We only have to take it!*

Legen Sie Gurken ein.



Birgit Kunz &amp; Mona Schmidke

Angelo Favia

#DUBISTAMZUG



#DUBISTAMZUG



*Pickle cucumbers.*



contributions. This finding is significant. It indicates that the visions of cultural democracy (where everybody gets a chance to become co-creator rather than a mere consumer of art) are viable. Comparing the number of people who submitted artworks (about 66%) with the number of people who identified themselves as artists of some kind (about 20%) makes clear that many people without artistic training wish to create and share artworks.

We can say that our experiment reveals a major social demand for co-creation of art. Economic models usually focus on consumption as the goal of market regulation (e.g. supply should adjust itself to meet the demand). Yet, we believe that in the field of art, this perception is out of place, for several reasons. First, as discussed above, much of the artistic field is dominated by experts, who decide what will be displayed in museums, galleries, and urban public spaces. This gives many people the impression that they do not understand art, which indicates that today's artistic world does not obey the market rules of supply adjusting itself to demand. Second, even if we focus on the market-based aspect of today's artistic world, it does not seem to capture the whole picture in this field.

Contrary to other producers — and contrary to the assumption of copyright laws — economic gain is not always the main motivation behind creative activity and behind the desire to share one's creativity.<sup>94</sup> Our experiment provides evidence that people wish to present their artworks without expectation of a monetary gain. If so, we can say that the opportunity to present one's artwork is in itself a subject of demand. Thus, our findings indicate that the current structure of the artistic world — where only few individuals have the opportunity to present their works to the public — does not reflect the real need for sharing one's creativity. We will revisit this point below, while discussing the motivation of the project's participants to share their art.

Another interesting finding is the modest place (about one-fifth of the contributions) dedicated to politics. This stands in a sharp contrast to today's highly politicized social discourse. An overwhelming majority of the contributions did not have any statement to agree or disagree with — indeed, few counter-arguments can be raised against a picture of a cat. When given an opportunity to present a contribution of their choice, most people chose to share content that marks them out as individuals — whether by a work of art, a personal story, or a picture they took — rather than signals their belonging to a certain political group. We thus believe that de-centralizing public discourse by allowing significant room for individual speech has the potential to blur the social division into “political tribes” and to de-polarize the social discourse.

As mentioned above, Talisse suggests that desaturating the social environment of politics could help us regain the ability to regard our co-citizens as people with valuable aspirations and pursuits that lie beyond politics. We believe that letting individual speech co-shape public

---

<sup>94</sup> E.g., JESSICA SILBEY, *THE EUREKA MYTH: CREATORS, INNOVATORS, AND EVERYDAY INTELLECTUAL PROPERTY* (2015); Rebecca Tushnet, *Economies of Desire: Fair Use and Marketplace Assumptions*, 51 WM. & MARY L. REV. 513, 520–22 (2009).

discourses could be a significant step in that direction. *Du bist am Zug* demonstrates that given the opportunity to express themselves individually, people show diverse sides of themselves: they express their creativity and aspirations; invite others into their personal and professional worlds; show landscapes and animals they observed; share their reflections and wishes. Thus, individual expressions could re-build the democratic discourse around a great variety of new topics, thereby enriching and de-polarizing our society.

Moreover, the political discourse itself has much to gain from individual speech. As mentioned above, scholars have proposed introducing visual and rhetorical tools — such as images and storytelling — into the democratic discourse. These tools could foster imagination and create empathy, thereby helping to overcome the difficulty of attending and appreciating perspectives that contradict one's political views. Indeed, participants that chose to present political messages did just that. As the examples above illustrate, they conveyed these messages in creative and personal ways, using pictures, rhetoric, and telling their personal stories.

We believe that this type of communication has the potential to create greater understanding and mend the common basis for political discourse. For instance, consider a statement touching upon the debate on migration, which is a highly polarizing topic in current German politics: “I am an artist in exile and cannot work here.” The personal component of this statement may reach into hearts of those who are generally opposed to migration. Similarly, the words “I fell asleep on February 24 and can't wake up. This is the worst dream I've ever had. Please help.” have the potential to evoke empathy and understanding on another highly debated topic — the role of Germany in the Russian-Ukrainian war.

An additional positive aspect for political discourse is bringing in new topics (the most notable example in our experiment was ME/CFS illness) and highlighting less prominent ones — for instance, discrimination of overweight people and animal abuse. Apart from the importance of including underrepresented interests in the public debate, these topics have a depolarizing potential. Since they do not stand in the center of hot political debates, “political tribes” do not have strong opinions about them; consequently, they might give rise to “cross-tribal” connections.

Apart from these positive effects, we believe that there is something essentially democratic about letting people decide on the very question of what topics should be included in the public debate, and to what extent. Today, the social discourse largely consists of a given list of political topics, and most people are able to express their opinions on these topics either in private conversation or on the social media. In both cases, they will usually be heard by like-minded individuals. Their participation in public debate primarily takes the indirect form of voting for politicians who represent their views on the topics included in the political arena. Letting people decide individually what topics should



belong in the public sphere would build up this sphere anew, in a way that is much closer to a genuinely free democratic discourse.

To sum up, our results point out that the social discourse might look different if people had the opportunity to take part in it individually, rather than as a part of large groups as happens now. Much space would be dedicated to artistic expression. People would have many opportunities to get a glimpse into the personal worlds of their co-citizens. Politics will occupy a smaller place than it does today, and the political discourse itself would take different, presumably less polarizing forms.

#### *D. What was the Participants' Motivation for Taking Part in the Project?*

##### *a. Results*

Our survey included the following question: "Why did you choose to participate in *Du bist am Zug*?" The most frequent reason given by the participants was that they liked the idea of the project — this motivation appeared in 47 out of the 131 answers. Some of the respondents simply stated: "because I liked the idea," "awesome project," "exciting campaign," and the like, while others explained what they liked about the project. The main aspects the participants mentioned in this context were giving everyone a chance to be seen, filling public space with art, and replacing advertising:

- It's a great idea to give all Berlin residents an equal chance to share their work – whatever it may be – with the city, thus granting many people an opportunity to be seen that they might otherwise never have had.
- A super great idea! To flood the city with art & artistic content - what could be better?! Thank you very much for that.
- Because I found it a charming idea to decorate public space not only with advertising, but with something that brings us forward socially and culturally. The world is more than just an advertising pillar for corporations.

Several respondents remarked that they wanted to support the idea of the project by their participation, so that the project succeeds and repeats itself.

The second most frequently mentioned motivation (45 answers) was using the chance to present something of one's own to the public — oneself, one's artwork, one's thoughts, something personal, one's problem, or something that one likes. Here are some examples:

- I wanted to share my favorite quote with Berlin!
- It appealed to me to show the way I see Berlin to others.

Some of the respondents emphasized that *Du bist am Zug* was perhaps their only chance to share something with a broad audience:

- I found it a unique experience to be able to exhibit something in Berlin that means so much to me personally.

Others noted that this was the first time they dared to present their artworks to an audience:

- I wanted to see if art of a non-professional would be selected for a billboard and to dare to appear in public with my art.
- I wanted to dare to share my writings and to take a big step in my favorite city.
- I am a creative person and produce many things, but usually do not dare to post or show the results anywhere. I give away the pictures, sewn or crafted things only for birthdays to my friends. With *Du bist am Zug*, I could just quietly and secretly dare to take my chance.

In the third largest group (25 answers), participants referred to their wish to make public spaces genuinely public and democratic, to actively design the city — together with others — as well as to become present, heard and, visible:

- I wanted to be heard.
- I found the idea of being visible in the street with something of mine exciting....
- I enjoyed the thought that my photos could be seen by many people.
- I found it great to be able to contribute my part in the design of the public space through my creativity.
- I liked the idea of returning the public space to the society.
- I enjoyed being a part of the public co-creation.
- For the democratization of public space, which should belong to all of us.
- Designing the city together!

Somewhat relatedly, the fourth type of motivation (14 answers) was filling the public space with art. Some participants specifically remarked that they would like art to replace commercial and political messages in the public space:

- I hate advertising, because it is so often successful with me – and was so happy to turn these countless private surfaces into a public realm and an art exhibition.
- It is a wonderful way to make art visible in public space – to inspire people, to bring a spark of beauty and poetry into their hearts, rather than overwhelming them with fear-mongering messages or consumerist advertisements as is often the case.
- I really wanted to take part in the campaign against visual pollution.

In the fifth group, 13 answers reflected the wish to see one's contribution in large in public space:

- The idea of seeing a picture of mine on a billboard in Berlin made me happy.
- Because it was a great idea to see your own photo in such a big print as part of the streetscape.

Other types of motivation we indicated formed smaller groups (2 to 7 answers). They were: trying something new, an occasion to undertake

a creative project, to see if one can make it and if the project will really function without a jury or professional judgement. Notably, only two participants mentioned that they were interested in reactions to their contributions.

*b. Discussion*

The motivations of the project's participants — democratizing public space, showing one's art and one's presence, beautifying the city, and replacing commercial messages — are very much reminiscent of those of graffiti writers. This lends support to the assumption that graffiti is a symptom of a larger phenomenon: a significant number of people share the wish to become visible in public space and to co-design the shared visual environment. It was especially interesting to see that many participants felt that taking part in the project would “democratize” public spaces, and return them to where they belong: the society. These results suggest that developing tools for personal expression in public space could fill in the vague concept of “right to the city” with meaningful content.

Another notable aspect here is the small number of participants that indicated their interest in receiving reactions. Presence, visibility, and the possibility to take part in the design of one's own city seem to be valuable in themselves, regardless of other people's feedback. Legal theories recognize several rationales for protecting speech, one of which is self-expression: an opportunity to speak one's mind, to express one's creativity may significantly contribute to the development of one's personality.<sup>95</sup> The respondents' motivations indicate that this speaker-focused — rather than perceiver-oriented — aspect of speech might be decisive in our context. It is important to create space for speech that would be seen and heard regardless of the number of supporters it has or the reactions it triggers; of course, this is not to suggest that incitement or hate speech should be allowed. Speech in public has intrinsic value for the speaker, which should serve as a sufficient basis for developing avenues for publicly visible expression.

This observation has a special implication for the field of art — a significant number of the respondents indicated their wish to present their artworks, to turn the city into an art exhibition, and to contribute their art to the visual urban design. This should motivate us to think anew about the field of art. We should ask ourselves whether it is necessary to have a highly exclusionist art world, in which experts or/and the market single out a small number of individuals as “artists” to the exclusion of all those who wish to engage in artistic activity and present their works to a broad audience. Our findings suggest that today's artistic world is too much viewer-oriented: art is defined by experts or the market. If some aspects of the artistic creation — which is an important part of human flourishing — are fulfilled when the works are presented to a

---

<sup>95</sup> OXFORD HANDBOOK OF FREEDOM OF SPEECH xiii (Adrienne Stone & Frederick Schauer eds., 2021).

broad audience, this might provide a valuable reason to rebuild the artistic world in a more artist-oriented way.

One could imagine another art world, in which everyone may have an outlet and audience for his or her creativity. For the sake of comparison, advertising occupies our attention without enjoying the status of art or demand. The omnipresence of commercial messages compels city inhabitants to perceive them, in spite of the widespread wish to avoid them. Meanwhile, commercial interests seem to provide a weaker basis for a right to occupy our attention than the desire of our co-citizens to share their art with us.

*E. What did the Participants Wish to Communicate with their Messages?*

*a. Results*

In our survey, we asked: “Tell us about your contribution — why did you choose it and what did you want to communicate?” Many participants gave lengthy answers to this question, and we classified these texts according to the main themes.

The largest category (31 answers) reflected the desire to bring something positive into other people’s lives. Participants told about their aspiration to arouse positive emotions, bring in some color into everyday life, send positive messages, spark phantasy, make other people smile and laugh, as well as to communicate hope, love, happiness, inner peace, and tranquility. Four respondents specifically noted their wish to inspire the passerby to experience the beauty of everyday moments. Four additional answers reflected the intention to encourage people to think positively about others and not to lose sight of those who are dear to them. Further answers in this category expressed wishes to give a compliment, reassure, motivate and support the viewers, to inspire them to challenge their inner limits and achieve greater freedom — “to spread their wings” — and to encourage them to feel good about themselves no matter what others think:

- I have chosen a work called "komplimentedusche" [compliment shower], which conveys to the viewer a compliment that has nothing to do with the external appearance.



In the third category, we had answers reporting the wish to share something personal — personal experiences and feelings, as well as things or beings that have special significance for the participants. Twelve answers related to personal experiences, six of them specifically to experiences during the Covid-19 pandemic, for instance:

- During the gloomy Corona time with the hard lockdowns, when everything was closed, my friends and I made an art exhibition in a vineyard. . . .
- It was a photo of me at the end of 2020 after the hard Corona year, which I used to get a maximum of fitness, so managed to get into the best physical shape of mine at the age of 42. . . .



Elias Kouloures

Die hier gezeigten Personen, Publikumsmitglieder, haben sich freiwillig an der Gewinnziehung beteiligt. Die Gewinnziehung wird durch die Medien übertragen und ist öffentlich. Die Gewinnziehung ist eine Veranstaltung, die von der Gewinnziehungsgesellschaft durchgeführt wird. Die Gewinnziehung ist eine Veranstaltung, die von der Gewinnziehungsgesellschaft durchgeführt wird.

#DUBISTAMZUG

Responsible Gambling Campaign  
 Wall

An additional six answers about personal experiences related to recurring events — such as receiving offensive remarks about one's illness, having to cope with male-dominated or homophobic world, or finding comfort in one's religion — as well as to specific events in the past, for instance, as a trip, a concert, or a show:

- I am a type 1 diabetic, and have to hear repeatedly what strange and hurtful prejudices people have about the disease. I wanted to stop that.

Further, seven answers in this category referred to sharing something the participants especially liked: one's favorite song (its title), a picture of one's favorite bird, a favorite building, musical instruments the participants played and wished to introduce to the others, as well as the respondents' enthusiasm about certain artistic styles:

- I wanted to show everyone how beautiful the Turkish guitar (saz) is. The instrument is still relatively unknown.







- Hagen is severely multiply disabled, and has difficulties with hand motor skills. He has painted “Mama” in one of his favorite colors. For him and us a masterpiece that we would like more people to see.



The fourth category included 20 answers that had a message about Berlin. Most of them were messages about how colorful, diverse, inclusive and beautiful it is. In addition, one participant had a critical message:

- Plastic bag in the wind on the Tempelhof field. The seemingly aesthetic image condemns garbage in Berlin.



Anke Hohnmeister

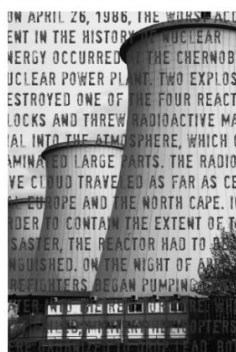
Die hier gezeigten Bilder zeigen (Fotografieren) nicht nur die Umweltverschmutzung, sondern auch die Folgen der Klimawandel. Die hier gezeigten Bilder zeigen (Fotografieren) nicht nur die Umweltverschmutzung, sondern auch die Folgen der Klimawandel. Die hier gezeigten Bilder zeigen (Fotografieren) nicht nur die Umweltverschmutzung, sondern auch die Folgen der Klimawandel.

#DUBISTAMZUG



The fifth category included seventeen answers about one's intention to share political and social messages. Six of them were anti-war messages, all referring, more or less directly to the ongoing war in Ukraine:

- With my contribution, I wanted to tell about the current events in Ukraine.
- My photo showed a still unrestored facade of a building that was damaged by bombs and shells. Much has to be done yet to repair all the damage caused by war, and there is already another war in Europe. I am thinking about it since February.
- It is the day of the nuclear accident in Chernobyl and at the same time, there are acute problems with nuclear power stations in the context of the war in Ukraine. I wanted to sensitize people to this topic, since there are many social decisions to be made, especially in Germany.



Svenja Arndt

Die hier gezeigten Bilder zeigen (Fotografieren) nicht nur die Umweltverschmutzung, sondern auch die Folgen der Klimawandel. Die hier gezeigten Bilder zeigen (Fotografieren) nicht nur die Umweltverschmutzung, sondern auch die Folgen der Klimawandel. Die hier gezeigten Bilder zeigen (Fotografieren) nicht nur die Umweltverschmutzung, sondern auch die Folgen der Klimawandel.

#DUBISTAMZUG



Three further answers referred to environmental protection, and the rest to specific problems that the participants wished to make visible, such as their illnesses, lack of social acceptance of gay people, insufficient respect and payment for illustrator's work, and the need to adopt street dogs:

- I painted the picture during my outing. Actually, the picture communicates my subjective feelings at that time. Ultimately, however, it says that even today, it can be difficult for queer people to show publicly whom they love.

The sixth category consisted of twelve answers, referring to the participants' wish to share their reflections and to motivate others to reflect — generally or upon specific topics, such as love or the vulnerability of our world:

- My contribution . . . reflects that we all need shelter, warmth, and compassion.
- I want to show that it is possible to transform horror into beauty, and that it is possible to be both tough and delicate at the same time . . . .
- Our Legacy - A plastic bag and a loaf of bread, that's what we leave behind. . . . A plastic dystopia.



Peter Reinert

Da hier gerade etwas von einer Plastikmüllschleife zu sehen ist, werden wir hier ein kleines Gedächtnis an die Person, die es so schön gemacht hat, zeigen. Wir hoffen, dass es Ihnen ein wenig Freude macht und Sie sich für die Kunst und die Kunst der Kunst freuen können. Wir hoffen, dass es Ihnen ein wenig Freude macht und Sie sich für die Kunst und die Kunst der Kunst freuen können.

**#DUBISTAMZUG**

Initiative für Kunst und Kultur in der Stadt

**Wall**

- I took a picture of colorful rubber shoes sold in southeast Turkey. These are worn there in the streets as well. People don't choose them by the designer or leather type, but only by size and, at best, by color. What seems as self-evident to us does not apply everywhere in the world.



Manuela Hubner

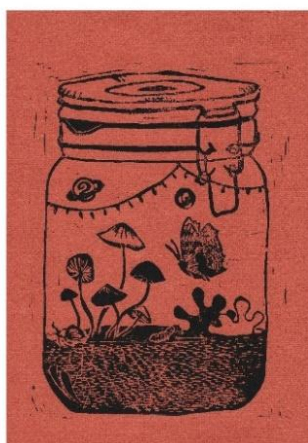
Die hier gezeigten Bilder sind urheberrechtlich geschützt. Die Weiterverbreitung ist ohne schriftliche Genehmigung der Wall Group. Die Weiterverbreitung ist ohne schriftliche Genehmigung der Wall Group. Die Weiterverbreitung ist ohne schriftliche Genehmigung der Wall Group. Die Weiterverbreitung ist ohne schriftliche Genehmigung der Wall Group.

#DUBISTAMZUG

Wall Group  
Wall Group

The seventh category consisted of seven answers. They are especially interesting; the participants told that they did not wish to communicate anything specific, just to share something beautiful, cool, or poetic:

- A poetic occurrence without explanation.
- My picture combines my favorite medium and my favorite motif: linocut and mushrooms. It has no special intention; it is simply beautiful.



Annicken Fröhling

Die hier gezeigten Bilder sind urheberrechtlich geschützt. Die Weiterverbreitung ist ohne schriftliche Genehmigung der Wall Group. Die Weiterverbreitung ist ohne schriftliche Genehmigung der Wall Group. Die Weiterverbreitung ist ohne schriftliche Genehmigung der Wall Group. Die Weiterverbreitung ist ohne schriftliche Genehmigung der Wall Group.

#DUBISTAMZUG

Wall Group  
Wall Group

The last category consists of two answers reflecting the motivation to connect to other people through one's contribution.

*b. Discussion*

Perhaps the most interesting finding here is the willingness to share something with everyone, rather than to reach out to one's own, or any specific group. This might indicate that individual communication tends to be less polarizing and thus has the potential to create more inclusive bases for social communication. The largest category we indicated — positive messages — gives another reason for optimism. Indeed, the extensive willingness to bring something positive, beautiful, and cheerful into other people's lives is one of the most promising findings our experiment delivered. It suggests that remodeling the social discourse to allow space for individual expression could considerably improve its atmosphere.

Another significant finding is further evidence about the substantial interest to present one's art to a broad audience. It reinforces our conclusion that there is significant demand for opportunities to exhibit one's art, and lends support to voices calling to democratize the artistic field, allowing everyone to co-create our shared culture. It is interesting to note that the participants only referred to their wish to share their artistic works, and did not mention any anticipation of feedback. This might further indicate the need to remodel the art world in a more artist- rather than consumer- or expert-oriented way.

Another interesting finding is the willingness to share highly personal content, such as one's experiences and feelings, memories of one's lost loved ones or a work of one's disabled child. This may indicate how differently social discourse might look if more space would be given to individual expression. While social discourse saturated with politics reduces people to their affiliation with one of rival "tribes," many of *Du bist am Zug*'s participants chose to expose unique and distinctive dimensions of their personalities and lives.

As mentioned above, the significant number of Berlin-related messages might be site-specific. This finding is nevertheless remarkable and can provide an interesting point of comparison for similar projects in other cities. It could be interesting to explore where people are more likely to communicate city-related messages, and what kind of city-related messages people communicate, and try to discover the interconnection between these tendencies and other city-related factors.

As for political messages, we can again witness the presence of topics that are absent from the regular political discourse — for instance, not-much-discussed illnesses, working conditions of illustrators, and adoption of street dogs. This provides an indication that individual expressions have the potential of broadening the political discourse and making it more fine-tuned. The same might be said about contributions inviting the passerby to reflect on certain topics, such as the vulnerability of our world, that these contributions referred to issues that are rarely debated. In addition to enriching the public discourse, reflecting upon

such issues may somewhat move the discourse away from highly disputed topics, thus potentially weakening the current social polarization.

A lesson we have learnt from the current project is that an opportunity to get access to the participants' comments could have improved it. As the examples above illustrate, some contributions incorporate meanings that are difficult to grasp without the author's explanation.

Finally, participants who answered that they did not wish to communicate anything give some further indication about the breadth the social discourse could have if co-shaped by individual speech. Such discourse would not only embrace a great variety of topics, but also include expressive speech non-reducible to any specific topic at all.

#### *F. Some Impressions from Additional Results*

The scope of this paper does not permit presenting all the results of our study. Yet, we would like to share, very briefly, our impressions about some of the additional results we have obtained from the survey.

We asked the participants about the reactions they received to their contributions, and how they made them feel. The answers made clear that our project was not built to allow meaningful interactions with strangers; most of the respondents reported that they have received reactions of friends and family, or superficial social media reactions, such as likes, emojis and general praise, or did not receive any reactions at all. Only a minority of the respondents told about meaningful discussions on the social media or interaction with the passerby in the street. Nevertheless, most respondents shared that their experience with the project was very positive; merely seeing one's contribution in large on a visible public spot and knowing that other people see it made the participants feel happy, excited, and proud. Many remarked that it was not important for them whether they received reactions or not. What mattered was that they could present themselves and their messages in a way that reaches other people.

An additional curious finding in this context is the answers to the following question: "Do you agree with the following statement: 'Letting people place their expressions on billboards creates meaningful communication?'" Sixty-four per cent of the respondents answered that they agree or strongly agree with this statement. This gives a clear indication that people do not necessarily perceive communication as something mutual, something that requires a reaction — meaningful communication may consist of sending one's message without expecting any answer.

This led us to reflect on the question whether the lack of meaningful possibility to comment on the contributions and interact with their authors was a drawback or a feature of our project. Communication without interaction gives the speaker a special position, allowing to send a clear and undisturbed message. Indeed, this is the way mass media (television, press, and radio) function, along with traditional forms of



artistic presentation (shows, movies, concerts, and exhibitions). For the sake of comparison, consider “legal walls” where graffiti is allowed. Everyone is free to write and paint on these walls, and one’s painting may be modified and complemented by others. While this may create a playground for interaction, this may also dilute the expressiveness of individual messages. While presenting personal messages on billboards does not allow interaction, it has the advantage of preserving the power of individual voices. Additional experiments, with modified conditions, are needed to explore the benefits and drawbacks of interactive and non-interactive speech.

The last findings we would like to mention is respondents’ reactions to contributions shared by other participants. First, an absolute majority of the respondents (74%) stated that they looked at many other people’s contributions.<sup>96</sup> To the question of whether they learnt something new and if so, what it was, the most frequent answers were that one learnt how diverse, creative, and talented one’s co-citizens were — many noted that this surprised and even overwhelmed them. “Everyone is an artist in one’s own way,” commented one respondent. Only two respondents remarked that they found the quality of some of the artworks too low. These findings provide an initial indication that people may understand and value art that has neither been approved by experts nor created by famous artists. This lends further support to the viability of ideas of cultural democracy.

Another significant group of respondents remarked that they learnt how much their co-citizens’ had to share, how great their need to share was, and how important such sharing was to (re)gain a sense of community. An additional recurrent answer was that insights in the personal worlds of others created a feeling of belonging and being together. Some respondents noted that the contributions inspired them, triggered emotions, gave food for thought, and broadened their horizon. Finally, many respondents noticed that they learnt about an illness they had been not aware of, and understood that it needs recognition and research.

These findings provide initial reference points for the potential of social discourse based on individual speech to foster social understanding, empathy, and a sense of community. Yet, these are initial insights into the experiment’s results. Comprehensive analysis will be presented in future publications.

## CONCLUSION & OUTLOOK

This paper presented the results of the experiment we conducted in March–August 2022 in the public space of Berlin. The goal of this experiment was to test a novel tool of democratic participation: individual speech. The results of our experiment provide initial evidence as to the possible functioning of the proposed tool.

---

<sup>96</sup> On a scale from 1 to 5, where 1 is “not at all” and 5 is “yes, a lot,” 72 out of the 131 respondents answered “5” and 25 answered “4.”

Our experiment revealed a significant desire — shared by people of different ages, genders, ethnicities, and occupations — to be visible in urban public space, and to co-design their city. We observed that, given an opportunity to submit content of their choice, an absolute majority of the participants shared images rather than texts. Some of the shared images incorporated texts, but most contained no words at all. This finding lends support to voices criticizing the logocentric culture and arguing that the social discourse should put greater emphasis on non-verbal expressive tools instead of focusing on rational argumentation.

In terms of content, most of the submitted contributions consisted of artworks of various kinds — such as paintings, drawings, collages, digital artworks, photographs, and poetry. By contrast, a relatively modest portion of submissions contained political messages. Additional significant categories of contributions included glimpses into the personal worlds of the participants, as well as wishes, inspiration, greetings, and advice. Many participants indicated that their motivation was to present themselves, some aspects of their lives, or their art. Others wished to bring in something positive — such as encouragement, beauty or poetry — into other people’s lives.

These results give a sense of how differently the social discourse might look if significant space were dedicated to individual expression. One can speculate that less place would be occupied by politics, more by art and creativity; people would present unique and distinctive aspects of their personalities rather than being reduced to their affiliation with one of the “political tribes;” and we would see more messages that seek to bring in something positive into other people’s lives. This leads us to believe that the tested democratic tool has the potential of desaturating the public discourse of politics, depolarizing it, and enriching it with new dimensions and horizons.

As for political messages submitted by the participants, most of them had personal and/or creative elements, and some of them touched upon subjects that are rarely debated, such as specific illnesses, discrimination of overweight people, or the need to adopt street dogs. We believe that these characteristics witness the ability of individual speech to expand the boundaries of the political debate, as well as to enrich it with elements evoking empathy and triggering the imagination.

All this data points out the potential of individual speech to contribute to depolarization of the social discourse, to create new bases for interconnectedness and thus help to “mend” democracy. Indeed, many respondents reported that the insights into the personal worlds of their co-citizens gave them a feeling of community and belonging.

Another significant finding of our experiment was the substantial number of participants, who reported their wish to co-design and beautify the shared visual space with their contributions, as well as their sentiment that in this way, they took part in “democratizing” the public space and returning it to the public, where it should belong. This indicates the potential of the proposed tool to advance the residents’

“right to the city” — which currently constitutes a rather vague concept — in a meaningful way.

Finally, an important finding of our experiment is the little weight the participants attached to reactions of others to their contributions, or the lack thereof. Our results reveal that the opportunity to be present, to show something of one’s own in urban public space, may be significant in itself, regardless of the others’ response. This finding indicates that creating opportunities for everyone to express oneself in a way that reaches an audience may significantly advance one’s freedom of speech. This finding has a particular significance in the field of art. It lends support to the ideas of cultural democracy and suggests that remodeling the artistic world in a more artist- rather than consumer- and expert-oriented way — that is, allowing everyone to co-design our shared culture — is in demand. This conclusion is supported by the evidence that a great number of the respondents enjoyed and admired the artworks submitted by *Du bist am Zug*’s participants, although these were neither made by famous artists nor approved by experts.

These are the conclusions we drew from the experiment. *Du bist am Zug* was a first attempt to test individual speech as a novel democratic tool. Further experiments — *inter alia*, in different locations and with modified conditions — are required to explore the feasibility of this tool further. Will the results replicate themselves in other locations or at another point in time in Berlin? Would creating avenues for communication with the authors of contributions improve the results? How would the experiment function in highly contested locations, such as Jerusalem — a divided and tense city? How would it function with a different medium of expression — for instance, posters on buses or trains, instead of billboards? In addition, we can assume that people who took part in our project were biased in its favor. It would be interesting to explore in further experiments what people who do not take part in projects of this kind think about them. These and many other questions remain to be explored in subsequent experiments.



# Using Common Law Property Doctrine to Advance Social Justice

JONATHAN L. ENTIN\*

## INTRODUCTION

Cases involving estates in land and future interests might not qualify as part of the “dogs” and “crud” that members of the Supreme Court who got on the outs with Chief Justice Warren Burger were likely to be assigned.<sup>1</sup> But, they might seem unattractive to lawyers and judges who must make sense of a “monstrously complex and mysterious body of law.”<sup>2</sup> That observation is not limited to matters involving the Rule Against Perpetuities, which the California Supreme Court once described as too difficult for lawyers exercising reasonable care to understand in dispatching a legal malpractice claim.<sup>3</sup>

Beyond technical complexity, some lawyers and judges might regard aspects of common law property doctrine as normatively objectionable, or even morally repugnant. For example, women enjoyed at best limited property rights under the common law, which allowed husbands to exercise dominion and control over their wives’ earnings as well as real and personal property.<sup>4</sup> Common law property doctrine also countenanced racial

---

\* David L. Brennan Professor Emeritus of Law, Case Western Reserve University. Thanks to Jonathan Adler, Atiba Ellis, Lawrence Mirel, Craig Nard, Elizabeth Rosenblatt, and participants in the Northeast Ohio Faculty Colloquium for helpful comments and suggestions, but they bear no responsibility for any errors, omissions, or other inadequacies.

<sup>1</sup> According to Justice Lewis Powell, “A dog is a case that you wish the Chief Justice had assigned to some other Justice.” A deadly dull case, “a tax case, for example.” Stuart Taylor, Jr., *Powell on His Approach: Ding Justice Case by Case*, N.Y. TIMES, July 12, 1987 (§ 1), at 1, 18. And as Justice Harry Blackmun explained, “If one’s in the doghouse with the Chief, he gets the crud,” by which he meant tax cases and sometimes Indian law cases. Stuart Taylor, Jr., *Reading the Tea Leaves of a New Term*, N.Y. TIMES, Dec. 22, 1986, at B14. A long-time colleague who specialized in tax and American Indian law often lamented that he did “crud and dogs.” See, e.g., Erik M. Jensen, *Of Crud and Dogs*, 58 TAX NOTES 1257 (1993).

<sup>2</sup> THOMAS F. BERGIN & PAUL G. HASKELL, PREFACE TO ESTATES IN LAND AND FUTURE INTERESTS 2 (2d ed. 1984).

<sup>3</sup> *Lucas v. Hamm*, 364 P.2d 685, 690–91 (Cal. 1962).

<sup>4</sup> See generally Reva B. Siegel, *Home as Work: The First Woman’s Rights Claims Concerning Wives’ Household Labor, 1850–1880*, 103 YALE L.J. 1073, 1082–85 (1994). Husbands had legal control over their wives’ earnings in most states until at least the latter part of the nineteenth century. See LINDA K. KERBER, NO CONSTITUTIONAL RIGHT TO BE LADIES: WOMEN AND THE OBLIGATIONS OF CITIZENSHIP 53–54 (1998). Husbands also had legal control over real property that their wives obtained or brought into the marriage, husbands obtained control of personal property their wives brought into their marriage, and husbands exercised legal dominion over real property that married couples held as tenants by the entirety. See *id.* at 13–14; Oval A. Phipps, *Tenancy by Entireties*, 25 TEMP. L.Q. 24, 24–26 (1951). Cf. *Kirchberg v. Feenstra*, 450 U.S. 455, 457 n.1 (1981) (explaining that the civil law system in Louisiana, which recognized community property and therefore was generally regarded as more favorable to women’s property rights than the common law, designated the husband as “head and master” of the

discrimination. We can see this in such cases as *Corrigan v. Buckley*,<sup>5</sup> where the Supreme Court effectively upheld the validity of restrictive covenants by dismissing, as “entirely lacking in substance,” a constitutional challenge to a private arrangement under which white landowners agreed to exclude Blacks from their neighborhood.<sup>6</sup> This was true despite the Court’s ruling, nearly a decade earlier, that state and local governments could not enact laws requiring racially segregated neighborhoods.<sup>7</sup> And the Court’s tacit approval of restrictive covenants encouraged their enormous expansion, which in turn contributed to extremely high levels of residential segregation.<sup>8</sup> Similarly, the doctrine of discovery, first systematically articulated in *Johnson v. McIntosh*,<sup>9</sup> devalued the long-standing presence of American Indians in what became the United States.<sup>10</sup> The Supreme Court has continued to recognize that doctrine in the twenty-first century.<sup>11</sup> The doctrine of adverse possession valorizes both the disruption and transformation of land at the expense of conservation and other values and is in tension with libertarian opposition to compelled transfers of land.<sup>12</sup>

---

marital community and allowed him unilaterally to encumber the family residence, a provision that the Supreme Court in that very case held to violate the equal protection rights of wives).

Common law legal disabilities on women were not confined to the property context. The common law rule that severely limited the ability of married women to enter into legally binding contracts was the principal basis for the denial of Myra Bradwell’s application for admission to the bar. See *Bradwell v. Illinois*, 83 U.S. (16 Wall.) 130, 131 (1873); *id.* at 141 (Bradley, J., concurring).

<sup>5</sup> *Corrigan v. Buckley*, 271 U.S. 323 (1926).

<sup>6</sup> *Id.* at 330. Although the covenant was a private agreement and therefore not subject to constitutional constraints, the Court later ruled that judicial *enforcement* of racially restrictive covenants did represent unconstitutional governmental action. See *Shelley v. Kraemer*, 334 U.S. 1, 20 (1948) (finding that state court enforcement of such covenants violated the Equal Protection Clause of the Fourteenth Amendment); see also *Hurd v. Hodge*, 334 U.S. 24, 33–36 (1948) (holding that judicial enforcement of such covenants in the District of Columbia violates 42 U.S.C. § 1982 and public policy); *Barrows v. Jackson*, 346 U.S. 249, 253–54 (1953) (concluding that a state court’s award of damages for breach of a racially restrictive covenant represents state action that violates the Fourteenth Amendment).

<sup>7</sup> *Buchanan v. Warley*, 245 U.S. 60 (1917).

<sup>8</sup> See JEFFREY D. GONDA, *UNJUST DEEDS: THE RESTRICTIVE COVENANT CASES AND THE MAKING OF THE CIVIL RIGHTS MOVEMENT* 15–54 (2015); RICHARD ROTHSTEIN, *THE COLOR OF LAW: A FORGOTTEN HISTORY OF HOW OUR GOVERNMENT SEGREGATED AMERICA* 77–91 (2017); RICHARD H. SANDER, YANA A. KUCHEVA & JONATHAN M. ZASLOFF, *MOVING TOWARD INTEGRATION: THE PAST AND FUTURE OF FAIR HOUSING* 69–76 (2018). On the high levels of residential segregation during this period, see DOUGLAS S. MASSEY & NANCY A. DENTON, *AMERICAN APARTHEID: SEGREGATION AND THE MAKING OF THE UNDERCLASS* 17–82 (1993); KARL E. TAEUBER & ALMA F. TAEUBER, *NEGROES IN CITIES: RESIDENTIAL SEGREGATION AND NEIGHBORHOOD CHANGE* 28–68 (1965).

<sup>9</sup> *Johnson v. McIntosh*, 21 U.S. (8 Wheat.) 543, 572–77, 581–84, 587–88, 591–92, 595 (1823).

<sup>10</sup> See, e.g., NED BLACKHAWK, *THE REDISCOVERY OF AMERICA: NATIVE PEOPLES AND THE UNMAKING OF U.S. HISTORY* 285–88 (2023); MARK CHARLES & SOONG-CHAN RAH, *UNSETTLING TRUTHS: THE ONGOING, DEHUMANIZING LEGACY OF THE DOCTRINE OF DISCOVERY* 13–23 (2019); ROBERT A. WILLIAMS, JR., *THE AMERICAN INDIAN IN WESTERN LEGAL THOUGHT: THE DISCOURSES OF CONQUEST* 312–17, 322–23 n.132–33 (1990); Blake A. Watson, *John Marshall and Indian Land Rights: A Historical Rejoinder to the Claim of “Universal Recognition” of the Doctrine of Discovery*, 36 SETON HALL L. REV. 481, 484–86 (2006).

<sup>11</sup> See *City of Sherrill v. Oneida Nation of N.Y.*, 544 U.S. 197, 203 n.1 (2005).

<sup>12</sup> On the disruption of land, see, e.g., John G. Sprankling, *An Environmental Critique of Adverse Possession*, 79 CORNELL L. REV. 816, 840–62 (1994); Eric T. Freyfogle, *The Construction of Ownership*, 1996 U. ILL. L. REV. 173, 173–80 (contending that the law encourages landowners to use their property

For whatever reason, courts have avoided or struggled with seemingly basic property concepts even when a focus on those concepts could have resolved disputes in a straightforward and entirely defensible manner. This article suggests that courts should embrace common law property doctrine despite whatever flaws it might contain when the doctrine is useful and provides a cogent basis for determining cases.<sup>13</sup> This position is analogous to the renewed interest in state constitutional law to protect individual rights,<sup>14</sup> as well as suggestions that progressive lawyers should pragmatically consider using formalist arguments that traditionally have been associated with conservative positions.<sup>15</sup> But the approach advocated in this article draws its main inspiration from the work of Charles Hamilton Houston (and later Thurgood Marshall) at the outset of what seemed like a quixotic challenge to segregation in education. They did not initially explicitly challenge the constitutionality of the notorious separate-but-equal doctrine but instead tried to use that doctrine to their advantage, changing their approach only when earlier victories undermined that doctrine and gave grounds for optimism that a direct attack could succeed. Note that the Houston-Marshall project involved an effort to change legal doctrine, whereas this article illustrates how established common law property doctrines sometimes can be used to promote socially desirable goals.

Part I considers a recent decision in which the Ohio Supreme Court rebuffed an effort to enforce deed restrictions on the property used by the Cleveland Botanical Garden. The court reached the correct result, but the main opinion focused more on “practical realities” than on the language of the deed conveying the property 140 years earlier.<sup>16</sup> Yet, interpreting the deed and applying traditional property doctrines would have reached the same result in a more satisfactory way.

---

in socially and environmentally destructive ways). On the tension between libertarianism and adverse possession, see Robert C. Ellickson, *Adverse Possession and Perpetuities Law: Two Dents in the Libertarian Model of Property Rights*, 64 WASH. U. L.Q. 723, 723–25 (1986).

<sup>13</sup> For an analogous analysis of the use of common law contract doctrine to combat racial discrimination, see Steven J. Burton, *Racial Discrimination in Contract Performance: Patterson and a State Law Alternative*, 25 HARV. C.R.-C.L. L. REV. 431, 445–58 (1990) (criticizing the Supreme Court’s decision in *Patterson v. McLean Credit Union*, 491 U.S. 164 (1989), which narrowly interpreted a Reconstruction statute forbidding racial discrimination in the making and enforcement of contracts that appears in what is now 42 U.S.C. § 1981(a), and explaining why a more careful attention to contract doctrine would have led to a different, and correct, result).

<sup>14</sup> Part of that interest arose from concern that the U.S. Supreme Court had interpreted individual rights more narrowly than critics thought appropriate. See William J. Brennan, Jr., *State Constitutions and the Protection of Individual Rights*, 90 HARV. L. REV. 489, 495–98 (1977). Proponents of this approach have emphasized that state constitutions might provide a basis for more expansive rights protection and also that state constitutions protect rights that the U.S. Constitution does not address. See, e.g., JEFFREY S. SUTTON, 51 IMPERFECT SOLUTIONS: STATES AND THE MAKING OF AMERICAN CONSTITUTIONAL LAW 22–172 (2018); Shirley S. Abrahamson, *Criminal Law and State Constitutions: The Emergence of State Constitutional Law*, 63 TEX. L. REV. 1141 (1985).

<sup>15</sup> The approach taken here is also analogous to suggestions that progressive lawyers should consider making formalist arguments, which are traditionally associated with conservative positions. See, e.g., Katie Eyer, *Textualism and Progressive Social Movements*, U. CHI. L. REV. ONLINE, Mar. 12, 2024, 1; Andrea Scoseria Katz, *The Lost Promise of Progressive Formalism*, 99 TEX. L. REV. 679 (2021).

<sup>16</sup> *Cleveland Botanical Garden v. Drewien*, 216 N.E.3d 544, 550 (Ohio 2022).

The Ohio case might seem innocuous in that the case came out right despite the opinion's analytical weaknesses. Sometimes, though, avoiding careful analysis of the relevant property doctrines can lead to egregiously incorrect statements of law in situations where traditional doctrine would produce the right result for the right reason. Part II of the article will analyze a Colorado Supreme Court decision<sup>17</sup> that used tortured reasoning to eviscerate an obnoxious racial restriction on property when a careful analysis of the document at issue would have shown its invalidity under well-established property doctrine.

Part III will illustrate the article's claim with reference to a Virginia Supreme Court decision<sup>18</sup> that used technical property doctrine to prevent a segregation academy that had been established in the wake of *Brown v. Board of Education*<sup>19</sup> to continue to benefit from a large trust that contained a whites-only provision. The Virginia decision illustrates the article's claim that common law property doctrines can be used for social good.

Finally, Part IV returns to the work of Houston and Marshall at the outset of the litigation campaign that culminated in *Brown*, showing how they laid the foundation for that landmark ruling by proceeding incrementally and relying on existing doctrine to erode "separate but equal" to the point where it could no longer stand. The cases and issues discussed here are not as portentous as that, but the superb legal work that Houston and Marshall did can serve as a model for other lawyers and judges handling less cosmic matters.

## I. THE INELEGANT OHIO CASE

In *Cleveland Botanical Garden v. Worthington Drewien*,<sup>20</sup> the Ohio Supreme Court rebuffed claims that the City of Cleveland had failed to maintain land that it had received in 1882 for park purposes. In reaching its substantially unanimous conclusion, the court failed to muster a majority opinion; there were three opinions subscribed to by six of the seven justices, while the holdout justice concurred only in the judgment without opinion.<sup>21</sup> Only one of the opinions identified the precise property interests at issue, and even that opinion failed to explain why the nature of those interests

---

<sup>17</sup> *Capitol Fed. Sav. & Loan Ass'n v. Smith*, 316 P.2d 252 (Colo. 1957).

<sup>18</sup> *Hermitage Methodist Homes of Va., Inc. v. Dominion Tr. Co.*, 387 S.E.2d 740 (Va. 1990).

<sup>19</sup> *Brown v. Bd. of Educ.*, 347 U.S. 483 (1954).

<sup>20</sup> *Cleveland Botanical Garden v. Drewien*, 216 N.E.3d 544 (Ohio 2022).

<sup>21</sup> Three justices subscribed to a plurality opinion announcing the judgment of the court. *Id.* at 545 (opinion of Brunner, J.). Two other justices subscribed to a concurring opinion. *Id.* at 553 (DeWine, J., concurring in judgment only). Another justice wrote only for himself, substantially agreeing with the decision except on one issue. *Id.* at 562 (Fischer, J., concurring in part and dissenting in part). The seventh member of the court, Justice Stewart, did not join any of those opinions, as she concurred in judgment only but did not write separately. *See id.* at 553.



mattered.<sup>22</sup> This oversight might have contributed to the analytical confusion.

In 1882, the industrialist and financier Jephtha Wade<sup>23</sup> conveyed 73 acres of land in the University Circle neighborhood of Cleveland, Ohio, to the city, subject to several restrictions. Most important, the city was to maintain the land as a park “to be open at all times to the public” and could allow its use “for no other purpose.”<sup>24</sup> Wade specified that he was granting what would be called Wade Park to the city “forever in trust . . . upon the express conditions” stated in the instrument of conveyance.<sup>25</sup> The deed further provided that, should any of the restrictions be breached with respect to any portion of the property that Wade had conveyed, the land would “revert to [Wade] or [his] heirs forever.”<sup>26</sup>

Beginning in the 1930s, the city allowed the Botanical Garden, a private nonprofit organization, to occupy part of Wade Park provided that this did not impede public access to the area. And in late 1964, the city formally leased a larger portion of Wade Park to the Botanical Garden, subject to Wade’s restrictions that this would not result in preventing public access to any portion of the park and that the Botanical Garden not charge admission except for special programs.<sup>27</sup> In 2001, the Botanical Garden leased additional land in the park under which it constructed a garage.<sup>28</sup> Some of Wade’s heirs eventually objected to the Botanical Garden’s charging admission and parking fees and its closing on Mondays, among other things.<sup>29</sup> The Botanical Garden then sought a declaratory judgment that it was not violating Wade’s deed restrictions. The objecting heirs counterclaimed but never tried to invoke their reversionary interest in the property.<sup>30</sup>

The Ohio Supreme Court virtually unanimously found that the Botanical Garden had not breached the restrictions in Jephtha Wade’s 1882 deed, although the justices used different methodologies to reach that conclusion.<sup>31</sup> The plurality opinion subscribed to by three of the seven

---

<sup>22</sup> See *id.* at 563–64 (Fischer, J., concurring in part and dissenting in part). The parties’ briefs likewise neglected to identify the property interests at issue.

<sup>23</sup> Wade was a telegraph pioneer who helped to found and later led Western Union. He was an official of several banks and a director of numerous railroads. He also was involved in the founding of the Case School of Applied Science, which later became known as Case Institute of Technology before becoming part of Case Western Reserve University. See C.H. CRAMER, CASE INSTITUTE OF TECHNOLOGY: A CENTENNIAL HISTORY, 1880–1980, at 11–12 (1980); *Wade, Jephtha Homer I*, ENCYC. OF CLEVELAND HIST., <https://case.edu/ech/articles/w/wade-jephtha-homer-i> (last visited Mar. 18 2025).

<sup>24</sup> *Cleveland Botanical Garden*, 216 N.E.3d at 546 (plurality opinion).

<sup>25</sup> *Id.* at 564 (Fischer, J., concurring in part and dissenting in part).

<sup>26</sup> *Id.* at 546–47 (plurality opinion).

<sup>27</sup> *Id.* at 547.

<sup>28</sup> *Id.*

<sup>29</sup> *Id.*

<sup>30</sup> *Cleveland Botanical Garden*, 216 N.E.3d at 547–48 (plurality opinion).

<sup>31</sup> One justice partially dissented, concluding that the validity of the Botanical Garden’s admission fees was not appropriate for resolution on summary judgment and should have been resolved at trial. *Id.* at 568–69 (Fischer, J., concurring in part and dissenting in part).

justices, without analyzing the deed's language in detail, emphasized the difficulty of operating "a beautiful and attractive park," as Wade called for in the deed, if the deed restrictions were read literally.<sup>32</sup> The principal concurrence, which was subscribed to by two justices, relied heavily on dictionaries that were extant when the conveyance took place in 1882 to find no breach of the restrictions.<sup>33</sup> And the partial concurrence emphasized "the plain language of the deed."<sup>34</sup>

The hasty focus on whether the Botanical Garden had violated the deed restrictions overlooked a logically prior, and potentially significant, question relating to the property interests that the deed created.<sup>35</sup> Jephtha Wade's 1882 deed conveyed Wade Park to the city "forever," suggesting a fee simple, but with the proviso that a breach of any of the deed restrictions would cause the property to "revert" to the grantor or his heirs.<sup>36</sup> This language appears to create a fee simple determinable, an estate in fee simple that automatically terminates when a specified event takes place.<sup>37</sup> The deed does contain an ambiguity with its reference to "express conditions" on the use of the land that became Wade Park.<sup>38</sup> This reference might suggest that Wade instead conveyed a fee simple subject to a condition subsequent, an estate in fee simple that allows the grantor or successor in interest to take steps to terminate the estate in the event of a breach of the condition.<sup>39</sup> Courts tend to construe an ambiguous conveyance as creating a fee simple subject to a

---

<sup>32</sup> *Id.* at 550 (plurality opinion).

<sup>33</sup> *Id.* at 554–55, 557 (DeWine, J., concurring in judgment only).

<sup>34</sup> *Id.* at 565 (Fischer, J., concurring in part and dissenting in part). The court might have justified its failure to address the precise nature of the property interests created by Jephtha Wade's 1882 conveyance by explicitly stating that it need not resolve that question because there was no breach of any of the restrictions contained in that conveyance. But none of the opinions said anything like that.

<sup>35</sup> The court might implicitly have attended to that question in a separate portion of the case involving whether Ohio's Marketable Title Act extinguished the reversionary interests that the 1882 deed created, but the discussion of that question did not relate to the main points in dispute. The Marketable Title Act "extinguish[es] such interests and claims, existing prior to the effective date of the root of title," OHIO REV. CODE § 5301.47(A), including "possibilities of reverter, and rights of entry or powers of termination for breach of condition subsequent," *id.* § 5301.49(A). A possibility of reverter is the future interest attached to a fee simple determinable. RESTATEMENT OF PROP. § 154(3) cmt. g (AM. L. INST. 1936). A power of termination or right of entry is the future interest attached to a fee simple subject to a condition subsequent. *Id.* § 155. The court unanimously ruled that the root of title here was the Wade deed of 1882 and that the express terms of the Marketable Title Act preserved the heirs' reversionary interest in the property. *Cleveland Botanical Garden*, 216 N.E.3d at 552 (plurality opinion); *id.* at 560 (DeWine, J., concurring in judgment only); *id.* at 562 (Fischer, J., concurring in part and dissenting in part).

<sup>36</sup> *Cleveland Botanical Garden*, 216 N.E.3d at 546–47 (plurality opinion); *id.* at 564 (Fischer, J., concurring in part and dissenting in part). The deed stated that city would hold the land "in trust," but both the plurality opinion and the partial concurrence agreed that a statute required the city to comply with the deed restrictions whether it was a trustee or the owner of the property. *Id.* at 551 (plurality opinion); *id.* at 563 (Fischer, J., concurring in part and dissenting in part). The principal concurrence did not address this question. In short, a majority of the court supported this conclusion, and no one explicitly disagreed.

<sup>37</sup> RESTATEMENT OF PROP. § 44 (AM. L. INST. 1936).

<sup>38</sup> *Cleveland Botanical Garden*, 216 N.E.3d at 564 (Fischer, J., concurring in part and dissenting in part).

<sup>39</sup> RESTATEMENT OF PROP. § 45 (AM. L. INST. 1936).

condition subsequent rather than a fee simple determinable out of distaste for forfeiture; violation of a restriction under a fee simple determinable results in automatic forfeiture, whereas violation of the same restriction under a fee simple subject to a condition subsequent requires the grantor to exercise the power of termination in order to regain possession.<sup>40</sup>

But a closer look at the deed suggests that Wade conveyed a fee simple determinable: if a breach occurred, the property would immediately revert to Wade or his heirs without the necessity of taking formal action to assert the breach and recover the property. To be sure, the deed does not contain words such as “until,” “so long as,” or “during” to refer to the city’s use of the land, which are common indicia of a determinable fee, but it does say that the property will revert to the grantor if any part of it is used in violation of the terms of the conveyance.<sup>41</sup> Still, the matter is not free from doubt.

Resolution of the nature of the property interests that the 1882 deed created could have implications for the resolution of the entire dispute.<sup>42</sup> If that deed created a fee simple determinable and the Botanical Garden breached any of the restrictions starting no later than 2003 when it began charging admission and parking fees along with limiting access to the grounds and closing on Mondays,<sup>43</sup> then the property immediately reverted to the heirs. Although some of the heirs consistently objected, they never took legal action to prevent those actions until they asserted their counterclaim in the Botanical Garden’s 2013 declaratory judgment action.<sup>44</sup> Even then, they did not assert that they now owned the property pursuant to the terms of the original deed.<sup>45</sup> To the extent that the counterclaim effectively involved an assertion that the Botanical Garden was trespassing on the heirs’ property, the assertion was untimely because the statute of limitations for trespass actions in Ohio is four years and the counterclaim

---

<sup>40</sup> *Id.* § 45 cmt. m (suggesting that a provision that, “if” a stated contingency occurs, the property “shall revert back” to the grantor, “more commonly manifests an intent to create an estate in fee simple subject to a condition subsequent”); 1 JOHN A. BORRON, JR., SIMES AND SMITH, *THE LAW OF FUTURE INTERESTS* § 248, at 281 (3d ed. 2002) (observing that “if the language is such as to require a choice between a determinable estate (which automatically terminates upon the happening of the prescribed event) or an estate on condition subsequent (which terminates only by election of the transferor or his successors), the latter, being less drastic, is to be preferred”); 1 MICHAEL ALLAN WOLF & J. GORDON HYLTON, *POWELL ON REAL PROPERTY* § 13.05[2] (2024) (explaining that courts tend to prefer a fee simple subject to a condition subsequent over a fee simple determinable because “[a]n *optional* forfeiture is less objectionable than an *automatic* forfeiture”). *See, e.g.*, *Storke v. Penn Mut. Life Ins. Co.*, 61 N.E.2d 552, 555 (Ill. 1945); *Oldfield v. Stoeco Homes, Inc.*, 139 A.2d 291, 297 (N.J. 1958); *Lawyers Tr. Co. v. City of Hous.*, 359 S.W.2d 887, 890 (Tex. 1962).

<sup>41</sup> RESTATEMENT OF PROP. § 44 cmt. 1 (AM. L. INST. 1936).

<sup>42</sup> The partial concurrence explained the difference between a fee simple determinable and a fee simple subject to condition subsequent, concluding that the Wade deed created a fee simple determinable, but that opinion never explained why the distinction might matter in this case. *Cleveland Botanical Garden*, 216 N.E.3d at 563–64 (Fischer, J., concurring in part and dissenting in part).

<sup>43</sup> *See id.* at 547 (plurality opinion).

<sup>44</sup> *Id.* at 547–48.

<sup>45</sup> *Id.* at 548.

was asserted about ten years after the alleged breach of the deed restrictions.<sup>46</sup>

On the other hand, there would be no timeliness problem if the deed created a fee simple subject to a condition subsequent. In that event, the heirs would have had to take steps to effect the reversion of the property after the Botanical Garden breached the deed restrictions. The heirs did not do so, which means that the city still owned the land that it leased to the Botanical Garden and therefore the statute of limitations for any alleged trespass by the Botanical Garden had not begun to run against the heirs.

In short, attention to the common law property doctrines relating to defeasible fees could have clarified the issues in the dispute about the Cleveland Botanical Garden. Only if the conveyance created a fee simple subject to a condition subsequent would the court have needed to address whether the Botanical Garden had breached any of the deed restrictions. If Wade created a fee simple determinable, the court could have dismissed the heirs' counterclaim as untimely without addressing the claim of breach.<sup>47</sup>

## II. THE MESSY COLORADO CASE

In *Capitol Federal Savings and Loan Association v. Smith*,<sup>48</sup> the Colorado Supreme Court ignored a doctrinally correct but complicated basis for rejecting a racially exclusionary arrangement and instead relied on unsound reasoning to get to an entirely supportable result. At issue was a 1942 agreement under which white landowners in a Denver neighborhood agreed not to sell or lease their property to Black people.<sup>49</sup> The signatories to the arrangement "covenant[ed]" to exclude Black people "from this date to January 1, 1990" and agreed that violators would forfeit their property to the remaining signatories who recorded a notice of claim.<sup>50</sup> In addition, violators were subject to damages and injunctive relief.<sup>51</sup> As we shall see, this wording was both clever and not clever enough.

Nearly fifteen years later, a group of Black plaintiffs who owned property subject to the exclusionary arrangement challenged its validity. White owners in the neighborhood sought to enforce the 1942 agreement and demanded that they be awarded possession of those properties. The trial

---

<sup>46</sup> OHIO REV. CODE § 2305.09(A).

<sup>47</sup> In addition, the heirs' disclaimer of any effort to enforce their reversionary interest could have focused attention on exactly what would have satisfied them. The appropriate relief presumably would have been equitable. See RESTATEMENT OF PROP. § 193 (AM. L. INST. 1936). Whether the arrangement was a fee simple determinable or a fee simple subject to a condition subsequent, the heirs could not have obtained damages. *Id.* § 194. The heirs might have been willing to settle their counterclaim for a modest financial payment had the court found that the Botanical Garden breached any of the restrictions contained in Wade's 1882 conveyance to the city, but there is no direct evidence supporting this possibility.

<sup>48</sup> *Capitol Fed. Sav. & Loan Ass'n v. Smith*, 316 P.2d 252 (Colo. 1957).

<sup>49</sup> *Id.* at 253.

<sup>50</sup> *Id.* at 254.

<sup>51</sup> *Id.*

court ruled for the Black plaintiffs, finding that the arrangement was an unlawful cloud on their title.<sup>52</sup> The state supreme court affirmed in a poorly reasoned opinion.

The opinion treated the 1942 agreement as a restrictive covenant that was unenforceable in a state court under the reasoning of then-recent U.S. Supreme Court rulings.<sup>53</sup> Those rulings recognized that *Corrigan* had upheld the legality of racially restrictive covenants but held that judicial enforcement of those covenants represented a form of governmental action that contravened the Fourteenth Amendment.<sup>54</sup> The defendants sought to avoid the force of those rulings by asserting that the agreement in question was not a covenant but instead involved an executory interest.<sup>55</sup> They further argued that the remedy for violation of the racial restriction differed from those at issue in the Supreme Court's cases because the remedy for violation included forfeiture, not simply an injunction or damages.<sup>56</sup>

The Colorado Supreme Court was having none of that: "No matter by what ariose terms the covenant under consideration may be classified by astute counsel, it is still a racial restriction in violation of the Fourteenth Amendment to the Federal Constitution."<sup>57</sup> The opinion continued: "High sounding phrases or outmoded common law terms cannot alter the effect of the [1942] agreement . . . . While the hands may seem to be the hands of Esau to a blind Isaac, the voice is definitely Jacob's."<sup>58</sup>

The court's rhetorical flourishes failed to engage with relevant legal doctrines. The 1942 agreement might superficially have looked like a covenant, because it provided for damages and injunctive relief. Those are standard remedies for violation of a covenant.<sup>59</sup> But forfeiture is not a remedy for violation of a covenant.<sup>60</sup> The defendants were quite correct in arguing that the forfeiture provision took the arrangement out of the covenant category. They were further correct in claiming that the agreement's provision for automatic forfeiture to third parties involved an executory interest.<sup>61</sup> And they were correct yet again that the arrangement for automatic forfeiture meant that a state court would not be enforcing the racial restriction, which would have occurred immediately on breach. In this sense, a fee simple subject to an executory limitation is analogous to a fee simple determinable and differs from a fee simple subject to a condition

---

<sup>52</sup> *Id.* at 253–54.

<sup>53</sup> *Id.* at 255.

<sup>54</sup> *Shelley v. Kraemer*, 334 U.S. 1, 20–21 (1948); *see also Barrows v. Jackson*, 346 U.S. 249, 254, 258 (1953) (holding that a state court's awarding of damages for violation of a racially restrictive covenant was also state action prohibited by the Fourteenth Amendment); cases cited *supra* note 6.

<sup>55</sup> *Capitol Fed.*, 316 P.2d at 254.

<sup>56</sup> *Id.*

<sup>57</sup> *Id.* at 255.

<sup>58</sup> *Id.*

<sup>59</sup> RESTATEMENT OF PROP. § 528 (AM. L. INST. 1944).

<sup>60</sup> *See id.*

<sup>61</sup> *Id.* § 25(1) (1936); *see also id.* § 46(1)(b) (explaining a fee simple subject to an executory limitation).

subsequent, where the grantor must affirmatively effect the forfeiture, typically by resorting to judicial remedies that represent state action for constitutional purposes.<sup>62</sup>

But accurately describing the arrangement as an executory interest actually renders the 1942 agreement even more vulnerable than it would have been had it qualified as a racially restrictive covenant. Relying on common law property principles could have rendered the arrangement void, not merely unenforceable. Here is why: Executory limitations are subject to the Rule Against Perpetuities.<sup>63</sup> The Rule Against Perpetuities requires that any interest subject to the Rule must vest, if ever, within twenty-one years of a life in being when the interest was created.<sup>64</sup> The agreement at issue in *Capitol Federal* was to have been effective between 1942 and 1990.<sup>65</sup> It was therefore possible for the executory interest to vest outside the perpetuities period in someone who was not a life in being within twenty-one years of the agreement's adoption, and that possibility exists without regard to such imaginative scenarios as a fertile octogenarian or an unborn widow.<sup>66</sup> Accordingly, the court could and should have found that interest void from the outset and stricken it.<sup>67</sup>

In short, the Colorado court's apparent aversion to common law property principles obscured how those principles could have been used to eliminate and not simply to render ineffective an obnoxious racial restriction.<sup>68</sup> This option admittedly might not have been available had the drafter of the restriction taken more care. Whoever drafted the document might have cleverly sought to obscure the distinction between a covenant and an executory limitation, but that person apparently was not sufficiently clever to avoid the perpetuities problem.

---

<sup>62</sup> See RESTATEMENT OF PROP. §§ 44, 45 (AM. L. INST. 1936).

<sup>63</sup> See *id.* §§ 370 cmts. g–i, o, 372, 374 (1944).

<sup>64</sup> *Id.* § 374 & cmt. b.

<sup>65</sup> See *Capitol Fed. Sav. & Loan Ass'n v. Smith* 316 P.2d 252, 254 (Colo. 1957).

<sup>66</sup> See RESTATEMENT (SECOND) OF PROP.: DONATIVE TRANSFERS § 1.4 cmt. h (AM. L. INST. 1983) (fertile octogenarian); *Id.* § 1.4 cmt. i (unborn widow).

<sup>67</sup> It is conceivable that invalidation of the executory interest would not have eliminated the racial restriction altogether. Someone might have argued that the forfeiture provision remained because the executory interest encompassed only forfeiture to third parties. On this view, a breach of the agreement would result in forfeiture to the grantor on the theory that this reflects the grantor's intent. See RESTATEMENT OF PROP. § 228 cmt. b (AM. L. INST. 1944). But that would not necessarily work in this situation. Excising the executory interest while retaining the racial restriction would probably mean that any property conveyed to a Black buyer would be forfeited to the conveyer, but it is difficult to understand why any potential individual conveyer would agree to such an arrangement. So even in the face of such an argument, a court could completely strike the racial restriction based on a judicial determination of the conveyer's preferred outcome. See *id.* § 402.

<sup>68</sup> Had this case arisen today instead of in 1957, the court could have disposed of the arrangement as a violation of the Fair Housing Act's ban on statements expressing a discriminatory preference based on race, color, religion, sex, familial status, or national origin, but that law was not adopted until 1968. See Civil Rights Act of 1968, 42 U.S.C. § 3604(c); ROBERT G. SCHWEMM, HOUSING DISCRIMINATION LAW AND LITIGATION §§ 15:8–15:12 (2024).

### III. THE SURPRISING VIRGINIA SEGREGATION ACADEMY CASE

A final example of the use of common law property doctrine to achieve a positive result comes from the Virginia Supreme Court's 1990 ruling in *Hermitage Methodist Homes of Virginia, Inc. v. Dominion Trust Co.*,<sup>69</sup> which arose as a late chapter in a dispute that had its roots in *Brown v. Board of Education*<sup>70</sup> and thwarted a segregation academy's possibly opportunistic effort to continue to benefit from a trust that contained a whites-only requirement. *Hermitage Methodist Homes* concerned the Prince Edward School Foundation, which was established in 1955 to run a private school for white children in Prince Edward County, Virginia, if and when a federal court ordered the local public schools to be desegregated.<sup>71</sup> Such an order seemed inevitable at that time, because the Prince Edward County school district was one of the original defendants in *Brown*,<sup>72</sup> and the Supreme Court had remanded the case to the district court with instructions to order desegregation "with all deliberate speed."<sup>73</sup> The desegregation order finally came in the spring of 1959.<sup>74</sup> Local officials promptly shut down the public schools, and the Foundation opened Prince Edward Academy, which enrolled virtually every white student in the county and hired most of the white teachers from the previously white public schools.<sup>75</sup> The Supreme Court eventually ordered the reopening of the public schools in 1964,<sup>76</sup> but the segregation academy continued to enroll most white children in the county for many years.<sup>77</sup>

Meanwhile, in 1956, Jack Adams, who lived about 50 miles west of Prince Edward County in Lynchburg, created a charitable testamentary trust that named the Prince Edward School Foundation as beneficiary. The trust document specified, however, that the Foundation would benefit from the trust only "[s]o long as [it] admits to any school operated or supported by it only members of the White Race."<sup>78</sup> In the event that the Prince Edward School Foundation breached the racial restriction by admitting any student

<sup>69</sup> *Hermitage Methodist Homes of Va., Inc. v. Dominion Tr. Co.*, 387 S.E.2d 740 (Va. 1990).

<sup>70</sup> *Brown v. Bd. of Educ.*, 347 U.S. 483 (1954).

<sup>71</sup> See BENJAMIN MUSE, VIRGINIA'S MASSIVE RESISTANCE 11–15, 58–62 (1961); BOB SMITH, THEY CLOSED THEIR SCHOOLS: PRINCE EDWARD COUNTY, VIRGINIA, 1951–1964, at 87–125 (1965).

<sup>72</sup> *Davis v. Cnty. Sch. Bd.*, 103 F. Supp. 337 (E.D. Va. 1952) (three-judge court), *rev'd sub nom. Brown*, 347 U.S. at 483.

<sup>73</sup> *Brown v. Bd. of Educ.*, 349 U.S. 294, 301 (1955).

<sup>74</sup> *Allen v. Cnty. Sch. Bd.*, 266 F.2d 507 (4th Cir. 1959) (per curiam).

<sup>75</sup> JILL OGLINE TITUS, BROWN'S BATTLEGROUND: STUDENTS, SEGREGATIONISTS, AND THE STRUGGLE FOR JUSTICE IN PRINCE EDWARD COUNTY, VIRGINIA 34–37 (2011).

<sup>76</sup> *Griffin v. Cnty. Sch. Bd.*, 377 U.S. 218, 234 (1964).

<sup>77</sup> See Jennifer E. Spreng, *Scenes from the Southside: A Desegregation Drama in Five Acts*, 19 U. ARK. LITTLE ROCK L. REV. 327, 393 (1997) (noting that 36% of white children were attending public schools by the end of the 1970s). Only seven white students enrolled in the overwhelmingly Black public schools in 1964 after the Supreme Court's reopening order. TITUS, *supra* note 75, at 165. In the early 1990s, about 80% of white children were attending public schools. CHRISTOPHER BONASTIA, SOUTHERN STALEMATE: FIVE YEARS WITHOUT PUBLIC EDUCATION IN PRINCE EDWARD COUNTY, VIRGINIA 245 (2011). And by 1997, about 40% of the public school students were white. Spreng, *supra*, at 401.

<sup>78</sup> *Hermitage Methodist Homes of Va., Inc. v. Dominion Tr. Co.*, 387 S.E.2d 740, 741 (Va. 1990).



who was not white, the income would be paid successively to either of three other educational institutions, all subject to the same whites-only requirement. And if all four of the educational institutions breached, the residual beneficiary would be a nonprofit assisted-living operator based in Richmond, which was not subject to any racial restriction.<sup>79</sup>

Prince Edward Academy operated on a whites-only basis for many years despite two significant legal setbacks. The more important setback was the loss of its federal tax exemption in 1978 under an Internal Revenue Service Ruling that denied favorable tax status to racially discriminatory private schools.<sup>80</sup> The Foundation unsuccessfully litigated the revocation of its tax-exempt status all the way to the Supreme Court, which declined to review the case despite three dissenting votes from Justices who thought the case worthy of plenary review.<sup>81</sup> The other setback came in a case holding that a Reconstruction-era civil rights law forbidding racial discrimination in the making and enforcement of contracts applied to the admissions policies of private schools.<sup>82</sup> The Foundation was legally bound by the latter ruling because an association to which it belonged had intervened in the litigation in the district court, but the ruling otherwise had little practical effect because no Black students had ever applied to the Academy at that time.<sup>83</sup>

The loss of the tax exemption did have serious consequences. It meant that donors could not take a tax deduction for contributions to the Foundation, which in turn put more pressure on the Academy to increase tuition to cover the development shortfall, which made it more difficult for parents to afford to send their children there.<sup>84</sup> The Foundation finally regained its tax-exempt status in 1986, assuring the IRS that it had a nondiscriminatory admissions policy and citing as evidence that it had previously admitted several Asian students, a fact that had been publicized in a national magazine article and the Academy's own newspaper.<sup>85</sup> The Foundation added a Black member to its board and admitted five Black students in the fall of 1986.<sup>86</sup>

These developments led the bank administering the Adams Trust to seek guidance from a state court about which beneficiary should receive the trust income. By then, not only Prince Edward Academy but all three of the alternative educational beneficiaries had admitted Black students and

---

<sup>79</sup> *Id.* at 742.

<sup>80</sup> Rev. Rul. 71-447, 1971-2 C.B. 230, 231.

<sup>81</sup> *Prince Edward Sch. Found. v. United States*, 450 U.S. 944, 944-49 (1981) (Rehnquist, J., dissenting from denial of certiorari). The Supreme Court later upheld the IRS policy. *Bob Jones Univ. v. United States*, 461 U.S. 574 (1983).

<sup>82</sup> *Runyon v. McCrary*, 427 U.S. 160 (1976) (interpreting Act of May 31, 1870, § 16, 16 Stat. 140, 144 (codified as amended at 42 U.S.C. § 1981(a))).

<sup>83</sup> See Jonathan L. Entin, *Defeasible Fees, State Action, and the Legacy of Massive Resistance*, 34 WM. & MARY L. REV. 769, 775 n.30 (1993).

<sup>84</sup> BONASTIA, *supra* note 77, at 245.

<sup>85</sup> Entin, *supra* note 83, at 795.

<sup>86</sup> BONASTIA, *supra* note 77, at 245; Entin, *supra* note 83, at 775 n.32.

therefore appeared to have breached the whites-only restriction.<sup>87</sup> The Foundation declared that it should continue to receive the income from the Adams Trust because the whites-only restriction was unconstitutional, an audacious claim given how the Foundation came into existence as part of Massive Resistance to *Brown*.<sup>88</sup>

Whatever the Foundation's audacity, its argument has a surface plausibility. When the Adams Trust was created, Virginia law required that any charitable gift for educational purposes be used to support only segregated instruction.<sup>89</sup> Consequently, the whites-only restriction was required by state law and therefore was the product of governmental compulsion.<sup>90</sup> But there are limits to that surface plausibility. The Foundation's argument assumes that both Adams, as the settlor, and the Foundation, as beneficiary, were either completely indifferent or at least neutral about racially mixed education and that they opted for whites-only instruction because of the state law. But we have every reason to believe that Virginia law reflected, rather than shaped, public opinion and behavior. Prince Edward County authorities litigated unsuccessfully all the way to the Supreme Court to preserve segregated schools, they closed the public schools in the face of a desegregation order, and Virginia was a hotbed of Massive Resistance in the wake of *Brown*.<sup>91</sup>

There was, however, a different constitutional analysis available, based on traditional property doctrines, although that argument might not have succeeded. The Foundation might have claimed that judicial enforcement of the Adams Trust's whites-only restriction was itself state action that violated the Fourteenth Amendment. This argument is analogous to the analysis that the Supreme Court used in the restrictive covenant cases.<sup>92</sup> But the argument might have foundered because of the nature of the common law property interests involved.

The whites-only restriction in the Adams Trust made the Prince Edward School Foundation a beneficiary "[s]o long as [it] admits to any school operated or supported by it only members of the White Race."<sup>93</sup> The trust document further provides that, in the event that the Foundation ever enrolls a student "who is not a member of the White Race," the income will go instead and in turn to several other educational institutions subject to the same restriction and then to Hermitage Methodist Homes.<sup>94</sup> Putting aside the

---

<sup>87</sup> *Hermitage Methodist Homes of Va., Inc. v. Dominion Tr. Co.*, 387 S.E.2d 740, 742 (Va. 1990).

<sup>88</sup> *Id.* at 742-43.

<sup>89</sup> *Id.* at 742.

<sup>90</sup> *Id.* at 743.

<sup>91</sup> See *supra* notes 69-76 and accompanying text; see generally JAMES W. ELY, JR., *THE CRISIS OF CONSERVATIVE VIRGINIA: THE BYRD ORGANIZATION AND THE POLITICS OF MASSIVE RESISTANCE* 30-107 (1976); see also NUMAN V. BARTLEY, *THE RISE OF MASSIVE RESISTANCE: RACE AND POLITICS IN THE SOUTH DURING THE 1950's*, at 80-81, 110-15 (1999).

<sup>92</sup> See *supra* notes 53-54 and accompanying text; see also *supra* notes 5-6 and accompanying text.

<sup>93</sup> *Hermitage Methodist Homes*, 387 S.E.2d at 741.

<sup>94</sup> See *id.* at 742.

alternative beneficiaries and concentrating for the moment only on the language creating the Foundation's interest, we see that the language of duration—"so long as"—is what typically appears in a fee simple determinable.<sup>95</sup> And a fee simple determinable expires immediately and automatically on the occurrence of a specified event.<sup>96</sup> No further action is required for the grantee to lose any claim to the property. Of particular significance, the grantor need not invoke a state court or other governmental authority to effect the forfeiture; the reversion occurs automatically as a matter of law. This contrasts with a fee simple subject to a condition subsequent, where the grantor reserves power of termination and must act affirmatively to regain possession.<sup>97</sup> A typical method by which a grantor exercises the power of termination is resort to state court, which the restrictive covenant cases tell us is a form of state action for Fourteenth Amendment purposes.

The Adams Trust's whites-only restriction differs from both of the above examples in that the income would go to a third party rather than to the grantor or his successor in interest. Therefore, the arrangement looks like a fee simple subject to an executory limitation.<sup>98</sup> And a fee simple subject to an executory limitation, like a fee simple determinable, expires automatically "upon the occurrence of a stated event."<sup>99</sup> Automatic expiration means that the third party need not resort to a court to obtain the property, because the property has already vested in the third party on the occurrence of the forbidden event—in this instance, Prince Edward Academy's admission of Black students.

Of course, the artificial distinction between a fee simple determinable or a fee simple subject to an executory limitation on the one hand, where forfeiture of the property interest occurs automatically, and a fee simple subject to a condition subsequent on the other, where judicial action is needed, blinks reality. In any of these scenarios, the party who obtains the property as a result of the forfeiture almost certainly will resort to a judicial remedy to confirm that party's legal right to the property.<sup>100</sup>

The Virginia Supreme Court hesitated to wade into this doctrinal quagmire. The court assumed without deciding that the whites-only restriction was unconstitutional and instead focused on common law property doctrines to resolve the dispute.<sup>101</sup> If the Constitution barred enforcement of the whites-only restriction, could the restriction simply be excised or severed from the Adams Trust? Or did the Foundation's entire

<sup>95</sup> RESTATEMENT OF PROP. § 44 cmt. 1 (AM. L. INST. 1936)

<sup>96</sup> *Id.* § 44(b).

<sup>97</sup> *Id.* §§ 45(b), 155.

<sup>98</sup> *See id.* § 46.

<sup>99</sup> *Id.* § 46(1)(b).

<sup>100</sup> Allison Dunham, *Possibility of Reverter and Power of Termination—Fraternal or Identical Twins?*, 20 U. CHI. L. REV. 215, 216 (1953).

<sup>101</sup> *Hermitage Methodist Homes of Va., Inc. v. Dominion Tr. Co.*, 387 S.E.2d 740, 744 (Va. 1990) ("[W]e will agree with Prince Edward . . . on the [constitutional] issue for purposes of this decision.").

interest fail? The Foundation urged that the racial restriction be stricken, but the court concluded that the entire interest failed. This meant that none of the educational institutions could benefit from the trust and that Hermitage Methodist Homes, which had an interest that had no racial restriction, should receive the income from the trust.

The Foundation relied for its argument to excise the whites-only restriction on the 1916 decision in *Meek v. Fox*,<sup>102</sup> in which the Virginia Supreme Court voided a condition subsequent that operated as a restraint on a daughter's marriage and left her with a fee simple estate.<sup>103</sup> The arrangement was not a limitation because the restriction did not define the duration of the daughter's estate.<sup>104</sup> From this precedent, the Foundation should remain as the Adams Trust's beneficiary without regard to the void whites-only restriction.<sup>105</sup>

Too clever by half, the court in effect responded. Invoking an even older precedent, *Daniel v. Lipscomb*,<sup>106</sup> the court pointed out that the Adams Trust's whites-only restriction did not involve a condition subsequent but rather an executory limitation because the future interest belonged to a third party rather than the grantor or his heirs.<sup>107</sup> The restriction defined the outer limit of the Foundation's interest: only during the time that the Academy taught white students exclusively. When and if the Academy admitted students of another race, its interest "would terminate" in favor of a successor beneficiary that complied with any applicable racial restriction or Hermitage Methodist Homes.<sup>108</sup> This reasoning was consistent with *Meek*, the Foundation's preferred precedent, which suggested a legally significant distinction between a condition subsequent and a limitation.<sup>109</sup>

From these old cases, the court drew the following conclusion: If a condition subsequent is invalid, a court may sever the invalid condition while leaving the primary interest intact; but if a limitation on a property interest is invalid, the entire property interest fails. In other words, because the whites-only restriction is void, the Foundation's interest as beneficiary must fail and it is left with no claim on the Adams Trust. The same analysis defeats the claims of the other educational institutions, so only Hermitage Methodist Homes remains as a beneficiary.<sup>110</sup>

To close the circle, the court observed that the same result would follow even if the whites-only restriction were consistent with the Constitution. In that event, all of the educational institutions would have violated the restriction because all of them conceded that they had admitted Black

---

<sup>102</sup> *Meek v. Fox*, 88 S.E. 161 (Va. 1916).

<sup>103</sup> *Id.* at 162–63.

<sup>104</sup> *Id.* at 162.

<sup>105</sup> *Hermitage*, 387 S.E.2d at 745.

<sup>106</sup> *Daniel v. Lipscomb*, 66 S.E. 850 (Va. 1910).

<sup>107</sup> *Hermitage*, 387 S.E.2d at 745.

<sup>108</sup> *Id.* at 746.

<sup>109</sup> *Id.* (citing *Meek*, 88 S.E. at 162–63).

<sup>110</sup> *Id.*

students. So, Hermitage Methodist Homes would still be the last beneficiary standing.<sup>111</sup>

The court never mentioned *Brown*, the Prince Edward County school closure, or Massive Resistance, but the justices must have known the context in which the Prince Edward School Foundation and Prince Edward Academy arose.<sup>112</sup> Perhaps the court should have addressed that history.<sup>113</sup> At the same time, the court did not have to do so to frustrate the Foundation's opportunistic effort to keep receiving income from the Adams Trust. It was able to do so by relying on seemingly arcane old property doctrines to hoist the Foundation on its own petard. And that is an important takeaway. Those doctrines might not be glamorous or even easy to work with, but they can be useful to lawyers making progressive arguments and judges who appreciate the possibility of applying old law in new contexts.

#### IV. SOME LESSONS FROM CHARLES HAMILTON HOUSTON

The notion that progressive lawyers should consider the utility of traditional doctrinal arguments receives important support from the way Charles Hamilton Houston approached the NAACP's challenge to the legality of segregated education that culminated in *Brown*. When he started his work, which soon also involved his former student Thurgood Marshall, the law was abysmal. The Supreme Court had endorsed the so-called "separate but equal" doctrine in *Plessy v. Ferguson*,<sup>114</sup> a transportation case,

<sup>111</sup> *Id.* The court had no occasion to address the Rule Against Perpetuities even though the executory interest in the Adams Trust might have vested more than 21 years after any life in being at the creation of the interest. See *supra* notes 63–67 and accompanying text. That was so because the Rule Against Perpetuities does not apply to an interest that transfers a benefit from one charity to another. RESTATEMENT OF PROPERTY § 397(1) (AM. L. INST. 1944). All of the beneficiaries of the Adams Trust were charities. See *Hermitage*, 387 S.E.2d at 741–42.

<sup>112</sup> We can infer the court's knowledge of the historical context of *Hermitage Methodist Homes* from the participation of retired Justice Albert S. Harrison, Jr., in the decision. *Hermitage*, 387 S.E.2d at 741. Justice Harrison had spent more than a dozen years on the court after serving as attorney general and governor during Massive Resistance. He was hardly a civil rights advocate during those years, being aligned with and supported by the segregationist forces that dominated Virginia politics for decades. See ELY, *supra* note 91, at 165–66; TITUS, *supra* note 75, at 131, 136. He was, for example, the lead defendant in a case that challenged Virginia laws against champerty, maintenance, and barratry that were aimed at civil rights lawyers. The Supreme Court initially ruled that a federal district court should have abstained from addressing the merits of the constitutional challenge to those laws until the state courts had a chance to consider them. *Harrison v. NAACP*, 360 U.S. 167 (1959). The Supreme Court later struck down those laws after the state courts had upheld them. *NAACP v. Button*, 371 U.S. 415 (1963), *rev'g* *NAACP v. Harrison*, 116 S.E.2d 55 (Va. 1960).

Still, as attorney general, he helped to precipitate a test case in which the state supreme court struck down one of the statutes at the heart of the effort to preserve segregation; as governor, he cooperated with efforts to provide formal education to Black children during the final year of the closure of Prince Edward County's public schools. BONASTIA, *supra* note 77, at 90, 142–44; ELY, *supra* note 91, at 75–76, 138, 174; MUSE, *supra* note 71, at 103–06; SMITH, *supra* note 71, at 238–40. This does not mean that the court manipulated the decision. Retired Justice Harrison sat by designation in about a dozen other cases during the period when *Hermitage Methodist Homes* was argued, and he had been sitting by designation periodically since he retired from regular active service nearly a decade earlier. See Entin, *supra* note 83, at 800 n.128.

<sup>113</sup> See Entin, *supra* note 83, at 797–800.

<sup>114</sup> *Plessy v. Ferguson*, 163 U.S. 537 (1896).

and soon extended its approval of segregation to education.<sup>115</sup> Indeed, by 1927, just a few years before Houston began his project, a unanimous Court concluded that the constitutionality of segregated schools was essentially settled.<sup>116</sup>

Houston therefore developed a long-term strategy aimed ultimately at eliminating segregated education by trying to make it too expensive to run genuinely equal separate schools.<sup>117</sup> One prong of that strategy involved post-college education because virtually no states that operated segregated educational systems provided any opportunity for graduate or professional education to Black graduates.<sup>118</sup> If separate but equal meant anything, nothing for Black would-be-students could never be equal to something for whites students.<sup>119</sup> The first case that he brought to the Supreme Court, *Missouri ex rel. Gaines v. Canada*,<sup>120</sup> reflected such long-term thinking. *Gaines* challenged the whites-only admission policies at the University of Missouri Law School at least in part because Missouri, unlike other segregationist states, offered to subsidize the expenses of Black law students at out-of-state institutions.<sup>121</sup> Therefore, even if the NAACP lost the case, other segregating states would face pressure to afford Black law students some opportunity for publicly subsidized legal education elsewhere.<sup>122</sup>

Perhaps Houston's strategy implicitly recognized the legitimacy of segregation, something that idealists might have rejected for entrenching a

---

<sup>115</sup> See *Cumming v. Cnty. Bd. of Educ.*, 175 U.S. 528 (1899); *Berea Coll. v. Kentucky*, 211 U.S. 45 (1908).

<sup>116</sup> *Gong Lum v. Rice*, 275 U.S. 78, 85–86 (1927) (“Were this a new question, it would call for very full argument and consideration; but we think that it is the same question which has been many times decided to be within the constitutional power of the state Legislature to settle, without intervention of the federal courts under the Federal Constitution.”).

<sup>117</sup> MARK V. TUSHNET, *MAKING CIVIL RIGHTS LAW: THURGOOD MARSHALL AND THE SUPREME COURT, 1936–1961*, at 13 (1994).

<sup>118</sup> MICHEL J. KLARMAN, *FROM JIM CROW TO CIVIL RIGHTS: THE SUPREME COURT AND THE STRUGGLE FOR RACIAL EQUALITY* 148 (2004); TUSHNET, *supra* note 117, at 13.

<sup>119</sup> MARK V. TUSHNET, *THE NAACP'S LEGAL STRATEGY AGAINST SEGREGATED EDUCATION, 1925–1950*, at 36 (1987).

<sup>120</sup> *Missouri ex rel. Gaines v. Canada*, 305 U.S. 337 (1938).

<sup>121</sup> See *id.* at 342–43.

<sup>122</sup> *Gaines* built on Houston's successful challenge to a similar out-of-state subsidy program in Maryland. The state courts ordered a Black applicant, Donald Murray, admitted to the University of Maryland law school. *Pearson v. Murray*, 182 A. 590, 594 (Md. 1936). Murray successfully completed his program and was hired by the attorney general's office that had represented the state in his challenge to the university's whites-only admission policy. Jonathan L. Entin, Sweatt v. Painter, *The End of Segregation, and the Transformation of Education Law*, 5 REV. LITIG. 3, 19 (1986). *Gaines* had a more ambiguous outcome. Missouri declined to admit Lloyd Gaines to the all-white law school, opting instead to open a separate school for Black students that Gaines challenged as not substantially equal to the University of Missouri's school. Gaines disappeared during the pendency of those proceedings. TUSHNET, *supra* note 119, at 73–74. Nevertheless, *Gaines* laid the foundation for additional challenges to segregated graduate and professional education that culminated in two cases that effectively outlawed the practice in higher education. *Sweatt v. Painter*, 339 U.S. 629 (1950) (establishing a rigorous definition of equality for segregated law schools); *McLaurin v. Okla. St. Regents*, 339 U.S. 637 (1950) (forbidding the segregation of students within a graduate program). Those were the Supreme Court's last educational segregation decisions before *Brown*.

deeply objectionable practice.<sup>123</sup> But consider a purer approach. In light of the Supreme Court's approval of segregation just a few years earlier, a frontal assault on separate but equal had no chance of success. The choice was not between the perfect and the good; it was between the better and the worse.

### CONCLUSION

As arcane as many common law property doctrines might seem, and as objectionable as some are, those doctrines can support positive results. *Cleveland Botanical Garden* properly rejected a far-fetched legal claim but failed both to generate a majority opinion or a satisfactory analysis of the relevant legal principles. *Capitol Federal* reached the right result, but the court offered an incoherent rationale for its decision. *Hermitage Methodist Homes* also came out correctly, even if the court failed to connect that dispute to Massive Resistance, and did so by connecting the result to apparently traditional legal concepts. American lawyers, frustrated by the complexities of common law property doctrines inherited from England where many of those doctrines have long since been superseded,<sup>124</sup> might agree with Justice Holmes's lament: "It is revolting to have no better reason for a rule of law than that so it was laid down in the time of Henry IV. It is still more revolting if the grounds upon which it was laid down have vanished long since, and the rule simply persists from blind imitation of the past."<sup>125</sup> Indeed, commentators in this country have long questioned the continuing vitality of some of the arcane property distinctions discussed in this article.<sup>126</sup> Whether we like it or not, though, those doctrines have largely persisted here. Pasteur often said that "chance favors only the prepared

---

<sup>123</sup> Some critics suggested that equalization of the separate schools might have been a more promising approach than directly attacking segregation. See, e.g., TUSHNET, *supra* note 119, at 107–08; W.E.B. Du Bois, *Does the Negro Need Separate Schools?*, 4 J. NEGRO EDUC. 328, 335 (1935). See also TOMIKO BROWN-NAGIN, *COURAGE TO DISSENT: ATLANTA AND THE LONG HISTORY OF THE CIVIL RIGHTS MOVEMENT* 357–408 (2011) (chronicling debate within Atlanta's Black community about the desirability of desegregation as opposed to community control of predominantly Black public schools); Derrick A. Bell, Jr., *Brown v. Board of Education and the Interest-Convergence Dilemma*, 93 HARV. L. REV. 518, 530–33 (1980) (suggesting that, whatever the original cogency of school desegregation, improving the quality of schools for Black children has become an important priority); cf. RACHEL LOUISE MARTIN, *A MOST TOLERANT LITTLE TOWN: THE EXPLOSIVE BEGINNING OF SCHOOL DESEGREGATION* 233–35 (2023) (summarizing the aftermath of the fraught experiences of the dozen Black students who desegregated a previously all-white high school in Clinton, Tennessee, in September 1956 following the first court order implementing *Brown*).

<sup>124</sup> See BERGIN & HASKELL, *supra* note 2, at 1.

<sup>125</sup> Oliver Wendell Holmes, Jr., *The Path of the Law*, 10 HARV. L. REV. 457, 469 (1897).

<sup>126</sup> See, e.g., Verner F. Chaffin, *Reverters, Rights of Entry, and Executory Interests: Semantic Confusion and the Tying Up of Land*, 31 FORDHAM L. REV. 303, 320–21 (1962); Dunham, *supra* note 100, at 233–34; Milton I. Goldstein, *Rights of Entry and Possibilities of Reverter as Devices to Restrict the Use of Land*, 54 HARV. L. REV. 248, 274–75 (1940); Gerald Korngold, *For Unifying Servitudes and Defeasible Fees: Property Law's Functional Equivalents*, 66 TEX. L. REV. 533, 536–39 (1988); Lawrence W. Waggoner, *Reformulating the Structure of Estates: A Proposal for Legislative Action*, 85 HARV. L. REV. 729, 740–43, 753–54 (1972).



mind.”<sup>127</sup> Lawyers should be prepared to make use of traditional doctrines when they can support good outcomes, and they should in any event expect courts to rely on traditional doctrines when those doctrines apply. These cases demonstrate why that makes sense.

---

<sup>127</sup> RENÉ J. DUBOS, *LOUIS PASTEUR: FREE LANCE OF SCIENCE* 101 (1960).

# DESIGNING CHILD WELFARE DISPUTE SYSTEMS: A FRAMEWORK FOR ADVANCING PARENTHOOD DISABILITY RIGHTS

RONI ROTHLEDER\*

## ABSTRACT

This article addresses a critical problem in the child welfare system: parents with disabilities, particularly those with intellectual, cognitive, and mental disabilities, disproportionately lose custody of their children due to systemic discrimination and lack of proper support. Although laws exist to protect the rights of people with disabilities, these rights are rarely implemented effectively in child welfare cases. The system frequently views children's interests as conflicting with their parents' disabilities, leading to unnecessary family separations.

While previous scholarship has identified these problems and called for reform, this article makes a novel contribution by directly tackling the implementation gap between disability rights principles and child welfare practice. It does so by applying the Disability-Rights-Based Dispute System Design framework, an analytical tool developed for implementing disability rights in various legal contexts, to the specific child welfare domain.

This innovative approach moves beyond theoretical critiques to offer specific guidance for reshaping how the child welfare system operates, focusing on preventing unnecessary child welfare interventions and improving court proceedings. Based on dispute system design (DSD) guidelines, the framework addresses six key areas: establishing clear goals that respect disability rights, involving all affected parties in decision-making, considering cultural and disability-related contexts, restructuring processes to be more accessible and supportive, providing necessary resources and support services, and ensuring success and accountability through continuous evaluation.

The article proposes several transformative recommendations, including legitimizing broader forms of parental support without jeopardizing parental status; reconceptualizing the parent-child relationship as interdependent rather than solely dependent; incorporating therapeutic jurisprudence while maintaining strong rights-based protections; ensuring proper disability-oriented legal education for professionals; and developing comprehensive early intervention and support systems. The design emphasizes prevention and proactive support while improving judicial processes. This approach promises to enhance access to justice not only for parents with disabilities but for all families in the child welfare system, particularly those from underprivileged communities.

## TABLE OF CONTENTS

INTRODUCTION .....	238
I. PARENTS WITH DISABILITIES AND CHILD WELFARE PROCEEDINGS	
242	
A. <i>Parents with Disabilities and Underprivileged Groups in Child Welfare Proceedings</i> .....	242
B. <i>The Lack of Implementation of Parenting Disability Rights in Child Welfare Policy and Proceedings</i> .....	246
C. <i>Calls for Fundamental Disability-Rights Redesign of the Child Welfare System</i> .....	249
II. REDESIGNING CHILD WELFARE PROCEEDINGS: A DISABILITY- RIGHTS-BASED DISPUTE SYSTEM .....	251
A. <i>Disability-Rights-Based Dispute System Design</i> .....	251
B. <i>Disability-Rights-Based Dispute System Design in Child Welfare Systems and Proceedings</i> .....	253
1. <i>Goals</i> .....	253
2. <i>Stakeholders</i> .....	254
3. <i>Context and Culture</i> .....	259
4. <i>Process and Structure</i> .....	262
5. <i>Resources</i> .....	275
6. <i>Successfulness, Accountability, &amp; Learning</i> .....	284
CONCLUSION .....	286

## INTRODUCTION

Sarah and Ben married five years ago. Sarah has schizophrenia, and Ben experiences temporary depressive episodes. They work part-time. They have a four-year-old daughter, Ella, and a one-year-old son, Ethan. Sarah's mother lives close to them and used to help them raise the children and keep up with the house chores. When her mother is diagnosed with Alzheimer's disease, Sarah experiences a crisis and is hospitalized. Ben tries to keep up with his job, the children, and the house chores but soon starts to experience a depressive episode.

Consequently, he wakes up late, does not always bring the children to daycare, and struggles with bathing and preparing meals. The municipal child protective services try to provide Ben with some help at home, but when he does not seem to cooperate, they turn to the district family court and ask to place the children in a temporary foster home. Ben is appointed a lawyer through the legal aid program, and the judge

orders social services to provide him with more help at home. However, Ben is reluctant to let a stranger in the house, especially concerning the care of Ella and Ethan, and stops returning his lawyer's calls. Meanwhile, the children are not attending daycare and are not visiting their mother in the hospital. Two months after the first hearing, the judge warns Ben that if the situation does not change immediately, she will place Ella and Ethan in foster care.

This scenario illustrates how the current child welfare system often fails to recognize and accommodate parental disabilities, leading to potentially unnecessary family separations. As Sarah and Ben's case demonstrates, the system typically responds with standardized interventions rather than disability-informed approaches that could address the root causes of family struggles. A system designed to account for disability rights could have provided this family with targeted support services, disability-appropriate communication methods, and accommodations — potentially preventing court involvement altogether.

Parents participating in child welfare proceedings usually belong to underprivileged and marginalized groups.<sup>1</sup> This article focuses on one of those groups: parents with disabilities. Parents with disabilities, predominantly those with mental disabilities (including intellectual, developmental, psychosocial, and psychiatric disabilities), face disproportionate scrutiny in child welfare proceedings.<sup>2</sup> Despite their frequent involvement in these proceedings, the system rarely acknowledges or accommodates their disability-related rights and needs<sup>3</sup> — as illustrated in Sarah and Ben's case.

Underlying this systemic failure is the persistent stigma that views people with disabilities as inherently incapable. This perception transforms disabled parenting from a fundamental right requiring

---

\* PhD (Law). Director of Disability Affairs at the Equity, Diversity, and Community Commission, Tel Aviv University, and former Director of the Disability Rights Legal Clinic at the Faculty of Law at Bar Ilan University. This article draws on my experience representing parents with disabilities in child welfare matters. This manuscript received an honorable mention from the Center for Law as Protection Student Research Competition, Deakin Law School, Australia. I am grateful to Gideon Sapir, Michal Alberstein, Susan Brooks, Mary Baginsky, Tali Gal, Sagit Mor, Yuval Sheer, Shiri Regev-Messalem, Naomi Rothenberg, Keren Tzafrir, and Tamar Ben-Dror for their invaluable insights and constructive suggestions. This research was conducted at Bar-Ilan University's Faculty of Law as part of a doctoral dissertation supervised by Professors Gideon Sapir and Michal Alberstein, with the generous support of the Shalem Foundation and Keshet Organization.

<sup>1</sup> Tricia N. Stephens, Colleen C. Katz, Caterina Pisciotto & Vicky Lens, *The View from the Other Side: How Parents and Their Representatives View Family Court*, 59 FAM. CT. REV. 491 (2021).

<sup>2</sup> NATIONAL COUNCIL ON DISABILITY, *ROCKING THE CRADLE: ENSURING RIGHTS OF PARENTS WITH DISABILITIES AND THEIR CHILDREN* (2012) [hereinafter: NCD *ROCKING THE CRADLE*]; Robyn M. Powell, *Family Law, Parents with Disabilities, and the Americans with Disabilities Act*, 57 FAM. CT. REV. 37 (2019); Elizabeth Lightfoot, Katharine Hill & Traci LaLiberte, *The Inclusion of Disability as a Condition for Termination of Parental Rights*, 34 CHILD ABUSE & NEGLECT 927 (2010); Hanna Bjorg Sigurjónsdóttir & James G. Rice, 'Evidence' of Neglect as a Form of Structural Violence: Parents with Intellectual Disabilities and Custody Deprivation, 6 SOC. INCLUSION 66 (2018); Chris Watkins, *Beyond Status: The Americans with Disabilities Act and the Parental Rights of People Labeled Developmentally Disabled or Mentally Retarded*, 83 CALIF. L. REV. 1415 (1995).

<sup>3</sup> Leslie Francis, *Maintaining the Legal Status of People with Intellectual Disabilities as Parents: The ADA and the CRPD*, 57 FAM. CT. REV. 21, 30 (2019).

support into a perceived societal burden requiring intervention. Consequently, even though parenting disability rights are legally recognized through various statutes and the Americans with Disabilities Act, parents and professionals struggle to implement these rights in practice.<sup>4</sup> The result is a legal response to disabled parenthood dominated by skepticism and presumptions of harm to children, leading to excessive reliance on adversarial proceedings, child removal, and termination of parental rights - outcomes that could often be prevented through proper disability accommodations and support.<sup>5</sup>

Drawing from recent literature documenting this implementation gap between disability rights law and child welfare practice,<sup>6</sup> this article proposes a novel solution: applying “dispute system design” (DSD) principles to create disability-responsive child welfare systems. Rather than focusing on individual cases, DSD develops comprehensive frameworks for preventing and managing recurring disputes.<sup>7</sup> Its six key elements — goals; stakeholders; context and culture; process and structure; resources; and successfulness, accountability and learning — provide a practical roadmap for systemic reform. This practical orientation makes DSD particularly valuable for implementing new policies and legal reforms in complex systems like child welfare.<sup>8</sup>

Specifically, this article uses a “*Disability-Rights-Based DSD*,” which focuses on managing disputes in disability-related fields,<sup>9</sup> such as psychiatric hospitalization, torts, legal capacity,<sup>10</sup> and child welfare. The Disability-Rights-Based DSD aims to develop practical solutions to varied cases and situations and ways to prevent or manage the autonomy-protection tension that underlies child welfare conflicts, aiming to design a comprehensive child welfare policy.

An essential contribution of this work is demonstrating how DSD principles can transform the preventive and judicial aspects of the child welfare system.<sup>11</sup> By redesigning early intervention services through a

---

<sup>4</sup> See Jasmine E. Harris, *Legal Capacity at a Crossroad: Mental Disability and Family Law*, 57 FAM. CT. REV. 14, 14 (2019).

<sup>5</sup> Francis, *supra* note 3, at 33. As Francis articulates, though most countries, including the United States, have moved away from sterilizing people with disabilities, the legal response to disabled parenthood is still dominated by negativity, doubt, and consideration of the disability as harmful to children, resulting in a high percentage of termination of parental rights. *Id.* “It is time,” she writes, “to consider seriously how efforts can be made to better realize the promise of the ADA and the CRPD for people with intellectual disabilities as parents.” *Id.*

<sup>6</sup> Robyn M. Powell, Susan L. Parish, Monika Mitra, Michael Waterstone & Stephen Fournier, *The Americans with Disabilities Act and Termination of Parental Rights Cases: An Examination of Appellate Decisions Involving Disabled Mothers*, 39 YALE L. & POL’Y REV. 157, 199–201 (2020).

<sup>7</sup> LISA BLOMGREN AMSLER, JANET K. MARTINEZ & STEPHANIE E. SMITH, DISPUTE SYSTEM DESIGN: PREVENTING, MANAGING, AND RESOLVING CONFLICT (2020); NANCY H. ROGERS, ROBERT C. BORDONE, FRANK E.A. SANDER & CRAIG A. MCEWEN, DESIGNING SYSTEMS AND PROCESSES FOR MANAGING DISPUTES 4 (2013).

<sup>8</sup> Stephanie Smith & Janet Martinez, *An Analytic Framework for Dispute Systems Design*, 14 HARV. NEGOT. L. REV. 123, 126 (2009).

<sup>9</sup> Roni Rothler, *Designing Access to Justice: A Disability-Rights-Based Dispute System*, 29(1) HARV. NEGOT. L. REV. (forthcoming).

<sup>10</sup> Roni Rothler, *Access to Legal Capacity: A Disability-Rights-Based Design*, 40 OHIO ST. J. DISP. RESOL. 77 (2024).

<sup>11</sup> This approach reflects a “public health perspective,” which is essentially preventive to the socio-legal system. For elaboration, see Michal Alberstein & Nadav Davidovitch, *Intersecting Professions: A Public Health Perspective on Law to Address Health Care Conflicts*, 5 INT’L J. CONFLICT ENGAGEMENT RESOL. 83, 85 (2017).

disability rights lens, we can often prevent the escalation to court involvement — as might have happened in Sarah and Ben’s case with proper disability accommodations. When judicial processes become necessary, DSD principles can help courts better balance disability rights with child welfare concerns. This comprehensive approach moves beyond the current reactive, court-centered model to create proactive solutions that respect disability rights while ensuring family well-being.

The ultimate goal of Disability-Rights-Based DSD in child welfare is to address the issue of *access to justice*. This argument aligns with the “access to justice” movement’s claim that unequal access to the legal system, resulting, among other things, from belonging to a disadvantaged social group, violates the equal protection of the law and infringes on the ability of individuals and groups to exercise their fundamental rights.<sup>12</sup>

The article proposes *Disability-Rights-Based DSD in child welfare policy as access to justice*: through the lens of DSD, such as a systematic analysis of the dispute according to the participant’s goals, the system’s structure and resources, the stakeholders, and the system’s successfulness and accountability, the article suggests the redesign of child welfare policy, which is practice-oriented and specifically sensitive to nuances of the children and the parents that are the system’s main stakeholders. Moreover, based on DSD’s focus on context and culture, this framework has the potential to endorse cultural diversities and enhance families’ resilience.

Although it focuses on disability, according to the universal approach,<sup>13</sup> such a design promises to provide better access to justice for everyone, especially for parents and children from underprivileged societies and groups.

The article proceeds as follows: Section I presents the phenomenon of parents with disabilities in child welfare proceedings, detailing the obstacles that prevent the full implementation of disability rights in this realm. Section II introduces the “Disability-Rights-Based DSD,” providing a comprehensive guideline for designing a disability-rights-sensitive child welfare system according to DSD’s six elements: goals, stakeholders, context and culture, process and structure, resources, and successfulness, accountability and learning. The conclusion provides a summary of the discussion presented in the article.

---

<sup>12</sup> Mauro Cappelletti & Bryant Garth, *Access to Justice: The Newest Wave in the Worldwide Movement to Make Rights Effective*, 27 BUFF. L. REV. 181, 186 (1978); Marc Galanter, *Access to Justice in a World of Expanding Social Capability*, 37 FORDHAM URB. L.J. 115, 124 (2010).

<sup>13</sup> Irving K. Zola, *Toward the Necessary Universalizing of a Disability Policy*, 83 MILBANK Q. 1 (2005).

# I. PARENTS WITH DISABILITIES AND CHILD WELFARE PROCEEDINGS

## A. Parents with Disabilities and Underprivileged Groups in Child Welfare Proceedings

Child welfare proceedings<sup>14</sup> are legal interventions concerning child safety and well-being in family life. These proceedings, also known as child protection or child dependency cases, enable state intervention in parental care.<sup>15</sup> The process encompasses both child protective services and subsequent judicial proceedings.

Child welfare judicial proceedings and decisions vary greatly. While some decisions merely instruct parents regarding care and education, the judicial power extends to decisions of parent-child separation through foster care or termination of the relationship through adoption. The judicial proceedings, initialized by the child protective services, take place in the general family or specialized courts, such as family drug courts, family treatment courts, family domestic violence courts, and youth courts. Usually, they occur after a failure to follow a non-judicial intervention plan.<sup>16</sup> Occasionally, parallel non-adjudicative proceedings such as “family group conferencing” occur, depending on the country’s or state’s applied laws and policies.<sup>17</sup> However, usually, the “parental autonomy / child-protection” paradigm prevails in child welfare proceedings, leading to long-lasting or even irreversible “all or nothing” decisions.<sup>18</sup>

There is a high correlation between parents who participate in child welfare proceedings and underprivileged conditions,<sup>19</sup> predominantly low socio-economic levels,<sup>20</sup> and parents who are characterized by

<sup>14</sup> The proceedings are also called “child protection” or “child dependency.” In this article, I will refer to the “child welfare proceedings,” which encompass the process within the child protective services and the judicial proceedings that usually follow it. This term reflects various aspects of safeguarding children from abuse, neglect, and exploitation. Still, it also has a broader scope that includes the overall well-being of children, covering aspects such as health, education, and family support.

<sup>15</sup> Harris, *supra* note 4, at 15; *see also* Powell, *supra* note 2, at 40 (discussing the constitutional grounds establishing the right to parent—care and control of one’s children—without state interference as a fundamental liberty protected by the 14<sup>th</sup> Amendment of the U.S. Constitution and its balance against the state’s rights to safeguard children from harm); Francis, *supra* note 3, at 26; Theresa Glennon, *Walking with Them: Advocating for Parents with Mental Illnesses in the Child Welfare System*, 12 TEMP. POL. & C.R. L. REV. 273, 294 (2003).

<sup>16</sup> For a detailed overview of the different means and procedures regarding child welfare, *see* Glennon, *supra* note 15, at 280–82. In this article, “child welfare proceedings” encompass the process within the child welfare protective services and the judicial proceedings that follow it.

<sup>17</sup> Susan L. Brooks & Ya’ir Ronen, *The Notion of Interdependence and Its Implications for Child and Family Policy*, 17 J. FEMINIST FAM. THERAPY, no. 3, 2006, at 23, 39.

<sup>18</sup> Francis, *supra* note 3, at 32.

<sup>19</sup> *See generally* Stephens, Katz, Pisciotto & Lens, *supra* note 1; Shanta Trivedi, *The Adoption and Safe Families Act is Not Worth Saving: The Case for Repeal*, 61 FAM. CT. REV. 315, 317 (2023) (focusing on the negative impact of adoption regulation on families of color). A recent British research study revealed similar findings since parents were racialized as black and black mixed race. GILLIAN HUNTER, MONICA THOMAS & NICOLA CAMPBELL, *EXPERIENCES OF PUBLIC LAW CARE PROCEEDINGS: A BRIEFING ON INTERVIEWS WITH PARENTS AND SPECIAL GUARDIANS* (2024).

<sup>20</sup> Stephens, Katz, Pisciotto & Lens, *supra* note 1; Guy Enosh & Tali Bayer-Topilsky, *Reasoning and Bias: Heuristics in Safety Assessment and Placement Decisions for Children at Risk*, 45 BRIT. J. SOC. WORK 1771, 1773 (2015).

“otherness.”<sup>21</sup> Over the years, research has revealed racial disproportionalities and disparities in the child welfare system<sup>22</sup> and distinct inaccessibility to justice.<sup>23</sup> Moreover, parents reported experiencing the proceedings as punitive and unsupportive spaces, even traumatic, where justice is not being served.<sup>24</sup> These feelings are directly linked to the high intimate exposure required within the proceedings.<sup>25</sup>

Overall, parents, and sometimes even their representatives, experience the courts as unfavorable and anti-therapeutic, raising three main themes: the absence of voice and feeling as not included in the proceedings and not considering their input, lack of understanding of the judicial process, and concerns regarding the proceedings’ fairness, including bias of the judicial decisions.<sup>26</sup> Specifically, research has found that parents often perceived themselves as outsiders or by-standers at court proceedings, even physically: sitting at the back of the courtroom or muted in virtual hearings, with very few opportunities to speak. Similarly, they reported a lack of understanding of the discussion between the judge and the legal professionals.<sup>27</sup>

Parents with disabilities,<sup>28</sup> predominantly mental disabilities, which include intellectual, developmental, psychosocial, and psychiatric disabilities,<sup>29</sup> may find themselves, more often than other parents, as

---

<sup>21</sup> Brooks & Ronen, *supra* note 17, at 24; Mayis Eissa & Anat Zeira, *The Backyard: Cumulative Trauma of Children from East Jerusalem Who Were Removed from Their Homes*, 153 CHILD ABUSE & NEGLECT 8 (2024).

<sup>22</sup> See Vicki Lens, *Judging the Other: The Intersection of Race, Gender, and Class in Family Court*, 57 FAM. CT. REV. 72 (2019) for both a general overview of racial and gender disproportionalities and a focus on the discrimination of poor mothers of color in child welfare proceedings.

<sup>23</sup> See generally DOROTHY ROBERTS, *TORN APART: HOW THE CHILD WELFARE SYSTEM DESTROYS BLACK FAMILIES — AND HOW ABOLITION CAN BUILD A SAFER WORLD* (2022) (stressing the oppressive intentions and effects of the family system towards marginalized communities, reinforcing gender and racial hierarchies). See also Anne K. McKeig & Mary Madden, *Family Court Enhancement Project: Improving Access to Justice*, 57 FAM. CT. REV. 107 (2019).

<sup>24</sup> See Stephens, Katz, Pisciotto & Lens, *supra* note 1 and the literature mentioned therein for discussion regarding parents’ displeasure with the proceedings and the need to enhance aspects of justice and therapeutic jurisprudence. See also discussion *infra* Section II.B.4.iv.; HUNTER, THOMAS & CAMPBELL, *supra* note 19.

<sup>25</sup> Stephens, Katz, Pisciotto & Lens, *supra* note 1, at 496 (“Unlike many other types of court proceedings, Family Court involves intimate and sustained relationships. Cases evolve over months and even years, with the normally private details of family life exposed and judged at virtually every court appearance.”)

<sup>26</sup> *Id.*, including the literature mentioned therein regarding the parents’ voice.

<sup>27</sup> HUNTER, THOMAS & CAMPBELL, *supra* note 19. See also Ravit Alfandari, *Partnership with Parents in Child Protection: A Systems Approach to Evaluate Reformative Developments in Israel*, 47 BRIT. J. SOC. WORK 1061, 1067–73 (2017) (exhibiting the limited partnership and collaboration between parents and the authorities).

<sup>28</sup> The term “disabilities” encompasses intellectual and developmental disabilities, psychiatric disabilities, physical disabilities, and sensory disabilities. Parents with all these kinds of disabilities are overrepresented in child protection proceedings. For some statistics and data regarding parents with disabilities in the United States, see Powell, *supra* note 2, at 39 (noting although estimates vary, it is clear that parents with disabilities exist within the system in significant numbers).

<sup>29</sup> The definition of disabilities with mental and intellectual characteristics varies across countries. Recent British research uses “learning disabilities” as a broader term. Mary Baginsky, *The Role of Adult Social Care for Parents with Learning Disabilities When a Child Is No Longer in Their Care*, NIHR SCH. FOR SOC. CARE RSCH. (2024), <https://www.sscr.nihr.ac.uk/projects/p203/> (last visited Apr. 2, 2025); NADINE TILBURY & BETH TARLETON, *SUBSTITUTED PARENTING: WHAT DOES THIS MEAN FOR PARENTS WITH LEARNING DISABILITIES IN THE FAMILY COURT*



litigants in child welfare proceedings.<sup>30</sup> Research has found that these parents face substantial and persistent discrimination and bias within the family law system, threatening their custody over their children.<sup>31</sup> This bias, based on historically rooted beliefs regarding parental inabilities,<sup>32</sup> is still manifested today through discriminatory child welfare, adoption, and reproductive health care policies<sup>33</sup> and practices that presume parental unfitness,<sup>34</sup> which are rooted in negative perceptions regarding their right or capability to parent.<sup>35</sup>

Moreover, under some regulations, having a disability, and specifically a mental disability, may, in and of itself, provide grounds for parental termination.<sup>36</sup> Consequently, research has found that children's protective services tend to consider their children to be at risk of

---

CONTEXT? (2023). Harris uses the term "mental disabilities" to include intellectual, developmental, psychosocial, and psychiatric disabilities. See Harris, *supra* note 4, at 18. At the same time, she acknowledges that, in many instances, there is a need for disaggregation and individualization in regulatory approaches. *Id.* Nevertheless, as she notes, current laws and regulations tend to approach mental disabilities in a unified nature. *Id.* For further reading regarding parents with psychiatric disabilities, see Robyn M. Powell, Susan L. Parish, Monika Mitra & Joanne Nicholson, *Responding to the Legal Needs of Parents with Psychiatric Disabilities: Insights from Parent Interviews*, 38 MINN. J.L. & INEQ. 69, 75–78 (2020).

<sup>30</sup> NCD ROCKING THE CRADLE, *supra* note 2, at 1; Lightfoot, Hill & LaLiberte, *supra* note 2, at 928; Sigurjónsdóttir & Rice, *supra* note 2, at 66; Watkins, *supra* note 2 at 1419; Harris, *supra* note 4, at 15; Powell, *supra* note 2, at 38; Elizabeth Lightfoot & Sharyn DeZelar, *The Experiences and Outcomes of Children in Foster Care Who Were Removed Because of a Parental Disability*, 62 CHILD. & YOUTH SERVS. REV. 22 (2016); Sharyn DeZelar & Elizabeth Lightfoot, *Use of Parental Disability as a Removal Reason for Children in Foster Care in the U.S.*, 86 CHILD. & YOUTH SERVS. REV. 128 (2018); Traci L. LaLiberte & Elizabeth Lightfoot, *Breaking Down the Silos: Examining the Intersection Between Child Welfare and Disability*, 7 J. PUB. CHILD WELFARE 471 (2013).

<sup>31</sup> Robyn M. Powell, *Legal Ableism: A Systematic Review of State Termination of Parental Rights Laws*, 101 WASH. U. L. REV. 423, 459–64 (2023). See also Powell, *supra* note 2, at 38; Robyn M. Powell, Susan L. Parish, Monika Mitra, Michael Waterstone & Stephen Fournier, *Terminating the Parental Rights of Mothers with Disabilities: An Empirical Legal Analysis*, 85 MO. L. REV. 1069, 1093 (2020).

<sup>32</sup> Robyn M. Powell & Michael A. Stein, *Persons with Disabilities and Their Sexual, Reproductive, and Parenting Rights: An International and Comparative Analysis*, 11 FRONTIERS L. CHINA 53 (2016) (analyzing the evolution of the curtailment of sexual, reproductive, and parenting rights for people with disabilities over time and across jurisdictions). For the influence of the eugenic movement on the restricting U.S. legislative history regarding family formation, see Powell, *supra* note 2, at 38–40.

<sup>33</sup> See generally Roni Rothler, *Disability Rights, Reproductive Technology, and Parenthood: Unrealized Opportunities*, 25 REPROD. HEALTH MATTERS 104 (2017).

<sup>34</sup> Powell, *supra* note 2, at 38.

<sup>35</sup> Ayelet Gur & Michael A. Stein, *Social Worker Attitudes Toward Parents with Intellectual Disabilities in Israel*, 42 DISABILITY & REHAB. 1803 (2020); Elizabeth Lightfoot & Sharyn DeZelar, *Social Work with Parents with Disabilities: Historical Interactions and Contemporary Innovations*, 18 REVISTA DE ASISTENTA SOCIALA 19 (2019) (describing the lack of supports or services available for parents with disabilities, and dearth of models for social work practice, presenting several contemporary innovations in social work practice for working with parents with disabilities).

<sup>36</sup> See Glennon, *supra* note 15, at 281 (explaining that courts may rely on a parent's mental illness that prevents them from being capable of providing proper care and control as a basis for removal and for determining that they are not able to meet their children's special needs); see also Francis, *supra* note 3, at 24 (noting that the laws of many states include intellectual disability in the list of factors to be considered in determining whether parents are unable to discharge their responsibilities, thus allowing their rights to be terminated). Further, in some states, statutes permit services needed for reasonable efforts at reunification to be bypassed in the case of parents with intellectual disabilities; sometimes, parents with intellectual disabilities are viewed by the authorities as children themselves and, therefore, conceptually, not fit for parenthood, Francis, *supra* note 3, at 28. According to Powell, these bypass provisions may generate assumptions that parents with an intellectual disability cannot benefit from services. See Robyn M. Powell, *Safeguarding the Rights of Parents with Intellectual Disabilities in Child Welfare Cases: The Convergence of Social Science and Law*, 20 CUNY L. REV. 127 (2016).

significant harm,<sup>37</sup> and they are more likely than other parents to have children removed from their care.<sup>38</sup>

This prevalence is usually linked to the difficulties some parents with disabilities experience, which affect their physical, intellectual, and mental parental capacities.<sup>39</sup> However, as noted by researchers in this field,<sup>40</sup> underlying these difficulties are social factors, specifically, a history of community segregation, eugenic policies and practices,<sup>41</sup> a disproportionate level of social disadvantage resulting from negative experiences of domestic abuse, childhood trauma, poverty, inadequate economic opportunities,<sup>42</sup> homelessness, absence of medical and social support, discrimination, and low self-esteem.<sup>43</sup> Those factors are the ones that often affect their ability to care for their children.

Indeed, a central issue of “disability-related parenting” is intersectionality. Intersectionality is a theoretical framework for understanding how aspects of a person’s identities (e.g., gender, sex, race, class, sexuality, religion, or disability) combine to create unique modes of discrimination and privilege.<sup>44</sup> Therefore, parents with disabilities from racial and ethnic minority backgrounds may experience even more significant child welfare system inequities than parents from either individual group owing to the intersection of racism and ableism.<sup>45</sup> Additionally, as parents with disabilities often experience high rates of poverty, low education, and unemployment, and depend on government

---

<sup>37</sup> Sharyn DeZelar & Elizabeth Lightfoot, *Who Refers Parents with Intellectual Disabilities to the Child Welfare System? An Analysis of Referral Sources and Substantiation*, 119 CHILD. & YOUTH SERVS. REV. (2020) (suggesting that the high prevalence of parents with intellectual disabilities within child welfare proceedings is also due to higher rates of referral from their social workers); see also Marjorie Aunos & Laura Pacheco, *Able or Unable: How Do Professionals Determine the Parenting Capacity of Mothers with Intellectual Disabilities*, 15 J. PUB. CHILD WELFARE 357 (2020).

<sup>38</sup> Nicole Buonocore Porter, *Mothers with Disabilities*, 33 BERKELEY J. GENDER L. & JUST. 75 (2018); DeZelar & Lightfoot, *supra* note 30; Powell, *supra* note 2, at 38 (documenting, through the studies discussed there, data from the United States, England, Canada, and Australia).

<sup>39</sup> See, e.g., LEONE HUNTSMAN, PARENTS WITH MENTAL HEALTH ISSUES: CONSEQUENCES FOR CHILDREN AND EFFECTIVENESS OF INTERVENTIONS DESIGNED TO ASSIST CHILDREN AND THEIR FAMILIES (2008).

<sup>40</sup> Harris, *supra* note 4, at 19; Powell, *supra* note 2; Francis, *supra* note 3.

<sup>41</sup> Angela Frederick, *Between Stigma and Mother-Blame: Blind Mothers’ Experiences in the USA Hospital Postnatal Care*, 37 SOCIO. HEALTH & ILLNESS 1127, 1130 (2015).

<sup>42</sup> Silvia Krumm, Thomas Becker & Silke Wiegand-Grefe, *Mental Health Services for Parents Affected by Mental Illness*, 26 CURRENT OP. PSYCHIATRY 362 (2013); Andrea Reupert & Darryl Maybery, *What Do We Know About Families Where Parents Have a Mental Illness? A Systematic Review*, 37 CHILD & YOUTH SERVICES 98 (2016); Alison Luciano, Joanne Nicholson & Ellen Meara, *The Economic Status of Parents with Serious Mental Illness in the United States*, 37 PSYCHIATRIC REHAB. J. 242 (2014).

<sup>43</sup> For an extensive British report on these issues, see UNIV. BRISTOL & ESMÉE FAIRBAIRN FOUND., GOOD PRACTICE GUIDANCE ON WORKING WITH PARENTS WITH A LEARNING DISABILITY (2021), <https://www.bristol.ac.uk/media-library/sites/sps/documents/wtpn/FINAL%202021%20WTPN%20UPDATE%20OF%20THE%20GPG.pdf> (last visited Apr. 2, 2025).

<sup>44</sup> Kimberle Crenshaw, *Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics*, 1989 U. CHI. LEGAL F. 139 (1989).

<sup>45</sup> Elizabeth Lightfoot & Elspeth Slayter, *Disentangling Over-Representation of Parents with Disabilities in the Child Welfare System: Exploring Child Maltreatment Risk Factors of Parents with Disabilities*, 47 CHILD. & YOUTH SERVS. REV. 283 (2014); Lightfoot & DeZelar, *supra* note 30.

benefits, they face an increased risk of child welfare system involvement.<sup>46</sup>

As people with disabilities, in general, suffer from specific discrimination, coined “ableism,” so do parents in the child welfare system. Albert and Powell<sup>47</sup> categorize this ableism into four categories: the first category is personal beliefs about people with disabilities among parents with disabilities and the attorneys who represent them (“internalized ableism”); the second is interpersonal judgment and bias towards parents with disabilities by professionals who work with them in the child welfare system (interpersonal ableism);<sup>48</sup> the third is discrimination against people with disabilities in the policies and practices of the child welfare system (institutional ableism); and the fourth is cumulative ableism across the child welfare system and other institutions, and its effects on parents with disabilities (structural ableism).

### *B. The Lack of Implementation of Parenting Disability Rights in Child Welfare Policy and Proceedings*

The legal response to ableism should be found within the corpus of “disability rights,” which is the legal manifestation of the social movement focusing on the discrimination and exclusion of people with disabilities. This discrimination and exclusion are manifested in the inaccessibility of places and services, which prevents participation in private and public activities. It is also manifested in social marginalization, such as placement in secluded institutions, denial of legal capacity, and, generally, pushing people with disabilities to the fringes of society.<sup>49</sup>

The disability rights discourse sheds light on the historical structuring of the legal subject, which has led to the inferiority of people with disabilities (and especially people with intellectual disabilities) who were, and sometimes still are, perceived as too incompetent to pass the threshold requirements of the rights discourse, such as rationality, autonomy, and independence, and as a consequence, as ineligible to fully participate in civil and social life or make decisions regarding their personal lives, let alone care for children. In this respect, disability rights emphasize the inherent human quality of people with disabilities, even if they do not adhere to the “normal” standards of participation and productivity.<sup>50</sup>

---

<sup>46</sup> Lightfoot & Slayter, *supra* note 45.

<sup>47</sup> Sasha M. Albert & Robyn M. Powell, *Ableism in the Child Welfare System: Findings from a Qualitative Study*, 46 SOC. WORK RSCH. 141 (2022).

<sup>48</sup> See Ron Shor & Maya Moreh-Kremer, *Identity Development of Mothers with Mental Illness: Contribution and Challenge of Motherhood*, 14 SOC. WORK MENTAL HEALTH 215 (2016); Clare Dolman, Ian Jones & Louise M. Howard, *Pre-Conception to Parenting: A Systematic Review and Meta-Synthesis of the Qualitative Literature on Motherhood for Women with Severe Mental Illness*, 16 ARCHIVES WOMENS' MENTAL HEALTH 173, 187 (2013).

<sup>49</sup> Roni Holler & Yael Ohayon, *Understanding Disability Policy Development: Integrating Social Policy Research with the Disability Studies Perspective*, SOC. POL'Y & SOC'Y, 2022, at 1, 3.

<sup>50</sup> Martha Nussbaum, *The Capabilities of People with Cognitive Disabilities*, 40 METAPHILOSOPHY 331, 335 (2009).

Disability rights are based on acknowledging that people with disabilities face particular obstacles and suffer from distinct inaccessibility to justice as a result of the inaccessibility and marginalization mentioned above.<sup>51</sup> In recent years, researchers have further emphasized the need for a broader concept of “*disability justice*” that addresses the marginality of groups with the intersectionality of disability and gender, people of color, immigrants, and LGBTQ+ people. They stress the importance of bearing all one’s identities and being included in society.<sup>52</sup>

Given the inaccessibility and marginalization experienced by people with disabilities, the provision of disability rights is based on a shift from an individualized bio-medical approach to a social approach that focuses not on the disability but on the current social construction and, therefore, calls for access to places, services, and personal support.<sup>53</sup> Regarding parenting, access and support should be provided for both child-bringing and child-raising since parents with disabilities are more likely to encounter obstacles in all parenting levels, including cases of assisted conception,<sup>54</sup> marital disputes regarding child custody,<sup>55</sup> and child welfare.<sup>56</sup> This duty to accommodate parenthood is legally manifested in national<sup>57</sup> and international legislation.<sup>58</sup> It is based on the understanding that the family realm is integral to adult life and that people with disabilities experience distinct obstacles in various parenting aspects.

According to this understanding, Article 23 of the United Nations Convention on the Rights of People with Disabilities (CRPD)<sup>59</sup> “Respect for Home and the Family” requires state parties to ensure equality for people with disabilities in family and parenthood. It includes the duty to ensure that their rights to marry and found a family based on free and full consent is recognized;<sup>60</sup> it renounces their right to decide “freely and responsibly” on the number and spacing of their children and to have access to information, reproductive and family planning education; it requires the provision of the means necessary to enable them to exercise

<sup>51</sup> Sagit Mor, *With Access and Justice for All*, 39 CARDOZO L. REV. 611, 612–13, 623 (2017).

<sup>52</sup> See, e.g., Natalie M. Chin, *Centering Disability Justice*, 71 SYRACUSE L. REV. 683 (2021); Patricia Berne, Aurora L. Morales & David Langstaff, *Ten Principles of Disability Justice*, 46 WOMEN’S STUD. Q. 227 (2018). See also Robyn M. Powell, *Care Reimagined: Transforming Law by Embracing Interdependence*, 122 MICH. L. REV. 1185, 1190–94 (2024) (analyzing the differences between “disability rights” and “disability justice”). Powell addresses their different focuses in relation to the notion of care; while “disability rights” focus on enhancing independence through the usage of care, “disability justice” pertains to more complex care relations that are interdependent. *Id.* See *infra* section II.B.2.b. for an in-depth discussion of these aspects of interdependence and their relation to parenthood.

<sup>53</sup> See generally MICHAEL OLIVER, *THE POLITICS OF DISABLEMENT: A SOCIOLOGICAL APPROACH* (1990).

<sup>54</sup> Rothler, *supra* note 33.

<sup>55</sup> NDC ROCKING THE CRADLE, *supra* note 2, at 120. Those kind of cases will not be examined thoroughly in this article. For examples of child custody cases where the abilities of parents with disabilities were questioned by their ex-spouses, see Powell, *supra* note 2, at 37–38.

<sup>56</sup> See *supra* Section I.A.

<sup>57</sup> NDC ROCKING THE CRADLE, *supra* note 2; Powell, *supra* note 2.

<sup>58</sup> United Nations Convention on the Rights of People with Disabilities, Art. 23, *opened for signature* Dec. 13, 2006, 2515 U.N.T.S. 3 (entered into force May 3, 2008) [hereinafter CRPD].

<sup>59</sup> CRPD, *supra* note 58.

<sup>60</sup> *Id.* at Art. 23(1)(a).

these rights;<sup>61</sup> and it addresses their rights to retain their fertility equally with others.<sup>62</sup>

Concerning child welfare proceedings, Article 23(2) of the CRPD poses a duty to ensure the rights and responsibilities of persons with disabilities relating to children's guardianship and to assist them in performing their child-rearing responsibilities. It also stresses that the child's best interests shall be paramount in all cases. Article 23(4) further asserts that the state should ensure that children are not separated from their parents against their will unless such separation is necessary for the child's best interest. It also states that in no case shall a child be separated from their parents based on a disability, either the child's or the parent's.

The U.S. administration signed the Convention, but it was not ratified. However, the Convention echoes the federal and state constitutional law defining the rights to conceive and to raise one's children as essential, fundamental civil rights, deriving the state's duty to make reasonable efforts to preserve and unify families, including the prevention or elimination of the need to remove children from home or safely return to their homes.<sup>63</sup>

Additionally, disability rights scholars and attorneys focusing on family have stressed the need to interpret and use domestic disabilities law, namely, the Americans with Disabilities Act (ADA)<sup>64</sup> and Section 504 of the Rehabilitation Act of 1973,<sup>65</sup> to argue a failure to accommodate or disparate treatment in family proceedings, including in-court accommodations, home assessments of parental capacity, or family reunification efforts,<sup>66</sup> and to promote family and parenting disability rights by eliminating discrimination and incorporating reasonable modifications into parents' and children's services.<sup>67</sup> In addition, they stress that federal and state constitutional law should be applied in courts

---

<sup>61</sup> *Id.*

<sup>62</sup> *Id.*

<sup>63</sup> For elaboration regarding U.S. family law on this matter, see Harris, *supra* note 4, at 16.

<sup>64</sup> Americans with Disabilities Act of 1990, 42 U.S.C. § 12101 et seq.

<sup>65</sup> Rehabilitation Act of 1973, § 504, 29 U.S.C. § 794 (2018).

<sup>66</sup> Harris, *supra* note 4, 16; Powell, *supra* note 2; Francis, *supra* note 3; Glennon, *supra* note 15, at 285–88 (providing an overview of the ADA's potential to advance disability rights in child welfare and the termination of parental rights). Consequently, child welfare services failing to "reasonably modify" services to accommodate parents' disabilities would violate the ADA. As Glennon shows, case studies assert that agencies have not made reasonable efforts to help parents regain custody of their children because the services provided to them prior to the termination were not tailored to their mental illnesses. Glennon, *supra* note 15. However, as she explains, attempts to use the ADA as a defense to the termination of parental rights for the benefit of parents with mental illnesses in child welfare cases were mainly unsuccessful. *Id.* at 276.

<sup>67</sup> Americans with Disabilities Act, 42 U.S.C. § 12102. Under Title II of the ADA, people with disabilities must have an equal opportunity to participate in and benefit from state and local governments' programs, services, and activities; Title III of the ADA focuses on the accessibility of private businesses (also known as public accommodations). Together, those titles should cover access to parenting-related services, both state and local government services, and places of public accommodations. Rachel N. Shute, Note, *Disabling the Presumption of Unfitness: Utilizing the Americans with Disabilities Act to Equally Protect Massachusetts Parents Facing Termination of Their Parental Rights*, 50 SUFFOLK U. L. REV. 493, 507–08 (2017).

to challenge disparate treatment in parental termination proceedings on due process grounds.<sup>68</sup>

Consequently, several states, the Department of Justice, and the American Bar Association (ABA), have adopted legislation and resolutions against disability discrimination in parental rights matters, including child welfare proceedings.<sup>69</sup> Also, over the past few years, there has been some improvement in enforcing ADA principles in child welfare cases, such as in providing accommodations for parents.<sup>70</sup>

However, as scholars note, very few decisions involving parents with disabilities raise ADA provisions.<sup>71</sup> The courts still view parenting as a “solo operation,” thus failing to apply ADA provisions to parenthood fully and ignoring their duties according to this law.<sup>72</sup> Another major problem detected regarding the application of the ADA is the courts’ decisions regarding the timing of disability rights claims. According to these decisions, such claims should be raised when the services were not provided, not during the (later) welfare proceedings.<sup>73</sup> Therefore, in practice, parenting disability rights are rarely discussed during child welfare proceedings.<sup>74</sup>

Powell and Albert<sup>75</sup> have found three themes indicating barriers and facilitators that affect ADA compliance in this field: knowledge, training, and information about the ADA by parents with disabilities, child welfare workers, and legal professionals; institutional support and resource availability; and factors related to the legal and social context, such as tensions between children’s rights and parents’ rights.

### *C. Calls for Fundamental Disability-Rights Redesign of the Child Welfare System*

While both national and international frameworks acknowledge the parenting rights of people with disabilities, translating these legal

---

<sup>68</sup> Harris, *supra* note 4, at 16; see also Michael E. Waterstone, *Disability Constitutional Law*, 63 EMORY L. J. 527 (2014); Sasha M. Albert, Robyn M. Powell & Jack Rubinstein, *Barriers and Solutions to Passing State Legislation to Protect the Rights of Parents With Disabilities: Lessons From Interviews With Advocates, Attorneys, and Legislators*, 33 J. DISABILITY POL’Y STUDS. 15, 17–21 (2021).

<sup>69</sup> Francis, *supra* note 3, at 22. As Francis notes, some inspiring exceptions of statutory approaches specifically link the ADA nondiscrimination requirements to child protection proceedings. Under the “South Carolina Persons with Disabilities Right to Parent Act,” courts and social service agencies must comply with the ADA and Section 504 of the Rehabilitation Act before taking any action in termination or removal proceedings impacting the parental rights of persons with disabilities. The Department of Social Services must make reasonable, individualized efforts, based on the parent’s specific disability, to avoid the removal of a child from the home and provide reasonable accommodations regarding accessing services available to all parents. Family court orders must make specific findings of reasonable efforts to address the parenting limits caused by a disability. *Id.* at 31.

<sup>70</sup> Press Release, U.S. Atty’s Off. E.D. Wash., Department of Justice (DOJ) and Washington Department of Children, Youth and Family Services Settle Claims of Americans with Disabilities (ADA) Violations (April 19, 2021), <https://www.justice.gov/usao-edwa/pr/departement-justice-doj-and-washington-department-children-youth-and-family-services>.

<sup>71</sup> Powell, Parish, Mitra, Waterstone & Fournier, *supra* note 6, at 199–201.

<sup>72</sup> Francis, *supra* note 3, at 28.

<sup>73</sup> *Id.* at 30.

<sup>74</sup> Powell, *supra* note 2.

<sup>75</sup> Robyn M. Powell & Sasha M. Albert, *Barriers and Facilitators to Compliance with the Americans with Disabilities Act by the Child Welfare System: Insights from Interviews with Disabled Parents, Child Welfare Workers, and Attorneys*, 32 STAN. L. & POL’Y REV. 119 (2021).

protections into meaningful safeguards within child welfare proceedings remains an unfulfilled promise. Those are still dominated by bias, stigma, and lack of accommodation and support, resulting in intervention and, many times, separation of children from their parents. Often, these interventions are based on “children’s best interests” grounds, which are perceived as contradictory to the parent’s disability.<sup>76</sup> As such, child welfare proceedings suffer from multi-level ableism,<sup>77</sup> reaching from the personal opinions and feelings of the stakeholders (professionals and parents) to the very core and infrastructure of this socio-legal system, thus infringing on disabled parents’ access to justice.<sup>78</sup>

This disconnect between ideals of disability rights and parenting was addressed by Harris, who identified a general gap between disability rights and family-law-related issues, such as parenting, adoption, reproductive rights, and marriage, arguing that a disability rights lens should be applied to family law. As Harris articulates, many times, disability is antithetical not only to child rearing but also to child-preliminary issues of intimacy, sexuality, and marriage.<sup>79</sup>

As scholars claim, a genuine “disability rights” interpretation of parenting would apply the social approach to family-related proceedings and shift the focus from the parent’s impairment to their disabling surroundings, such as the inaccessibility of places and services that should support parenting.<sup>80</sup> As Francis notes, “[p]arenting is as much a function of schools, community supports, families and neighbors, and even social services, as it is of the characteristics of individual parents. Seeing the disabled parent in isolation forgets that other parents may not be viewed in this way.”<sup>81</sup>

---

<sup>76</sup> *Id.*

<sup>77</sup> See Albert & Powell, *supra* note 47.

<sup>78</sup> Cappelletti & Garth, *supra* note 12, at 186. Following the depiction of justice as an inherently changing concept, achieved by pushing back against injustice, Galanter, *supra* note 12, at 124, and arguing for a dynamic conception of access to justice, Lydia Nussbaum, *ADR, Dynamic (In)Justice, and Achieving Access: A Foreclosure Crisis Case Study*, 88 FORDHAM L. REV. 2337, 2338 (2020), the meaning of “access to justice” has transformed from a formal state duty to enable people to defend their claims into an approach focusing on the state’s obligation to provide an affordable, effective justice system accessible to all. Cappelletti & Garth explain that “access to justice” focuses on procedural justice, reveals barriers in the legal procedure, and promotes lowering the costs of litigation and legal representation (via state-funded attorneys, NGOs, or legal clinics), shortening the length of the proceedings, and making legal information available and accessible for all. Cappelletti & Garth, *supra* note 12, at 183–86. Galanter adds a focus on the advantage “repeating players” have in litigation processes. Marc Galanter, *Afterword: Explaining Litigation*, 9 L. SOC’Y. REV. 347, 360–66 (1975). This approach shows that formal access cannot bring just outcomes in a hierarchic system. Lawrence M. Friedman, *Access to Justice: Some Historical Comments*, 37 FORDHAM URB. L.J. 3, 4 (2010).

<sup>79</sup> See Harris, *supra* note 4, at 15 (describing “soft” means to regulate family in the disability realm through, e.g., the absence of sex education and inaccessibility of gynecological equipment and services, as the risk of sexual harm usually underlies and justifies restricting regulations and policy.) See also Elizabeth Pendo, *Reducing Disparities Through Health Care Reform: Disability and Accessible Medical Equipment*, 4 UTAH L. REV. 1057 (2010); Elizabeth Pendo, *Disability, Equipment Barriers, and Women’s Health: Using the ADA to Provide Meaningful Access*, 2 ST. LOUIS U. J. HEALTH L. & POL’Y, 15, 16–17 (2008).

<sup>80</sup> Elizabeth B. Lightfoot & Traci L. LaLiberte, *Approaches to Child Protection Case Management for Cases Involving People with Disabilities*, 30 CHILD ABUSE & NEGLECT 381, 389 (2006) (finding a lack of standardization in providing services regarding disability within child protection).

<sup>81</sup> Francis, *supra* note 3, at 25.

As Harris suggests, meaningful legal reform implementing disability rights in family law (including child welfare cases) demands a critical redesign of deeply embedded legal constructions and standards that fail to consider people with disabilities in the normative baseline from which courts measure deviance and incapacity. Therefore, she suggests moving beyond individual accommodation in family law toward more inclusive legal standards and broader structural reforms, aiming at “a universal design of family law standards,”<sup>82</sup> echoing the suggestions made by Roberts,<sup>83</sup> Trivedi,<sup>84</sup> and Powell<sup>85</sup> regarding the need not to amend, but to abolish, dismantle, and redesign adoption and child welfare regulation. The following Section will suggest a detailed outline of such systematic redesign.

## II. REDESIGNING CHILD WELFARE PROCEEDINGS: A DISABILITY-RIGHTS-BASED DISPUTE SYSTEM

### A. Disability-Rights-Based Dispute System Design

As described in Section I, a major challenge lies within the *comprehensive implementation* of the existing knowledge and data regarding parenting disability rights in the design of the child welfare system. In this Section, I will tackle this implementation problem by outlining the principles for designing child welfare systems and proceedings rooted in disability rights principles. This design is based on an infrastructure that enhances access to justice in all disability rights fields: the “Disability-Rights-Based Dispute System Design.”<sup>86</sup>

The Disability-Rights-Based Dispute System Design merges disability rights and dispute resolution principles using the analytical lens of “Dispute System Design” (DSD). DSD emerged as an outgrowth of the alternative dispute resolution (ADR) movement, seeking institutional court reform through non-legal dispute resolution methods.<sup>87</sup> Building on these foundations and extending to broader contexts, DSD encompasses process design that allows organizations, institutions, states, or individuals to more effectively manage, prevent,

---

<sup>82</sup> Harris, *supra* note 4, at 17. For an extensive study of parents with mental illness that suggests structural reforms in policy and services and “speaking the language” of DSD, see JOANNE NICHOLSON, KATHLEEN BIEBEL, BETSY HINDEN, ALEXIS HENRY & LAWRENCE STIER, *CRITICAL ISSUES FOR PARENTS WITH MENTAL ILLNESS AND THEIR FAMILIES* 1, 48 (2001).

<sup>83</sup> Dorothy Roberts, *Why Abolition*, 61 FAM. CT. REV. 229, 231 (2023).

<sup>84</sup> Trivedi, *supra* note 19, at 338.

<sup>85</sup> Robyn M. Powell, *Under the Watchful Eye of All: Disabled Parents and the Family Policing System's Web of Surveillance*, 112 CALIF. L. REV. 2005, 2061 (2024) [hereinafter Powell, *Under the Watchful Eye*]; Robyn M. Powell, *Achieving Justice for Disabled Parents and Their Children: An Abolitionist Approach*, 33 YALE J.L. & FEMINISM 37, 81 (2022) [hereinafter Powell, *Abolitionist Approach*]. Powell, Parish, Mitra, Waterstone & Fournier further suggested the “Inequalities Conceptual Framework for Disabled Parents Involved with the Child Welfare System” as a means that can help in the system’s redesign. Robyn M. Powell, Susan L. Parish, Monika Mitra, Michael Waterstone & Stephen Fournier, *Child Welfare System Inequities Experienced by Disabled Parents: Towards a Conceptual Framework*, 39 DISABILITY & SOC’Y 291, 295–304 (2024).

<sup>86</sup> Rothler, *supra* note 9.

<sup>87</sup> Smith & Martinez, *supra* note 8, at 124. The term “dispute system design” was first articulated by Ury, Brett, and Goldberg in the late 1980s. WILLIAM L. URY, JEANNE M. BRETT & STEPHEN B. GOLDBERG, *GETTING DISPUTES RESOLVED: DESIGNING SYSTEMS TO CUT THE COSTS OF CONFLICT* 133 (1988).



or resolve both individual and recurring conflicts. The framework rests on six fundamental elements: *goals, stakeholders, context and culture, process and structure, resources, and successfulness, accountability and learning*. Crucially, DSD's scope encompasses not only dispute resolution but also conflict management and prevention, fostering a problem-solving culture within organizations while providing multiple access points that combine rights-based and interests-based approaches.<sup>88</sup>

DSD's practical and analytical framework facilitates disability rights implementation alongside other principles. The 'Disability-Rights-Based DSD' advances this further by interpreting DSD's six core elements through a disability rights lens, as shown in TABLE 1. This approach structures the design around disability rights objectives while addressing implementation barriers. The model moves beyond procedural changes to challenge fundamental assumptions in existing legal frameworks.<sup>89</sup>

**TABLE 1: DISABILITY RIGHTS INTERPRETATION TO DISPUTE SYSTEM DESIGN'S ELEMENTS**

	DSD ELEMENTS	DISABILITY RIGHTS INTERPRETATION
1	Goals	Advancing disability rights
2	Stakeholders	Nothing about us without us
		Interdependence
3	Context and culture	Disability context
		Disability culture
4	Process and structure	Accessibility and accommodations
		Universal design
		Procedural justice and disability
		The structure of conflict-resolution institutions and their relevance to disability
5	Resources	Legitimizing the cost of disability and its accommodations
		Support and assistance
		Social, therapeutic, and care resources
		Disability-oriented legal education and professional training
6	Successfulness, accountability, and learning	Achieving disability rights goals

The Disability-Rights-Based DSD combines practical and justice-oriented approaches through two key features: *first*, it inherently

<sup>88</sup> See generally AMSLER, MARTINEZ & SMITH, *supra* note 7; ROGERS, BORDONE, SANDER & MCEWEN, *supra* note 7, at 201.

<sup>89</sup> Rothler, *supra* note 9. For a thorough implementation of the Disability-Rights-Based DSD in legal capacity, see Rothler, *supra* note 10.

provides *access* to disability justice by directly confronting disability rights implementation challenges, offering practical application tools and enhanced justice access. This is accomplished by introducing dispute management tools to disability rights while reinterpreting DSD guidelines through a disability rights perspective, as detailed in the table.

*Second*, applying disability rights perspectives to DSD's six elements strengthens DSD's capacity to achieve justice — a core DSD objective<sup>90</sup> — beyond disability-specific contexts, particularly in systems marked by power imbalances or historical inequities. This interpretation incorporates universal disability rights principles such as socially constructed barriers, hierarchies, marginalization, universal design, accessibility, accommodations, and interdependence.<sup>91</sup>

As elaborated in Section I, parents with disabilities are highly involved in the child welfare system, a system which fails to fully address their parenthood disability rights. In this section, I will utilize the Disability Rights-Based DSD to address this challenge by suggesting redesigning the system and its proceedings. As shown in detail, such a design will enhance parenthood disability rights since its infrastructure is based on disability rights core principles, considering and overcoming existing barriers to their implementation. Moreover, this design is compatible with handling child welfare issues since it enables a nuanced design for different cases,<sup>92</sup> providing courts diverse dispute management tools<sup>93</sup> and emphasizing preventive measures.<sup>94</sup>

## *B. Disability-Rights-Based Dispute System Design in Child Welfare Systems and Proceedings*

### *1. Goals*

The first DSD component addresses the system's *goals*, encompassing values, outcomes, and priorities<sup>95</sup> (see Table 1). In disability-rights-based DSD, these include a fundamental 'meta-goal' of advancing disability rights and disability justice, recognizing that negative disability perceptions stem from social constructs embedded within systems. This approach advocates viewing disability as socially-dependent rather than inherently limiting,<sup>96</sup> and embraces disability as enriching human diversity. This aligns with the CRPD's disability

---

<sup>90</sup> AMSLER, MARTINEZ & SMITH, *supra* note 7, at 8, 14; ROGERS, BORDONE, SANDER & MCEWEN, *supra* note 7, at 205; Mariana Hernandez Crespo G., foreword, *Introduction to the Symposium: Leveraging on Disruption: The Potential of Dispute System Design for Justice, Accountability, and Impact in Our Global Economy*, 13 U. ST. THOMAS L.J. 159, 164 (2017).

<sup>91</sup> Rothler, *supra* note 9.

<sup>92</sup> Nofit Amir & Michal Alberstein, *Designing Responsive Legal Systems: A Comparative Study*, 22 PEPP. DISP. RESOL. L.J. 263, 308 (2022).

<sup>93</sup> Hadas Cohen & Michal Alberstein, *Multilevel Access to Justice in a World of Vanishing Trials: A Conflict Resolution Perspective*, 47 FORDHAM URB. L.J. 1, 21 (2019).

<sup>94</sup> Alberstein & Davidovich, *supra* note 11, 85.

<sup>95</sup> AMSLER, MARTINEZ & SMITH, *supra* note 7, at 74.

<sup>96</sup> As elaborated in AMSLER, MARTINEZ & SMITH, *supra* note 7, at Section I.B.

definition, which incorporates identity, anti-discrimination, community inclusion, and policy participation elements.<sup>97</sup>

Promoting disability rights as one of the system's goals entails transformative qualities. As mentioned in Sections I and as elaborated by Francis, the current legislation on child welfare and parenthood does not only ignore disability rights but is contradictory to those rights. As she explains, current parental rights termination statutes assess disability through an individualized lens, focusing solely on parents' isolated capabilities rather than adopting a social model of disability. This approach ignores how disability intersects with environmental and social factors — including community support, educational systems, and social services. While other parents are evaluated within their support networks, disabled parents are often assessed in isolation, without considering how reasonable accommodations and support systems could enable effective parenting. State laws notably lack the requirement to evaluate parenting ability in conjunction with available family, community, or social support resources.<sup>98</sup>

Moreover, since the child welfare system encompasses significant therapeutic and welfare components, it tends to be viewed through the traditional bio-medical disability paradigm,<sup>99</sup> resulting in a deficit-focused approach, as detailed in Section I. However, establishing disability rights as an explicit system goal would necessitate critically examining the system's norms and regulations for disability rights compliance. Additionally, a disability rights focus would emphasize that conflict resolution must serve the broader goal of disability rights realization.<sup>100</sup> This consideration is particularly crucial given the power disparities between persons with disabilities and the institutions they typically depend on.<sup>101</sup>

The following Disability-Rights-Based Dispute System Design components — stakeholders, context and culture, process and structure, and resources — will help clarify *how* disability rights as a goal could be achieved in the child welfare system.

## 2. Stakeholders

The second DSD component addresses *stakeholders*. Based on the principle that people support what they help create,<sup>102</sup> individuals, groups, and organizations who host, use, or are affected by a system play a vital role in DSD development.<sup>103</sup>

---

<sup>97</sup> Gerard Quinn & Anna Arstein-Kerslake, *Restoring the 'Human' in 'Human Rights': Personhood and Doctrinal Innovation in the UN Disability Convention*, in THE CAMBRIDGE COMPANION TO HUMAN RIGHTS LAW 36, 38–39 (Conor Gearty & Costas Douzinas eds., 2012).

<sup>98</sup> Francis, *supra* note 3, at 25.

<sup>99</sup> As mentioned *supra* section I.B.

<sup>100</sup> Rothler, *supra* note 9, at 15.

<sup>101</sup> TOM SHAKESPEARE, DISABILITY RIGHTS AND WRONGS REVISITED 1 (2013).

<sup>102</sup> ROGERS, BORDONE, SANDER & MCEWEN, *supra* note 7, at 265.

<sup>103</sup> *Id.* at 225–47. For an overview of stakeholders' "participatory approaches" in decision-making processes and their critiques, see PRADIP N. THOMAS & ELSKE VAN DE FLIET, INTERROGATING THE THEORY AND PRACTICE OF COMMUNICATION FOR SOCIAL CHANGE: THE BASIS FOR A RENEWAL 39 (2015).

*i. Nothing About Us Without Us*

Disability theory enriches this stakeholder approach in two ways.<sup>104</sup> First, the principle of ‘nothing about us without us,’ central to the CRPD,<sup>105</sup> requires consulting persons with disabilities on policies affecting them. This counters the traditional dominance of disability discourse by family members, social workers, and medical professionals.<sup>106</sup>

As mentioned in Section I.A., this rule is fundamental in child welfare proceedings, where parents have often reported feeling like outsiders in their hearings and not having their input considered,<sup>107</sup> and where findings showed a minimal realization of partnership with parents in terms of allowing them power to influence child welfare decisions.<sup>108</sup> Apart from making more room for the parents’ opinions in the proceedings and policy-making, this rule can be achieved by advancing “parents advocates,” who are parents with experience in child welfare or family court involvement who escort other parents in the proceedings.<sup>109</sup>

Additionally, the participation rule is relevant not only for the parents but also for their children. As Gal explains,<sup>110</sup> even in unstable family settings, parents, adults who are alternative caretakers, and professionals can enhance children’s ability to participate. To encourage this, training for mainstreaming child participation should be allocated through social organizations and a regulatory regime that requires, promotes, funds, or at least enables child-inclusive processes.<sup>111</sup>

While designing the child welfare regime, it is, therefore, crucial to involve both children and parents with disabilities themselves in the design and operation.<sup>112</sup> Given the nature of child welfare barriers, it is imperative to include parents with intellectual and cognitive disabilities.

<sup>104</sup> Rothler, *supra* note 9, at 21.

<sup>105</sup> CRPD, *supra* note 58, at the Preamble, subsection 13: “Considering that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programs, including those directly concerning them”; Article 4(4) adds that “[i]n the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, State Parties shall closely consult with and actively involve persons with disabilities.”

<sup>106</sup> For a thorough explanation of the slogan’s origin in the 1990s, see JAMES I. CHARLTON, *NOTHING ABOUT US WITHOUT US: DISABILITY, OPPRESSION AND EMPOWERMENT* 3 (1998).

<sup>107</sup> Stephens, Katz, Pisciotto & Lens, *supra* note 1.

<sup>108</sup> Alfandari, *supra* note 27, at 1067–73.

<sup>109</sup> Stephens, Katz, Pisciotto & Lens, *supra* note 1, at 495; Powell further mentions the importance of disabled parents as leaders. See Powell, *Abolitionist Approach*, *supra* note 85, at 91.

<sup>110</sup> Tali Gal, *An Ecological Model of Child and Youth Participation*, 79 *CHILD. & YOUTH SERVS. REV.* 57, 62–63 (2017).

<sup>111</sup> *Id.* at 62. Gal explains that a budgetary basis for participatory practices should support such encouragement. *Id.* The UN Committee on Children’s Rights published its General Comment on child participation, specifying nine basic requirements for meaningful child participation. According to this, all processes that involve children must be transparent and informative, voluntary, respectful, relevant, child-friendly, inclusive, supported by training, safe and sensitive to risk, and accountable *Id.* at 63.

<sup>112</sup> For the importance of collaboration and partnership with parents in child welfare proceedings, see Alfandari, *supra* note 27, at 1063.

This is critical given their historical inferiority and communication differences.<sup>113</sup>

## ii. Interdependence

The second disability aspect relevant to DSD's stakeholder component is *interdependence*, which is crucial to child welfare. Interdependence recognizes that perceived independence stems from reliance on others.<sup>114</sup> This applies universally, including to people with disabilities whose autonomy often depends on support services. The concept aligns with a broader understanding of 'care' as reciprocal relationships<sup>115</sup> rather than unidirectional support, acknowledging personal and relational elements beyond technical assistance.<sup>116</sup>

Interdependence extends beyond physical support to the concept of 'choice.' While liberal theories define choice through independent evaluation and prioritize self-reliance as prerequisite for autonomy, feminist and disability scholars argue this emphasis on independence as essential for personhood overlooks fundamental values of trust, caring, and interdependence. Understanding relatedness and interconnectedness reveals that choice-making abilities develop only through relationships and supportive environments.<sup>117</sup> Therefore, an interdependent interpretation of parental choices must include necessary support systems for making and acting on those choices.<sup>118</sup> This framework embraces *relational autonomy*, emphasizing the social context of individual existence<sup>119</sup> and others' central role in decision-making.<sup>120</sup>

Interdependence's relevance to DSD's stakeholder component reflects DSD's relationship-centered approach. DSD requires incorporating or considering the interests of all stakeholders in the

<sup>113</sup> Amita Dhanda, *Universal Legal Capacity as a Universal Human Right*, in MENTAL HEALTH AND HUMAN RIGHTS: VISION, PRAXIS, AND COURAGE 177, 178 (Michael Dudley, Derrick Silove & Fran Gale eds., 2012) (explaining the historical inferiority of people with intellectual disabilities and the way they were overlooked at the beginning of the disability rights social struggle, lacking voice to influence).

<sup>114</sup> See Eva Feder Kittay, *The Ethics of Care, Dependence, and Disability*, 24 *RATIO JURIS* 49, 50 (2011); Martha A. Fineman, *Cracking the Foundational Myths: Independence, Autonomy, and Self-Sufficiency*, 8 *J. GENDER SOC. POL'Y & L.* 13, 14 (2000).

<sup>115</sup> Janice McLaughlin, *Understanding Disabled Families: Replacing Tales of Burden with Ties of Interdependency*, in *ROUTLEDGE HANDBOOK OF DISABILITY STUDIES* 402, 409 (Nick Watson, Alan Roulstone & Carol Thomas eds., 2012).

<sup>116</sup> For a review of the concept of "care" in relation to disability, see Eva Feder Kittay, *Care and Disability: Friends or Foes*, in *THE OXFORD HANDBOOK OF PHILOSOPHY AND DISABILITY* 416 (Adam Cureton & David Wasserman eds., 2020). For elaboration on care and disability, specifically regarding disability and interdependence, see Powell, *supra* note 52, and Jonathan Herring, *Disability and Care*, 12 *J. INDIAN L. & SOC'Y* 35 (2021).

<sup>117</sup> In the early 1980s, Carol Gilligan revealed how the atomistic discourse is lacking, ignoring the basic insight that we mature to interdependence and not to independence. CAROL GILLIGAN, *IN A DIFFERENT VOICE* (1982). Roni Holler, Shirli Werner, Yotam Tolub & Miriam Pomerantz, *Choice Within the Israeli Welfare State: Lessons Learned from Legal Capacity and Housing Services*, in *CHOICE, PREFERENCE, AND DISABILITY: POSITIVE PSYCHOLOGY AND DISABILITIES SERIES* 87, 95 (Roger J. Stancliffe, Michael L. Wehmeyer, Karrie A. Shogren & Brian H. Abery eds., 2020) (addressing a similar disability angle of interdependence).

<sup>118</sup> Holler, Werner, Tolub & Pomerantz, *supra* note 117, at 95.

<sup>119</sup> *RELATIONAL AUTONOMY: FEMINIST PERSPECTIVES ON AUTONOMY, AGENCY, AND THE SOCIAL SELF* (Catriona Mackenzie & Natalie Stoljar eds., 2000).

<sup>120</sup> Jennifer K. Walter & Lainie Friedman Ross, *Relational Autonomy: Moving Beyond the Limits of Isolated Individualism*, 133 *PEDIATRICS*, Supp no. 1, at 16, 18–19 (2014).

design process, including those targeted by the design and the professionals operating the current system who may resist changes.<sup>121</sup> It's crucial to understand which stakeholders participated in the initial system design and whose interests are represented for existing systems. This comprehensive stakeholder approach aligns with social policy reform theories.<sup>122</sup>

Consequently, when designing child welfare systems, "interdependence" has three primary meanings: the *first* is a vision of parent's and children's rights as inseparable and interdependent; the *second* is the interdependent relationship parents have with others; The *third* is the interdependent relationship parents have with their children.

Susan Brooks and Ya'ir Ronen described *the first aspect of interdependence* within the child welfare context. They view the child-parent relationship as a system of interdependence that draws its content from therapeutic law, preventive law, culturally sensitive law, and family system theory. According to this approach, and drawing from Martha Minow's work, they argue that children's and parent's rights should be unified, defying the tendency to assess them automatically.<sup>123</sup> They describe this approach as presenting a more realistic and protective perspective toward the child and their family, benefitting underprivileged populations characterized by "otherness," whose parenting is often questioned legally.<sup>124</sup>

*The second aspect of interdependence* within the child welfare context is connected to Bronfenbrenner's ecological approach to children's development, according to which children are dependent not only on their parents but on other family members<sup>125</sup> (the microsystem); the mesosystem, such as education, health, and welfare services; the exosystem, such as the parent's workplace, parental social networks, and government and non-government agencies; and the broad regulatory regime of the macrosystem. All these have interdependent relationships

---

<sup>121</sup> AMSLER, MARTINEZ & SMITH, *supra* note 7, at 10. In addition to the immediate parties in conflict, stakeholders can be individuals or entities that are subsidiary to or constituents of those parties, as well as others directly or indirectly affected by the outcome of the dispute. *Id.* at 29. For existing systems, it is essential to learn which stakeholders were involved in the system's initial design and whose interests are represented. SMITH & MARTINEZ, *supra* note 8, at 131. It is also important to note that stakeholders do not have equivalent power and that the dictum to engage all stakeholders in a DSD process does not address how to resolve competing interests. AMSLER, MARTINEZ & SMITH, *supra* note 7, at 104.

<sup>122</sup> Holler & Ohayon *supra* note 49, at 10.

<sup>123</sup> Martha Minow, *Comments on "Suffering, Justice, and the Politics of Becoming"* by William E. Connolly, 20 CULTURE, MED. & PSYCHIATRY 279, 285 (1996).

<sup>124</sup> BROOKS & RONEN, *supra* note 17, at 30 (focusing on the family (parents and other family members) when assessing rights). As an example, Brooks & Ronen describe that, from the child's perspective, it makes no sense to prosecute a mother victimized by domestic violence or to punish her for failure to protect her child in any other way since such an approach often leads to separating the child from her or making it more difficult for her to fulfill her parental role. *Id.* This separation deprives the child of his right to a self-constructed identity. *Id.*

<sup>125</sup> See Convention on the Rights of the Child, art. 5, opened for signature Nov. 20, 1989, 1577 U.N.T.S. 3, 59 (entered into force Sept. 2, 199) [hereinafter CRC] (stating the importance of the extended family and the community). The U.S. Administration has signed the Convention but has not ratified it. Status of Treaties: Chapter IV No. 11. See also BROOKS & RONEN, *supra* note 17, at 38 (showing the CRC's clear foundation on interdependence, and clarifying that the state's primary responsibility towards the child is to respect the role of the nuclear and extended family and the community in the child's life rather than to intervene to protect the child from them).

with the parents, directly or indirectly affecting their parenthood. Therefore, they should be considered in the system's design and implementation.<sup>126</sup>

During the implementation stage, particular attention should be paid to the professional stakeholders. Policy implementation is often integral to the policy-making process, especially in cases where the implementation stage is open to broad interpretation, leaving professionals with relatively high discretionary power.<sup>127</sup> This is especially true in child welfare since social work and therapeutic professionals play a hegemonic role in shaping its boundaries, as elaborated in Section I.

Moreover, positive relationships with these stakeholders should be enhanced in the DSD process to contribute to the design's success<sup>128</sup> through different means, such as constructive contracts<sup>129</sup> and creating a pleasant environment by mentioning common values<sup>130</sup> and fostering common goals.<sup>131</sup> "Family Group Conferences," where the family actively designs the care plan together with community members and professional services, can exemplify such a collaborative process.<sup>132</sup> Throughout the design, the designer should focus on empowering "weaker" sides,<sup>133</sup> including parents and children. These steps will help keep stakeholders on equal footing, make the interactions pleasant, and increase their depth.<sup>134</sup>

*The third aspect of interdependence* is understanding the parent-child relationship as interdependent, where *both* parties provide care and value for the relationship. According to this understanding, parents with disabilities do not have to choose between being "care receivers" (and therefore unfit parents) or "care providers" (and thus deny their disability) and can openly and legitimately be aided in their parental roles without jeopardizing their parental status. This legitimization opens the path for broader accommodations and support for parents (as will be elaborated further in Sections II.B.4.i. and II.B.5.ii.), aiming not

---

<sup>126</sup> Urie Bronfenbrenner, *Toward an Experimental Ecology of Human Development*, 32 AM. PSYCH. 513, 514 (1997); Urie Bronfenbrenner, *Ecology of the Family as a Context for Human Development: Research Perspectives*, 22 DEV. PSYCH. 723 (1986).

<sup>127</sup> Holler & Ohayon, *supra* note 49, at 10.

<sup>128</sup> ROGERS, BORDONE, SANDER & MCEWEN, *supra* note 7, at 225, 243.

<sup>129</sup> Differences between members of groups that distrust and dislike one another can lead individuals to attribute ulterior motives for innocent actions, insult each other, and be dishonest, resulting in unstable agreements. Social scientists identified characteristics that tend to promote constructive contracts: positive shared activities, participants who are personable and have common values, extensive interactions, working together toward a common goal, and equal status. Negotiators with higher levels of trust for each other are more likely to use cooperative negotiation techniques, disclose information, and understand the other's perspective. Trust between the parties to a single dispute increases the chances of reaching a long-lasting agreement. Without these situational characteristics, bringing together people who distrust and misunderstand one another runs the risk of reinforcing divisions, hatred, and prejudice. Therefore, in creating a system, designers might consider building activities promoting constructive contracts. *Id.* at 229–30.

<sup>130</sup> *Id.* at 234.

<sup>131</sup> *Id.* at 126 (asserting that constructive contracts could be part of the system's design or drafted within a specific case)

<sup>132</sup> See Brooks & Ronen, *supra* note 17, at 39–40 (noting that family group conferences serve the family's procedural justice).

<sup>133</sup> ROGERS, BORDONE, SANDER & MCEWEN, *supra* note 7, at 235.

<sup>134</sup> *Id.* at 244.

only at the children's functional needs but also at broader parental aspects such as relationships and self-growth. Such support, therefore, will not be limited to helping parents fulfill functional tasks since it can encompass broader support means, including, in some cases, support that was characterized (and therefore denied) as substitutional, which will be provided while keeping and valuing the parent-child relationship.

This approach is connected to the understanding of interdependency, disability, and care, according to the writing by Fink<sup>135</sup> and Powell,<sup>136</sup> who reveal that “[c]are work is the hidden twin of disability.”<sup>137</sup> They claim that reimagining “care” according to disability justice values is necessary, including allocating resources to acquire proper care and acknowledging the needs and rights of formal and non-formal caregivers. Most of all, as they claim, society should abolish its ableistic approach to care and realize that disability and care provision should not be considered a burden but part of family life. As Powell concludes, support for care transforms disability from a source of fear into a celebration of interdependence and shared humanity, embracing diversity as enriching family life and fostering dignity and opportunity for all.<sup>138</sup>

As mentioned above, this reimagination of the care that is provided for people with disabilities can also benefit disabled parents caring for their children. It reminds us that taking care of children (whether with or without a disability) is not only a task of technical care but one that enriches life. It focuses on parents' (im)proper and unsupported place as caregivers. It shows how interdependence provides room for broader parent-child relationships since it is not based on one-sided functional dependence but depicts a reciprocal relationship where both sides are co-dependent in their path to realizing their autonomy. Such a relationship legitimizes the child's dual role as the dependent side of the relationship and as a provider of valuable assets such as meaning, company, community, parents' growth, a sense of belonging and security, and love.

### 3. Context and Culture

The third DSD component is *context and culture*. *Context* represents the circumstances surrounding system diagnosis and design, while *culture* encompasses shared patterns of perception, belief, behavior, and meaning attribution within a group.<sup>139</sup> Cultural influences on fairness perceptions in disputes<sup>140</sup> necessitate aligning conflict processes with organizational culture<sup>141</sup> and developing cultural

---

<sup>135</sup> JENNIFER NATALYA FINK, *ALL OUR FAMILIES: DISABILITY LINEAGE AND THE FUTURE OF KINSHIP* (2022).

<sup>136</sup> Powell, *supra* note 52.

<sup>137</sup> FINK, *supra* note 135, at xv.

<sup>138</sup> Powell, *supra* note 52.

<sup>139</sup> AMSLER, MARTINEZ & SMITH, *supra* note 7, at 30.

<sup>140</sup> *Id.* at 32.

<sup>141</sup> *Id.* at 31. In this respect, DSD deals with ADR's critics of being detached from the culture in which the dispute occurs.



awareness among designers to address intercultural dynamics.<sup>142</sup> In disability-rights-based DSD, these contextual and cultural elements must be viewed through a disability rights perspective.<sup>143</sup>

### *i. Disability Context*

First and foremost, disability must be recognized as a *contextual* phenomenon where perceived limitations emerge from environmental interactions.<sup>144</sup> Accordingly, the design context should frame disability as a socio-political construct arising from systemic power inequities,<sup>145</sup> acknowledging how societal structures sustain discrimination against persons with disabilities.<sup>146</sup>

Consequently, the designer must recognize how the system's context is embedded in systemic discrimination against persons with disabilities across life domains — from sheltered workshops and segregated education to institutional living, medical paternalism, and restrictive guardianship practices.<sup>147</sup> Concerning parenthood, this discrimination and exclusion include the stigmatization regarding disabled parenting and the inaccessibility of places and services that relate to parenting or are supposed to provide parental support, as detailed further in Sections II.B.4.i. and II.B.5.ii. These opinions and practices lead to and normalize the legally-based denial of parenting as described in Section I.

Therefore, *context-wise*, the child welfare system design should consider the negative historical interaction between disability and society, resulting in exclusion and marginalization.<sup>148</sup> In the context of child welfare and parenting, it is imperative to acknowledge that people with disabilities, especially intellectual disabilities, experience discouragement from parenting from an early age and, therefore, might not even expect to be parents.<sup>149</sup> Given this understanding, a designer who wishes to promote a disability consciousness in child welfare systems and cases should be aware of two main issues: The first is the potential opposition of various institutions and individuals, including

---

<sup>142</sup> Jayne S. Docherty, *Culture and Negotiation: Symmetrical Anthropology for Negotiators*, 87 MARQ. L. REV. 710 (2004); Judith Resnik, *Many Doors? Closing Doors? Alternative Dispute Resolution and Adjudication*, 10 OHIO ST. J. DISP. RESOL. 211 (1995); Sukhsimranjit Singh, *Access to Justice and Dispute Resolution Across Cultures*, 88 FORDHAM L. REV. 2407, 2423 (2020) (claiming that without an established structure and precedent in place, ADR may only provoke low-quality justice for the impoverished).

<sup>143</sup> Rothler, *supra* note 9.

<sup>144</sup> See, e.g., Michael A. Stein, Anita Silvers, Bradley A. Areheart & Leslie Pickering Francis, *Accommodating Every Body*, 81 U. CHI. L. REV. 689 (2014); Theresia Degener, *Disability in a Human Rights Context*, 5 LAWS, No. 34, Aug. 25, 2016, at 16.

<sup>145</sup> Claire Tregaskis, *Social Model Theory: The Story So Far . . .*, 17 DISABILITY AND SOC'Y 457, 462 (2002).

<sup>146</sup> For elaboration regarding the principles and historical roots of disability studies and the social approach, see OLIVER, *supra* note 53, at 30–33; Mor, *supra* note 51, at 645; and the literature mentioned there.

<sup>147</sup> Holler & Ohayon, *supra* note 49, at 2–3.

<sup>148</sup> See OLIVER, *supra* note 53.

<sup>149</sup> Sheila Gould & Karen Dodd, 'Normal People Can Have a Child but Disability Can't': *The Experiences of Mothers with Mild Learning Disabilities Who Have Had Their Children Removed*, 42 BRIT. J. LEARNING DISABILITIES 27 (2012).

health professionals and family members,<sup>150</sup> as elaborated in Section I. The second is the empowerment of people with disabilities, who hold opposing opinions regarding themselves as parents. Therefore, the system should be designed to overcome both kinds of objection by providing institutions, professionals, and individuals with information and practical tools, as will be elaborated further in Sections II.B.4 and II.B.5.

## ii. Disability Culture

Regarding *culture*, designers must recognize the distinctive *disability culture* that has emerged from the lived experiences and perspectives of people with disabilities. This approach reconceptualizes disability, moving beyond views of socially constructed or individually based inferiority<sup>151</sup> to embrace it as an expression of human diversity.<sup>152</sup> This cultural framework emphasizes disability's positive contributions, including expanded perspectives, liberation from societal constraints, and the development of empowering personal and collective identities.<sup>153</sup> In parenting, such benefits regarding children's sense of autonomy, openness to differences, and resilience were mainly discussed.<sup>154</sup>

A disability-culture consciousness calls for legitimizing and mainstreaming the life experiences of parents with disabilities, which often challenge traditional concepts of what is "normalcy" and of social expectations.<sup>155</sup> Thus, the designer should be aware of the importance of social recognition of the disability experience.<sup>156</sup> Moreover, when designing legal systems, it is imperative to implement the disability context and culture among lawyers representing parents with disabilities.<sup>157</sup>

<sup>150</sup> HOLLER, WERNER, TOLUB & POMERANTZ, *supra* note 117, at 96.

<sup>151</sup> See generally, SHAKESPEARE, *supra* note 101, at 1.

<sup>152</sup> John Swain & Sally French, *Towards an Affirmation Model of Disability*, 15 DISABILITY & SOC'Y 569, 579 (2000). For a disability justice approach that emphasizes another angle of disability culture, shedding light on the intersection of disability and historically excluded groups such as women, people of color, immigrants, and LGBTQ+, stressing the importance of bearing all of one's identities together, see Chin, *supra* note 52.

<sup>153</sup> Swain & French, *supra* note 152, at 579–80.

<sup>154</sup> Adam Cureton, *Some Advantages to Having a Parent with a Disability*, 42 J. MED. ETHICS 31, 32 (2016). In her best-selling book, Jeanette Walls describes her childhood life with parents who are described as having mental disabilities; alongside the difficulties, she describes a loving atmosphere and a unique perspective of life, which is embedded her writing career. See JEANETTE WALLS, *THE GLASS CASTLE* (2005).

<sup>155</sup> SHAKESPEARE, *supra* note 101, at 1. For a cultural approach in family and child welfare cases, see Brooks & Ronen, *supra* note 17, at 36–39.

<sup>156</sup> Robina Goodlad & Sheila Riddell, *Social Justice and Disabled People: Principles and Challenges*, 4 SOC. POL'Y & SOC'Y 45, 46–47 (2005).

<sup>157</sup> Glennon, *supra* note 15; Powell, *supra* note 2. The aspect of disability-conscious legal education will be discussed in depth *infra* Section II.B.5.iv.. See also, e.g., Michael E. Waterstone, Michael Ashley Stein & David B. Wilkins, *Disability Cause Lawyers*, 53 WM. & MARY L. REV. 1287 (2012) (describing the central role of "cause lawyers" in advancing disability rights); Susan L. Brooks & Robert G. Madden, *Introduction, Relationship-Centered Lawyering: The Emerging 'Science' of Professionalism*, in RELATIONSHIP-CENTERED LAWYERING: SOCIAL SCIENCE THEORY FOR TRANSFORMING LEGAL PRACTICE (Susan L. Brooks & Robert G. Madden eds., 2010) (detailing issues of disability-related relationship and communication among lawyers); Roni Rothler, *Clinical Legal Education and Therapeutic Jurisprudence in the Disability Rights Clinic*, in THINKING

The inclination to embrace disability culture will enable the child welfare system to be open and responsive to the authentic conduct, opinions, and decisions of parents with disabilities, even when they do not adhere to the “conventional” habits. A disability culture sensitivity might also indirectly benefit other parents, not necessarily those with disabilities, characterized by “otherness,” as described by Brooks & Ronen,<sup>158</sup> since it will increase the system’s adherence to different cultural aspects of parenting, forming a substantial multicultural policy framework.

#### 4. Process and Structure

The fourth DSD component — process and structure — addresses dispute prevention, management, and resolution systems. Processes span formal mechanisms like trials, mediation, and arbitration to varied methods tailored to specific conflicts and organizations. These can function as integrated systems or separate pathways.<sup>159</sup> Best practice typically involves designing multiple options incorporating interest- and rights-based strategies with the flexibility to move between them.<sup>160</sup> Designers must also consider how proposed systems interact with existing legal frameworks and courts’ receptiveness to changes.<sup>161</sup>

When designing a child welfare framework, designers must consider how discriminatory historical practices and systemic barriers shaped current processes,<sup>162</sup> leading to adverse outcomes for parents with disabilities.<sup>163</sup> The design should incorporate disability rights principles and mechanisms to address and overcome these obstacles.

In her article, *Family Law, Parents with Disabilities, and the Americans with Disabilities Act*,<sup>164</sup> Robyn Powell directly addresses the structural reforms necessary for the strategic deployment of the ADA in child welfare proceedings. She identifies four major issues: individualized treatment, courtroom accessibility, accessible and appropriate parenting evaluations, and enhanced professional responsibility requirements for family law practitioners. Drawing from Powell’s insight on the need for structural reforms, this Section will outline the disability-rights-related mechanisms to design the system’s process and structure, focusing not only on court proceedings but on all levels of the child welfare system. According to the Disability-Rights-Based DSD, “Process & Structure” should include four critical elements: accessibility and accommodations, universal design, procedural justice, and attention to the structure of the socio-legal system.

---

CLINICAL LEGAL EDUCATION: PHILOSOPHICAL AND THEORETICAL PERSPECTIVES 37 (Omar Madhloom & Hugh McFaul eds., 2022) (addressing lawyers’ necessity of disability culture knowledge).

<sup>158</sup> Brooks & Ronen, *supra* note 17, at 25.

<sup>159</sup> Smith & Martinez, *supra* note 8, at 130–31.

<sup>160</sup> *Id.* at 128.

<sup>161</sup> AMSLER, MARTINEZ & SMITH, *supra* note 7, at 126.

<sup>162</sup> Mor, *supra* note 51, at 613; Holler & Ohayon, *supra* note 49, at 2–3.

<sup>163</sup> See *supra* Section I.

<sup>164</sup> Powell, *supra* note 2.

*i. Accessibility and Accommodations*

Accessibility obligations reflect disability rights' unique combination of 'negative' civil-political and 'positive' social rights.<sup>165</sup> Physical and structural barriers make purely 'negative' anti-discrimination measures insufficient — disability rights must include both negative liberties and affirmative duties.<sup>166</sup> These require public and private actors to actively redesign spaces and services by eliminating structural and institutional barriers.<sup>167</sup> In the justice system context, accessibility focuses on removing obstacles to courts, law, and justice that people with disabilities encounter when engaging with legal and social support systems.<sup>168</sup>

As Powell elaborates,<sup>169</sup> in the United States, these accessibility duties of public entities (including courts) are manifested in Title II of the ADA. Those include the duty to provide an equal opportunity to participate in services, programs, and activities; to administer services, programs, and activities in the most integrated setting and appropriate to the needs of people with disabilities; not to impose criteria that might screen out people with disabilities; to provide auxiliary aids and services; not to place surcharges on people with disabilities to cover costs of nondiscriminatory treatment; and not to deny services due to inaccessible facilities.

Accordingly, public entities must provide reasonable modifications in policies, practices, and procedures to avoid disability-based discrimination. Title III of the ADA prohibits discrimination against people with disabilities by places of public accommodations, including professional offices such as attorneys and health care professionals. Those places must not apply eligibility criteria that screen out persons with disabilities, make reasonable modifications in policies and procedures to ensure access to services and facilities and provide

---

<sup>165</sup> Neta Ziv, *The Social Rights of People with Disabilities: Reconciling Care and Justice*, in *EXPLORING SOCIAL RIGHTS: BETWEEN THEORY AND PRACTICE* 369 (Daphne Barak-Erez & Aeyal M. Gross eds., 2007).

<sup>166</sup> Robert L. Burgdorf, Jr., *The Americans with Disabilities Act: Analysis and Implications of a Second-Generation Civil Rights Statute*, 26 HARV. C.R.-C.L. L. REV. 413, 453 (1991).

<sup>167</sup> Stein, Silvers, Areheart & Pickering Francis, *supra* note 144; Ziv, *supra* note 165. Accessibility and the duty to accommodate are rooted in most international obligations articulated by the CRPD. CRPD, *supra* note 58. Specifically, Article 9 is dedicated to accessibility and acknowledges it as the precondition for full participation in all aspects of life on an equal basis with others. *Id.* at Art. 9. According to the Article, accessibility, including identifying and eliminating obstacles and barriers, should be interpreted broadly: accessibility to the physical environment, transportation, information, technology, facilities, and services, using technology-based and live assistance. *Id.* Moreover, discrimination against people with disabilities includes denying reasonable accommodation. *See id.* at Arts. 2, 5, 13, 14, 24, 27; Shivan Quinlivan, *Reasonable Accommodation: An Integral Part of the Right to Education for Persons with Disabilities*, in *THE RIGHT TO INCLUSIVE EDUCATION IN INTERNATIONAL HUMAN RIGHTS LAW* 169 (Gauthier de Beco, Shivan Quinlivan & Janet E. Lord eds., 2019).

<sup>168</sup> Mor, *supra* note 51, at 613–14, 621. For a discussion on positive duties regarding supported decision-making, see Terry Carney, *Clarifying, Operationalising, and Evaluating Supported Decision-Making Models*, RSCH. AND PRAC. INTELL. & DEV. DISABILITIES 46 (2014).

<sup>169</sup> Powell, *supra* note 2, at 42.

auxiliary aids and services, including meeting physical accessibility guidelines.<sup>170</sup>

As Powell explains, in addition to accessibility duties, the ADA mandates an affirmative accommodation obligation. The courts must modify their services to accommodate particular disabilities, ensuring meaningful access. These ADA provisions can and should be applied in child welfare cases, specifically in individualized treatment, courtroom accessibility, accessible and appropriate parenting assessments, and attorneys' legal obligations.<sup>171</sup>

Powell shows how the individualized treatment of parents<sup>172</sup> is a matter of accessibility and reasonable modifications. She claims that by treating each case individually and consistent with facts and objectives, courts will be less inclined to act upon stereotypes and (negative) generalizations about people with disabilities and better assess the "reasonability" of the modifications needed by everyone. She adds on the importance of courtroom accessibility allowing for meaningful participation, which is imperative for parents, and which denial can result in unfavorable decisions.<sup>173</sup>

Next, Powell tackles the imperative issue of *professional reports* assessing accommodations and evaluating parental capacity.<sup>174</sup> As she shows, many of the mental health professionals who are involved in child welfare cases lack experience or training related to parents with disabilities. Therefore, they do not know how to assess accommodations or perform parental capacity evaluations accommodating various disabilities.<sup>175</sup> She concludes that parenting evaluations must be fully accessible, include reasonable modifications, and comply with the ADA's individualized treatment requirements.<sup>176</sup>

Child welfare system design must ensure accessibility across multiple dimensions: proceedings, institutions, courts, and support services. This requires creating structures that enable accommodated, non-stigmatic, and individualized participation, with particular focus on making legal procedure information accessible. This comprehensive approach to accessibility aligns with Mor's broad access to justice

---

<sup>170</sup> *Id.* As Powell elaborates, those duties are subject to defenses in circumstances that render the accommodations "unreasonable" because they are too costly, too risky, or alter the nature of the existing services. *Id.* See also Title II of the Americans with Disabilities Act of 1990, 42 U.S.C. § 12102.

<sup>171</sup> Powell, *supra* note 2, at 44.

<sup>172</sup> *Id.* at 43–44.

<sup>173</sup> *Id.* at 44.

<sup>174</sup> *Id.* at 45. See Jon Amundson & Glenda Lux, *Tippins and Wittmann Revisited: Law, Social Science, and the Role of the Child Custody Expert 14 Years Later*, 57 FAM. CT. REV. 88, 95–102 (2019) (similarly addressing issue of experts' opinions regarding child custody evaluations and the way irrelevant information and biased opinions might harm parental rights).

<sup>175</sup> Powell, *supra* note 2. As Powell shows, this lack of accommodation violates Articles II and III of the Americans with Disabilities Act of 1990, 42 U.S.C. § 12102.

<sup>176</sup> Powell, *supra* note 2, at 45 (noting that these individualized treatment requirements were also mandated in guidance issued in 2015 by the U.S. Departments of Justice and Health and Human Services to child welfare agencies and courts). Gur & Stein, *supra* note 35 (also detecting a lack of the necessary training for professionals—namely, social workers—that work with parents with intellectual disabilities and reporting the needed training for empowering social workers to act on behalf of their client's parenting rights).

framework.<sup>177</sup> At the policy level, accessibility should facilitate collaborative governance, enabling people with disabilities to actively shape the laws and procedures affecting their lives.<sup>178</sup>

## ii. Universal Design

The second disability rights element within DSD’s ‘process and structure’ is *universal design*<sup>179</sup> — creating products and environments usable by all people without adaptation.<sup>180</sup> This approach aims to accommodate diverse ages, body types, and intellectual capacities, recognizing that systems accessible to people with disabilities often benefit broader populations.<sup>181</sup>

Providing universally designed places and services will help increase the number of parents (with or without disabilities) who can understand and use those places and services without special accommodations. Such universal design can *prevent* conflicts and thus render the involvement of the legal system unnecessary.<sup>182</sup>

The second aspect of universal design concerns the design of parenthood’s *meaning*. Harris<sup>183</sup> specifically addresses this issue of a universal redesign of family law. As she explains, the remedy of accommodations (as mentioned in *supra* Section II.B.4.i.) might not be sufficient for parents who “even with accommodations cannot meet those normative expectations.” Therefore, a meaningful intervention would be to consider reshaping the norm of parenthood by “reimagining the core duties of parents and goals of parenting.” As she suggests, parental fitness does not necessarily entail functional care, such as assisting children with homework or bathing them independently.

Universal design in child welfare would challenge conventional definitions of parenting, fitness, and neglect. As Harris notes, viewing parental capacity through a communal lens — where parents can delegate tasks while maintaining decision-making authority, similar to non-disabled parents employing caregivers — reduces justification for terminating parental rights of people with disabilities who may execute parental roles differently. As she further explains, the ideal of “super-competence” attributed to parenthood, and especially to motherhood, is unreachable for nondisabled and disabled mothers alike, making

<sup>177</sup> Mor, *supra* note 51, at 631–33.

<sup>178</sup> AMSLER, MARTINEZ & SMITH, *supra* note 7, at 56.

<sup>179</sup> Mor, *supra* note 51, at 620 (noting that the principle of universal design was not fully integrated into the CRPD’s vision of access and is mainly mentioned in the general obligations sections, not in particular articles such as article 9, which deals with accessibility). Nevertheless, Mor believes that such a vision of universal design should guide our understanding of access to justice. *Id.*

<sup>180</sup> MOLLY FOLLETTE STORY, JAMES L. MUELLER & RONALD L. MACE, *THE UNIVERSAL DESIGN FILE: DESIGNING FOR PEOPLE OF ALL AGES AND ABILITIES* (1998). See also, Mor, *supra* note 51, at 624; AIMI HAMRAIE, *BUILDING ACCESS: UNIVERSAL DESIGN AND THE POLITICS OF DISABILITY* (2017).

<sup>181</sup> Mor, *supra* note 51, at 620, 624.

<sup>182</sup> See Brooks & Ronen, *supra* note 17, at 32–33 (suggesting the adoption of the lens of “preventive law” in family cases, calling for professionals—mainly lawyers—to identify their clients’ “soft spots” in advance, to prevent risk situations).

<sup>183</sup> Harris, *supra* note 4, at 17.

disabled mothers seem unfit for parenthood.<sup>184</sup> It is the wrong assumption that able-bodied parents execute custodial duties independently, leading to a lack of public (and legal) support for parents who require assistance performing some tasks. Therefore, universalizing parenting will potentially benefit not only parents with disabilities but all parents who have different abilities and needs — whether temporary or permanent — and parenting styles, cultures, and traditions without being categorized as pathologies.<sup>185</sup>

If disability will not be depicted as a deficit but as diversity (as suggested in *supra* Section II.B.3.ii), and if we understand that parents, with or without disability, need and are entitled to assistance, we will achieve a better and more wholesome depiction of parenthood, thus eliminating or diminishing certain negative feelings and situations such as anxiety, stress, or postpartum depression.<sup>186</sup> As a result, disabled parents' needs will be legitimized and will not necessarily provide the grounds for children's removal.<sup>187</sup> It will also legitimize and even provide official status for relationships between children and significant adults other than the biological parents who take part in raising them without jeopardizing parental status.<sup>188</sup>

### iii. Procedural Justice

The emphasis on *process and structure* in design reflects understanding that satisfaction stems from both outcomes and procedural elements.<sup>189</sup> This connects to the third disability rights aspect — *procedural justice*. Procedural justice encompasses multiple elements: impartiality, the right to be heard, legal grounds for decisions, neutral procedures and decision-makers, dignified treatment of participants, and trustworthy decision-making authorities.<sup>190</sup>

Research demonstrates that participants in legal processes heavily weigh procedural justice in their overall evaluation, particularly valuing opportunities to be heard, respectful treatment, and interaction with unbiased, trustworthy third parties.<sup>191</sup> DSD principles therefore emphasize participant involvement in shaping solutions based on lived

<sup>184</sup> See also Christina Minaki, *Scrutinizing and Resisting Oppressive Assumptions About Disabled Parents*, in *DISABLED MOTHERS: STORIES AND SCHOLARSHIP BY AND ABOUT MOTHERS WITH DISABILITIES* 31 (Gloria Filax & Dena Taylor eds., 2014). This “super competence” is also derived from Western standards of “intensive parenting,” which the Justice system echoes and portrays. See Gaia Bernstein & Zvi Triger, *Over-Parenting*, 44 U.C. DAVIS L. REV. 1221 (2011).

<sup>185</sup> For a similar suggestion in the field of labor, see Einat Albin, *Universalising the Right to Work of Persons with Disabilities: An Equality and Dignity Based Approach*, in *THE RIGHT TO WORK: LEGAL AND PHILOSOPHICAL PERSPECTIVES* 61 (Virginia Mantouvalou ed., 2014).

<sup>186</sup> Gloria Filax & Dena Taylor, *Introduction*, in *DISABLED MOTHERS: STORIES AND SCHOLARSHIP BY AND ABOUT MOTHERS WITH DISABILITIES I* (Gloria Filax & Dena Taylor eds., 2014).

<sup>187</sup> Harold Braswell, *My Two Moms: Disability, Queer Kinship, and the Maternal Subject*, 30 *HYPATIA* 234 (2015).

<sup>188</sup> ANDREW BAINHAM & STEPHEN GILMORE, *CHILDREN—THE MODERN LAW* 181–85, 205–10 (4th ed. 2013).

<sup>189</sup> AMSLER, MARTINEZ & SMITH, *supra* note 7, at 16, 35.

<sup>190</sup> *Id.* at 16–17. For a discussion regarding the importance of procedural justice in family and child welfare cases, see Brooks & Ronen, *supra* note 17, at 39–40.

<sup>191</sup> ROGERS, BORDONE, SANDER & MCEWEN, *supra* note 7, at 23.

experience and promoting procedural fairness.<sup>192</sup> This focus on procedural justice is especially crucial given the historical silencing of people with disabilities' authentic voices.

As discussed in Section I.A., procedural justice is significantly lacking in child welfare proceedings. Parents (with and without disabilities) reported an absence of voice and felt as if they were not included in the proceedings and that their input was not considered. They also reported a lack of understanding of the judicial process and concerns regarding the proceedings' fairness, including bias in the judicial decisions.<sup>193</sup> Additionally, they reported feeling that the process was moving too quickly toward court proceedings and being rushed into making life-changing decisions about the care arrangements of their children.<sup>194</sup> Research has shown that judges' conduct significantly shaped parents' court experience and fueled their hope, reporting to especially note and remember aspects of judicial kindness and informal and formal positive and negative comments.<sup>195</sup>

Procedural justice, manifested in neutrality and the authorities' respectful behavior, is also vital for children.<sup>196</sup> Notably, children's *participation* in the process was found to be an important aspect of child welfare proceedings. Tali Gal elaborated on this issue,<sup>197</sup> stressing findings that show how children's ability to participate is changeable<sup>198</sup> and encourages states to foster child participation. As she describes, research has found that children's effective participation depends on support and encouragement provided by relationships based on trust and respect, communication, and precise information.<sup>199</sup> Specifically, children personally invited to meet with the authority — whether a judge or a social worker — during family court proceedings relating to parental disputes were more keen to have a say in the process.<sup>200</sup> Gal also explains that children are sensitive to tokenistic participation, which leads to frustration and anger, as opposed to genuine interest in their perspectives.<sup>201</sup>

<sup>192</sup> AMSLER, MARTINEZ & SMITH, *supra* note 7, at 15.

<sup>193</sup> Stephens, Katz, Pisciotta & Lens, *supra* note 1; Sara P. Schechter, *Family Court Case Conferencing and Post-Dispositional Tracking: Tools for Achieving Justice for Parents in the Child Welfare System*, 70 FORDHAM L. REV. 427 (2001); HUNTER, THOMAS & CAMPBELL, *supra* note 19.

<sup>194</sup> HUNTER, THOMAS & CAMPBELL, *supra* note 19.

<sup>195</sup> *Id.*

<sup>196</sup> Gal, *supra* note 110, at 61; JEANETTE LAWRENCE, SAFEGUARDING FAIRNESS FOR CHILDREN IN INTERACTIONS WITH ADULTS IN AUTHORITY (May 2003), <https://www.aic.gov.au/sites/default/files/2020-05/200001-35.pdf>.

<sup>197</sup> Gal, *supra* note 110, at 59.

<sup>198</sup> *Id.* at 59 (explaining that research has suggested a gradual process of developing children's participation ability (coined "scaffolding")).

<sup>199</sup> Michael Gallagher, Mark Smith, Mark Hardy & Heather Wilkinson, *Children and Families' Involvement in Social Work Decision Making*, 26 CHILD. & SOC'Y 74 (2012).

<sup>200</sup> Tamar Morag, Dori Rivkin & Yoa Sorek, *Child Participation in the Family Courts—Lessons from the Israeli Pilot Project*, 26 INT'L J.L. POL'Y & FAM. 1 (2012).

<sup>201</sup> Jodi Hall, Joan Pennell, & R.V. Rikard, *Child and Family Team Meetings: The Need for Youth Participation in Educational Success*, in INTERNATIONAL PERSPECTIVES AND EMPIRICAL FINDINGS ON CHILD PARTICIPATION: FROM SOCIAL EXCLUSION TO CHILD-INCLUSIVE POLICIES 207 (Tali Gal & Benedetta Duramy eds., 2015); Chelsea Marshall, Bronagh Byrne & Laura Lundy, *Face to Face: Children and Young People's Right to Participate in Public Decision-Making*, in INTERNATIONAL PERSPECTIVES AND EMPIRICAL FINDINGS ON CHILD PARTICIPATION: FROM



Another key consideration in procedural justice and disability is self-identity. Dorfman's research on social security benefits demonstrates that individuals who embrace the social model of disability view medical and individual model-based procedures as procedurally unjust — reporting lack of control, silenced voices, poor representation, pressure for inauthentic self-presentation, and labor market discouragement.<sup>202</sup> Since child welfare proceedings similarly rely on medicalized and individual models rather than parenting disability rights frameworks, parents who identify with the social model are likely to perceive these proceedings as lacking procedural fairness.

Consequently, parents and children should actively participate in the proceedings and the system's design, aiming to design a system that answers procedural justice challenges. One of those challenges addresses the complex and sometimes temporary nature of family circumstances and parents' and children's changing needs and interests (as discussed in Section I). Hence, procedural justice requires enhanced court involvement in implementing the ordered custody plan.<sup>203</sup> This can be achieved by establishing ground rules regarding the temporary nature of these decisions. They should be revisited periodically to ensure that limitations on parenthood are minimized.

Finally, a fundamental procedural justice aspect involving time is the immediacy and availability of support, which is often crucial in child welfare matters. Welfare services and courts alike are reluctant to implement parenting disability rights when presented with cases of apparent neglect, which can result from insufficient accommodations, accessibility, and support. These cases portray children's rights as opposed to their parents', usually resulting in separation. When provided early, various parenting resources, accommodations, and support are far more valuable and can help prevent such risky situations.<sup>204</sup> Therefore, adopting a "Disability-Rights-Based DSD" in child welfare should emphasize early attention to disability rights.

Another procedural justice aspect in child welfare proceedings is attaining proper legal representation. Given the hierarchies between people with disabilities, families, and professionals and the weight of the parenthood rights at stake, legal representation is crucial, including free-of-charge representation for people who cannot afford it.<sup>205</sup> However,

---

SOCIAL EXCLUSION TO CHILD-INCLUSIVE POLICIES 357 (Tali Gal & Benedetta Duramy eds., 2015). See also Tali Gal & Dahlia Schilli-Jerichower, *Mainstreaming Therapeutic Jurisprudence in Family Law: The Israeli Child Protection Law as a Case Study*, 55 FAM. CT. REV. 177, 185–86 (2017) (addressing guidelines on children's participation in child welfare proceedings from a Therapeutic Jurisprudence (TJ) perspective, and explaining that children's participation should be tailored to their abilities through a mechanism for empowering them and allowing them to participate according to their abilities, wishes, and best interests).

<sup>202</sup> Doron Dorfman, *Re-Claiming Disability: Identity, Procedural Justice, and the Disability Determination Process*, 42 L. & SOC. INQUIRY 195 (2017).

<sup>203</sup> Kristen M. Blankley, *Online Resources and Family Cases: Access to Justice in Implementation of a Plan*, 88 FORDHAM L. REV. 2121, 2122 (2020).

<sup>204</sup> For the importance of early intervention and advocacy for disabled parents, see Glennon, *supra* note 15, at 299.

<sup>205</sup> As mentioned *supra* Section I, Powell identifies proper legal representation as one of the accessibility requirements for advancing parenting rights for people with disabilities. Powell, *supra* note 2.

the formal representation is not enough: parents reported feeling that their lawyer did not adequately represent their views on life or challenge aspects of evidence that they considered wrong or unfair.<sup>206</sup> Therefore, as will be elaborated *infra* Section II.B.5.iv., lawyers representing parents with disabilities should be “disability-educated,” focus on fairness and justice, enhance clients’ trust and respect for the law and its actors, and increase clients’ feeling that they were treated fairly. They should fully inform their clients about the procedures and criteria for legal decisions in accessible language according to their client’s needs and ensure they are treated with respect by other legal professionals.<sup>207</sup> Notably, lawyers should support their clients’ decision-making process within the representation, refrain from making decisions for the client’s best interests, and respect their wishes regarding the legal procedure.<sup>208</sup>

The timing of legal representation presents another critical concern. While formal representation is typically assigned only upon court filing, significant parent-agency interactions and decisions often occur during pre-filing stages without legal counsel. For parents with disabilities, this creates heightened vulnerability to power imbalances and potential rights violations. Moreover, early legal representation could facilitate better conflict resolution with child welfare authorities, potentially preventing unnecessary court proceedings.<sup>209</sup>

*iv. The Process and Structure of the Justice System:  
Socio-Legal Aspects and Therapeutic Jurisprudence in  
the Child Welfare System’s Design*<sup>210</sup>

Finally, a disability-rights-based DSD must address the justice system’s process and structure.<sup>211</sup> With their complexity, multiple stakeholders, and lasting impact, child welfare cases are particularly suited for a DSD-based tribunal approach. This framework can create space for nuanced conflict resolution models that embrace non-binary justice concepts and enhance legal dispute processing.<sup>212</sup>

---

<sup>206</sup> HUNTER, THOMAS & CAMPBELL, *supra* note 19, at 4.

<sup>207</sup> David M. Boulding & Susan L. Brooks, *Trying Differently: A Relationship-Centered Approach to Representing Clients with Cognitive Challenges*, 33 INT’L J.L. & PSYCHIATRY 448, 451 (2010).

<sup>208</sup> For a detailed explanation of such legal representation of clients with mental disabilities regarding psychiatric hospitalization, see Michael L. Perlin & Naomi M. Weinstein, *Said I, ‘But You Have No Choice’ Why a Lawyer Must Ethically Honor a Client’s Decision About Mental Health Treatment Even if It Is Not What S/He Would Have Chosen*, 15 CARDOZO PUB. L., POL’Y & ETHICS J. 73, 78 (2016).

<sup>209</sup> Powell, *Under the Watchful Eye*, *supra* note 85, at 2059.

<sup>210</sup> In the original “Disability-Rights-Based DSD,” therapeutic jurisprudence was part of the aspect of “resources.” Rothler, *supra* note 9, at 42–43. However, in the context of child welfare, it seems fitter to discuss it within the aspect of “process & structure.” *Id.* at 33–34.

<sup>211</sup> See generally Mor, *supra* note 51 (discussing broadly the connection between disability and access to justice and its implications on the justice system). For a comprehensive analysis of how legal systems can adjust to be more responsive and human-centered, see Amir & Alberstein, *supra* note 92.

<sup>212</sup> Michal Alberstein, *Judicial Conflict Resolution (JCR): A New Jurisprudence for an Emerging Judicial Practice*, 16 CARDOZO J. CONFLICT RESOL. 879, 889–90 (2015). For a similar argument regarding the complex blend of rights and interests in child welfare cases, see Shelley Kierstead, *Therapeutic Jurisprudence and Child Protection*, 17 BARRY L. REV. 31, 33 (2011).

For example, tribunals could adopt community court principles focusing on rehabilitation and ‘multidoor courthouse’ approaches.<sup>213</sup> This system routes cases based on their characteristics to the most suitable resolution method.<sup>214</sup> The tribunal can work with other institutional actors to address issues through alternatives to traditional trials,<sup>215</sup> such as family mediation and ‘Family Group Conferencing.’<sup>216</sup> This flexible design better accommodates diverse cases and disputes.

Additionally, the tribunal design can incorporate a multidisciplinary team including legal, health, social services, financial, and education professionals,<sup>217</sup> alongside people with disabilities who have direct child welfare experience, human rights organizations, and family members. These participants could serve either as court advisors or judicial team members, depending on case needs.

Particular attention should be given to the system’s dual socio-legal characteristics, such as emphasis on the court’s ecological and therapeutic capacities.<sup>218</sup> Indeed, every legal field has social implications;<sup>219</sup> however, in child welfare proceedings, social and legal aspects are often inseparable. This is because the legal case revolves around the state’s intervention in social aspects of family, relationships, and care.<sup>220</sup>

Importantly, child welfare cases (as well as other family-related cases such as divorce or legal capacity issues) are mainly *future-focused* as opposed to other legal cases (such as criminal law, torts, and contracts), which contain futural aspects but are primarily focused on the investigation of the past. The case’s “futuristic” character highlights the cruciality of social and therapeutic individual evolvment and family-oriented change.

This tight socio-legal connection is also portrayed — and enhanced — by the professionals who play essential roles in the proceedings, mainly social, therapeutic, and legal experts. Federal legal statutes also mention this socio-legal connection, which demands that child welfare social workers and legal professionals adjudicating child welfare cases collaborate more frequently.<sup>221</sup> Therefore, a socio-legal structure for the

---

<sup>213</sup> Frank E. A. Sander & Stephen B. Goldberg, *Fitting the Forum to the Fuss: A User-Friendly Guide to Selecting an ADR Procedure*, 10 NEGOT. J. 49, 51 (1994).

<sup>214</sup> AMSLER, MARTINEZ & SMITH, *supra* note 7, at 112.

<sup>215</sup> Alberstein, *supra* note 212, at 889–90.

<sup>216</sup> See Kierstead, *supra* note 212, at 34. For the advantages of involving children and parents in the decision-making process through such means, see Gal & Schilli-Jerichower, *supra* note 201, at 186.

<sup>217</sup> Such as the “parents advocates” described in Stephens, Katz, Pisciotto & Lens, *supra* note 1, at 495.

<sup>218</sup> For a thorough analysis of family court’s that promote family justice, see BARBARA A. BABB & JUDITH D. MORAN, *CARING FOR FAMILIES IN COURT: AN ESSENTIAL APPROACH TO FAMILY JUSTICE* (2019) (particularly Chapter 2 emphasizing the interdisciplinary paradigm through the court’s ecological and therapeutic capacities).

<sup>219</sup> BRIAN Z. TAMANAHA, *A GENERAL JURISPRUDENCE OF LAW AND SOCIETY* (2001).

<sup>220</sup> Kathleen Coulborn Faller & Frank E. Vandervort, *Interdisciplinary Clinical Teaching of Child Welfare Practice to Law and Social Work Students: When World Views Collide*, 41 U. MICH. J. L. REFORM 121 (2007).

<sup>221</sup> See, e.g., Adoption Assistance and Child Welfare Act of 1980, Pub. L. No. 96-272, §422(b)(2), 94 Stat. 500, 517 (codified as amended 42 U.S.C. § 1397); Adoption and Safe Families

proceedings should be investigated. A brief discussion of the obstacles and suggested boundaries for such a structure follows.

The insufficiency of social and therapeutical content in family courts has been at the center of the family court's criticism. Critics have noted the failure to ensure essential services and treatment for parents and children:<sup>222</sup> they characterized courts as a harsh environment populated with multiple actors that makes it difficult for parents and their representatives to navigate.<sup>223</sup>

Others have found that although family and youth courts are officially supposed to portray a therapeutic setting, they usually run in an adversarial manner, enhancing conflict, inefficiency, and failure to seize opportunities.<sup>224</sup> It was argued that contextual factors, such as trauma<sup>225</sup> and bias, multiply the anti-therapeutic effects of family courts<sup>226</sup> and that attention to such social and therapeutic content might not only help the families but alleviate some stress attributed to professionals such as lawyers, social workers, and judges.<sup>227</sup>

Research has suggested that this lack of attention to combining legal and social content results from differences in professional education programs between lawyers and social workers. This leads to obstacles in collaborating in their future professional lives and prevents the system from adequately meeting the needs of children and families.<sup>228</sup> Kierstead elaborates on these inherent and substantial differences in the professional conduct of lawyers and social workers, focusing on their different approaches to defining and solving family-related problems.<sup>229</sup> Coulborn Faller and Vandervort further explain other aspects of difficulty in collaborating, given their different roles in child welfare cases, ethical guidelines, approaches and methods of intervention, and social statuses.<sup>230</sup>

Those obstacles result in both “under-collaboration” and “over-collaboration.” As for “under-collaboration,” as mentioned above, child welfare cases require a very tight, often future-oriented, client-lawyer-social professional collaboration. Unlike a tort claim, where the lawyer interacts with the client mainly to receive the relevant documents and

---

Act of 1997, Pub. L. No. 105-89, 111 Stat. 2115 (1997) (codified as amended in scattered sections of 42 U.S.C.); Sarah Taylor, *Educating Future Practitioners of Social Work and Law: Exploring the Origins of Inter-Professional Misunderstanding*, 28 CHILD. & YOUTH SERVS. REV. 638, 639 (2006).

<sup>222</sup> Lens, *supra* note 22; Barbara A. Babb, *Family Courts are Here to Stay, So Let's Improve Them*, 52 FAM. CT. REV. 642 (2014).

<sup>223</sup> Stephens, Katz, Pisciotto & Lens, *supra* note 1, at 1.

<sup>224</sup> Gal & Schilli-Jerichower, *supra* note 201, at 185–86.

<sup>225</sup> For a discussion on the trauma that characterizes many parents and children whose cases are heard in family courts, see Stephens, Katz, Pisciotto & Lens, *supra* note 1, at 505 (arguing that this trauma is not properly (or at all) addressed by the court due to a lack of attention to therapeutic content).

<sup>226</sup> *Id.*

<sup>227</sup> *Id.* (suggesting that judges have a key role in mediating contextual factors such as trauma and bias in family court, providing a supportive and therapeutic environment for adjudicating cases). For further reading on legal professionals' stress, see Carly Schrever, Carol Hulbert & Tania Sourdin, *The Privilege and the Pressure: Judges' and Magistrates' Reflections on the Sources and Impacts of Stress in Judicial Work*, 31 PSYCHIATRY, PSYCH. & L. 327 (2024).

<sup>228</sup> Taylor, *supra* note 221, at 639–40.

<sup>229</sup> See Kierstead, *supra* note 212, at 43.

<sup>230</sup> Faller & Vandervort, *supra* note 220, at 143.

information, a lawyer handling a child welfare case usually must prove that the client's parental conduct will improve. Consequently, as the case evolves, the lawyer is involved in many care details, aiming to present the client's life to the authorities to yield favorable legal results (which often might ignore some unfavorable aspects of the client's life).<sup>231</sup> This requires much more client interaction and collaboration with their families and professionals such as therapists and social workers.

Therapeutic content and collaboration become essential for legal representation since the lawyer aspires to help the client act a certain way. However, lawyers are not trained in social or therapeutic professional conduct and do not know how to provide therapeutic counsel, which leaves room for the client's autonomic evolution. Without proper collaboration with social professionals, this complex mixture of legal and therapeutic content in the case can lead to unfavorable results. For example, lawyers representing parents might get too involved in their lives, trying to take over their tasks and ending up failing and frustrated.<sup>232</sup>

However, a lack of social and therapeutic training, combined with the importance attributed to children's best interests by the lawyers who represent their parents, can also lead to over-collaboration with social services: lawyers would be more inclined to collaborate with the welfare authorities, who play a dual role as providers of support for parents and as opponents.<sup>233</sup>

Overcoming these issues of under-collaboration and over-collaboration, focusing on the legal case's relevant social and therapeutic aspects instead of ignoring them or treating them as subtexts, will better serve parents, children, and professionals. The holistic approach mainly enhances collaboration between children's and parents' attorneys. While narrow models encourage viewing these roles in isolation, a collaborative framework identifies shared goals while presenting distinct perspectives to decision-makers. For instance, a child's attorney might advocate for school accommodation based on the child's academic and social development. In contrast, the parent's attorney emphasizes how the lack of such support impacts family stability and parental functioning.

Therapeutic jurisprudence (TJ) suggests such a balanced socio-legal approach. Accordingly, it was proposed as a favorable approach and structure for family courts that might help alleviate some of the flaws

---

<sup>231</sup> As explained by Kierstead, *supra* note 212, at 42–43, the lawyer will usually strive to develop a case theory based on the client's desired outcome, which may lead her to look for specific evidence and ignore others. Social workers and therapeutic professionals usually adopt a more comprehensive approach, integrating all the circumstances.

<sup>232</sup> Rothler, *supra* note 157, at 40. This kind of conduct of lawyers/professionals as "rescuers" who might later become aggressive is compatible with Karpman's "drama triangle." Stephen B. Karpman, *Fairy Tales and Script Drama Analysis*, 7 TRANSACTIONAL ANALYSIS BULL. 26, 39 (1968). The drama triangle is a social model of human interaction often used in psychotherapy. It comprises three characters: the victim, the persecutor, and the rescuer, as roles that people often adopt in interpersonal conflicts. *Id.* Lawyers might begin as rescuers, but when parents fail to follow their instructions, they feel like victims, which leads them to act aggressively toward their clients.

<sup>233</sup> See Glennon, *supra* note 15, at 282–83 (explaining that this dual role might lead lawyers and parents to agree to support plans that do not fit their wishes or needs for fear of vexing the social worker whom they depend upon for a positive evaluation).

when dealing with cases of child neglect.<sup>234</sup> TJ views the law and legal institutions as having the potential to be therapeutic agents. It examines the therapeutic and anti-therapeutic characterizations of the law, policy processes, and the structure of legal institutions, detecting which legal arrangements lead to successful therapeutic outcomes and why. Consequently, it aims to advance human dignity through legal events, using those events as benchmarks to enhance the participants' psychological wellbeing.<sup>235</sup> According to TJ, in family disputes, the formal legal discussion of parenthood and child welfare can provide a therapeutic opportunity to assess relationships, detect strengths, provide the necessary support, and enhance the well-being of parents and children.<sup>236</sup>

As Stephens, Katz, Pisciotto & Lens suggest, a TJ approach in family court could more adequately fulfill the court's primary mission of helping families and the expressed need of parents who participate in the proceedings and their representatives. Such TJ approach includes being adequately treated by judges, reduced caseload that would help professionals form closer relationships with the parents, attention to parents' trauma, a collaborative environment that includes the parents and considers their opinions, assisting parents in preparing for court hearings, avoiding punishing attitude, and celebrating accomplishments.<sup>237</sup>

Stephens, Katz, Pisciotto & Lens and Gal & Schilli-Jerichower point to the crucial role of judges and the importance of adopting TJ style judging, including acknowledging the parents' emotional reactions and their individuality, building relationships over time, compassion, and support.<sup>238</sup> Gal and Schilli-Jerichower add that a TJ-oriented definition

---

<sup>234</sup> See generally, Stephens, Katz, Pisciotto & Lens, *supra* note 1; Gal & Schilli-Jerichower, *supra* note 201, at 185–86.

<sup>235</sup> TJ was founded by David Wexler and Bruce Winick in the late 1980s and is considered part of the “comprehensive law movement.” See Susan Daicoff, *The Comprehensive Law Movement*, 19 *TOURO L. REV.* 825 (2004). It views the law and legal institutions as therapeutic agents. TJ strives to integrate treatment services with judicial case processing, provide ongoing judicial intervention, close monitoring of and immediate response to behavior, and create multidisciplinary involvement and collaboration with community-based and government organizations. *JUDGING IN A THERAPEUTIC KEY: THERAPEUTIC JURISPRUDENCE AND THE COURTS 7* (Bruce J. Winick & David B. Wexler eds., 2003). Different aspects of TJ are practiced in various “problem-solving courts,” and the desired outcomes include psychological well-being, health, dignity, and compassion, alongside the traditional legal considerations of due process, civil liberties and rights, and economic efficiency. David C. Yamada, *Teaching Therapeutic Jurisprudence*, 50 *U. BALT. L. REV.* 425, 431, 433 (2021). See generally Michael L. Perlin & Meghan Gallagher, *Why a Disability Rights Tribunal Must Be Premised on Therapeutic Jurisprudence Principles*, 10 *PSYCH. INJ. & L.* 244 (2017) (discussing the connection of disability rights tribunals, problem-solving courts, and TJ).

<sup>236</sup> Susan L. Brooks, *Therapeutic Jurisprudence and Preventive Law in Child Welfare Proceedings: A Family Systems Approach*, 5 *PSYCH., PUB. POL'Y & L.* 951, 951–54 (1999); Kierstead, *supra* note 212; Stephens, Katz, Pisciotto & Lens, *supra* note 1, at 493–94; Barbara A. Babb, *An Interdisciplinary Approach to Family Law Jurisprudence: Application of an Ecological and Therapeutic Perspective*, 72 *IND. L.J.* 775 (1997).

<sup>237</sup> Stephens, Katz, Pisciotto & Lens, *supra* note 1, at 493–94.

<sup>238</sup> *Id.* at 294–95. For scholarship elaborating on TJ in family courts and child welfare issues, see, e.g., Kierstead, *supra* note 212, at 33; Gal & Schilli-Jerichower, *supra* note 201, at 187 (elaborating on the principles of therapeutic judging that have been developed in the context of problem-solving courts involving “(1) the expression of empathy toward family members, including

of child neglect examines the full range of the child's changing needs and how these needs are satisfied rather than focusing on the parents' behavior or omissions.<sup>239</sup> Another TJ-related child welfare solution articulated by Brooks and Ronen is the practice of open adoption, as opposed to the more common closed adoption practice that does not answer the therapeutic needs of many children.<sup>240</sup>

Acknowledging the socio-legal nature of child welfare cases might also affect the prolongment of the proceedings for rehabilitation purposes, which is also one of TJ's characteristics portrayed in the conduct of community courts.<sup>241</sup> A socio-legal therapeutic jurisprudence approach would also challenge the practice of closing cases once parental care reaches a minimal threshold. Instead, it would require that proceedings conclude only after establishing and monitoring long-term support systems. This ensures parents with disabilities have sustained success, prevents cyclical system re-entry, and transforms institutions from reactive to proactive entities.

Despite TJ's apparent relevance to child welfare, its implementation requires caution given disability rights advocates' concern that therapeutic discourse can undermine rights advancement.<sup>242</sup> Arstein-Kerslake and Black propose guidelines for TJ implementation that protect both disability rights and individual wellbeing.<sup>243</sup> Their approach aligns TJ with critical disability theory, prioritizing autonomy and preferences of people with disabilities while recognizing potential threats to dignity. In child welfare tribunals, this means balancing interdisciplinary collaboration with privacy rights — requiring attorneys to contribute to therapeutic outcomes while maintaining client confidentiality.<sup>244</sup>

While the tribunal's collaborative structure is valuable, its primary function remains dispute *management* rather than mere *resolution*, with parenting disability rights evolving through case adjudication. Given the fundamental rights involved, rights-promoting adversarial procedures should be the dominant approach, particularly for high-conflict cases, while maintaining other interest-based options.<sup>245</sup>

---

those accused of abuse or neglect; (2) using dialectic communication rather than lecturing; (3) involving relatives; (4) expressing satisfaction and happiness or disappointment and sadness according to the degree to which the parents achieved their therapeutic goals; and (5) addressing the family holistically").

<sup>239</sup> Gal & Schilli-Jerichower, *supra* note 201, at 184.

<sup>240</sup> Brooks & Ronen, *supra* note 17, at 31.

<sup>241</sup> Tali Gal & Hadar Dancig-Rosenberg, *Evaluating the Israeli Community Courts: Key Issues, Challenges and Lessons*, 62 INT'L ANNALS CRIMINOLOGY 104, 107 (2024).

<sup>242</sup> Anna Arstein-Kerslake & Jennifer Black, *Right to Legal Capacity in Therapeutic Jurisprudence: Insights from Critical Disability Theory and the Convention on the Rights of Persons with Disabilities*, 68 INT'L J.L. & PSYCHIATRY, 2020, at 1, 3 (broadly addressing the use of TJ in disability rights cases, particularly in legal capacity and finding that although TJ initially highlighted the importance of autonomy as enhancing wellbeing, over the years, legal capacity rights were often overlooked in the TJ process mainly due to the contradiction between therapy and disability rights, which is also relevant for child welfare cases).

<sup>243</sup> *Id.* at 4.

<sup>244</sup> *Id.* at 8.

<sup>245</sup> Jennifer F. Lynch, *Beyond ADR: A Systems Approach to Conflict Management*, 17 NEGOT. J. 207 (2001).

Attorneys, especially, must maintain ethical obligations to clients, even when collaborating with court teams or addressing broader community issues.<sup>246</sup> Given child welfare cases' tendency toward therapeutic interests and professional paternalism (as described in this Section above), the design requires careful checks and balances to prioritize rights promotion and establish specific ethical guidelines for legal representation that balance both legal and therapeutic objectives.

### 5. Resources

The fifth DSD component addresses *resources*. System design requires understanding available and potential resources for implementation and evaluation.<sup>247</sup> Within disability-rights-based DSD, resource considerations encompass four key disability rights issues, beginning with accommodation cost justification.<sup>248</sup>

#### *i. Legitimizing the Cost of Disability and the Necessary Accommodations*

Since disability rights advancement necessitates resource redistribution,<sup>249</sup> designers must establish legitimacy for associated costs. Implementing a new or revised child welfare framework encompasses legislative changes, funding allocation for parent support services, and court rulings on budgetary matters affecting accessibility and accommodations. This underscores the importance of building an ideological foundation that validates parenting disability rights and justifies the requisite financial investments.

The legitimization and need for resource-allocation to disability parenthood rights echoes Powell's writing on resource allocation for care.<sup>250</sup> As she writes, as a result of current policy, many people with disabilities (and their family members) lack access to paid care, pushing them to "choose" institutional solutions and further distancing them from society.<sup>251</sup> In child welfare cases, this lack of access to care work within the framework of the family results in the removal of children from their homes.

Public consent is crucial for resource allocation. As Braswell explains, this entails altering the able-bodied conception of

---

<sup>246</sup> Arstein-Kerslake & Black, *supra* note 242, at 4.

<sup>247</sup> AMSLER, MARTINEZ & SMITH, *supra* note 7, at 35.

<sup>248</sup> Rothler, *supra* note 9, at 34.

<sup>249</sup> Mor, *supra* note 51, at 628, 645. See Ziv, *supra* note 165 (discussing distributive justice and disability).

<sup>250</sup> Powell, *supra* note 52, at 1206. As Powell elaborated, supporting Fink's writing, Fink, *supra* note 135, this need to allocate resources addressing the needs of disabled people, their children, and care persons while advancing inclusivity and dignity is crucial for the next step in advancing disability rights in general. Powell, *supra* note 52, at 1201. Powell addresses explicitly the practice of institutionalizing people with disabilities and argues that allocating significantly more funding for "home and community-based services," making it accessible for more people with disabilities, is not only legally mandated, but tends to be more cost-effective for states, better meet people's healthcare needs, increase employment for family members, and reduce racial disparities. *Id.* at 1202. However, as she explains, acquiring these services is hindered by legal and bureaucratic impediments, placing significant burdens on people with disabilities, their families, and caregivers. *Id.*

<sup>251</sup> Powell, *supra* note 52, at 1192.



parenthood<sup>252</sup> that requires an imaginary “super-competence” — a requirement that damages all parents, primarily parents with disabilities, who are perceived as inherently unfit for parenthood.<sup>253</sup> As explained in Section II.B.2.ii., the false assumption regarding parental independence leads to a lack of public recognition for parental support, rendering parents who need or request such support incompetent and unfit. This approach primarily damages parents with disabilities.<sup>254</sup> Additionally, as elaborated by Francis, parenthood was never at the forefront of the struggle to advance disability rights, which focused on issues that were considered more pressing, such as employment, health care, housing, and legal capacity. It, therefore, failed to challenge parents’ discrimination within the child welfare system.<sup>255</sup>

One way to achieve public consent is by adopting a different approach and definition of parenthood.<sup>256</sup> This first phase of acknowledging the importance of parenthood disability rights by adopting an alternative view of parenting is crucial to justifying resource allocation. The allocation of these resources will entail two main benefits: first, their preventive nature might render the need for child welfare legal intervention unnecessary. Second, their existence will support parenthood disability rights legislation, creating practical accommodation, assistance, and universalizing parenting rights. Without them, legal statutes will remain a dead letter. Empirical findings regarding the importance of preserving relationships with birth parents, even in situations and phases when they are unable to care for their children,<sup>257</sup> should also serve for the legitimization of parenthood disability rights.

Beyond explicitly recognizing resources needed for parenting disability rights, the design must address three additional components: support and assistance mechanisms, social and therapeutic resources, and disability-rights-oriented legal education.<sup>258</sup> These elements transform the ideological commitment to disability parenting rights into practical implementation.

## *ii. Support and Assistance: Lessons from Legal Capacity*

Support and assistance represent essential mechanisms for meaningful disability rights implementation, as recognized by the CRPD.<sup>259</sup> While accessibility provides foundational access (as described

---

<sup>252</sup> Braswell, *supra* note 187 at 240 (addressing motherhood and arguing that the ableistic vision of parenthood mainly damages women).

<sup>253</sup> *Id.* at 240; Harris, *supra* note 4, at 17; ROSEMARIE GARLAND THOMSON, EXTRAORDINARY BODIES: FIGURING PHYSICAL DISABILITY IN AMERICAN CULTURE AND LITERATURE 26 (1997).

<sup>254</sup> Harris, *supra* note 4, at 17.

<sup>255</sup> Francis, *supra* note 3, at 25.

<sup>256</sup> *Id.* at 31 (noting that some organizations, such as the “Lurie Institute for Disability Policy,” have started to devote their attention to reproductive and parenting issues).

<sup>257</sup> Vivek S. Sankaran & Christopher E. Church, *The Ties That Bind Us: An Empirical, Clinical, and Constitutional Argument Against Terminating Parental Rights*, 61 FAM. CT. REV. 246, 257–59 (2023).

<sup>258</sup> Rothler, *supra* note 9, at 41.

<sup>259</sup> CRPD, *supra* note 58 (including in Article 23, “Respect for Home and Family”).

in Section II.B.4.i.), comprehensive personal support systems are crucial for full participation and inclusion.<sup>260</sup> This dual framework establishes both ‘negative’ protections against oppression and ‘affirmative’ rights to support.<sup>261</sup>

The fact that parents with disabilities (like all other parents) require support and assistance in child-rearing is obvious. It was also acknowledged that for many parents, adequate support was the answer for acquiring parenting skills and caring for children<sup>262</sup> and that many times, support means are inadequate.<sup>263</sup> As explained in Section I.B., the question regards the *kind* of support and its *extent*: while some narrow, parental support was considered legitimate, extended types of support were rendered illegitimate, resulting in a denial of support and consequently, the removal of children from their homes. Additionally, as Glennon explains, the very structure of support plans might prove unfit for parents with mental disabilities, and they might also be reluctant to seek support for fear of being stigmatized.<sup>264</sup>

Therefore, when redesigning child welfare systems according to disability rights principles, it is essential to acknowledge parents’ need for support and broaden our vision regarding the nature of this support.<sup>265</sup> As Francis suggests, given the similarities in the importance of their

<sup>260</sup> *Id.* at Arts. 12(3) (concerning legal capacity); 16(2) (fight against exploitation); 19(b) (independent living); 23(2)–(3) (family life); 24(2)(d)–(f), 3(a), and 4 (education); 27(1)(e) (work); 30(4) (participation in cultural life); and 29(a)(iii) (participation in political and public life).

<sup>261</sup> See Robert D. Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making*, 19 HUM. RTS. BRIEF, no. 2, at 8, 9 (2012), for the salience of “support” as a disability rights mechanism throughout the CRPD. Abolishing the policing of families and replacing it with family support is a central claim made by Roberts, *supra* note 83, at 231.

<sup>262</sup> Researchers have reported that parents greatly preferred informal support, which is more emotional and flexible, over formal support, which they found overwhelming and confusing. Glennon, *supra* note 15, at 291; NICHOLSON, BIEBEL, HINDEN, HENRY & STIER, *supra* note 82, at 1482; Elizabeth Lightfoot & Traci LaLiberte, *Parental Supports for Parents With Intellectual and Developmental Disabilities*, 49 INTELL. & DEV. DISABILITIES 388 (2011); Elizabeth Lightfoot, Traci LaLiberte & Minhae Cho, *Parental Supports for Parents with Disabilities: The Importance of Informal Supports*, 96 CHILD WELFARE 89 (2018).

<sup>263</sup> Sharyn DeZelar & Elizabeth Lightfoot, *Parents with Disabilities: A Case Study Exploration of Support Needs and the Potential of a Supportive Intervention*, 100 FAMS. SOC’Y 293 (2019) (pointing to the fact that the overall support networks of parents with disabilities were fragile); see also Sharyn DeZelar & Elizabeth Lightfoot, *Enhancing Supports for Parents with Disabilities: A Qualitative Inquiry into Parent Centered Planning*, 24 J. FAM. SOC. WORK 263 (2021) (elaborating on the benefits of parents-centered planning intervention); Mary Baginsky, *How Parents With Learning Disabilities Lack Support Before, During and After Care Proceedings*, COMMUNITY CARE (June 11, 2024), <https://www.communitycare.co.uk/2024/06/11/how-parents-with-learning-disabilities-lack-support-before-during-and-after-care-proceedings/>.

<sup>264</sup> Glennon, *supra* note 15, at 282, 296–300 (providing examples for modifying support means to accommodate parents with mental disabilities); Elizabeth Lightfoot & Sharyn DeZelar, *Parent Centered Planning: A New Model for Working with Parents with Intellectual and Developmental Disabilities*, 114 CHILD. & YOUTH SERVS. REV., July 2020 (introducing “parent-centered planning,” which includes an individual’s parenting desires and goals, along with the needs of the parent’s child).

<sup>265</sup> Scholarship has elaborated on the necessary support for parents with disabilities within the child welfare system. See Powell, *Under the Watchful Eye*, *supra* note 85, at 2061–64; Powell, *Abolitionist Approach*, *supra* note 85, at 97; Powell, Parish, Mitra, Waterstone & Fournier, *supra* note 6, at 210; Melissa M. Ptaceka, Lauren D. Smitha, Robyn M. Powell & Monika Mitra, *Experiences With and Perceptions of the Child Welfare System During the Perinatal Period of Mothers With Intellectual and Developmental Disabilities*, J. PUB. CHILD WELFARE, June 3, 2024 at 1, 15–22; Sasha M. Albert & Robyn M. Powell, *Supporting Disabled Parents and Their Families: Perspectives and Recommendations from Parents, Attorneys, and Child Welfare Professionals*, 15 J. PUB. CHILD WELFARE, 530, 534 (2021).

depiction as constitutional liberties, the change that the field of *legal capacity* has undergone can and should inspire recognition of parental capacity and the provision of support for parental actions and decisions, as follows.<sup>266</sup>

The human right to legal capacity encompasses both legal personhood and legal agency, allowing individuals to participate in undertakings, transactions, and decisions about their lives. Following recent national and international policy and legislation reforms, the right to receive the necessary *support* in making those decisions has become inherent to the right to legal capacity.<sup>267</sup> “Support” is a broad term encompassing arrangements of varying types and intensities, aiming to enable legal capacity while respecting people’s rights, will, and preferences.<sup>268</sup> Additionally, support systems must include safeguards to protect against abuse equally from others.<sup>269</sup>

As Francis articulates, while legal capacity is the person’s right to make decisions regarding her life, parenting essentially entails a person’s right to make decisions regarding *her child’s* life.<sup>270</sup> Adopting the new paradigm for legal capacity for all, will, therefore, broaden the legitimization of disabled parenthood. Accordingly, Francis suggests that parenthood capacities should be viewed on a spectrum. As contemporary courts should favor limited guardianship, supported decision-making mechanisms, and tailored safeguards over plenary guardianship,<sup>271</sup> so should the child welfare system allow for a limited exercise of parental duties rather than terminate parental relations.<sup>272</sup>

Currently, child welfare proceedings offer limited ‘permanency’ options for removed children: return to parent, adoption, placement with kin, or continued Social Services care. This binary approach — either full parental care or removal to foster care — fails to address the nuanced needs of parents with disabilities and their children. The system requires

<sup>266</sup> Francis, *supra* note 3, at 32.

<sup>267</sup> CRPD, *supra* note 58, at Article 12(3); U.N. COMMITTEE ON THE RIGHTS OF PERSONS WITH DISABILITIES, GENERAL COMMENT NO. 1 (2014) [hereinafter General Comment No. 1]: ARTICLE 12: EQUAL RECOGNITION BEFORE THE LAW, ¶ 16; Anna Arstein-Kerslake & Eilíonóir Flynn, *The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: A Roadmap for Equality Before the Law*, 20 INT’L J. HUM. RTS. 471, 476–477 (2016) (defining means of support to exercise legal capacity).

<sup>268</sup> Arstein-Kerslake & Flynn, *supra* note 267, at 478. This broad definition of support includes formal state-operated support and informal support by family members or friends. Accordingly, a person should be able to choose one or more support persons to assist them with certain decisions, peer support or advocacy, including self-advocacy support, for other kinds of decisions, and assistance in communication in other instances. Given the pros and cons of each type of support, Arstein-Kerslake and Flynn suggest that best legal capacity systems should include a variety of supports, both formal and informal and that according to the General Comment’s principles, the support will be tailored to each person’s needs, or at least meet a range of different needs. *See also* General Comment No. 1, *supra* note 267, ¶ 18. Close attention should be given to implementing supported decision-making mechanisms, ensuring they provide genuine choice and control rather than serve a bureaucratic purpose. Anna Arstein-Kerslake, Joanne Watson, Michelle Browning, Jonathan Martinis & Peter Blanck, *Future Directions in Supported Decision-Making*, 37 DISABILITY STUDS. Q., no. 1, 2017, <https://dsq-sds.org/index.php/dsq/article/view/5070/4549>.

<sup>269</sup> General Comment No. 1, *supra* note 267, ¶ 20; Determining adequate safeguards is a delicate task since the protection must respect the person’s rights, will, and preferences (or at least, their best interpretation), *id.* ¶ 21, including the right to take risks and make mistakes, *id.* ¶ 20.

<sup>270</sup> Francis, *supra* note 3, at 31.

<sup>271</sup> Arstein-Kerslake & Flynn, *supra* note 267, at 479.

<sup>272</sup> Francis, *supra* note 3, at 32.

more creative, individually-tailored solutions that could include supported parenting arrangements or maintaining meaningful parental roles even when children reside elsewhere.

As mentioned above, a critical aspect of the new legal capacity paradigm is the right to receive support in exercising one's legal capacity. This aspect is vital to parenting since, as Francis notes, courts tend to consider parenting as a "solo operation" and, therefore, evaluate the skills of parents with intellectual disabilities without regard to the support that is available to them. Based on these assessments, they might terminate parental relations, stating that it is unreasonable to provide long-lasting support.<sup>273</sup>

Similarly, recent British research has brought to light the court's and professionals' tendency to define situations of "substituted parenting" as one that justifies the separation of children from their parents. It happens when the authorities seem to think the support they have identified as necessary is too extensive. They consider the high level of support required to equate to "substituted parenting," which, they say, is detrimental as it confuses children as to who the parent is.<sup>274</sup>

Answering this difficulty is the path legal capacity legislation has paved in recent years. It prioritizes people's right to exercise their legal capacity according to their will and preferences while acknowledging their right to support in all aspects of their lives. It focuses on people with intellectual and mental disabilities, broadening the scope of instrumental and non-instrumental support. Since support — broadly defined — was determined as inherent to legal capacity, new support means can be legitimized for parenting, extending their scope from limited instrumental support usually provided for parents with physical disabilities to broad care that includes emotional aspects and formal recognition of other significant adults such as family and caretakers, without jeopardizing the original parental connections.<sup>275</sup>

As Francis notes, supportive arrangements for parents might include extensive instrumental support of care, such as daily home services and communal living arrangements, opening new possibilities for meaningful parental involvement.<sup>276</sup> They can also include broad care support, such as acknowledging other adults' participation in child-rearing. Therefore, it holds the promise to influence the legitimization of disabled parenthood, broadening the definition of support to realize it, and opening opportunities for delegating the exercise of parental decisions.<sup>277</sup>

---

<sup>273</sup> *Id.* at 26, 28 (noting that the press of time, common in these kind of cases, may be particularly difficult for parents with intellectual disabilities, who may need more services, take longer to access these services and take longer to benefit from them).

<sup>274</sup> TILBURY & TARLETON, *supra* note 29.

<sup>275</sup> Francis, *supra* note 3, at 33.

<sup>276</sup> *Id.*

<sup>277</sup> As Harris, *supra* note 4, at 14, explains, this delegation should not be viewed as different from the "conventional" delegation of the exercise of parental decisions to other people who care for the house and children, such as nannies or housecleaners. Consequently, parents with disabilities would not be stripped of their parental status if they cannot execute the tasks associated with that role.

*iii. Social, Therapeutic, and Care Resources*

Therapeutic, care, and social resources are crucial in implementing disability rights within child welfare design. While acknowledging tensions between therapeutic approaches and disability rights,<sup>278</sup> therapeutic support often plays a significant role for parents with disabilities and their children. Therefore, system design must ensure accessible therapeutic and social resources aligned with disability rights principles.<sup>279</sup> Some of these resources can be accessed through existing public health and social institutions, minimizing additional budgetary impact.

This exhaustion of benefits and rights has the potential to have an immediate effect on parenting. For instance, housing benefits will help parents better care for their children. A father entitled to weekly counseling sessions will acquire more skills that reduce the need for intrusive actions. Similarly, disability benefits or other means of support for *children* help to alleviate the burden and stress from their parents.

Social and therapeutic supports form vital infrastructure for child and family wellbeing. These include parental leave policies, healthcare access, social services, and benefits that ensure children's rights to proper nutrition, healthcare, parental care, and living conditions.<sup>280</sup> As Gal explains, support networks and institutions can provide parents with information, education, and assistance accessing rights and benefits.<sup>281</sup> Importantly, these services should be delivered respectfully, recognizing parents' capacity for growth and changing resource needs over time.<sup>282</sup>

However, while the exhaustion of therapeutic services for children within the child welfare system is trivial, suggesting those services for parents is more complicated. For example, as mentioned in Section I.B., parents might be reluctant to admit to having a disability, (rightfully) fearing that this might damage their chances of keeping their children. This practice of hiding the disability does not provide grounds for seeking and accepting assistance. Second, therapy for parents within the framework of a child welfare case might seem coercive, raising

---

<sup>278</sup>See discussion *supra* Section II.B.4.iv.

<sup>279</sup>The lack of disability rights implementation in mental health systems was addressed by the World Health Organization (WHO), encouraging governments and policy-makers to transform mental health systems and base them on recovery, rights, and inclusion. The report focuses on policy reform, law, services, and building the capacity of stakeholders and groups to address stigma and discrimination and to implement rights-based approaches in mental health services and the community. WORLD HEALTH ORG. & OFF. OF THE HIGH COMM'R OF HUM. RTS., MENTAL HEALTH, HUMAN RIGHTS AND LEGISLATION: GUIDANCE AND PRACTICE (Oct. 9, 2023), [https://www.ohchr.org/sites/default/files/documents/publications/WHO-OHCHR-Mental-health-human-rights-and-legislation\\_web.pdf](https://www.ohchr.org/sites/default/files/documents/publications/WHO-OHCHR-Mental-health-human-rights-and-legislation_web.pdf); Glennon, *supra* note 15, at 283 (noting that parents with mental disabilities might encounter labor problems, which might lead to difficulties in attaining welfare assistance).

<sup>280</sup>Tali Gal, *A Socioecological Model of Children's Rights*, in THE OXFORD HANDBOOK OF CHILDREN'S RTS. LAW 119 (Jonathan Todres & Shani M. King eds., 2020).

<sup>281</sup>*Id.* at 130.

<sup>282</sup>Francis, *supra* note 3, at 27 (noting a significant theme in the case law is viewing intellectual disabilities as unchangeable despite evidence that supports their abilities to learn and develop capabilities with appropriate services).

dilemmas regarding combining legal and therapeutic aspects, as discussed in Section II.B.4.iv.<sup>283</sup>

Finally, social and therapeutic resources should also consider parents whose children were already removed from their care. Research has shown that those parents felt abandoned by the system, feeling angry, shocked, confused, and grieved, even suicidal and self-harming, over the removal of their children. Proper attendance to their needs would help to alleviate at least some of these negative consequences.<sup>284</sup>

#### *iv. Disability-Oriented Legal Education and Professional Training*

The final resource component in Disability-Rights-Based DSD is *legal education and professional training*. While legal representation is crucial for accessing rights within child welfare systems,<sup>285</sup> effective advocacy requires disability-conscious representatives committed to removing physical, communicational, and stigma-based barriers.<sup>286</sup>

Therefore, disability-sensitive legal education and rights training<sup>287</sup> for legal professionals (lawyers and judges)<sup>288</sup> represent a crucial resource for advancing parental disability rights. This education, deliverable through law schools and legal clinics,<sup>289</sup> should encompass disability studies theory, the evolution from medical to social approaches, disability rights principles, legislation, and an understanding of how people with disabilities interact with justice systems.<sup>290</sup>

<sup>283</sup> Stephens, Katz, Pisciotto & Lens, *supra* note 2, at 493–94; Babb & Moran, *supra* note 218, at 37, 43 (suggesting that therapeutic attention should also be given to the parents and not only the children within the framework of TJ).

<sup>284</sup> HUNTER, THOMAS & CAMPBELL, *supra* note 19.

<sup>285</sup> Ravit Alfandari, *Legal Advocacy for Parents in Child Protection: Not a Question of If, But a Question of How*, 49 BRIT. J. SOC. WORK 1601 (2019). While highlighting the legal advantages of being represented by a council, the research has also found the key role lawyers had in providing parents with emotional support and the positive evaluation of the representation by the welfare authority professionals. *Id.* at 1608.

<sup>286</sup> Mor, *supra* note 51, at 637. According to the American Bar Association (ABA) Model Rules of Professional Conduct, when an attorney represents a client “with diminished capacity,” they “shall, as far as reasonably possible, maintain a normal client-lawyer relationship with the client” MODEL RULES OF PRO. CONDUCT r. 1.14 (AM. BAR ASS’N 2002). For recent comments regarding applying this provision and suggesting a revision in drafting legal ethics rules about the representation of clients with disabilities and mental health issues, see David R. Kanter, “Normal,” 33 S. CAL. REV. L. & SOC. JUST. 427 (2024) (pointing to the need to involve therapeutic professionals in the drafting process, distinguish between different “diminished capacity” situations, and provide more meaningful education on this matter for law students as future lawyers, moving towards a “client-centered-representation”).

<sup>287</sup> EILIONÓIR FLYNN, *DISABLED JUSTICE? ACCESS TO JUSTICE AND THE UN CONVENTION ON THE RIGHTS OF PEOPLE WITH DISABILITIES* (2015).

<sup>288</sup> Stephanie Ortoleva, *Inaccessible Justice: Human Rights, Persons with Disabilities and the System*, 17 ISLA J. INT’L & COMPAR. L. 2 (2011) (discussing the importance of training professionals, community education, and awareness); Powell, Parish, Mitra, Waterstone & Fournie *supra* note 6, at 203 (discussing further claims regarding professional training).

<sup>289</sup> See generally, J. Damian Ortiz, *The Need to Make Clinical Teaching Mandatory as Part of the Experiential Methodology to Prepare Students for the Practice of Law in the Twenty-First Century*, 57 UIC L. REV. 697 (2024).

<sup>290</sup> Several authors have elaborated on disability-oriented lawyers and law students. See, e.g., Rothler, *supra* note 157, at 36–40; see also Boulding & Brooks, *supra* note 207; Voula Marinos & Lisa Whittingham, *The Role of Therapeutic Jurisprudence to Support Persons with Intellectual and*

Disability-oriented legal representation rests on fundamental knowledge of disability rights ('hard' knowledge) and expertise in managing client-lawyer relationships when disability is present ('soft' knowledge).

Powell broadly addressed the first, claiming that although the ADA has, so far, done little to protect disabled people's parenting rights (as elaborated in Section I.B.), when used correctly, it can serve as an essential tool for family law attorneys. Hence, she contends that family law practitioners must comprehensively understand the ADA's strengths and limitations.<sup>291</sup> This includes ensuring full and broad access to the courtroom, including physical access,<sup>292</sup> communication access, and nondiscriminatory conduct.<sup>293</sup> Additionally, lawyers must provide accommodations for clients in their offices to ensure the client's full participation in the representation.<sup>294</sup> Powell concludes that attorneys should use three main strategies to ensure that the rights of parents with disabilities are protected: raise the ADA early and often, educate the courts by providing social science evidence regarding misconceptions about parents with disabilities, and make sure that judges base their decision on the individual's circumstances as required by the ADA and not on prejudice and bias;<sup>295</sup> and partner with disability rights organizations.<sup>296</sup> As Powell elaborates, attorneys should advocate for more training on parents with disabilities and the ADA for judges and court personnel.<sup>297</sup> The importance of educating child welfare professionals and developing coordinated and comprehensive treatment services was also addressed by Glennon<sup>298</sup> as a means to diminish discrimination and prejudice against parents and the misapplication of the ADA in the child welfare arena.

This professional education is particularly crucial given children's frequent interactions with foster parents, welfare officials, attorneys, and judges. When these actors maintain ableist perspectives toward parents with disabilities, their attitudes may influence children's views, creating additional barriers to reunification and undermining disability rights-based solutions. This concern extends to cases involving young children whose attorneys may present positions on their behalf, making it essential that these legal representatives embrace disability rights frameworks to prevent perpetuating systemic discrimination.

---

*Developmental Disabilities in the Courtroom: Reflections from Ontario, Canada*, 63 INT'L J.L. & PSYCHIATRY 18 (2019); Henry Dlugacz & Christopher Winner, *The Ethics of Representing Clients with Limited Competency in Guardianship Proceedings*, 4 ST. LOUIS U. J. HEALTH L. & POL'Y 331 (2011).

<sup>291</sup> Powell, *supra* note 2, at 38.

<sup>292</sup> *Id.* at 44.

<sup>293</sup> *Id.* at 45.

<sup>294</sup> *Id.* at 46. Powell mentions the National Council on Disability, NCD ROCKING THE CRADLE, *supra* note 2, finding that even though Title III of the ADA mandates private attorneys to provide clients with disabilities reasonable accommodations since attorneys are generally required to absorb the costs of accommodations, they may decline these kind of cases, justifying the declining on other grounds. Powell, *supra* note 2, at 46.

<sup>295</sup> Powell, *supra* note 2, at 44, 47.

<sup>296</sup> *Id.* at 46.

<sup>297</sup> *Id.* at 47 (citing NCD ROCKING THE CRADLE, *supra* note 2).

<sup>298</sup> Glennon, *supra* note 15, at 292–93.

The second foundation of a disability-oriented representation is “soft” knowledge regarding the client-lawyer relationship in the presence of a disability. Boulding and Brooks addressed this issue broadly and asserted that representation in disability-related legal systems<sup>299</sup> should aim to foster positive and relationship-centered lawyer-client relationships<sup>300</sup> based on accessibility, with particular attention and respect to the client’s wishes regarding the legal procedure.<sup>301</sup> Powell, Parish, Mitra & Nicholson further elaborate on attorneys’ need for a profound understanding of mental health, including assisting clients beyond litigation and their role in access to additional legal services that the parents may require.<sup>302</sup>

Rovner<sup>303</sup> shed light on the way litigation, which is aimed at defining and shaping the disability in a way that is compatible with the ADA (or other relevant legislation) and the theory of the case, may be antithetical to the way the client sees herself, and therefore harm the genuine identity of disabled people.<sup>304</sup> Applying her scholarship on child welfare cases draws two main conclusions: the first, that parents should be given complete information and be consulted regarding the way their disability is portrayed in the litigation; the second, that child welfare cases (as opposed to cases where compensatory damage is at the focus) may provide grounds for litigation that acknowledges the disability and the difficulties that might arise from it, on the one hand, while still stressing positive aspects regarding the person, not just for the sake of being politically correct but as the case’s strategy, which requires putting the parents’ strengths at the front.

Given the intersectionality of disability and poverty,<sup>305</sup> lessons of representation can be learned from the practice of “poverty-informed social work” and poverty-informed lawyering. This paradigm calls for professionals to stand alongside their clients and empower their fight. It calls for culturally sensitive representation, acknowledging the power differences between the lawyers and their clients. This kind of sensitivity sheds a different light on clients’ behaviors, such as reluctance to cooperate, delay, or hiding information. It views the professional-client

---

<sup>299</sup> Boulding & Brooks, *supra* note 207, at 451. *See generally* Brooks & Madden, *supra* note 157.

<sup>300</sup> Boulding & Brooks, *supra* note 207, at 451.

<sup>301</sup> *See* Perlín & Weinstein, *supra* note 208, at 78. Litigating and judging in child welfare cases can also be very stressful and expose professionals to vicarious trauma. For a recent special issue on judicial and lawyer well-being and stress, *see* JUDICIAL AND LAWYER WELLBEING AND STRESS, 31 PSYCHIATRY, PSYCH. & L. 315–586 (2024).

<sup>302</sup> Powell, Parish, Mitra & Nicholson, *supra* note 29, at 95–105 (noting that such assistance includes taking more time to explain the legal process, assisting with administrative tasks, and coordinating with other supports and services, including access to legal assistance in other areas).

<sup>303</sup> Laura L. Rovner, *Perpetuating Stigma: Client Identity in Disability Rights Litigation*, 2001 UTAH L. REV. 247.

<sup>304</sup> Drawing from Martha Minow’s writing on the way identity is shaped through relationships. *See* MARTHA MINOW, NOT ONLY FOR MYSELF: IDENTITY, POLITICS, AND THE LAW 30–58 (1997); Martha Minow, *Identities*, 3 YALE J. L. & HUMANS. 97 (1991).

<sup>305</sup> *See, e.g.*, Glennon, *supra* note 15, at 292 (explaining that poverty (and race) are risk factors for parents with mental illnesses who are involved in the child welfare system because they must turn to the public system for assistance, thus risking separation from their children); DOROTHY ROBERTS, SHATTERED BONDS: THE COLOR OF CHILD WELFARE 16–19 (2002); Powell, *Abolitionist Approach*, *supra* note 85, at 92.



relationship as an arena that can enhance these power differences or social justice and asks lawyers to choose the latter.<sup>306</sup>

As elaborated in Section II.B.4.iv., apart from these aspects of representation, it is vital to address the unique position of parents' attorneys in child welfare cases, which sometimes call for enhanced collaboration with the welfare authorities for the overall well-being of the family — parents and children alike. It is, therefore, essential to develop special ethical rules that will allow lawyers to collaborate with the welfare authorities, therapeutic professionals, and guardians regarding the children, keep parents' authentic voices at the forefront of the case, and follow rules of zealous advocacy.

#### 6. *Successfulness, Accountability, and Learning*

Aligned with its practice-oriented approach, DSD concludes with an evaluation component: its sixth element centers on *successfulness*, *accountability*, and *learning*. For stakeholders to develop confidence in and utilize the dispute system, they require comprehensive information about its effectiveness.<sup>307</sup> The evaluation must encompass and critically examine all five preceding elements: goals, stakeholders, context and culture, process and structure, and resources<sup>308</sup> while progressing beyond mere conceptual translation to a dedicated commitment to achieving its multifaceted objectives.<sup>309</sup>

Essentially, an effective system accomplishes its intended goals. Consequently, the evaluation will be intricately linked to the system's specific objectives, assessing their impact on addressing individual child welfare conflicts, including prevention, management, and resolution.<sup>310</sup> However, by disability-rights-based DSD guidelines,<sup>311</sup> *successfulness* extends beyond immediate conflict resolution. It should also be defined by the system's capacity to achieve broader parenting goals, such as developing supportive mechanisms for parents, strengthening parental relationships, elevating public understanding of disabled parenting's advantages and significance, and dismantling the pervasive stigma and bias prevalent in this domain.

The assessment must thoroughly investigate the design's universal applicability and accessibility, particularly for parents with diverse disabilities, with special attention to those with mental and intellectual disabilities. It should ensure that beyond resolving specific disputes, the system contributes to developing constructive and positive approaches for the future collective benefit of individuals with disabilities. The evaluation should examine whether each dispute is comprehensively settled and serves as a learning opportunity, ultimately aiming to advance parenthood rights. An additional critical aspect of a successful

---

<sup>306</sup> MICHAL KRUMER-NEVO, *RADICAL HOPE: POVERTY-AWARE PRACTICE FOR SOCIAL WORK* (2020).

<sup>307</sup> AMSLER, MARTINEZ & SMITH, *supra* note 7, at 86.

<sup>308</sup> Smith & Martinez, *supra* note 8, at 132–33.

<sup>309</sup> ROGERS, BORDONE, SANDER & MCEWEN, *supra* note 7, at 320.

<sup>310</sup> AMSLER, MARTINEZ & SMITH, *supra* note 7, at 88 and 130 (noting that measuring conflict prevention is challenging).

<sup>311</sup> Rothler, *supra* note 9.

design is incorporating disability rights and disability consciousness within judicial discourse.

All parenthood policies, legislation, and tribunals should undergo rigorous evaluation through the lens of disability rights principles. The assessment team must include parents with disabilities who have personally navigated child welfare legal proceedings alongside other pertinent stakeholders. The evaluation should systematically and comprehensively scrutinize the system's success in achieving disability rights and parenthood goals while adhering to broader DSD considerations. These include minimizing transaction costs, ensuring outcome satisfaction across participants, fostering disputant relationships, and addressing dispute recurrence.<sup>312</sup> The system should implement continuous assessment mechanisms that enable judges to re-evaluate periodically and, if necessary, correct their decisions.

Addressing the *accountability* dimension of the DSD assessment requires a deep examination of the willingness to accept responsibility and be answerable for actions. This involves exploring the intricate relationships between the system's designer and its oversight body and between system managers and stakeholders.<sup>313</sup>

Effective system accountability demands a balanced and equitable approach to responsibility across all participants in child welfare proceedings. It requires that the mechanisms for ensuring compliance and adherence apply uniformly without privileging any group of actors. When accountability is used inconsistently, it undermines the fundamental integrity of the dispute-resolution process, creating power dynamics that can obstruct meaningful engagement and comprehensive problem-solving. The ideal system should establish a framework where all participants — parents, institutional actors, professionals, and support services — are equally subject to the same accountability standards, fostering a more just and transparent approach to addressing child welfare challenges.

On a functional level, equitable accountability will dramatically diminish existing power imbalances and help alleviate feelings of marginalization and unequal treatment among parents, avoiding their systematic disengagement, feeling unheard, disempowered, and increasingly alienated from the system designed to support them.

Initially, the child welfare system's diverse operators — including professionals, policymakers, and parents with disabilities — must verify that child welfare cases are handled in strict accordance with disability rights principles. This verification must now explicitly include mechanisms to ensure institutional accountability, creating reciprocal responsibility among all system participants. Subsequently, system designers must identify opportunities for continuous improvement, drawing insights from accumulated case-by-case knowledge. Furthermore, designers should facilitate user understanding by disseminating information on system operations to people with

---

<sup>312</sup> AMSLER, MARTINEZ & SMITH, *supra* note 7.

<sup>313</sup> *Id.* at 75.

disabilities and professionals in an accessible manner,<sup>314</sup> ensuring transparency in information processes.<sup>315</sup>

These strategic steps aim to enhance the system's credibility, foster trust in its processes, amplify the cooperation and participation of people with disabilities and professionals, and encourage ongoing feedback.<sup>316</sup> When executed effectively, these measures would justify the continued resource investment in system development and promote a more comprehensive realization of parenthood disability rights and support measures.<sup>317</sup>

The learning component serves as the concluding element of this final DSD stage. Guided by learning principles, the system should transcend mere dispute processing. It must incorporate an educational and training mechanism for all stakeholders, generating a dynamic learning process from accumulated knowledge to advance parenthood disability rights.

### CONCLUSION

This article addresses the persistent challenge of implementing disability rights within child welfare proceedings, offering a novel, practical framework for systemic reform by applying the Disability-Rights-Based Dispute System Design. The analysis reveals how current child welfare systems often fail to meaningfully incorporate disability rights principles despite existing legal protections, leading to discriminatory outcomes for parents with disabilities.

The article's primary contribution is bridging the gap between theoretical disability rights and practical implementation in child welfare settings. Applying the Disability-Rights-Based DSD framework provides a structured reform approach that addresses preventive measures and judicial proceedings. This comprehensive framework encompasses several key innovations.

A fundamental aspect of this framework is its reconceptualization of parenting and disability. It moves beyond the traditional focus on functional care to embrace broader concepts of interdependence and relational parenting. This shift challenges the prevailing tendency to view parents with disabilities in isolation and instead recognizes the legitimate role of support networks in all parenting contexts.

The framework provides practical guidance for implementing disability rights at multiple levels of the child welfare system. It emphasizes developing early intervention and support mechanisms to prevent unnecessary court involvement while restructuring court processes to ensure meaningful accessibility and accommodation. It calls for creating comprehensive support systems that legitimize various forms of assistance without stigmatizing parents, establishing disability-conscious professional training and education, and implementing robust accountability measures to ensure ongoing system improvement.

---

<sup>314</sup> *Id.* at 37.

<sup>315</sup> Smith & Martinez, *supra* note 8, at 132–33.

<sup>316</sup> *Id.*

<sup>317</sup> AMSLER, MARTINEZ & SMITH, *supra* note 7, at 74.

Notably, the framework addresses the complex balance between therapeutic and rights-based approaches in child welfare. It demonstrates how therapeutic jurisprudence principles can be incorporated while maintaining strong protections for parental rights and avoiding the pitfalls of medical model approaches to disability.

The implications of this redesign extend beyond parents with disabilities. By adopting universal design principles and emphasizing accessible, supportive approaches to family preservation, the framework has the potential to benefit all families involved in the child welfare system, particularly those from marginalized communities. It promotes a more nuanced understanding of family support needs and challenges the binary thinking that often characterizes child welfare decision-making.

This framework provides a roadmap for concrete policy reform and system redesign. Its emphasis on prevention, support, and rights-based intervention offers a promising path toward a more equitable and effective child welfare system. The ultimate goal of this redesign is to create a child welfare system that truly serves its intended purpose: supporting families and maintaining children's well-being while respecting the fundamental rights and dignity of parents with disabilities. This article contributes to the broader project of creating more just and inclusive social institutions by providing practical tools for achieving this balance.

# Laws, Policies, and Regulations Affecting Florida's Indian River Lagoon

VICTORIA CARPENTER\*

## TABLE OF CONTENTS

I. THE HISTORY OF THE INDIAN RIVER LAGOON: AN OVERVIEW.....	289
II. AN ESTUARY IN DISTRESS: A CALL TO ACTION.....	290
III. FEDERAL LAWS, REGULATIONS, AND POLICIES THAT AFFECT THE INDIAN RIVER LAGOON .....	291
<i>The Federal Water Pollution Control Act (FWPCA) of 1948.....</i>	292
<i>The National Environmental Policy Act (NEPA) of 1970 .....</i>	292
<i>The Clean Water Act (CWA) of 1972 .....</i>	293
<i>The Coastal Zone Management Act (CZMA) of 1972 .....</i>	295
<i>The Marine Mammal Protection Act (MMPA) of 1972.....</i>	295
<i>The Endangered Species Act (ESA) of 1973.....</i>	296
<i>The National Estuary Program (NEP) of 1987 .....</i>	297
<i>The North American Wetlands Conservation Act (NAWCA) of 1989 .....</i>	297
<i>The Estuary Restoration Act (ERA) of 2000.....</i>	298
<i>The Comprehensive Everglades Restoration Plan (CERP) of 2000 .....</i>	298
<i>The Bipartisan Congressional Estuary Caucus of 2017 .....</i>	299
<i>The Bipartisan Infrastructure Law of 2021 .....</i>	300
IV. STATE LAWS, REGULATIONS, AND POLICIES THAT AFFECT THE INDIAN RIVER LAGOON.....	300
<i>The Florida Air and Water Pollution Control Act (FAWPCA) of 1967 .....</i>	301

---

\* Acknowledgements: First, I express my deepest appreciation for Dr. Duane De Freese for allowing me to intern with the Indian River Lagoon National Estuary Program (IRLNEP). You are a fantastic mentor and inspiration to me. Your confidence in me is a gift I will always cherish. Thank you. Secondly, I am incredibly grateful for the rest of the IRLNEP team: Kathy Hill, Daniel Kolodny, Erin Bergman, KJ Ayres, Caleta Scott, Heather Stapleton, and Jessy Wayles. Thank you all for your unwavering support. I truly enjoyed working with you all. Lastly, I would like to thank Clay Henderson for his help in editing this paper.

<i>Florida Pollutant Discharge Prevention and Control Act (FPDPCA) of 1970</i> .....	301
<i>The Florida Environmental Protection Act of 1971</i> .....	302
<i>The Florida Water Resources Act of 1972</i> .....	302
<i>The Aquatic Preserves Act of 1975</i> .....	303
<i>Protecting Florida’s Drinking Water</i> .....	304
<i>The Surface Water Improvement and Management (SWIM) Act of 1987</i> .....	305
<i>Florida’s Land Acquisition Programs</i> .....	305
<i>The Indian River Lagoon System and Basin Act of 1990</i> .....	306
<i>The Indian River Lagoon National Estuary Program (IRLNEP)</i> ..	307
<i>The Florida Department of Environmental Protection (FDEP)</i> ..	308
<i>House Bill 1379: \$100 Million Towards Restoring the Indian River Lagoon</i> .....	311
V. THE FUTURE OF THE INDIAN RIVER LAGOON.....	312
LAGOON LAWS: TIMELINE.....	313
FEDERAL LAWS INFOGRAPHIC .....	314
STATE LAWS INFOGRAPHIC .....	315

## I. THE HISTORY OF THE INDIAN RIVER LAGOON: AN OVERVIEW

Humankind first interacted with the Indian River Lagoon (IRL) approximately 12,000–15,000 years ago<sup>1</sup> when the first hunters and gatherers occupied the area.<sup>2</sup> In the mid-1600s, Spanish settlers arrived,<sup>3</sup> spreading disease and conducting slavery and warfare efforts that diminished the native population.<sup>4</sup> During the 1760s, the British took dominion of the IRL region.<sup>5</sup> Over time, Spanish and English settlements became agriculturally dependent and approximately 3,000

---

<sup>1</sup> *History Summary*, BREVARD CNTY.: SPACE COAST FLA., <https://www.brevardfl.gov/HistoricalCommission/HistorySummary> (last visited May 27, 2024); *Living on the Lagoon*, ONE LAGOON, <https://onelagoon.org/living-on-the-lagoon/> (last visited June 3, 2024).

<sup>2</sup> *Community: History*, TOWN OF GRANT-VALKARIA, FLA., <https://grantvalkaria.org/community/page/history>.

<sup>3</sup> *Living on the Lagoon*, ONE LAGOON, <https://onelagoon.org/living-on-the-lagoon/> (last visited June 3, 2024).

<sup>4</sup> *History of the Indian River Lagoon*, Brevard Indian River Lagoon Coalition, (Aug 27, 2018), <https://helphelagoon.org/history-indian-river-lagoon/>.

<sup>5</sup> *Living on the Lagoon*, ONE LAGOON, <https://onelagoon.org/living-on-the-lagoon/> (last visited June 3, 2024).

acres of the lagoon were drained by 1770.<sup>6</sup> Then, in the 1830s, the U.S. Army and Florida militia entered the IRL watershed during the Second Seminole War.<sup>7</sup> By the 1870s, the lagoon became a bustling trading center home to railroads, bridges, and steamboats.<sup>8</sup> During the 1890s, the IRL was significantly drained to support the region's citrus production.<sup>9</sup> In the 1900s, wetlands were surrounded by dikes and flooded to prevent pesky mosquito breeding and mosquito-borne disease, which destroyed nearly 70% of the lagoon's mangroves.<sup>10</sup> The popularization of automobiles in the 1930s led to the construction of causeways that divided the lagoon and produced harmful runoff.<sup>11</sup> By the 1970s, nearly 303,900 people lived in the IRL region.<sup>12</sup> As the population grew, so did the pollution.

## II. AN ESTUARY IN DISTRESS: A CALL TO ACTION

The IRL watershed occupies 40% of Florida's coast, houses over 4,400 plant and animal species, and generates approximately \$7.6 billion annually towards Florida's economy.<sup>13</sup> The lagoon is frequently used for recreational purposes: swimming, fishing, boating, water sports, biking, hiking, wildlife viewing, and more.<sup>14</sup> Excessive human conduct, however, has harmed the IRL: rapid development, habitat destruction, overharvesting, runoff, and drainage.<sup>15</sup> Repeated misuse



FIGURE 1: IRL Preserve Park at Sunset. Florida DEP News (@FLDEPNews), X (Jan 19, 2023, 6:00 PM), <https://x.com/FLDEPNews/status/1616208914302832654>.

<sup>6</sup> ST. JOHNS RIVER WATER MGMT. DIST. & THE INDIAN RIVER LAGOON NATIONAL ESTUARY PROGRAM, *INDIAN RIVER LAGOON: AN INTRODUCTION TO A NATURAL TREASURE* (2007) [hereinafter *INDIAN RIVER LAGOON INTRODUCTION*].

<sup>7</sup> *History Summary*, BREVARD CNTY.: SPACE COAST FLORIDA <https://www.brevardfl.gov/HistoricalCommission/HistorySummary> (last visited May 27, 2024).

<sup>8</sup> *INDIAN RIVER LAGOON INTRODUCTION*, *supra* note 6 at 34.

<sup>9</sup> *Restoration of Indian River Lagoon Preserve*, FLORIDA STATE PARKS, <https://www.floridastateparks.org/learn/restoration-indian-river-lagoon-preserve> (last visited Feb. 5, 2025).

<sup>10</sup> Nathaniel Osborn, *Oranges and Inlets: An Environmental History of Florida's Indian River Lagoon* (Aug. 2012) (M.A. thesis, Florida Atlantic University) (ProQuest).

<sup>11</sup> *Indian River Lagoon Encyclopedia- National Estuary*, INDIAN RIVER LAGOON PROJECT, [https://indianriverlagoonnews.org/guide/index.php/Category:National\\_Estuary](https://indianriverlagoonnews.org/guide/index.php/Category:National_Estuary) (last updated Apr 8, 2023).

<sup>12</sup> *INDIAN RIVER LAGOON INTRODUCTION*, *supra* note 6.

<sup>13</sup> *Importance*, ONE LAGOON, <https://onelagoon.org/importance/> (last visited Nov. 28, 2023).

<sup>14</sup> *Experience the Indian River Lagoon*, ARCGIS STORYMAPS, <https://storymaps.arcgis.com/collections/59b60744fa654fbfa8a65a59ee6d0ae9> (last visited Aug. 13, 2023).

<sup>15</sup> *How Valuable is the Indian River Lagoon?*, RESTORE OUR SHORES, <https://restoreourshores.org/importance/> (last visited Mar. 29, 2023).

and neglect have destroyed the lagoon's important ecosystems. If we continue this behavior, the IRL, as we know it, will cease to exist.<sup>16</sup>

It is not too late to change our behavior and restore the balance of our nation's environment. Both state and federal laws, implemented and enforced by multiple agencies, protect our nation's water resources, including the IRL. As our environment evolves, so must our laws, policies, and regulations.

### III. FEDERAL LAWS, REGULATIONS, AND POLICIES THAT AFFECT THE INDIAN RIVER LAGOON

The earliest U.S. environmental laws were enacted in the late 1800s and early 1900s. For example, the Rivers and Harbors Act of 1899 authorized the federal government to regulate activities throughout waters of the United States.<sup>17</sup> The Lacey Act of 1900 is one of our nation's oldest wildlife protection laws, aimed at addressing the overhunting of birds.<sup>18</sup> In the 1960s, publications, such as Rachel Carson's *Silent Spring*,<sup>19</sup> and natural disasters, including the 1969 Cuyahoga River fires, increased society's awareness of environmental degradation caused by human conduct. During the 1970s, major federal laws, such as the Clean Water Act, National Environmental Policy Act, and Endangered Species Act, were implemented to address growing environmental concerns.<sup>20</sup> While environmental restoration is challenging, enforcement of past environmental laws has proven successful. Regrettably, centuries of environmental degradation forced society to recognize the importance of the environment. Now that we are aware of the damage we've inflicted, we must strive to rectify it. Below is an overview of federal



FIGURE 2: Ohio's Cuyahoga River in flames, one of over a dozen times the river caught fire before environmental standards improved.

<sup>16</sup> *Our Issues*, THE INDIAN RIVERKEEPER, <https://www.theindianriverkeeper.org/our-issues/> (last visited May 27, 2024).

<sup>17</sup> *Rivers and Harbors Act*, NOAA FISHERIES (archived 20 Feb. 2025), <https://web.archive.org/web/20240814175910/https://www.fisheries.noaa.gov/inport/item/59646>.

<sup>18</sup> *The Lacey Act*, NAT'L WHISTLEBLOWER CTR., (Apr. 19, 2021), <https://www.whistleblowers.org/what-is-the-lacey-act/>.

<sup>19</sup> RACHEL CARSON, *SILENT SPRING* (1962).

<sup>20</sup> Richard Lazarus & Sara Zdeb, *Environmental Law & Politics*, 29 *Insights L. & Soc'y* 3.1 (Jan. 5, 2021).



laws, regulations, and policies that promote effective water resource management and marine ecosystem restoration.

*A. The Federal Water Pollution Control Act (FWPCA) of 1948*

The first major U.S. law addressing water pollution was the Federal Water Pollution Control Act (FWPCA) of 1948. This 1948 Act authorized Public Health Services to collaborate with other federal, state, and local entities to implement water pollution prevention programs.<sup>21</sup> The Act was soon amended by the FWPCA of 1956, which made states, with support from Public Health Services, predominantly responsible for enacting water pollution control programs.<sup>22</sup> The shift towards state power was exemplified when President Eisenhower rejected a bill that would return pollution program control back to federal agencies. Eisenhower wrote, “[t]he Federal Government can help, but it should stimulate State and local action rather than provide excuses for inaction.”<sup>23</sup> The Water Quality Act of 1965 provided states with federal funding to ensure they complied with newly established water quality standards.<sup>24</sup>

*B. The National Environmental Policy Act (NEPA) of 1970*

The National Environmental Policy Act (NEPA), deemed the “Magna Carta” of environmental law, was enacted in January 1970.<sup>25</sup> NEPA established nationwide environmental policy and created the Council on Environmental Quality (CEQ). NEPA required that all practical means be used to ensure nature and humankind coexist for future generations.<sup>26</sup> To achieve this goal, NEPA required an Environmental Impact Statement (EIS) be published for all public works projects. The EIS requirement promoted transparency by requiring federal agencies to publicize environmental impacts, resources used, and alternative solutions to every proposed decision they made that affected the environment.<sup>27</sup>

NEPA’s ambitious goals would be impossible without the CEQ being established as part of the Executive Office of the President.<sup>28</sup>

---

<sup>21</sup> 33 U.S.C. §1251 (amended 1972).

<sup>22</sup> Curtiss M. Everts, Jr. & Arve H. Dahl, *The Federal Water Pollution Control Act of 1956*, 47 AM. J. PUB. HEALTH 305, 305 (1957).

<sup>23</sup> Dwight D. Eisenhower, *Veto of Bill to Amend the Federal Water Pollution Control Act*, THE AM. PRESIDENCY PROJECT, <https://www.presidency.ucsb.edu/node/234979> (last visited Jan. 28, 2025).

<sup>24</sup> *Making Water Quality a National Priority*, MICH. IN THE WORLD, [https://michiganintheworld.history.lsa.umich.edu/environmentalism/exhibits/show/main\\_exhibit/pollution\\_politics/water-quality-shift-in-priorit](https://michiganintheworld.history.lsa.umich.edu/environmentalism/exhibits/show/main_exhibit/pollution_politics/water-quality-shift-in-priorit) (last visited May 30, 2024).

<sup>25</sup> NAT’L ENV’T POL’Y ACT (Jan. 20, 2021), <https://ceq.doe.gov>.

<sup>26</sup> National Environmental Policy Act, § 102, 42 U.S.C. 4331(a) (1969).

<sup>27</sup> *Id.* § 4332(2)(C).

<sup>28</sup> NAT’L ENV’T POL’Y ACT (Jan. 20, 2021), <https://ceq.doe.gov>.

The CEQ forces federal agencies to comply with NEPA, interprets NEPA requirements, proposes national policies that promote environmental wellbeing, and deals with NEPA-related conflict.

Essentially, NEPA made agencies consider the environmental consequences of their actions by requiring them to publicize certain information. The CEQ acts as the enforcer and problem-solver when issues arise.

### *C. The Clean Water Act (CWA) of 1972*

The Environmental Protection Agency (EPA) was established by executive order, following the passage of NEPA in 1970. Creating the EPA resolved past conflicts between federal and state actors fighting over who controlled environmental programs.<sup>29</sup> Now, one agency, the EPA, dealt with all environmental responsibilities. Two years later, the Clean Water Act (CWA) of 1972 was passed, which authorized the EPA to create nationwide water quality standards.<sup>30</sup> The CWA also established the National Pollutant Discharge Elimination System (NPDES) program, which prohibited pollutant discharge from point sources into U.S. waters without a permit.<sup>31</sup> A point source is “any single identifiable source of pollution from which pollutants are discharged, such as a pipe, ditch, ship or factory smokestack.”<sup>32</sup> Put differently, the CWA regulated and protected wetlands by requiring a permit for dredging or filling of wetlands which were deemed waters of the United States.

The EPA and CWA promoted nationwide consistency while simultaneously allowing individual states to address water pollution locally. To further the CWA's wastewater treatment efforts, Congress signed the Municipal Wastewater Treatment Construction Grant Amendments in 1981. These Amendments provided federal funding for environmentally conscious construction and water treatment projects. This funding decreased the economic burden that states would have faced from prioritizing local environmental needs.<sup>33</sup> Six

---

<sup>29</sup> *The Origins of EPA*, U.S. ENV'T PROT. AGENCY, <https://www.epa.gov/history/origins-epa> (last visited June 5, 2023).

<sup>30</sup> Clean Water Act, 33 U.S.C. § 1251 *et seq.*; *Summary of the Clean Water Act*, U.S. ENV'T PROT. AGENCY, <https://www.epa.gov/laws-regulations/summary-clean-water-act> (last visited June 22, 2023).

<sup>31</sup> *NPDES Permit Basics*, U.S. ENV'T PROT. AGENCY, <https://www.epa.gov/npdes/npdes-permit-basics> (last visited Dec. 11, 2023).

<sup>32</sup> *Point Source Pollution Tutorial*, NAT'L OCEANIC AND ATMOSPHERIC ADMIN., [https://oceanservice.noaa.gov/education/tutorial\\_pollution/03pointsource.html](https://oceanservice.noaa.gov/education/tutorial_pollution/03pointsource.html) (June 1, 2024).

<sup>33</sup> *Statement on Signing the Municipal Wastewater Treatment Construction Grant Amendments of 1981*, RONALD REAGAN LIBR. (Dec. 29, 1981), <https://www.reaganlibrary.gov/archives/speech/statement-signing-municipal-wastewater-treatment-construction-grant-amendments-1981>.

years later, the Water Quality Act of 1987 created the Clean Water State Revolving Fund (CWSRF), which replaced the Construction Grant Amendments. This Act established EPA-state partnerships which furthered local efforts addressing water quality by providing federal support.<sup>34</sup>

As populations grew, non-point source pollution became a growing concern. Non-point pollution occurs “when runoff from rain and snowmelt carries pollutants into waterways such as rivers, streams, lakes, wetlands, and even groundwater.”<sup>35</sup> Previously, NPDES permitting applied to easily identifiable point source pollution. However, the Combined Sewer Overflows (CSO) program of 1994, expanded NPDES permitting to non-point pollution sources, such as stormwater and wastewater overflows. The Wet Weather Water Quality Act of 2000 required all permits, orders, or decrees post-1994 to conform to CSO program standards.<sup>36</sup> For example, in 2000, Florida’s NPDES Stormwater Program required permitting before non-point sources, such as municipal separate storm sewer systems (MS4s), construction activities, or industrial activities could discharge water. Florida’s non-point source discharge is monitored to prevent toxic runoff from entering state waters, such as the IRL.<sup>37</sup>

The Beaches Environmental Assessment and Coastal Health Act (BEACH Act) of 2000 required states, territories, and tribes with coastal waters to adopt new or revised standards based on EPA coastal testing and monitoring results. This Act provided states with EPA funding to help them comply with newly developed standards. Further, the EPA was required to alert the public when potential coastal recreational water problems arose.<sup>38</sup>

More actors were needed to assist these increasing pollution prevention efforts. In 2014, President Obama signed the Water Resources Reform and Development Act (WRRDA), which required the United States Army Corps of Engineers (USACE) to maintain America’s waterways (including wetlands), address natural disasters,

---

<sup>34</sup> *History of the Clean Water Act*, U.S. ENV’T PROT. AGENCY, <https://www.epa.gov/laws-regulations/history-clean-water-act> (last visited June 22, 2023).

<sup>35</sup> *What Is Nonpoint Source Pollution?*, ILL. ENV’T PROT. AGENCY, <https://epa.illinois.gov/topics/water-quality/watershed-management/nonpoint-sources/what-is-nonpoint-source-pollution.html> (last visited June 13, 2024).

<sup>36</sup> *Combined Sewer Overflows (CSOs)*, U.S. ENV’T PROT. AGENCY, <https://www.epa.gov/npdes/combined-sewer-overflows-csos> (last visited Oct. 5, 2023).

<sup>37</sup> *NPDES Stormwater Program*, FLORIDA DEP’T OF ENV’T PROT., <https://floridadep.gov/water/stormwater> (last visited May 31, 2024).

<sup>38</sup> *About the BEACH Act*, U.S. ENV’T PROT. AGENCY, <https://www.epa.gov/beaches/about-beach-act> (last visited Dec. 12, 2023).

and promote environmental restoration.<sup>39</sup> USACE, the main supporter of our nation's infrastructure, placed environmental sustainability at its forefront because of the WRRDA.<sup>40</sup>

#### *D. The Coastal Zone Management Act (CZMA) of 1972*

During the 1970s, heavy development and construction occurred in coastal regions. While coastal infrastructure boosts our nation's economic success, it also threatens the natural world. The Coastal Zone Management Act (CZMA) of 1972 balanced coastal economic and environmental concerns.<sup>41</sup> The CZMA aimed to “preserve, protect, develop, and where possible, to restore or enhance the resources of the nation's coastal zone.”<sup>42</sup> The CZMA established the National Coastal Zone Management Program, National Estuarine Research Reserve System, and Coastal and Estuarine Land Conservation Program (CELCP). The Management Program administers coastal management programs, the Reserve completes studies that further our nation's understanding of estuaries, and CELCP provides funding to state and local governments to purchase and conserve threatened coastal or estuarine land.<sup>43</sup>

#### *E. The Marine Mammal Protection Act (MMPA) of 1972*

The Marine Mammal Protection Act (MMPA) was passed in October of 1972 to address human conduct, such as littering and overfishing, that severely threatened marine mammal species. MMPA established a national policy that prevented the extinction and depletion of marine mammals.<sup>44</sup> MMPA made it illegal to harass, feed, hunt, capture, or kill any marine mammal.<sup>45</sup> The Marine Mammal Commission was created to study the effectiveness of current marine mammal protection laws and suggest necessary improvements.<sup>46</sup> Under the MMPA, the National Oceanic and Atmospheric Administration (NOAA) protects whales, dolphins, porpoises, seals, and sea lions.

---

<sup>39</sup> *Water Resources Reform and Development Act (WRRDA) of 2014*, U.S. ARMY CORPS OF ENG'RS, <https://www.usace.army.mil/Missions/Civil-Works/Project-Planning/Legislative-Links/wrrda2014/>.

<sup>40</sup> *About Us*, U.S. ARMY CORPS OF ENG'RS, <https://www.usace.army.mil/about/> (last visited May 30, 2024).

<sup>41</sup> *Coastal Zone Management Act*, BUREAU OF OCEAN ENERGY, <https://www.boem.gov/environment/environmental-assessment/coastal-zone-management-act> (last visited May 31, 2024).

<sup>42</sup> *Coastal Zone Management Act*, NOAA OFFICE FOR COASTAL MGMT., <https://coast.noaa.gov/czm/act/> (last visited May 31, 2024).

<sup>43</sup> *Id.*

<sup>44</sup> *Marine Mammal Protection Act*, MARINE MAMMAL COMM'N, <https://www.mmc.gov/about-the-commission/our-mission/marine-mammal-protection-act/> (last visited May 2, 2024).

<sup>45</sup> *Marine Animals and the Marine Mammal Protection Act*, THE MARINE MAMMAL CTR., <https://www.marinemammalcenter.org/marine-mammal-protection-act> (last visited May 31, 2024).

<sup>46</sup> *Our Mission*, MARINE MAMMAL COMM'N, <https://www.mmc.gov/about-the-commission/our-mission/> (last visited Feb. 3, 2023).

The U.S. Fish and Wildlife Service (USFWS) protects walruses, manatees, sea otters, and polar bears.<sup>47</sup>

*F. The Endangered Species Act (ESA) of 1973*

Unfortunately, population growth and human conduct has harmed species far beyond just marine mammals. In December of 1973, the Endangered Species Act (ESA) was passed to preserve declining species and their environments. The ESA is implemented by the USFWS and National Marine Fisheries Service (NMFS).<sup>48</sup> The ESA allows individuals and organizations to request species be listed as “endangered” or “threatened,” and the FWS and NMFS analyze species before adding them to these lists. Once approved, these protected species and their environments undergo recovery plans carried out by federal, state, tribal, and local officials. The recovery status of listed species is constantly monitored. Once a species recovers, it is removed from the list. The ESA has helped 99% of protected species avoid extinction.<sup>49</sup>



FIGURE 3: A Florida manatee, a species saved by the endangered species act

Approximately fifty-three species of animals living within the IRL’s watershed are classified as “threatened” or “endangered” and protected under the ESA.<sup>50</sup> For example, in the 1970s, less than 1,000 manatees remained in Florida, so they became protected under the ESA. In 2019, over 6,000 manatees existed because of stricter boat speed regulations and ESA programs improving seagrass habitats.<sup>51</sup> As of January 2024, the Florida Fish and Wildlife Commission (FFWC) reported approximately 7,000 to 11,000 manatees currently live in Florida.<sup>52</sup> Unfortunately, harmful algae blooms have degraded seagrass habitats which caused a manatee mortality event; manatees

<sup>47</sup> *Marine Mammal Protection Act Policies, Guidance, and Regulations*, NOAA FISHERIES (May 2, 2023) <https://www.fisheries.noaa.gov/national/marine-mammal-protection/marine-mammal-protection-act-policies-guidance-and-regulations>.

<sup>48</sup> *Endangered Species Act*, DEFS. OF WILDLIFE, <https://defenders.org/endangered-species-act>.

<sup>49</sup> *The US Endangered Species Act*, WORLD WILDLIFE FUND, <https://www.worldwildlife.org/pages/the-us-endangered-species-act> (last visited May 2, 2024).

<sup>50</sup> INDIAN RIVER LAGOON INTRODUCTION, *supra* note 6, at 6.

<sup>51</sup> Kim Dinkins, *The Endangered Species Act Turns 50!*, SAVE THE MANATEE (Oct. 1, 2023), <https://savethemanatee.org/THE-ENDANGERED-SPECIES-ACT-TURNS-50/>.

<sup>52</sup> Diba Mohtasham, *A Florida Park Just Saw a Record Number of Manatees Gather Together in Its Waters*, NPR (Jan. 29, 2024, 3:36 PM), <https://www.npr.org/2024/01/29/1227564655/manatee-numbers-at-florida-state-park-increase>.

are currently being reviewed to move from “threatened” to “endangered.”<sup>53</sup>

#### *G. The National Estuary Program (NEP) of 1987*

In 1987, the National Estuary Program (NEP) was established under §320 of the CWA.<sup>54</sup> NEPs are non-regulatory (lacking enforcement authority) programs that create Comprehensive Conservation and Management Plans (CCMPs) addressing the needs of 28 estuaries of national significance. CCMPs are long-term, localized plans that restore water quality and protect living resources within estuary watersheds.<sup>55</sup> These plans are executed with EPA guidance, assistance, and partial funding.<sup>56</sup> All NEPs have a multi-stakeholder Management Conference to ensure all voices are heard and local needs are met. Essentially, NEPs protect estuarine ecosystems by executing a plan shaped by the public. For example, the Indian River Lagoon National Estuary Program (IRLNEP), formally established in 1991, was initially sponsored by Saint John's River and South Florida Water Management District. Now, however, the IRLNEP is sponsored by the Indian River Lagoon Council which consists of representatives from the five lagoon-bordering counties, St. Johns River and South Florida Water Management Districts, and the Florida Department of Environmental Protection (FDEP).<sup>57</sup> The IRLNEP's Management Conference consists of many local partners to ensure all communities receive the support they need. These stakeholders shape the IRLNEP's CCMP, which addresses the unique needs of the IRL watershed.<sup>58</sup>

#### *H. The North American Wetlands Conservation Act (NAWCA) of 1989*

In 1989, the North American Wetlands Conservation Act (NAWCA) began funding wetlands conservation projects through the U.S. Standard Grant Program, U.S. Small Grant Program, Mexico Program, and

---

<sup>53</sup> *Algae Blooms and Seagrass Loss*, SAVE THE MANATEE CLUB (June 19, 2024), <https://savethemanatee.org/manatees/algae-blooms>.

<sup>54</sup> *Overview of the National Estuary Program*, U.S. ENV'T PROT. AGENCY, (June 12, 2024), <https://www.epa.gov/nep/community-based-watershed-management-handbook>.

<sup>55</sup> *Id.*

<sup>56</sup> *Id.*

<sup>57</sup> *The Indian River Lagoon NEP*, ONE LAGOON, <https://onelagoon.org/irlnep/> (last visited Apr. 23, 2024).

<sup>58</sup> To learn more about the IRLNEP, see discussion *infra* Section IV, State Laws, Regulations, and Policies that Impact the Indian River Lagoon.

Canada Program.<sup>59</sup> Grants are approved by the North American Wetlands Conservation Council in collaboration with the Migratory Bird Conservation Commission during two annual application review cycles.<sup>60</sup> Several of these funded projects directly benefited the IRL: Invasive Species Eradication & Mangrove Planting In The IRL (2005), Invasive Species Eradication & Habitat Enrichment In The IRL (2008), Critical Bird Habitat Restoration In The IRL (2008), St. Johns River Headwaters Project (2010), Critical Bird Habitat Restoration in the NWRs of the IRL (2011), and IRL Coastal Wetlands (2012).<sup>61</sup> Overall, NAWCA has funded preservation of over 32 million acres of wetlands, including areas far beyond the IRL.<sup>62</sup>

### *I. The Estuary Restoration Act (ERA) of 2000*

Local action insufficiently addressed estuarine ecosystem decline; federal action needed to occur. Nearly half of our nation's population lives near estuarial waters, and many rely on estuaries for recreational, resource, educational, economic, and environmental purposes. Human activity, such as lawn fertilization, untreated sewage, wastewater discharge, construction, industrial activities, and surface runoff destroys estuary ecosystems.<sup>63</sup> In November of 2000, the Estuary Restoration Act (ERA) federally addressed wetland habitat loss and ongoing damage. The ERA declared estuaries a national priority, funded restoration projects, created partnerships throughout public and private sectors, and developed a unified approach to estuary restoration.<sup>64</sup> The ERA established the Estuary Habitat Restoration Council, consisting of representatives from NOAA, the USFWS, the EPA, Department of Agriculture, and USACE.<sup>65</sup> The Council monitors estuaries, recommends programs for funding, and implements federal protection programs.

### *J. The Comprehensive Everglades Restoration Plan (CERP) of 2000*

---

<sup>59</sup> *North American Wetlands Conservation*, U.S. FISH & WILDLIFE SERV., <https://www.fws.gov/program/north-american-wetlands-conservation> (last visited May 8, 2024).

<sup>60</sup> *Id.*

<sup>61</sup> *DBHC Grant Summary Query Application*, U.S. FISH & WILDLIFE SERV., <https://www.fws.gov/grantsum/gQuery> (last visited June 1, 2024).

<sup>62</sup> *North American Wetlands Conservation*, U.S. FISH & WILDLIFE SERV., <https://www.fws.gov/program/north-american-wetlands-conservation> (last visited May 8, 2024).

<sup>63</sup> *Basic Information About Estuaries*, U.S. ENV'T PROT. AGENCY, <https://www.epa.gov/nep/basic-information-about-estuaries> (last visited Mar. 14, 2024).

<sup>64</sup> *The Estuary Restoration Act*, NAT'L OCEANIC & ATMOSPHERIC ADMIN., <https://www.fisheries.noaa.gov/national/habitat-conservation/estuary-restoration-act> (last visited Feb. 26, 2024).

<sup>65</sup> *Estuary Habitat Restoration Council*, U.S. ARMY CORPS OF ENG'RS, <https://www.usace.army.mil/Missions/Environmental/Estuary-Restoration/Estuary-Habitat-Restoration-Council/> (last visited June 1, 2024).

Congress passed the Comprehensive Everglades Restoration Plan (CERP) in 2000 to protect, restore, and preserve the South Florida ecosystem while simultaneously addressing other water-related needs. This Plan has cost over \$10.5 million and has a 35+ year timeline, making CERP the largest hydrologic restoration project this nation has ever seen.<sup>66</sup> CERP has directly benefitted the IRL through the the C-44 Reservoir and Stormwater Treatment Area project. This multi-billion dollar project consists of a 3,400-acre reservoir, a high-performing pump station, and 6,300 acres of stormwater treatment areas.<sup>67</sup> This project is expected to capture harmful runoff, reduce average annual total nutrient loads, and improve the Southern IRL with a projected 60,500 acre-feet of new water storage and 3,600 acres of new wetlands.<sup>68</sup>

#### *K. The Congressional Estuary Caucus of 2017*

Improving America's estuaries was prioritized due to their ecological and economic significance. In 2017, the bipartisan Congressional Estuary Caucus formed to educate government officials on the importance of estuaries and their protection programs.<sup>69</sup> The Caucus encourages ongoing Congressional discussion of national estuaries. Currently, forty congressional members have joined the caucus, including Florida Congressman Bill Posey as Co-Chair.<sup>70</sup> The Caucus holds estuary expert briefings that educate our nation's leaders on algal blooms, coastal resilience, and estuarine ecosystems. These conversations lead to the implementation and support of programs working towards estuary conservation.<sup>71</sup> Estuaries are indispensable: they house roughly 40% of the U.S. population, contribute to approximately 47% of the country's gross domestic product, and support more than 68% of commercial fish catch.<sup>72</sup> Initiatives, such as the bipartisan Congressional Estuary Caucus, are critical to ensuring estuaries continue to thrive.

---

<sup>66</sup> *Comprehensive Everglades Restoration Plan (CERP)*, NAT'L PARKS SERV. (Mar 17, 2025), <https://www.nps.gov/ever/learn/nature/cerp.htm>.

<sup>67</sup> *Indian River Lagoon - South C-44 Reservoir & STA*, U.S. ARMY CORPS OF ENG'RS (March 2004), <https://www.saj.usace.army.mil/Missions/Environmental/Ecosystem-Restoration/Indian-River-Lagoon-South/>.

<sup>68</sup> *Id.*

<sup>69</sup> *Congressional Estuaries Caucus*, RESTORE AMERICA'S ESTUARIES, <https://estuaries.org/advocacy/> (last visited Mar. 19, 2024).

<sup>70</sup> *Indian River Lagoon*, CONGRESSMAN BILL POSEY: REPRESENTING THE 8TH DIST. OF FLA. (archived Dec. 17, 2024), <https://web.archive.org/web/20240815145922/https://posey.house.gov/issues/issue/?IssueID=111851>.

<sup>71</sup> *About the Estuary Caucus*, CONGRESSIONAL ESTUARY CAUCUS (archived Dec. 13, 2024), <https://web.archive.org/web/20240725013904/https://posey.house.gov/estuaries/>.

<sup>72</sup> *Why Are Estuaries Important?*, RESTORE AMERICA'S ESTUARIES (Sept. 21, 2022), <https://estuaries.org/why-are-estuaries-important/>.



*L. The Bipartisan Infrastructure Investment and Jobs Act of 2021*

The aforementioned laws, policies, and regulations require funding to be successful. In 2021, the bipartisan Infrastructure Investment and Jobs Act was enacted to improve America's infrastructure and competitiveness.<sup>73</sup> This funding aimed to “rebuild America’s roads, bridges and rails, expand access to clean drinking water, ensure every American has access to high-speed internet, tackle the climate crisis, advance environmental justice, and invest in communities that have too often been left behind.”<sup>74</sup> A guidebook was published for communities to understand the funding application process, eligibility, and uses.<sup>75</sup>

The infrastructure law allocated \$132 million towards the EPA’s NEP for a five-year time frame (2022–2027). The \$132 million supports nationwide projects addressing climate resilience, equity, and estuary water and ecosystem quality. The infrastructure law’s funding supports plans developed in NEP’s CCMPs.<sup>76</sup>

#### IV. STATE LAWS, REGULATIONS, AND POLICIES THAT AFFECT THE INDIAN RIVER LAGOON

We’ve just covered 73 years of federal laws, regulations, and policies that affect the IRL. Now, imagine you’re in Florida in the year 1967. The state is experiencing a tourism boom, followed by major urban and agricultural growth.<sup>77</sup> The EPA has yet to be established, so the struggle between federal and state monitoring of water pollution persists. The Water Quality Act of 1965 was recently passed, providing states with federal funding so they can comply with newly established water quality standards.<sup>78</sup> It is time for Florida to take control.

---

<sup>73</sup> Infrastructure Investment and Jobs Act, 23 U.S.C.A § 101 (2021).

<sup>74</sup> *Fact Sheet: The Bipartisan Infrastructure Deal*, NAT’L ARCHIVES (Aug. 5, 2021), <https://bidenwhitehouse.archives.gov/briefing-room/statements-releases/2021/08/05/fact-sheet-the-bipartisan-infrastructure-investment-and-jobs-act-advances-president-bidens-climate-agenda/>.

<sup>75</sup> *Guidebook to the Bipartisan Infrastructure Law*, NAT’L ARCHIVES (last updated Jan. 2024), <https://bidenwhitehouse.archives.gov/build/guidebook/>.

<sup>76</sup> *Biden-Harris Administration Announces \$132 Million for EPA’s National Estuary Program from the Bipartisan Infrastructure Law*, U.S. ENV’T PROT. AGENCY (July 26, 2022), <https://www.epa.gov/newsreleases/biden-harris-administration-announces-132-million-epas-national-estuary-program>.

<sup>77</sup> *Living on the Lagoon*, ONE LAGOON, <https://onelagoon.org/living-on-the-lagoon/> (last visited May 1, 2024).

<sup>78</sup> *Making Water Quality a National Priority*, MICH. IN THE WORLD, [https://michiganintheworld.history.lsa.umich.edu/environmentalism/exhibits/show/main\\_exhibit/pollution\\_politics/water-quality-shift-in-priorit](https://michiganintheworld.history.lsa.umich.edu/environmentalism/exhibits/show/main_exhibit/pollution_politics/water-quality-shift-in-priorit) (last visited May 30, 2024).

*A. The Florida Air and Water Pollution Control Act (FAWPCA) of 1967*

As Florida's population continued to grow, so did the state's pollution. While the Florida Air and Water Pollution Control Act (FAWPCA) of 1967 addressed all pollution, we will focus solely on water pollution regulations. FAWPCA aimed to conserve and improve Florida's waters to protect humans, ecosystems, wildlife, and Florida's social and economic wellbeing.<sup>79</sup> The Act authorized a pollution council to establish water quality standards, identify pollution sources, and constantly monitor water quality to ensure current measures were effective. The council established programs, regulations, and permit requirements that promoted compliance with Florida's water quality standards.<sup>80</sup> FAWPCA allowed Florida to review and establish water quality standards, a responsibility granted to states under the FWPCA of 1956.<sup>81</sup>

*B. Florida Pollutant Discharge Prevention and Control Act (FPDPCA) of 1970*

As a response to multiple oil spills, Florida Statutes Chapter 376 declared, "the preservation of this use [of the seacoast of the state] is a matter of the highest urgency and priority."<sup>82</sup> In 1970, the Florida Pollutant Discharge Prevention and Control Act (FPDPCA) prohibited vessels from discharging oil or pollutants into Florida's territorial waters; those who refused to comply were responsible for cleanup costs.<sup>83</sup> FPDPCA provided FDEP and FFWC with the Florida Coastal Protection Trust Fund (FCPTF) to aid in restoration efforts. FDEP developed discharge criteria, assessed damages, coordinated emergency response to spills, and created procedures for removing pollutants. FFWC helped damaged wildlife and removed derelict vessels or helped local governments do so.<sup>84</sup> Under FPDPCA, vessels carrying more than 10,000 gallons of pollutants were required to have a discharge prevention and control contingency plan, an onboard discharge officer who executes the plan, compliant discharge prevention gear, a FDEP-issued discharge prevention and response certificate, and

---

<sup>79</sup> Michael T. Olexa, Tatiana Borisova & Jana Caracciolo, 2021 *Handbook of Florida Water Regulation*.: *Florida Air and Water Pollution Control Act*, ASKIFAS (June 22, 2021), <https://edis.ifas.ufl.edu/publication/FE607>.

<sup>80</sup> *Id.*

<sup>81</sup> *Water Quality Standards*, FLA. DEP'T OF ENV'T PROT., <https://floridadep.gov/dear/water-quality-standards> (last visited June 3, 2024).

<sup>82</sup> *Pollutant Discharge Prevention and Removal (Florida Statutes: Title XXVIII Natural Resources; Conservation, Reclamation, and Use; Chapter 376; Ss. 376.011-376.86)*, FAOLEX DATABASE, (Aug. 1, 2018), <https://www.fao.org/faolex/results/details/en/c/LEX-FAOC182725/>.

<sup>83</sup> Settlement Guidelines for Civil and Administrative Penalties, State of Florida (Office of General Counsel 2022).

<sup>84</sup> *FWC Wildlife Health Program*, FLA FISH & WILDLIFE CONSERVATION COMM'N (2022), <https://myfwc.com/research/wildlife/health/program/>.

insurance covering potential spillage.<sup>85</sup> By creating regulations and holding the noncompliant accountable, FPDPCA addressed environmental disasters caused by vessel discharge.

### *C. The Florida Environmental Protection Act of 1971*

Florida's 1968 Constitution declared, "[i]t shall be the policy of the state to conserve and protect its natural resources and scenic beauty. Adequate provision shall be made by law for the abatement of air and water pollution and of excessive and unnecessary noise and for the conservation and protection of natural resources."<sup>86</sup> The Florida Environmental Protection Act of 1971<sup>87</sup> authorized parties to seek injunctive relief to force noncompliant parties to comply with environmental standards, to prevent parties from violating environmental laws, rules, or regulation, or even prevent an individual from obtaining a license or permit if their conduct would cause pollution or environmental degradation.<sup>88</sup> Thus, the Florida Environmental Protection Act of 1971 created a legal consequence for those actively harming the environment.

### *D. The Florida Water Resources Act of 1972*

Historically, all Florida property owners had equal rights to use water on their property if their usage did not harm surrounding property owners.<sup>89</sup> Two Florida water management districts existed, the Southwest Florida Water Management District and the Central and Southern Florida Flood Control District, which focused on isolated issues, including mosquito control and irrigation.<sup>90</sup> In April 1972, The Florida Water Resources Act created a cohesive water resource management framework consisting of five water management districts: Northwest Florida Water Management District, Suwannee River Water Management District, St. Johns River Water Management District, Southwest Florida Water Management District, and South Florida Water Management District.<sup>91</sup> Water Management Districts

---

<sup>85</sup> Michael T. Olexa, Tatiana Borisova & Jana Caracciolo, *2021 Handbook of Florida Water Regulation: Florida Pollutant Discharge Prevention and Control Act*, ASKIFAS, (June 18, 2021), <https://edis.ifas.ufl.edu/publication/FE585>.

<sup>86</sup> FLA. CONST. art. II, §7 (1968).

<sup>87</sup> FLA. STAT. § 403.412 (2023).

<sup>88</sup> Roger B. Handberg, *The Florida Attorney General's Environmental Protection Authority*, 85 FLA. BAR J., no. 9, 2011, at 26.

<sup>89</sup> Tatiana Borisova, Michael T. Olexa & Jana Caracciolo, *2021 Handbook of Florida Water Regulation: Florida Water Resources Policy*, ASKIFAS (June 24, 2021), <https://edis.ifas.ufl.edu/publication/FE1043>.

<sup>90</sup> FLA. STAT. §373.026 (2021); *Our Work*, S. FLA. WATER MGMT. DIST., <https://www.sfwmd.gov/our-work> (last visited Feb 5, 2025).

<sup>91</sup> *History*, S. FLA. WATER MNG'T DIST., <https://www.sfwmd.gov/who-we-are/history> (last visited June 10, 2024).

became based around watersheds, as opposed to political boundaries. For example, the IRL falls within the St. Johns River and South Florida Water Management Districts.<sup>92</sup> These five districts construct and operate district works, regulate consumptive use of water and water systems, supervise water well construction, and evaluate water supplies.<sup>93</sup>

The Florida Water Resources Act created a water management district network that promotes consistency and efficiency. The Act established a water use permitting system, which allows surface and groundwater withdrawal for beneficial use, such as public water supply, irrigation, industrial use, and power generation. When water withdrawals exceed a certain limit, however, permits are required. To receive a permit, individuals must prove their water usage is beneficial, consistent with public interest, and doesn't interfere with other pre-existing uses.<sup>94</sup> There are separate permits for well construction and Environmental Resource Permits (ERP) for any conduct altering surface water flow (e.g. dredging, restoration projects, construction, wetland impacts, and any activities that generate runoff).<sup>95</sup>

Overall, The Florida Water Resources Act of 1972 created watershed boundary water management districts that were responsible for water supply, surface water management, wetlands, and other major regulatory considerations.

#### *E. The Aquatic Preserves Act of 1975*

By 1975, several regulations protected Florida's water resources. The Aquatic Preserves Act of 1975 set aside inland and coastal areas as state-owned land to ensure these areas remain undeveloped and in their natural

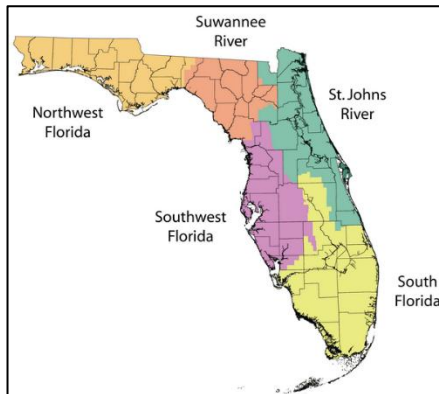


FIGURE 4: Map of Florida Water Management Districts. *Water Management Districts, FLA.* DEP'T OF ENV'T PROT. (Mar. 4, 2025), <https://floridadep.gov/owper/water-policy/content/water-management-districts>

<sup>92</sup> For a map of Florida's water management districts, see *Who We Are*, S. FLA. WATER MNG'T DIST., <https://www.sfwmd.gov/who-we-are> (last visited June 12, 2024).

<sup>93</sup> Joëlle Hervic, *Water, Water Everywhere?*, Part II, 77 FLA. BAR J., no. 1, 2003, at 49.

<sup>94</sup> FLORIDA'S WATER PERMITTING PORTAL, <http://flwaterpermits.com/> (last visited July 1, 2024); *Water Use Permit*, SW. FLA. WATER MGMT. DIST., <https://www.sfwmd.state.fl.us/business/epermitting/water-use-permit> (last visited Sept. 15, 2024).

<sup>95</sup> *Environmental Resource Permitting Help*, FLA. DEP'T OF ENV'T PROT., <https://floridadep.gov/water/submerged-lands-environmental-resources-coordination/content/environmental-resource-0> (last visited June 12, 2024). To learn more about the ERP Permitting Process, see discussion *infra* Section IV.K, Florida Department of Environmental Protection (FDEP).

condition.<sup>96</sup> Certain bodies of water are designated as “aquatic preserves” so their “aesthetic, biological and scientific values may endure for the enjoyment of future generations.”<sup>97</sup> Once an area becomes an aquatic preserve, it cannot be altered and remains under state control forever. The Indian River from Malabar to Fort Pierce, Banana River, and Mosquito Lagoon are all recognized aquatic preserves. Currently, Florida has 41 aquatic preserves, which ensures these natural areas will prevail into future generations.<sup>98</sup>

#### *F. Protecting Florida’s Drinking Water*

The 1974 Federal Safe Water Drinking Act (SWDA) protected public health by regulating our nation’s drinking water. SWDA authorized the EPA to establish nationwide drinking water quality standards.<sup>99</sup> Drinking water quality varies drastically, so states, with EPA guidance, needed to take matters into their own hands.

The Florida Water Quality Assurance Act (WQAA) of 1983 addressed groundwater protection and hazardous waste contamination.<sup>100</sup> Due to a growing population and increased agricultural-dependency, Florida’s groundwater became the state’s main drinking source. The WQAA protects Florida’s groundwater by providing funding for groundwater improvement projects.<sup>101</sup> WQAA allows parties to seek legal remedies for discharge or water pollutant related issues; the party must prove the occurrence of prohibited discharge or another pollutive condition to be heard in court.<sup>102</sup> Thus, the WQAA provides funding to improve Florida’s groundwater and holds those who do not comply accountable.

Florida has always prioritized their water resources. The state initially focused on protecting marine ecosystems and wildlife but shifted to focusing on drinking water following the WQAA. Florida’s State Underground Petroleum Environmental Response (SUPER) Act of 1986 required routine

---

<sup>96</sup> *Living on the Lagoon*, ONE LAGOON, <https://onelagoon.org/living-on-the-lagoon/> (last visited May 1, 2024).

<sup>97</sup> *Aquatic Preserve Program*, FLA. DEP’T OF ENV’T PROT., <https://floridadep.gov/rcp/aquatic-preserve> (last visited June 12, 2024).

<sup>98</sup> *A Boating and Angling Guide to Tampa Bay: Aquatic Preserves*, FLA. MARINE, [https://ocean.floridamarine.org/boating\\_guides/tampa\\_bay/pages/aquatic\\_preserves.html](https://ocean.floridamarine.org/boating_guides/tampa_bay/pages/aquatic_preserves.html) (last visited June 12, 2024).

<sup>99</sup> *Overview of the Safe Drinking Water Act*, U.S. ENV’T PROT. AGENCY (Jan. 23, 2025), <https://www.epa.gov/sdwa/overview-safe-drinking-water-act>.

<sup>100</sup> Wade L. Hopping & William D. Preston, *The Water Quality Assurance Act of 1983 – Florida’s “Great Leap Forward” into Groundwater Protection and Hazardous Waste Management*, 11 FLA. ST. U. L. REV. 599, 601 (1983).

<sup>101</sup> Alexa J. Lamm & Pei-wen Huang, *Water Quality Assurance Act: What Is It and How Can We Talk About It?*, POL’Y EXTENSION PROGRAM, [https://www.piecenter.com/pep/wp-content/uploads/PEP\\_WQAA\\_Final.pdf](https://www.piecenter.com/pep/wp-content/uploads/PEP_WQAA_Final.pdf) (last visited June 12, 2024).

<sup>102</sup> Lauren D. Brooks, *The New Scope of Florida’s Water Quality Assurance Act*, 95 FLA. BAR J., no. 6, 2021, at 48.

drinking water well sampling and investigations of contaminated petroleum facilities, such as service stations and fuel oil sites.<sup>103</sup> Under the SUPER Act, contaminated drinking water areas, such as leaking underground storage tanks or surface spills, are identified. Suspected areas are investigated, and if contaminated, the public is immediately notified of potential health effects and offered alternative sources of clean drinking water.<sup>104</sup>

#### *G. The Surface Water Improvement and Management (SWIM) Act of 1987*

The Surface Water Improvement and Management (SWIM) Act of 1987 required Florida's five water management districts to identify priority bodies of water and implement improvement projects.<sup>105</sup> Florida's Legislature stated that surface waters were declining and could no longer provide safe recreational opportunities, drinking water, habitat for plant and animal species, or economic benefits.<sup>106</sup> To fix this decline, pollution sources and environmentally degrading conduct were identified. Once identified, Water Management Districts developed plans to improve Florida's surface water ecosystems and conducted studies to further understand the causes of environmental decline.<sup>107</sup> The SWIM Act exemplifies how agencies, such as Florida's Water Management Districts, must remain adaptable and willing to address Florida's changing environmental needs.

#### *H. Florida's Land Acquisition Programs*

Florida is home to many large, intact ecosystems, which is rare in the eastern United States. Without land acquisition efforts, such as Preservation 2000 (P2000), such ecosystems would be non-existent. Massive population influxes in the 1990s severely harmed Florida's natural resources. A 1990 evaluation of Florida's ecosystems predicted, "at the 1990 rate of development, about 3 million acres of wetlands and forests would be converted to other uses by the year 2020."<sup>108</sup> Florida's freshwater, ecological diversity, open space,

---

<sup>103</sup> *SUPER Act Program*, FLA. HEALTH COLUMBIA CNTY. (Jan. 31, 2025, 2:25 PM), <https://columbia.floridahealth.gov/programs-and-services/environmental-health/SUPER%20Act/index.html>.

<sup>104</sup> *Well Surveillance Program (SUPER Act Program)*, FLA. HEALTH LEE CNTY. (Jan. 3, 2019, 2:04 PM), <https://lee.floridahealth.gov/programs-and-services/environmental-health/super-act/index.html>.

<sup>105</sup> Vивиanna Bendixson, *Surface Water Improvement and Management (SWIM) Program*, SW. FLA. WATER MGMT. DIST. (Nov. 2022), <https://www.swfwmd.state.fl.us/about/newsroom/surface-water-improvement-and-management-swim-program>.

<sup>106</sup> FLA. STAT. § 373.451(2); *see also* JOHN W. TURCOTTE, OFF. OF PROGRAM POL'Y ANALYSIS AND GOV. ACCOUNTABILITY, FOLLOW-UP REPORT ON THE SURFACE WATER IMPROVEMENT AND MANAGEMENT PROGRAM 1 (1998).

<sup>107</sup> FLA. STAT. § 373.451 (2024).

<sup>108</sup> *History of State Lands*, FLA. DEP'T OF ENV'T PROT. (Mar. 14, 2024, 12:34 PM), <https://floridadep.gov/lands/lands-director/content/history-state-lands>.

recreational lands, and rich biodiversity was predicted to decline. Improving and expanding pre-existing land acquisition programs, such as the Aquatic Preserves Act, was deemed the ideal solution.

P2000, established in 1990, is the most ambitious land acquisition program the country has ever seen. Once land is purchased under P2000, it is guaranteed to remain untouched. P2000 was a \$3 billion land preservation fund disbursed over a ten-year period in \$300 million annual increments. This funding established over 1.8 million acres of conservation land throughout Florida.<sup>109</sup> This funding was sourced from “documentary stamps,” the taking of a small percentage of money collected from real estate transactions.<sup>110</sup> In 1998, the Indian River Lagoon Blueway was added to P2000’s priority list. Subsequently, 11,038 acres of the IRL were purchased for \$45,794,168.<sup>111</sup>

The legislature passed “Florida Forever” in 1999 because voters authorized an amendment to the constitution to allow a dedicated state tax to fund both land acquisition and restoration.<sup>112</sup> All funding was achieved solely through documentary stamps.<sup>113</sup> In 2023, 17,022 IRL acres were purchased for \$787,897,669, promoting economic success and preserving one of the country’s most biodiverse ecosystems. Florida Forever has established 907,412 acres of conservation land for approximately \$3.3 billion; 2.6 million acres of Florida’s 10 million acres of conservation land have been established through P2000 and its successor thus far.<sup>114</sup>

### *I. The Indian River Lagoon System and Basin Act of 1990*

In 1990, the Indian River Lagoon System and Basin Act of 1990 was created to protect the IRL from discharges from wastewater treatment plants and improper septic system usage.<sup>115</sup> The Act aimed to (1) eliminate surface water discharge, (2) investigate the possibility of reusing water, and (3) centralization wastewater collection and treatment facilities.<sup>116</sup>

---

<sup>109</sup> *Id.*

<sup>110</sup> *Florida Documentary Stamp Tax*, FLA. DEP’T OF REVENUE, [https://floridarevenue.com/taxes/taxesfees/Pages/doc\\_stamp.aspx](https://floridarevenue.com/taxes/taxesfees/Pages/doc_stamp.aspx) (last visited June 12, 2024).

<sup>111</sup> FLA. DEP’T OF ENV’T PROT., DIV. OF STATE LANDS, 2024 FLORIDA FOREVER PLAN: SUMMARY OF RECOMMENDATIONS AND STATUS AS OF DECEMBER 2023 423 (May 24, 2024).

<sup>112</sup> FLA. CONST. art. VII, § 11(e).

<sup>113</sup> *Florida Forever: Public Land Conservation*, THE NATURE CONSERVANCY (Mar. 16, 2021), <https://www.nature.org/en-us/about-us/where-we-work/united-states/florida/stories-in-florida/florida-forever-public-funding-story/>.

<sup>114</sup> *Florida Forever*, FLA. DEP’T OF ENV’T PROT., <https://floridadep.gov/floridaforever> (last visited June 14, 2024).

<sup>115</sup> Comm. Substitute for H.B. No. 3247, 11th Leg., Reg. Sess. (Fla. 1980).

<sup>116</sup> *Reuse Statutory Authority*, FLA. DEP’T OF ENV’T PROT. (Apr. 18, 2022), <https://floridadep.gov/water/domestic-wastewater/content/reuse-statutory-authority>.

In 1987, Section 320 of the CWA established the NEP to “identify, restore and protect estuaries along the coasts of the United States.”<sup>117</sup> Water conservation is ingrained in Florida’s Constitution and legal framework. To further protect the state’s water resources, the IRL was nominated for inclusion into the NEP in 1990. After EPA review, the IRLNEP was established in 1991. The SWIM Act of 1987 authorized Florida’s water management districts to restore priority bodies of water; the IRLNEP worked to restore the IRL. With such analogous goals, the SWIM plan and IRLNEP merged to create the Indian River Lagoon Program.<sup>118</sup>

The IRLNEP is one of 28 NEPs nationwide; the NEP network structure ensures each estuary of national significance has its unique needs addressed. Currently, the IRLNEP is governed by a policy committee the Indian River Lagoon Council, which was established in February 2015. The Council consists of representatives of the five lagoon-bordering counties, the St. Johns River and South Florida Water Management Districts, and the FDEP.<sup>119</sup> All IRLNEP decisions are governed by the Council, with input from a management conference, STEM advisory committee, and citizens' advisory committee.<sup>120</sup>

The IRLNEP promotes the continuation of quality sediment and water in the IRL; supports a healthy ecosystem home to diverse species, commerce, and recreation; raises awareness and encourages teamwork to protect the IRL; and identifies and develops funding to support projects that protect the IRL. These goals are addressed in a CCMP; the IRLNEP published their initial CCMP in 1996, with updates and further plans published in 2008 and 2019.<sup>121</sup> The IRL Vital Signs Wheel consists of 32 action plans that collectively create an



FIGURE 5: IRL Vital Signs Wheel. *Steps to Success*, ONE LAGOON (Spet. 25, 2024), <https://onelagoon.org/steps-to-success/>.

<sup>117</sup> Sam Ziegler, *Oceans, Coasts, and Estuaries*, U.S. ENV'T PROT. AGENCY (Jan. 19, 2017), <https://19january2017snapshot.epa.gov/www3/region9/water/oce/estuaries.html>; *see also* Clean Water Act § 320, 33 U.S.C. § 1330 (2024).

<sup>118</sup> *Living on the Lagoon*, ONE LAGOON, <https://onelagoon.org/living-on-the-lagoon/> (last visited May 1, 2024).

<sup>119</sup> *The Indian River Lagoon NEP*, ONE LAGOON, <https://onelagoon.org/irlnep/> (last visited Apr. 23, 2024).

120 *Id.*

<sup>121</sup> *Resources*, ONE LAGOON, <https://onelagoon.org/resources/> (last visited Nov. 29, 2023).



optimally healthy lagoon.<sup>122</sup> The aforementioned stakeholders identify relevant action plans and collaboratively generate a CCMP that outlines the necessary steps in achieving a healthy IRL.

While the IRLNEP has supported many successful projects, the EPA highlights the License Plate Revenue project as an NEP Success Story. First, 12,000 registered Florida vehicle owners signed a lagoon plate purchase agreement. Then, with approval from a Florida state representative and senator, and a \$15,000 one-time administration fee paid to the Florida Department of Motor Vehicles, the Indian River Lagoon Specialty License Plate Revenue Program was established. The IRLNEP receives \$15 from each license plate sale, which has raised more than \$4 million in just seven years (approximately \$400,000 annually). Vehicle owners pay the plate fee annually, which establishes a steady funding source. From that funding, 80% of license plate proceeds support habitat restoration, while the other 20% supports environmental education projects. The lagoon license plate ranks 16th out of Florida's 103 specialty license plates.<sup>123</sup>

The IRLNEP improves the health of the IRL by collaborating with diverse stakeholders to establish a CCMP that describes the steps to achieving the ideal Lagoon status. The License Plate Program is just one project working towards improving the IRL.

#### K. The Florida Department of Environmental Protection (FDEP)

Historically, the Department of Environmental Regulation and Department of Natural Resources implemented many of Florida's environmental regulations. In 1993, however, these two departments merged, forming the FDEP,<sup>124</sup> the lead agency in managing and protecting Florida's environment.<sup>125</sup> FDEP's Division of Water Resource Management implements all state-level water regulations



FIGURE 6: IRL License Plate Sample. *The IRL License Plate*, ONE LAGOON (Aug. 13, 2024), <https://onelagoon.org/irl-license-plate/>.

<sup>122</sup> *Steps to Success*, ONE LAGOON (Sept. 25, 2024), <https://onelagoon.org/steps-to-success/>.

<sup>123</sup> *Indian River Lagoon National Estuary Program (NEP)(FL) Uses License Plate Revenue Supports Environmental Education and Habitat Restoration*, U.S. ENV'T PROT. AGENCY (May 14, 2024), <https://www.epa.gov/nep/indian-river-lagoon-national-estuary-program-nep-fl-uses-license-plate-revenue-supports>.

<sup>124</sup> *Florida Department of Environmental Protection*, GULFBASE, <https://www.gulfbase.org/organization/florida-department-environmental-protection> (last visited June 17, 2024).

<sup>125</sup> Handberg, *supra* note 88.

and is the point of contact for federal water programs.<sup>126</sup> Under the Florida Water Resources Act, FDEP and Florida's five water management districts manage all state water resources.<sup>127</sup> Analogous to how the EPA undertakes all federal environmental responsibilities, FDEP undertakes all state environmental responsibilities.<sup>128</sup>

The FDEP administers the Total Maximum Daily Load (TMDL) program. Under the CWA, states must submit a list of surface waters that are non-compliant with the EPA's federal water quality standards. FDEP established TMDL limits, or the amount of pollution a body of water can inhabit during a specified time period and still remain compliant with federal water quality standards.<sup>129</sup> The Florida Watershed Restoration Act (FWRA) of 1999 extended federal TMDL requirements to the state level.<sup>130</sup> State water quality standards are published in Florida's Administrative Code and the FDEP ensures impaired waters are identified, reported to the EPA, and improved and monitored until compliant.<sup>131</sup>

The FDEP administers state environmental permitting programs. For example, the FWPCA of 1972 established the NPDES program which prohibited the discharge of pollutants from a point source into United States waters without a permit.<sup>132</sup> In Florida, any conduct altering surface water flow, such as restoration projects, dredging, filling, or any activity that generates stormwater runoff, requires an ERP permit. ERP permits are processed by either a water management district or FDEP, depending on the activity.<sup>133</sup> If your project consists of dredging or filling in waters of the United States or involves construction in or on navigable U.S. waters, then you will need federal authorization from USACE.<sup>134</sup> Minor projects (e.g. small docks, derelict vessel removal), occurring in USACE regulated waters may

---

<sup>126</sup> *Division of Water Resource Management*, FLA. DEP'T OF ENV'T PROT., <https://floridadep.gov/water> (last visited June 17, 2024).

<sup>127</sup> *Water Supply*, FLA. DEP'T OF ENV'T PROT. (Dec. 17, 2024, 1:37 PM), <https://floridadep.gov/owper/water-policy/content/water-supply>.

<sup>128</sup> *The Origins of EPA*, U.S. ENV'T PROT. AGENCY (June 5, 2023), <https://www.epa.gov/history/origins-epa>.

<sup>129</sup> Michael T. Olexa, Tatiana Borisova & Jana Caracciolo, *2021 Handbook of Florida Water Regulation: Florida Air and Water Pollution Control Act*, ASKIFAS (June 22, 2021), <https://edis.ifas.ufl.edu/publication/FE607>.

<sup>130</sup> Kati W. Migliaccio, Yuncong Li & Thomas A. Obreza, *Evolution of Water Quality Regulations in the United States and Florida*, IFAS EXTENSION: U. FLA., ABE 381, Dec. 2007, at 1, 2.

<sup>131</sup> FLA. ADMIN. CODE ANN. 62-302, 62-302.530.

<sup>132</sup> *NPDES Permit Basics*, U.S. ENV'T PROT. AGENCY (Dec. 11, 2023), <https://www.epa.gov/npdes/npdes-permit-basics>.

<sup>133</sup> *Environmental Resource Permitting Coordination, Assistance, Portals*, FLA. DEP'T OF ENV'T PROT. (June 9, 2023), <https://floridadep.gov/water/submerged-lands-environmental-resources-coordination/content/environmental-resource-permitting>.

<sup>134</sup> *Obtain a Permit*, U.S. ARMY CORPS OF ENG'RS, <https://www.usace.army.mil/Missions/Civil-Works/Regulatory-Program-and-Permits/Obtain-a-Permit/> (last visited Mar. 1, 2025).

qualify for a State Programmatic General Permit (SPGP), where USACE delegates the state to provide both state and federal authorization. If a project is approved for SPGP during the state's review, then no additional federal application is required. However, if a project doesn't qualify for a SPGP, a separate federal permit application must be submitted.<sup>135</sup>

As the environment changes, so must the responsibilities of different agencies. The Clean Waterways Act of 2021 transferred authority from the Department of Health to the DEP to deal with the Onsite Sewage Program by creating a temporary sewage department in the FDEP. Local governments must create septic mediation plans; FDEP oversees local plans, provides funding, and offers guidance.<sup>136</sup> This Act prohibits wastewater facilities from discharging into the IRL without proper waste treatment. The Department of Agriculture and Consumer Services was tasked with bi-annual inspections of agricultural sites and their runoff, prioritizing those adjacent to the IRL.<sup>137</sup> This Act also increased fine limits from \$10,000 to \$50,000 for total administrative penalties and raised the cap per violator from \$5,000 to \$10,000. Overall, the Clean Waterways Act addressed multiple water resource issues, including wastewater treatment, stormwater, and agriculture. The IRL has been prioritized due to its ecological and economic importance.<sup>138</sup>

Oftentimes, laws, policies, and regulations are amended to reach maximum effectiveness. Environmental laws, policies, and regulations must adapt as humanity's knowledge of the natural world expands. For example, on June 28, 2024, Senate Bill 7040 (SB 7040) changed pre-existing ERP laws by implementing stricter requirements for the operation, maintenance, and inspection of stormwater projects.<sup>139</sup> However, to avoid repetitive review, projects being inspected under another stormwater law are not subject to inspection under SB 7040.<sup>140</sup> For example, projects adhering to Florida's Best

---

<sup>135</sup> *State 404 Program*, FLA. DEP'T OF ENV'T PROT. (July 16, 2024, 2:02 PM), <https://floridadep.gov/water/submerged-lands-environmental-resources-coordination/content/state-404-program>.

<sup>136</sup> *Governor Ron DeSantis Signs SB 712 "The Clean Waterways Act"*, EXEC. OFF. OF THE GOVERNOR RON DESANTIS (June 30, 2020), <https://www.flgov.com/eog/news/press/2020/governor-ron-desantis-signs-sb-712-clean-waterways-act>.

<sup>137</sup> Marlowe Starling, *DeSantis Signs Sweeping New Environmental Law for Cleaner Water*, FLA. TIMES-UNION (July 1, 2020, 8:21 AM), <https://www.jacksonville.com/story/news/environment/2020/07/01/desantis-signs-sweeping-new-environmental-law-for-cleaner-water/41714235/>.

<sup>138</sup> *See Bill Summary for SB 712: Environmental Resource Management*, FLA. SENATE, <https://www.flsenate.gov/Committees/bills/summaries/2020/html/2136>.

<sup>139</sup> *ERP Stormwater Resource Center*, FLA. DEP'T OF ENV'T. PROT. (Dec. 13, 2024, 5:57 PM), <https://floridadep.gov/water/engineering-hydrology-geology/content/erp-stormwater-resource-center>.

<sup>140</sup> *CS/SB 7040 — Ratification of the Department of Environmental Protection's Rules Relating to Stormwater*, FLA. SENATE, <https://www.flsenate.gov/Committees/BillSummaries/2024/html/3441> (last visited July 1, 2024).

Management Practices (BMP) Plan are not subject to repeat inspection under SB 7040. BMPs are methods proven to be the most effective and practical way to improve water quality in an area.<sup>141</sup> BMPs can be implemented by individuals and industries or businesses.<sup>142</sup> For example, the FDEP implemented Operation Cleansweep, an affordable, environmentally friendly way for farmers, pest control services, and golf course operators to dispose of pesticides.<sup>143</sup>

*L. House Bill 1379: \$100 Million Towards Restoring the Indian River Lagoon*

Previously, the IRL was mentioned generally in legislation, such as the Clean Waterways Act of 2020 (SB 712), which required local governments to create wastewater treatment plans, prevented wastewater treatment facilities from discharging into the Indian River Lagoon without extensive treatment, and granted the DEP more authority to deal with stormwater regulations.<sup>144</sup> However, House Bill 1379 (HB 1379), signed into effect in May of 2023, was implemented solely to improve the IRL.<sup>145</sup> DeSantis declared Florida must “continue[] its momentum to protect Florida’s environment, especially the IRL.”<sup>146</sup> This Bill allocated \$100 million towards IRL improvement projects, created the IRL Protection Program—a new IRL water quality monitoring program—and established new requirements for septic systems within the IRL watershed. HB 1379 was geared towards reducing excessive nutrients from entering the IRL, which protects seagrass, prevents algal blooms, and improves ecosystems for species such as the Florida Manatee. To achieve this goal, Basin Management Action Plan (BMAP) projects and onsite sewage treatment and disposal systems (OSTDS) requirements were implemented. Enhanced nutrient-reducing onsite sewage treatment and disposal systems (ENR-OSTDS) were installed with every new septic system.<sup>147</sup> While this Bill is

---

<sup>141</sup> *Agricultural Best Management Practices*, FLA. DEP’T OF AGRIC. & CONSUMER SERVS., <https://www.fdacs.gov/Agriculture-Industry/Water/Agricultural-Best-Management-Practices> (last visited July 24, 2024).

<sup>142</sup> *Best Management Practices (BMPs)*, S. FLA. WATER MGMT. DIST., <https://www.sfwmd.gov/doing-business-with-us/bmps> (last visited July 24, 2024).

<sup>143</sup> *Operation Cleansweep for Pesticides*, FLA. DEP’T OF ENV’T PROT. (Mar. 11, 2024), <https://floridadep.gov/waste/permitting-compliance-assistance/content/operation-cleansweep-pesticides>.

<sup>144</sup> CS/CS/SB 712, 2020 Leg., 1st Reg. Sess. (Fla. 2020).

<sup>145</sup> FLA. STAT. § 373.469 (2024).

<sup>146</sup> *Governor Ron DeSantis Awards \$100 Million for Projects to Restore the Indian River Lagoon*, EXEC. OFF. OF THE GOVERNOR RON DESANTIS (December 18, 2023), <https://www.flgov.com/2023/12/18/governor-ron-desantis-awards-100-million-for-projects-to-restore-the-indian-river-lagoon/>.

<sup>147</sup> See FLA. DEP’T OF ENV’T PROT., 2023 FLORIDA LEGISLATIVE SESSION: HOUSE BILL 1379, [https://floridadep.gov/sites/default/files/DEP\\_HB1379\\_SB1632\\_OnePageDocument\\_05042023-v02.pdf](https://floridadep.gov/sites/default/files/DEP_HB1379_SB1632_OnePageDocument_05042023-v02.pdf).

relatively recent (July 1, 2023), the IRL has already benefited from its funding, monitoring, and requirements.

#### V. THE FUTURE OF THE INDIAN RIVER LAGOON

The IRL is one of the most biologically diverse estuaries in North America, contributes heavily to Florida's economy, and provides jobs and natural resources.<sup>148</sup> While the Lagoon has improved, recovering from years of man-made pollution and harm takes time. Constant funding and adaptive laws, regulations, policies, and programs ensure the Lagoon's changing needs are met. 71% of earth is covered in water; the IRL is just one example.<sup>149</sup> As we learn more about the environment, the legal frameworks protecting it must adapt. Earth's demands are not fixed, but rather mutable; our laws, policies, and regulations must reflect that. To improve our environment, we must think like our environment.<sup>150</sup>

---

<sup>148</sup> Harbor Branch Oceanographic Institute, *Indian River Lagoon — Facts and Figures*, FLA. ATL. UNIV., <https://www.fau.edu/hboi/research/marine-ecosystem-conservation/irlo/outreach/irl-facts-and-figures/> (last visited Sept. 1, 2024).

<sup>149</sup> Water Science School, *How Much Water Is There on Earth*, U.S. GEOLOGICAL SURV. (Nov. 13, 2019), <https://www.usgs.gov/special-topics/water-science-school/science/how-much-water-there-earth>.

<sup>150</sup> Douglas P. Wheeler & Douglass Lea, *Rediscovering Ecology*, 16 EPA J., no. 6, 1990, at 34, 34.

## LAGOON LAWS: TIMELINE

**Laws, Policies, and Regulations  
of the  
Indian River Lagoon**

The Federal Water Pollution Control Act (FWPCA) of 1948

The Florida Air and Water Pollution Control Act of 1967

The National Environmental Policy Act of 1970

The Florida Pollutant Discharge Prevention & Control Act of 1970

The Florida Environmental Protection Act of 1971

The Clean Water Act of 1972

The Florida Water Resources Act of 1972

The Coastal Zone Management Act of 1972

The Marine Mammals Protection Act of 1972

The Endangered Species Act of 1973

The Safe Water Drinking Act of 1974

The Aquatic Preserves Act of 1975

The Florida Water Quality Assurance Act of 1983

The Florida SUPER Act of 1986

The National Estuary Program (NEP) of 1987

The Surface Water Improvement and Management Act 1987

The North American Wetlands Conservation Act of 1989

The IRL System and Basin Act of 1990

Preservation 2000 (Est. 1990)

The IRL National Estuary Program (Est. 1991)

The FL Department of Environmental Protection (Est. 1992)

Florida Forever (Est. 1999)

The Estuary Restoration Act of 2000

The Comprehensive Everglades Restoration Plan of 2000

The Bipartisan Congressional Estuary Caucus of 2017

The Bipartisan Infrastructure Law of 2021

House Bill 1379 (Est. 2023)

## FEDERAL LAWS INFOGRAPHIC

## Federal Environmental Laws

<b>Federal Water Pollution Control Act (1948)</b>	1st major U.S. law addressing water pollution; implemented pollution control programs
<b>National Environmental Policy Act (1970)</b>	Requires federal agencies to consider impacts of decisions before making them
<b>Clean Water Act (1972)</b>	Authorizes EPA to improve U.S. water quality
<b>Coastal Zone Management Act (1972)</b>	Protects/manages U.S. coastal resources; addresses coastal development issues
<b>Marine Mammal Protection Act (1972)</b>	Protects marine mammals in U.S. waters by prohibiting the taking of these animals
<b>Endangered Species Act (1973)</b>	Protects plants, fish, and wildlife that are listed as threatened or endangered
<b>Safe Water Drinking Act (1974)</b>	EPA protects drinking water supplies
<b>National Estuary Program (1987)</b>	Protects/restores the ecological integrity and water quality of 28 estuaries in the U.S.
<b>N. American Wetlands Conservation Act (1989)</b>	Authorizes grants to protect, restore, and enhance wetlands and their habitats
<b>Estuary Restoration Act (2000)</b>	Addresses damage to estuaries and the increasing loss of wetlands.
<b>Comprehensive Everglades Restoration Plan (2000)</b>	Restores, protects, and preserves Florida's everglades ecosystems
<b>Bipartisan Congressional Estuary Caucus (2017)</b>	Educates Congress on the importance of our nation's estuaries
<b>Bipartisan Infrastructure Law (2021)</b>	Made investments in drinking water and wastewater infrastructure



## STATE LAWS INFOGRAPHIC

## State Environmental Laws

<b>FL Air &amp; Water Pollution Control Act (1967)</b>	Establishes general framework for water and air quality regulations in Florida
<b>FL Pollutant Discharge Prevention &amp; Control Act (1970)</b>	Prevents vessels from discharging oil or other pollutants in Florida waters
<b>FL Environmental Protection Act (1971)</b>	Creates a legal consequence for those actively harming the environment
<b>FL Water Resources Act (1972)</b>	Created 5 Water Management Districts
<b>Aquatic Preserves Act (1975)</b>	Establishes aquatic preserves
<b>FL Water Quality Assurance Act (1983)</b>	Protects FL ground water quality; reduces surface/ground water contamination
<b>FL SUPER Act (1986)</b>	Identifies and reduces contaminated drinking water sites
<b>Surface Water Improvement and Management Act (1987)</b>	Protects, restores, and maintains Florida's surface water bodies; water management districts identify priority bodies of water
<b>Indian River Lagoon and Basin Act (1990)</b>	Improves domestic wastewater facilities in Indian River Lagoon region
<b>Preservation 2000 (1990)</b>	Provides funding for land acquisition
<b>Indian River Lagoon National Estuary Program (1991)</b>	Promotes a healthy lagoon, healthy community, and healthy economy.
<b>FL Dept. of Environmental Protection (1972)</b>	Protects, conserves, & manages natural resources; enforces state environmental laws
<b>Florida Forever (1999)</b>	Buys land for conservation and recreation
<b>House Bill 1379 (2023)</b>	Directly supports IRL conservation



# The Hidden Death Penalty: Access to Cancer Diagnostics and Medicaid/Medicare in Prisons

EMMAKATE FOLEY\*

## ABSTRACT

*Cancer is the leading cause of inmate death in state and federal prisons in the United States.<sup>1</sup> This paper examines the systematic barriers to cancer diagnostics within prisons, including the lack of access to regular screenings and the exclusion of incarcerated individuals from Medicaid and Medicare under the Federal Inmate Exclusion Policy (MIEP).<sup>2</sup> These shortcomings contribute to delayed diagnoses, higher rates of late-stage cancers, and preventable deaths, violating constitutional protections against cruel and unusual punishment as established in *Estelle v. Gamble*.<sup>3</sup> Moreover, untreated cancers result in increased healthcare costs upon prisoner release, burdening the public health system.<sup>4</sup> This paper proposes two key solutions: repealing MIEP to extend Medicaid and Medicare coverage to prisons, and implementing regular cancer screening programs. Together, these measures aim to reduce cancer mortality, improve prisoner health outcomes, and ensure compliance with constitutional standards while mitigating long-term public health costs.*

---

\* J.D. Candidate, University of Connecticut School of Law, May 2025. I thank Professor John Cogan for sparking my interest in this topic through his passion and expertise in health law, for providing invaluable feedback during my editing process, and for encouraging me to submit my paper for publication. I thank the Connecticut Public Interest Law Journal for their hard work on this article. And last, but certainly not least, I'm deeply thankful for the support of my family and friends. A special thank you to my Mom, Kate Sullivan Foley, who I grew up admiring as a writer—her excellent storytelling, eye for grammar, and work ethic remain my blueprint.

<sup>1</sup> *Incarceration Associated with Higher Cancer Mortality, Yale Study Shows*, YALE SCH. MED. (Sept. 16, 2022), <https://medicine.yale.edu/news-article/incarceration-associated-with-higher-cancer-mortality-yale-study-shows/>.

<sup>2</sup> See generally *infra* Part II (discussing lack of access to cancer diagnostics and Medicare and Medicaid in prisons).

<sup>3</sup> See generally *infra* Part III (discussing harms produced by the access issues in prisons).

<sup>4</sup> See *infra* Part II.C (discussing increased public healthcare costs).

## INTRODUCTION

A prison sentence in the United States<sup>5</sup> not only deprives individuals of their liberty and freedom, but also stands to pose a profound threat to their physical health. Despite the various safety risks that prisoners face living behind bars,<sup>6</sup> cancer remains the leading cause of mortality among the incarcerated population in state and federal prisons.<sup>7</sup> This reality stems, in part, from the lack of access to cancer diagnostic care and the exclusion of prisoners from Medicare and Medicaid coverage. Across correctional facilities nationwide, these access issues result in death—instead of release—marking the end of many sentences.<sup>8</sup> In addition to increased mortalities, lack of access to diagnostics and insurance for prisoners increases public health costs and violates the constitutional principles announced in *Estelle v. Gamble*.<sup>9</sup> With over two million people incarcerated in the United States,<sup>10</sup> this healthcare disparity demands attention and reform.

This paper explores the cancer healthcare disparity plaguing the United States prison system, and in turn, the American public health system at large. Part I discusses the lack of access to cancer diagnostic care and Medicaid and Medicare coverage in prisons. Part II then explores the harms produced by this access problem, including increased prisoner mortality, increased public health costs, and unvindicated constitutional rights. Finally, Part III proposes a repeal of the Federal Medicaid and Medicare Inmate Exclusion Policy, alongside an increase in regular screening procedures, as potential solutions to ameliorate these unresolved harms. To note, available data on healthcare and cancer outcomes in prison are limited, largely acquired through just a handful of comprehensive studies, personal stories, and

---

<sup>5</sup> When discussing incarcerated populations, this paper is referring exclusively to prisoners in state and federal correctional facilities in the United States.

<sup>6</sup> E. Ann Carson, *Mortality in State and Federal Prisons, 2001–2019 — Statistical Tables*, BUREAU OF JUST. STAT., (Dec. 2021), <https://bjs.ojp.gov/content/pub/pdf/msfp0119st.pdf> (discussing causes of death in prisons).

<sup>7</sup> *Incarceration Associated with Higher Cancer Mortality, Yale Study Shows*, *supra* note 1; Christopher R. Manz, Varshini S. Odayar & Deborah Schrag, *Disparities in Cancer Prevalence, Incidence, and Mortality for Incarcerated and Formerly Incarcerated Patients: A Scoping Review*, 10 *CANCER MED.* 7277, 7286 (2021); Lisa V. Puglisi, Tyler N.A. Winkelman, Cary P. Gross & Emily A. Wang, *Cancer Prevalence Among Adults with Criminal Justice Involvement from a National Survey*, 35 *J. GEN. INTERN. MED.* 967, 968 (2019) (finding that “lung cancer, cervical cancer, and alcohol-related cancers are significantly more common among Americans with a history of criminal justice involvement compared with the general population”).

<sup>8</sup> *See, e.g.*, PENAL REFORM INT’L, *DEATHS IN PRISON* (Dec. 2022), <https://cdn.penalreform.org/wp-content/uploads/2022/12/Deaths-in-prison-briefing.pdf>.

<sup>9</sup> In *Estelle v. Gamble*, the Supreme Court held that deliberate indifference to a prisoner’s medical needs violates the Eighth Amendment’s prohibition against cruel and unusual punishment. *See Estelle v. Gamble*, 429 U.S. 97, 104–05 (1976). For a more in-depth discussion on this case, see *infra* Part II.B (discussing constitutional violations and increased litigation as a harm generated by the lack of access to diagnostics and Medicare and Medicaid in prisons).

<sup>10</sup> JOHN D. CARL & MARY D. LOOMAN, *A COUNTRY CALLED PRISON: MASS INCARCERATION AND THE MAKING OF A NEW NATION* 13 (2d ed. 2024); *see also* Carson, *supra* note 6.

litigation.<sup>11</sup> The paucity of research on cancer in prisons has resulted in data gaps that prevent a comprehensive understanding of this problem.<sup>12</sup> This paper explores the issue to the extent that it is currently researched.

## I. ACCESS TO DIAGNOSTICS AND MEDICAID/MEDICARE COVERAGE

While cancer claims countless lives each year, there are several proven ways to reduce its deadly impact.<sup>13</sup> Two critical measures—regular screenings to detect cancer at an early stage and health insurance to cover these services—are areas where prisons fall short.

### A. Lack of Access to Diagnostic Care

In a personal submission to the *Prison Journalism Project*, Kevin Connell, a prisoner in Virginia, penned, “[e]arly diagnosis is the most critical element in achieving positive cancer outcomes, which is perhaps why I’ve seen so few happy endings in [twenty-five] years of incarceration.”<sup>14</sup> Connell’s testimony underscores the grim truths of cancer diagnostics in prisons.<sup>15</sup> This reality is fueled by a troubling paradox: incarcerated individuals are at a higher risk of developing cancer,<sup>16</sup> yet they are significantly less likely to receive the early diagnoses needed to save their lives.<sup>17</sup>

### 1. Higher Cancer Incidence Rates in the Incarcerated Population

Incarcerated individuals have a twenty-two percent higher likelihood of cancer incidence when compared to the general population.<sup>18</sup> This is largely

---

<sup>11</sup> *The Impact of Incarceration on Cancer Outcomes*, UNIV. FLA. COLL. MED., <https://radonc.med.ufl.edu/researchlabs/current-radiation-oncology-research-at-uf/the-impact-of-incarceration-on-cancer-outcomes/> (last visited Nov. 20, 2024) [hereinafter UF COLL. MED.].

<sup>12</sup> See generally Manz, Odayar & Schrag, *supra* note 7 (reviewing the twenty available studies regarding cancer incidence in United States jails and prisons).

<sup>13</sup> AM. CANCER SOC’Y, CANCER FACTS AND FIGURES 2021, <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2021/cancer-facts-and-figures-2021.pdf>.

<sup>14</sup> Kevin A. Connell, *The Cancer Sign That’s Everywhere in Prison*, PRISON JOURNALISM PROJECT (July 11, 2024), <https://prisonjournalismproject.org/2024/07/11/cancer-in-prison>.

<sup>15</sup> To note, there is little—if any—data on the differences in cancer care between public and private, maximum and minimum security, and co-ed and all-women’s prisons. However, this paper addresses the prison system at large with data encompassing all types of prisons.

<sup>16</sup> See Manz, Odayar & Schrag, *supra* note 7, at 7278.

<sup>17</sup> See, e.g., Hassan Aziz, Ruth L. Ackah, Amy Whitson, Bridget Oppong, Samilia Obeng-Gyasi, Carrie Sims & Timothy M. Pawlik, *Cancer Care in the Incarcerated Population: Barriers to Quality Care and Opportunities for Improvement*, 156 JAMA SURGERY 964, 968 (2021) (“Incarcerated patients commonly present to oncology clinics with advanced stages of cancer and a history of prolonged signs and symptoms.”); Lisa Puglisi, Alexandra A. Halberstam, Jenerius Aminawung, Colleen Gallagher, Lou Gonsalves, Dena Schulman-Green, Hsiu-Ju Lin, Rajni Metha, Sophia Mun, Oluwadamilola T. Oladeru, Cary Gross & Emily A. Wang, *Incarceration and Cancer-Related Outcomes (ICRO) Study Protocol: Using a Mixed-Methods Approach to Investigate the Role of Incarceration on Cancer Incidence, Mortality and Quality of Care*, 2021 BMJ OPEN 1, 3 (2021).

<sup>18</sup> See Manz, Odayar & Schrag, *supra* note 7, at 7278.

attributed to the prevalence of key cancer risk factors and the overrepresentation of low-income and minority groups within prisons.

With respect to the key risk factors, individuals in the criminal justice system have higher rates of smoking (82%) and substance abuse (67%) when compared to the general population.<sup>19</sup> These behaviors significantly increase cancer risk, with, for example, smoking accounting for twenty percent of U.S. cancers<sup>20</sup> and excessive alcohol consumption raising risks for stomach, pancreatic, and prostate cancers.<sup>21</sup> Additionally, the prison population struggles at high rates with cancer-causing conditions including hepatitis C, HIV, AIDS, obesity, and chronic stress.<sup>22</sup>

In conjunction with these risk factors, the demographics of prisons are already vulnerable to negative cancer outcomes. Incarcerated populations are “largely drawn from the most disadvantaged part of the nation’s population: . . . disproportionately minority, and poorly educated.”<sup>23</sup> Black Americans are incarcerated at nearly five times the rate of whites, and Latinx Americans are incarcerated at nearly 1.5 times the rate of whites.<sup>24</sup> Moreover, people earning “less than 150 percent of the federal poverty level are [fifteen] times more likely to be charged with a felony.”<sup>25</sup> While discussing the health disparities that exist within those populations is beyond the scope of this paper, it suffices to state that in the United States, racial

---

<sup>19</sup> Cyrus Ahalt, Timothy Buiser, Janet Myers & Brie Williams, *Smoking and Smoking Cessation Among Criminal Justice-Involved Older Adults*, 12 TOBACCO USE INSIGHTS 1, 1–3 (2019). One study which assessed nearly 19,000 prisoners across ten counties identified 1/4 of the population as having a former or current alcohol or drug use disorder. See Seena Fazel, Isabel A. Yoon & Adrian J. Hayes, *Substance Use Disorders in Prisoners: An Updated Systematic Review and Meta-Regression Analysis in Recently Incarcerated Men and Women*, 112 ADDICTION 1725, 1733 (2017).

<sup>20</sup> *How Smoking Tobacco Affects Your Cancer Risk*, AM. CANCER SOC’Y 1 <https://www.cancer.org/content/dam/CRC/PDF/Public/8345.00.pdf> (last updated Nov. 19, 2024).

<sup>21</sup> *Alcohol and Cancer*, CTR. DISEASE CONTROL & PREVENTION, <https://www.cdc.gov/cancer/risk-factors/alcohol.html> (last updated Jan. 29, 2025).

<sup>22</sup> See UF COLL. MED., *supra* note 11; Emily Hoff, Andrea Warden, Ruby Taylor & Ank E. Nijhawan, *Hepatitis C Epidemiology in a Large Urban Jail: A Changing Demographic*, 138 PUB. HEALTH REPS. 248, 248 (2022) (noting that “[n]early 1 in 3 people with hepatitis C virus (HCV) infection pass through the criminal justice system annually.”).

<sup>23</sup> THE GROWTH OF INCARCERATION IN THE UNITED STATES: EXPLORING CAUSES AND CONSEQUENCES (Jeremy Travis, Bruce Western & Steve Redburn, eds. 2014). Another study noted that the United States prison population is “disproportionate[ly] of ethnic and racial backgrounds, [and] often originate from . . . vulnerable socio-economic regions.” UF COLL. MED., *supra* note 11.

<sup>24</sup> ASHLEY NELLIS, SENT. PROJECT, THE COLOR OF JUSTICE: RACIAL AND ETHNIC DISPARITY IN STATE PRISONS 5 (Oct. 13, 2021), <https://www.sentencingproject.org/app/uploads/2022/08/The-Color-of-Justice-Racial-and-Ethnic-Disparity-in-State-Prisons.pdf> (“In 12 states, more than half the prison population is Black: Alabama, Delaware, Georgia, Illinois, Louisiana, Maryland, Michigan, Mississippi, New Jersey, North Carolina, South Carolina, and Virginia.”).

<sup>25</sup> Tara O’Neill Hayes & Margaret Barnhorst, *Incarceration and Poverty in the United States*, AM. ACTION F. (June 30, 2020), <https://www.americanactionforum.org/research/incarceration-and-poverty-in-the-united-states/>.

minorities<sup>26</sup> and low-income individuals<sup>27</sup> experience higher rates of death from cancer regardless of incarceration status, largely due to their limited access to health insurance, primary care, and cancer preventative resources.<sup>28</sup>

With known cancer risk factors and vulnerable populations confined within prisons, the higher rates of cancer incidence within this population are unsurprising. Nevertheless, this population's likelihood of receiving a life-saving diagnosis remains low.

## *2. Incarcerated Populations are Less Likely to Receive Early Diagnosis Due to Delayed or Unavailable Screenings*

The World Health Organization (WHO) recommends no more than one month between symptom presentation and diagnosis for cancer cases.<sup>29</sup> This guidance reflects the well-known understanding that the earlier cancer is detected, the more likely someone is to survive.<sup>30</sup> Prisons, however, are grossly underperforming on WHO's target as screenings are limited and "cancer is diagnosed at more advanced stages" within the incarcerated population.<sup>31</sup>

---

<sup>26</sup> *Cancer Disparities in the Black Community*, AM. CANCER SOC'Y, <https://www.cancer.org/about-us/what-we-do/health-equity/cancer-disparities-in-the-black-community.html> (last visited Dec. 11, 2024) ("African Americans have a higher cancer burden and face greater obstacles to cancer prevention, detection, treatment, and survival. In fact, Black people have the highest death rate and shortest survival of any racial/ethnic group for most cancers in the U.S."); *Cancer and African American People*, CTR. DISEASE CONTROL & PREVENTION, <https://www.cdc.gov/cancer/health-equity/african-american.html> (last visited Dec. 11, 2024) ("Black people have the highest death rate for cancer overall.").

<sup>27</sup> See generally Joseph M. Unger, Anna B. Moseley, Christabel K. Cheung, Raymond U. Osarogiagbon, Banu Symington, Scott D. Ramsey & Dawn L. Hershman, *Persistent Disparity: Socioeconomic Deprivation and Cancer Outcomes in Patients Treated in Clinical Trials*, 39 J. CLINICAL ONCOLOGY 1339, 1339 (2017); Hayes & Barnhorst, *supra* note 25.

<sup>28</sup> Valentina A. Zavala, Paige M. Bracci, John M. Carethers, Luis Carvajal-Carmona, Nicole B. Coggins, Marcia R. Cruz-Correa, Melissa Davis, Adam J. de Smith, Julie Dutil, Jane C. Figueiredo, Rena Fox, Kristi D. Graves, Scarlett Lin Gomez, Andrea Llera, Susan L. Neuhausen, Lisa Newman, Tung Nguyen, Julie R. Palmer, Nynikka R. Palmer, Eliseo J. Pérez-Stable, Sorbarikor Piawah, Erik J. Rodriguez, María Carolina Sanabria-Salas, Stephanie L. Schmit, Silvia J. Serrano-Gomez, Mariana C. Stern, Jeffrey Weitzel, Jun J. Yang, Jovanny Zabaleta, Elad Ziv & Laura Fejerman, *Cancer Health Disparities in Racial/Ethnic Minorities in the United States*, BRIT. J. CANCER 315, 316–18 (2021).

<sup>29</sup> PATRICIA H. DAVID, OFF. CORRECTIONS OMBUDS, OCO INVESTIGATION OF DELAYED CANCER DIAGNOSIS AND MANAGEMENT 15 (Jan. 14, 2021), <https://oco.wa.gov/sites/default/files/Delayed%20Cancer%20Diagnosis%20and%20Management%20Final%20with%20DOC%20Response.pdf> (citing WORLD HEALTH ORGANIZATION, GUIDE TO CANCER EARLY DIAGNOSIS (Feb. 16, 2017), <https://iris.who.int/bitstream/handle/10665/254500/9789241511940-eng.pdf>).

<sup>30</sup> Jennifer T. Loud & Jeanne Murphy, *Cancer Screening and Early Detection*, 33 SEMINARS ONCOLOGY NURSING 121, 128 (2017) ("Cancer screening recommendations have been shown to significantly decrease the mortality from certain cancers (i.e., cervical and colorectal), while more modestly decreasing mortality of others.").

<sup>31</sup> Oluwadamilola T. Oladeru, Jenerius A. Aminawung, Hsiu-Ju Lin, Lou Gonsalves, Lisa Puglisi, Sophia Mun, Colleen Gallagher, Pamela Soulos, Cary P. Gross & Emily A. Wang, *Incarceration Status and Cancer Mortality: A Population Based Study*, 17 PLOS ONE, no. 9, 2022, at 1, 2.

Timely access to cancer screenings in prisons is a largely unexplored area.<sup>32</sup> Available data, however, reveal access to regular screenings—or access to screenings at all—are largely uncommon,<sup>33</sup> but variable depending on the correctional facility.<sup>34</sup> According to one study, 13.9% of federal prisoners and 20.1% of state prisoners had received no medical examinations since their incarceration.<sup>35</sup> More specifically, for breast cancer, some studies report zero percent of women receiving mammograms<sup>36</sup> during their incarceration, while others report up to fifty percent receiving screenings.<sup>37</sup> These statistics stand in sharp contrast to the American Cancer Society’s recommendation that women over the age of forty-five should get mammograms annually.<sup>38</sup> With respect to colorectal cancer, the American Cancer Society similarly recommends regular screenings starting at age forty-five.<sup>39</sup> However, one study found that “only [twenty-percent] of [incarcerated] male patients were up to date with . . . screening.”<sup>40</sup> Other cancers, including lung and hepatocellular carcinoma, currently have no studies specifically assessing screening frequencies in correctional facilities. However, the negative outcomes for these types of cancers in prisons indicate that screening procedures are poor.<sup>41</sup> For example, the Yale School of Medicine explored screenings in Connecticut prisons and found that, despite the lack of reporting on screening frequency, it was clear based on the high rates of cancer mortality that the inmates were “under-screened and under-detected.”<sup>42</sup>

<sup>32</sup> See e.g., Christopher R. Manz, Varishini S. Odayar & Deborah Schrag, *Cancer Screening Rates and Outcomes for Justice-Involved Individuals: A Scoping Review*, 29 J. CORR. HEALTH CARE 220, 222 tbl. 1 (2023); Oladeru, Aminawung, Lin, Gonsalves, Puglisi, Mun, Gallagher, Soulos, Gross & Wang, *supra* note 31, at 2.

<sup>33</sup> See UF COLL. MED., *supra* note 11; Andrew P. Wilper, Steffie Woolhandler, Wesley Boyd, Karen E. Lasser, Danny McCormick, David H. Bor & David U. Himmelstein, *The Health and Health Care of US Prisoners: Results of a Nationwide Survey*, 99 AM. J. PUB. HEALTH 666, 670 (2009).

<sup>34</sup> See Aziz, Ackah, Whitson, Oppong, Obeng-Gyasi, Sims & Pawlik, *supra* note 17, at 966 (noting that screening access is “heavily dependent on (1) the state in which the individual is incarcerated, (2) the length of incarceration, and (3) arrangements for health care . . . and follow-up made by each individual correctional institution”).

<sup>35</sup> It can be inferred from this data that “no medical examinations” include no cancer screenings. See *id.* at 968.

<sup>36</sup> Yoshiko Iwai, Alice Yunzi L. Yu, Samantha M. Thomas, Tyler Jones, Kelly E. Westbrook, Andrea K. Knittel & Oluwadamilola M. Fayanju, *Examining Inequities Associated with Incarceration Among Breast Cancer Patients*, 13 CANCER MED., May 15, 2024, at 2.

<sup>37</sup> Manz, Odayar & Schrag, *supra* note 32, at 225.

<sup>38</sup> *American Cancer Society Guidelines for the Early Detection of Cancer*, AM. CANCER SOC’Y, <https://www.cancer.org/cancer/screening/american-cancer-society-guidelines-for-the-early-detection-of-cancer.html> (last visited Dec. 14, 2024).

<sup>39</sup> *Id.*

<sup>40</sup> Manz, Odayar & Schrag, *supra* note 32, at 227.

<sup>41</sup> Jingxuan Zhao, Sandhya Kajeeepeta, Christopher R. Manz, Xuesong Han, Leticia M. Nogueira, Zhiyuan Zheng, Qinjin Fan, Kewei Sylvia Shi, Fumiko Chino & K. Robin Yabroff, *County-Level Jail and State-Level Prison Incarceration and Cancer Mortality in the United States*, 117 J. NAT’L CANCER INST. 157 (2024) (finding high mortality rates for lung and liver cancers in state prisons).

<sup>42</sup> Ilana B. Richman, Pamela R. Soulos, Hsiu-ju Lin, Jenerius A. Aminawung, Oluwadamilola Oladeru, Lisa B. Puglisi, Emily A. Wang & Cary P. Gross, *Incarceration and Screen-Detectable Cancer*

Once, or if, cancer is detected in inmates following a screening, the disease has typically entered a later stage which worsens survival rates.<sup>43</sup> In a study on Connecticut prisons, 58.8% of prisoners were diagnosed at a metastasized stage compared to 31.9% in the never incarcerated group.<sup>44</sup> Results overall identified nearly two-thirds of prison patients already had regional spread at the time of diagnosis.<sup>45</sup> Furthermore, the Office of the Corrections Ombuds (OCO) conducted an investigation of state prison inmates in Seattle, Washington<sup>46</sup> which revealed an average of 6.5 months for prisoners to be diagnosed with cancer after the presentation of initial symptoms.<sup>47</sup> Some, however, reported diagnoses up to seventeen months after symptom onset.<sup>48</sup> Importantly, these late-stage diagnoses are occurring with cancers that have effective screening options,<sup>49</sup> namely, cervical, lung, colorectal, and liver cancers.<sup>50</sup> One study examined the differences in diagnostics for cancer tumor staging in prisoners versus non-prisoners.<sup>51</sup> For colorectal cancer, the tumors of prisoners were diagnosed at a ninety-two percent worsened stage than non-prisoners; for liver cancer, there was a twenty-one percent differential.<sup>52</sup>

Cervical cancer offers another stark example of this diagnostic disparity. In the general population, cervical cancer is considered highly treatable. About 12,000 women in the United States each year are diagnosed with cervical cancer, and approximately ninety-two percent of those women

---

*Diagnosis Among Adults in Connecticut*, 116 J. NAT'L CANCER INST. 485, 485 (2023); Sujata Srinivasan, *Connecticut Prisons Likely Under-Screen, Under-Diagnose Cancer, Study Finds*, CT MIRROR (Dec. 6, 2023, 8:00 AM), <https://ctmirror.org/2023/12/06/ct-prisons-cancer-screening-yale-school-medicine/>.

<sup>43</sup> Isabella Backman, *How Incarceration Raises Risk of Cancer Diagnosis and Death—Even After Release*, YALE SCH. MED. (Mar. 17, 2023), <https://medicine.yale.edu/news-article/how-incarceration-raises-risk-of-cancer-diagnosis-and-death-even-after-release/>; Manz, Odayar & Schrag, *supra* note 7.

<sup>44</sup> Oladeru, Aminawung, Lin, Gonsalves, Puglisi, Mun, Gallagher, Soulos, Gross & Wang, *supra* note 31, at 7.

<sup>45</sup> *Id.*

<sup>46</sup> See DAVID, *supra* note 29.

<sup>47</sup> Jim Brunner, *Investigation Finds More Deadly Delays in Cancer Diagnosis and Treatment at Washington State Prisons*, SEATTLE TIMES (Mar. 30, 2021, 10:27 AM), <https://www.seattletimes.com/seattle-news/law-justice/investigation-finds-more-deadly-delays-in-cancer-diagnosis-and-treatment-at-washington-state-prisons/>.

<sup>48</sup> *Id.* One individual studied, Michael Boswell, pleaded for months to receive treatment for a bleeding lesion on his back. The staff, however, consistently told him the lesion was benign. Months later, he received an aggressive skin cancer diagnosis. Boswell died only a month later at age 37. Boswell had a known family history of cancer and overt symptoms, but the delayed care for an initially treatable condition still culminated in his death. Boswell's experience was not idiosyncratic in Monroe Correctional Facility—the OCO report identified many other similarly situated prisoners, with some not getting diagnoses until 17 months after symptom presentation. *Id.*

<sup>49</sup> See generally Manz, Odayar & Schrag, *supra* note 32.

<sup>50</sup> *Id.*

<sup>51</sup> See generally Kathryn I. Sunthakar, Kevin N. Griffith, Stephanie D. Talutis, Amy K. Rosen, David B. McAneny, Matthew H. Kulke, Jennifer F. Tseng & Teviah E. Sachs, *Cancer Stage at Presentation for Incarcerated Patients at a Single Urban Tertiary Care Center*, 15 PLOS ONE 1 (2020).

<sup>52</sup> *Id.* at 7 tbl.2.

survive.<sup>53</sup> Incarcerated women, however, are largely immune from these success rates.<sup>54</sup> First, they are disproportionately affected by cervical cancer, with an estimated risk of four to five times higher than that of women in the general population.<sup>55</sup> Yet, according to a recent survey, only thirty-six percent of prisons offered onsite colposcopy, and even fewer (9%) offered on-site procedures like excision treatments.<sup>56</sup> Furthermore, follow-up of abnormal pap smear results is often delayed.<sup>57</sup> A twelve-month study conducted in the Ohio prison system found that out of 170 abnormal pap smear results among the incarcerated women, only 24.4% of those abnormalities received any follow-up.<sup>58</sup>

As stated by the American Cancer Fund, “[e]arly detection saves lives.”<sup>59</sup> Consequently, the failure of prisons to provide timely screenings operates, effectively, as a death sentence for many inmates. Even where screenings are available, however, the limited access to Medicare and Medicaid for prisoners poses another barrier to access.

#### *B. Medicaid and Medicare Inmate Exclusion Policy*

The Social Security Act of 1965 prohibits federal Medicaid and Medicare funding for the care of “inmate[s] of a public institution,” except where an inmate is “a patient of a medical institution” for twenty-four hours or longer.<sup>60</sup> In other words, when a prisoner receives healthcare within their correctional facility, they are exempt from using Medicaid or Medicare to

<sup>53</sup> *Cervical Cancer Statistics*, CTR. DISEASE CONTROL & PREVENTION (June 13, 2024), <https://www.cdc.gov/cervical-cancer/statistics/index.html>. (“Each year in the United States, about 11,500 new cases of cervical cancer are diagnosed and about 4,000 women die of this cancer.”).

<sup>54</sup> Alexa N. Kanbergs, Mackenzie W. Sullivan, Morgan Maner, Lauren Brinkley-Rubinstein, Annkathryn Goodman, Michelle Davis & Sarah Feldman, *Cervical Cancer Screening and Follow-Up Practices in U.S. Prisons*, 64 AM. J. PREVENTATIVE MED. 244, 246–48 (2023); Ingrid A. Binswanger, Shane Mueller, C. Brendan Clark & Karen L. Cropsey, *Risk Factors for Cervical Cancer in Criminal Justice Settings*, 20 J. WOMEN’S HEALTH 1839, 1841–44 (2011); Amanda Emerson, Marissa Dogan, Elizabeth Hawes, Kiana Wilson, Sofia Mildrum Chana, Patricia J. Kelly, Megan Comfort & Megha Ramaswamy, *Cervical Cancer Screening Barriers and Facilitators from the Perspectives of Women with a History of Criminal-Legal System Involvement and Substance Use*, 12 HEALTH & JUST., no. 9, 2024, at 1, 1–12.

<sup>55</sup> Kanbergs, Sullivan, Maner, Brinkley-Rubinstein, Goodman, Davis & Feldman, *supra* note 54, at 247; Emerson, Dogan, Hawes, Wilson, Chana, Kelly, Comfort & Ramaswamy, *supra* note 54.

<sup>56</sup> Kanbergs, Sullivan, Maner, Brinkley-Rubinstein, Goodman, Davis & Feldman, *supra* note 54, at 247; Emerson, Dogan, Hawes, Wilson, Chana, Kelly, Comfort & Ramaswamy, *supra* note 54.

<sup>57</sup> Kanbergs, Sullivan, Maner, Brinkley-Rubinstein, Goodman, Davis & Feldman, *supra* note 54, at 247; Emerson, Dogan, Hawes, Wilson, Chana, Kelly, Comfort & Ramaswamy, *supra* note 54.

<sup>58</sup> Abnormal pap smear results are indicative of potential cervical cancer. See *HPV and Pap Test Results: Next Steps After an Abnormal Cervical Cancer Screening Test*, NAT’L CANCER INST. (June 6, 2024), <https://www.cancer.gov/types/cervical/screening/abnormal-hpv-pap-test-results>.

<sup>59</sup> *Early Detection, Early Prevention*, AM. CANCER FUND, <https://americancancerfund.org/early-detection-early-prevention/> (last visited Dec. 14, 2024).

<sup>60</sup> This policy is known as the Medicaid/Medicare Inmate Exclusion Policy. 42 U.S.C. § 1396d(a)(32)(A) (2006).



pay for those services.<sup>61</sup> However, if a prisoner goes to a hospital, they may be permitted.<sup>62</sup> This exclusion policy is particularly significant because a large segment of the prison population would be eligible for—and benefit from—access to this health insurance.

Medicaid is designed to provide healthcare to the nation's "most economically disadvantaged populations."<sup>63</sup> Yet prisons, which incarcerate some of the poorest people in this nation,<sup>64</sup> are excluded from its coverage. Well over half of prisoners are impoverished, compared to the national poverty rate of 11.8%.<sup>65</sup> A study conducted by the Prison Policy Initiative found that seventy-two percent of women and fifty-seven percent of men were earning less than \$22,000 per year prior to incarceration.<sup>66</sup> And, even for those who were not in poverty before prison, incarceration virtually eliminates income potential.<sup>67</sup> The average minimum wage for incarcerated workers is 86 cents.<sup>68</sup> While Medicaid eligibility varies depending on state and household size, the American Journal of Preventative Medicine estimates that, at least for states participating in Medicaid expansion, eighty to ninety percent of the incarcerated population would qualify for Medicaid.<sup>69</sup> With respect to Medicare, the purpose is to provide coverage to individuals aged sixty-five or older.<sup>70</sup> Yet, the prison population, which is aging prolifically, is exempt from this care. Presently, about three percent of the prison population is over age sixty-five.<sup>71</sup> However, between 2007 and 2010, the number of "prisoners age[d] 65 and older grew at a rate 94 times

---

<sup>61</sup> See Alysse G. Wurcel, Katharine London, Erika L. Crable, Nicholas Cocchi, Peter J. Koutoujian & Tyler N.A. Winkelman, *Medicaid Inmate Exclusion Policy and Infectious Diseases Care for Justice-Involvement Populations*, (Mar. 14, 2024), <https://pmc.ncbi.nlm.nih.gov/articles/PMC10986832/pdf/23-0742.pdf>.

<sup>62</sup> *Id.*

<sup>63</sup> *Medicaid 101*, MACPAC, <https://www.macpac.gov/medicaid-101/> (last visited Dec. 10, 2024).

<sup>64</sup> See Hayes & Barnhorst, *supra* note 25.

<sup>65</sup> *Id.*

<sup>66</sup> Bernadette Rabuy & Daniel Kopf, *Prisons of Poverty: Uncovering the Pre-Incarceration Incomes of the Imprisoned*, PRISON POL'Y INITIATIVE (July 9, 2015), <https://www.prisonpolicy.org/reports/income.html>; See Hayes & Barnhorst, *supra* note 25.

<sup>67</sup> Amanda Y. Agan & Michael D. Makowsky, *The Minimum Wage, EITC, and Criminal Recidivism*, 58 J. HUM. RESOURCES 1712, 1713 (2023).

<sup>68</sup> Wendy Sawyer, *How Much Do Incarcerated People Earn in Each State*, PRISON POL'Y INITIATIVE (Apr. 10, 2017), <https://www.prisonpolicy.org/blog/2017/04/10/wages/>.

<sup>69</sup> Alexander Testa & Lauren C. Porter, *Previous Incarceration, Health Insurance, and the Affordable Care Act in the U.S.*, 65 AM. J. PREVENTIVE MED. 1034, 1034 (2023).

<sup>70</sup> *Introduction to Medicare*, CTRS. FOR MEDICAID & MEDICARE SERVS. (Apr. 3, 2023), <https://www.cms.gov/medicare/coordination-of-benefits-and-recovery/coordination-of-benefits-and-recovery-overview/medicare-secondary-payer/downloads/introduction-to-medicare.pdf>.

<sup>71</sup> This value comes from the most recent report from the Department of Justice on the age demographic in prisons. See LAUREN G. BEATTY & TRACY L. SNELL, U.S. DEP'T. OF JUST., *PROFILE OF PRISON INMATES*, 2016, (Dec. 2021), <https://bjs.ojp.gov/content/pub/pdf/ppi16.pdf>.

the overall prison population.”<sup>72</sup> NPR reports that “by one measure, about [one] third of all prisoners will be considered geriatric by 2030.”<sup>73</sup>

With a large sum of the prison population eligible for this insurance, such services would be instrumental to improving healthcare access. Without this access, however, most prisons provide medical care through contracted healthcare providers.<sup>74</sup> Prisoners then are responsible for, often cost-prohibitive, co-pays. For example, the Prison Policy Initiative reports that in West Virginia prisons, “a single visit to the doctor would cost almost an entire month’s pay for an incarcerated person.”<sup>75</sup> With Medicaid and Medicare available, however, most preventative and screening services are covered.<sup>76</sup> Medicare Part A generally covers cancer treatment you receive as an inpatient, while Part B “covers many medically necessary cancer-related services . . . on an outpatient basis.”<sup>77</sup> Similarly, Medicaid generally covers most of cancer treatment care.<sup>78</sup>

Although MIEP permits prisoners to use Medicaid or Medicare when hospitalized in an outside facility for over twenty-four hours, this provision proves mostly futile.<sup>79</sup> Due to security concerns and transportation challenges, “access to true emergency care [is often] delayed.”<sup>80</sup> An inmate who is ill cannot dial 911 or reach out to their primary care provider—instead, they must convince a prison guard that they are in need of treatment and then see in-house medical personnel to decide whether further treatment is needed.<sup>81</sup> Although not reviewed in the available data on prison healthcare, personal testimonies reveal that the system described above often results in prisoners not receiving outside medical care.<sup>82</sup> This is bolstered by

<sup>72</sup> *Report Examines Trends in U.S. Aging Prison Population*, NAT’L COMM’N ON CORRECTIONAL HEALTH CARE (2010), <https://www.ncchc.org/aging-prison-population/>.

<sup>73</sup> Meg Anderson, *The U.S. Prison Population is Rapidly Graying. Prisons Aren’t Built for What’s Coming*, NPR (Mar. 11, 2024, 5:12 AM), <https://www.npr.org/2024/03/11/1234655082/prison-elderly-aging-geriatric-population-care>.

<sup>74</sup> See generally Roger Watson, Anne Stimpson & Tony Hostick, *Prison Healthcare: A Review of the Literature*, 41 INT’L J. NURSING STUDS. 119, 121 (2004).

<sup>75</sup> Wendy Sawyer, *The Steep Cost of Medical Co-pays in Prison Puts Health at Risk*, PRISON POL’Y INITIATIVE (Apr. 9, 2017), <https://www.prisonpolicy.org/blog/2017/04/19/copays/>.

<sup>76</sup> See *Medicare Coverage for Cancer Prevention and Early Detection*, AM. CANCER SOC’Y, <https://www.cancer.org/cancer/financial-insurance-matters/understanding-health-insurance/government-funded-programs/medicare/medicare-coverage-for-cancer-prevention-and-early-detection.html> (last updated Feb. 13, 2025); *What is a Medicaid Co-Pay?*, FREEDOM CARE, <https://freedomcare.com/medicaid-copay/> (last visited Dec. 14, 2024).

<sup>77</sup> *Medicare & Medicaid*, FORCE, <https://www.facingourrisk.org/support/insurance-paying-for-care/treatment/medicare-and-medicaid> (last visited Apr. 12, 2025).

<sup>78</sup> *Medicaid and Cancer Care Access: Policy Brief*, AM. SOC’Y OF CLINICAL ONCOLOGY (Aug. 2022) <https://web.archive.org/web/20240517170225/https://society.asco.org/sites/new-www.asco.org/files/content-files/advocacy-and-policy/documents/2022-Medicaid-Cancer-Access.pdf> (last visited Dec. 14, 2024).

<sup>79</sup> See *infra* Part II (explaining the story of Ferdinand Dix as one example).

<sup>80</sup> Marc Shalit & Matthew R. Lewin, *Medical Care of Prisoners in the USA*, 364 MED., CRIME & PUNISHMENT 34, 34 (2004).

<sup>81</sup> *Id.*

<sup>82</sup> See, e.g., Sam McCann, *Health Care Behind Bars: Missed Appointments, No Standards, and High Costs*, VERA (June 29, 2022), <https://www.vera.org/news/health-care-behind-bars-missed-appointments-no-standards-and-high-costs>.

research that reveals the high rates of missed medical appointments within prisons. For example, the New York Department of Corrections reported over 1,000 missed medical appointments in December 2021 alone.<sup>83</sup> On Rikers Island, there were 11,789 missed medical appointments in April 2022.<sup>84</sup>

The Medicare/Medicaid Inmate Exclusion Policy (MIEP) imposes significant barriers to prison healthcare access, leaving prisoners with few options, most of which are prohibitively expensive. Eliminating MIEP could make a material difference in the delivery of prison healthcare, which is further discussed in Part III.

## II. THE HARM

Ferdinand Dix was sentenced to serve six years in an Arizona state prison.<sup>85</sup> He did not make it out alive.<sup>86</sup> For over two years, Dix complained to prison officials of a chronic cough, shortness of breath, and other alarming symptoms.<sup>87</sup> As his complaints and suffering were disregarded, lung cancer metastasized to his liver, lymph nodes, and other major organs.<sup>88</sup> His body soon became “infested with tumors,” and his abdomen bloated to the size “of a full-term pregnant woman” because of a mass “four times [the size] of a normal liver.”<sup>89</sup> Still, prison officials delayed examination.<sup>90</sup> Eventually, and unsurprisingly, Dix fell into an unresponsive state.<sup>91</sup> Only then, the prison transported him to an outside hospital where he died a few weeks later.<sup>92</sup> Dix’s mother filed a lawsuit over the matter, claiming that but for the prisoner’s failure to provide appropriate diagnostic and treatment care, her son would still be alive.<sup>93</sup>

The story of Ferdinand Dix is far from unique—across the United States, the lack of access to timely cancer diagnostics and health insurance as discussed in Part I results in a myriad of harms. This Part will explore such harms including (1) increased mortalities; (2) litigation over constitutional violations; and (3) increased healthcare costs.

---

<sup>83</sup> *Id.*

<sup>84</sup> *Id.*

<sup>85</sup> *Survivors of Prison Violence — Arizona*, BLOGSPOT (Feb. 22, 2012), <https://azprisonersurvivors.blogspot.com/2012/02/aspc-tucson-deaths-in-custody-ferdinand.html>; Victoria Bekiempis, *Don’t Get Cancer if You’re in Prison*, NEWSWEEK MAG. (July 22, 2015, 9:54 AM), <https://www.newsweek.com/2015/07/31/dont-get-cancer-if-youre-prison-356010.html>; Molly Rothschild, Note, *Cruel and Unusual Prison Healthcare: A Look at the Arizona Class Action Litigation of Parsons v. Ryan and Systemic Deficiencies of Private Health Services in Prison*, 61 ARIZ. L. REV. 945, 946–48 (2019).

<sup>86</sup> *See Survivors of Prison Violence — Arizona*, *supra* note 85.

<sup>87</sup> *Id.*

<sup>88</sup> *Id.*

<sup>89</sup> *Id.*

<sup>90</sup> *Id.*

<sup>91</sup> *Id.*

<sup>92</sup> *See Survivors of Prison Violence — Arizona*, *supra* note 85.

<sup>93</sup> *Id.*; Complaint at 8, *Wallace v. Ariz. Dep’t Corr.*, No. 2:12-cv-00302 (D. Ariz. Feb. 16, 2012), ECF No. 3.

### A. Increased Morality Among Prisoners

Each year someone spends incarcerated in the United States decreases their life expectancy by two years.<sup>94</sup> Cancer is the leading contributor to this stark reality, accounting for approximately thirty percent of all deaths in state and federal prisons.<sup>95</sup> Several studies, however, consider this statistic a gross underrepresentation of reality.<sup>96</sup> While the exact value of cancer mortalities in prison remains uncertain, these deaths are undoubtedly on the rise. In 2018, the Bureau of Justice Statistics reported that the mortality rate for cancer in state prisons was the highest since 2001.<sup>97</sup> Another study revealed that between 2004 and 2016, prison cancer mortalities rose by fifty-nine percent.<sup>98</sup>

Cancer survival rates are lower for those incarcerated. One comprehensive study reviewed sixteen prison systems and identified that “[i]ncarcerated patients with cancer have a 92% higher 5-year mortality than the general population.”<sup>99</sup> Similar studies on individual prisons have variable results, but the data remains bleak. For example, in a 2022 study of Connecticut prisons, the overall five-year survival rate for screenable cancers was 67.4% for those diagnosed while incarcerated, and 85.2% among those never incarcerated.<sup>100</sup> These results varied depending on the type of cancer. With respect to breast cancer, the “five-year survival rate was lowest for incarcerated patients (60%), compared to those . . . never incarcerated (89.5%).”<sup>101</sup> In a similar Texas study, there was a “four-fold higher death rate from hepatocellular carcinoma compared to the rest of the United States population.”

These lowered survival rates render cancer the leading cause of death in prisons, outsizing mortalities caused by suicide, homicide, heart disease, and alcohol- and drug-related illnesses.<sup>102</sup> One study found that between 2000 and 2018, cancer accounted for 16,277 total mortalities within

<sup>94</sup> See McCann, *supra* note 82; Emily Widra, *Incarceration Shortens Life Expectancy*, PRISON POL’Y INITIATIVE (June 26, 2017), [https://www.prisonpolicy.org/blog/2017/06/26/life\\_expectancy/](https://www.prisonpolicy.org/blog/2017/06/26/life_expectancy/).

<sup>95</sup> *Incarceration Associated with High Risk of Mortality, Yale Study Shows*, *supra* note 1.

<sup>96</sup> CAROLINE ISAACS, DEATH YARDS: CONTINUING PROBLEMS WITH ARIZONA’S CORRECTIONAL HEALTH CARE 13–15 (Oct. 2013), <https://afscarizona.org/wp-content/uploads/2014/03/death-yards-continuing-problems-with-arizonas-correctional-health-care-2013.pdf> (explaining death reporting systems in prisons to highlight that “natural causes” deaths reported—if investigated further—would likely reveal people dying of cancer that went undiagnosed).

<sup>97</sup> Aziz, Ackah, Whitson, Oppong, Obeng-Gyasi, Sims & Pawlik, *supra* note 17, at 965.

<sup>98</sup> Manz, Odayar & Schrag, *supra* note 7, at 7278.

<sup>99</sup> Christopher Manz, Brett Nava-Coulter, Emma Voligny & Alexi A. Wright, *Cancer Care Delivery in Prisons: From Barriers to Best Practices*, 20 JCO ONCOLOGY PRAC. 49, 49 (2024).

<sup>100</sup> Oladeru, Aminawung, Lin, Gonsalves, Puglisi, Mun, Gallagher, Soulos, Gross & Wang, *supra* note 31, at 5.

<sup>101</sup> *Id.*

<sup>102</sup> Jessica L. Adler & Weiwei Chen, *Jail Conditions And Mortality: Death Rates Associated With Turnover, Jail Size, And Population Characteristics*, 42 HEALTH AFFS. 849, 852–53 (2023); *Mortality: Death and Dying*, PRISON POL’Y INITIATIVE, <https://www.prisonpolicy.org/visuals/mortality.html> (last visited Dec. 14, 2024) (outlining death causes in prison).

correctional facilities.<sup>103</sup> Another study reported that higher incarceration rates in state prisons were associated with higher overall state mortality rates.<sup>104</sup>

This great volume of deaths, importantly to note, are far from peaceful. NPR reviewed court and medical records and conducted interviews with the families and lawyers of prisoners who died of cancer during incarceration.<sup>105</sup> Of the findings across prisons, one commonality emerged: their final weeks were marked by extreme pain and suffering.<sup>106</sup> Joseph Guadagnoli, incarcerated in West Virginia, died of cancer after complaining of symptoms for months. On December 1, he submitted a sick call request stating, “I cannot breathe . . . I have been asking for [help for] seven months.”<sup>107</sup> In another case, Michael Bougher, a California prisoner, fainted over five times before doctors discovered a brain tumor the size of an egg.<sup>108</sup> Many other prisoners endured such prolonged suffering, reporting unaddressed symptoms of severe stomach pain, nausea, migraines, muscle cramps, and shortness of breath.<sup>109</sup>

The increased likelihood of death from cancer in prison is a direct consequence of the failure to provide adequate access to care and insurance.<sup>110</sup> This reality runs afoul to the constitutional right prisoners have to receive adequate healthcare, which has culminated in a litany of litigation.

#### *B. Rights Not Vindicated: Expensive Litigation and Persistent Constitutional Violations*

The lack of access to regular cancer screenings and appropriate health insurance presents a constitutional violation. In *Estelle v. Gamble*, the Supreme Court held that “deliberate indifference” to the medical needs of prisoners violates the Eighth Amendment’s protection against “cruel and unusual punishment,” imposing a constitutional duty on the government to provide adequate medical care to those it incarcerates.<sup>111</sup> In its ruling, the Court emphasized that denying medical care to prisoners leads to unnecessary suffering that is incompatible with “contemporary standards of decency.”<sup>112</sup> In 1993, the Court extended *Gamble*, ruling that prisons must not only address inmates’ immediate health concerns, but also avoid creating

---

<sup>103</sup> Manz, Odayar & Schrag, *supra* note 7, at 7280.

<sup>104</sup> *New Study Finds Higher County-Level Jail and State-Level Prison Incarceration Rates Associated With Higher County- and State-Level Cancer Mortality Rates*, AM. CANCER SOC’Y (Sept. 17, 2024), <https://pressroom.cancer.org/study-incarceration-rates-cancer>.

<sup>105</sup> Meg Anderson, *1 in 4 Inmate Deaths Happens in the Same Federal Prison. Why?*, NPR (Sept. 23, 2023, 6:00 AM), <https://www.npr.org/2023/09/23/1200626103/federal-prison-deaths-butner-medical-center-sick-inmates>.

<sup>106</sup> *Id.*

<sup>107</sup> *Id.*

<sup>108</sup> *Id.*

<sup>109</sup> *Id.*

<sup>110</sup> *See supra* Part I (discussing access issues).

<sup>111</sup> *Estelle v. Gamble*, 429 U.S. 97, 104–05 (1976).

<sup>112</sup> *Id.* at 103.

conditions that “risk . . . serious damage” to their *future* health.<sup>113</sup> Then, in 1964, *Cooper v. Pate* held that prisoners could challenge the legality of prison conditions in federal court.<sup>114</sup>

Unsurprisingly, the coupling of *Cooper* and the constitutional duties emanating from *Gamble* have been the foothold of much prison healthcare litigation.<sup>115</sup> For deaths marked by ignored medical complaints, missed doctor appointments, and severe pain and suffering, *Gamble* would ostensibly set a clear path forward.<sup>116</sup> However, litigation has proven to be a “diminished [avenue]” for vindication,<sup>117</sup> as prisons continue to fall short of their responsibilities despite reprimands.<sup>118</sup> Most cases on the issue result in either ineffective settlements or injunctions.<sup>119</sup> For example, in 2012, the ACLU sued the Arizona State Prison system over its failure to provide “basic health care and minimally adequate condition[s]” to its inmates.<sup>120</sup> The suit was settled in 2014 upon the prison system’s “promise” to improve conditions.<sup>121</sup> However, in the following seven years, preventable suffering and deaths persisted.<sup>122</sup> The lawsuit then was re-filed where a federal judge then issued a “thorough and sweeping injunction . . . requiring the Arizona Department of Corrections . . . to make ‘substantial’ changes to ensure medical care reaches constitutional standards.”<sup>123</sup> Time will tell whether the injunction will be upheld, but history suggests its likely failure. In *Parsons v. Ryan*, prisoners of the Arizona Department of Corrections (ADC) filed a class action lawsuit claiming that the prisons put them at “substantial risk of

<sup>113</sup> *Helling v. McKinney*, 509 U.S. 25, 35 (1993).

<sup>114</sup> *Cooper v. Pate*, 378 U.S. 546, 546 (1964) (per curiam).

<sup>115</sup> See Rothschild, *supra* note 85, at 950.

<sup>116</sup> The argument is that, where correctional facilities ignore complaints of medical symptoms and access to screenings and treatments are limited, the prison is failing to protect the future and current health of their inmates.

<sup>117</sup> Rothschild, *supra* note 85, at 971.

<sup>118</sup> See Rothschild, *supra* note 85.

<sup>119</sup> Tori Collins, *When Fines Don’t Go Far Enough: The Failure of Prison Settlements and Proposals for More Effective Enforcement Methods*, 76 MAINE L. REV. 132, 1423–46 (2024) (“[T]here is little motivation to comply with a settlement when it is not the actors within prisons, but the state or federal department overseeing them that is held responsible. As one commentator notes, ‘settlement agreements—just like remedies stipulated by a final [] judgment—depend on a [government’s] willingness to commit to the terms of its agreement.’ Though trial courts can choose to impose imprisonment on high-ranking officials who have been held in contempt, they are often hesitant to do so.” (alterations in original) (footnotes omitted)).

<sup>120</sup> *Jensen v. Thornell*, No. CV-12-00601, Order and Permanent Injunction (D. Ariz. Apr. 7, 2023); Corene Kendrick & Maria Morris, *Federal Judge Finds Arizona’s Prison Health Care is “Plainly Grossly Inadequate” and Unconstitutional*, ACLU (Jul. 8, 2022), <https://www.aclu.org/news/prisoners-rights/federal-judge-finds-arizonas-prison-health-care-is-plainly-grossly-inadequate-and-unconstitutional>; see also *Jensen v. Thornell*, ACLU, <https://www.aclu.org/cases/jensen-v-thornell?document=parsons-v-ryan-rebuttal-declaration-eldon-vail-attachments> (last updated Apr. 7, 2023) (reporting on the *Jensen* case).

<sup>121</sup> *Jensen v. Thornell*, ACLU, *supra* note 120.

<sup>122</sup> *Id.*

<sup>123</sup> *Id.*

unnecessary pain and suffering . . . and death.”<sup>124</sup> The case resulted in a \$4.9 million settlement with a stipulation between parties that the ADC would be monitored for compliance.<sup>125</sup> However, the monitoring was unsuccessful, and eventually the court removed the monitoring requirement noting that it was “‘ill-advised’ for the ADC to continue ‘defending its noncompliance.’”<sup>126</sup> *Parsons* showcases how prisons often side-step court-orders because “due to their closed environments, largely hidden from public view, [prisons] create a space where abuse is . . . likely to go unnoticed and unaccounted for.”<sup>127</sup>

The line of Supreme Court cases addressing prison healthcare outlines specific standards that are plainly being unmet. The result has been a flood of litigation, but little material change. Consequently, the rights of prisoners to receive healthcare remains largely unvindicated.

### C. Increased Healthcare Costs

This prison cancer problem is, in fact, not just a prison problem. While prisons spend an estimated \$8.1 billion on health care services each fiscal year,<sup>128</sup> many expenses are pushed down the line for the public health system to incur. Ninety-five percent of prisoners eventually get released,<sup>129</sup> and studies establish that this post-release period is a highly vulnerable time for their health.<sup>130</sup> 1 in 70 are hospitalized within the first week of leaving their correctional facility, and 1 in 12 are hospitalized within 90 days.<sup>131</sup> Essentially, people are leaving prison sicker than when they entered, and healthcare providers are thus faced with the added challenge of treating individuals whose health has worsened due to inadequate care while incarcerated. Cancer, specifically, is a leading cause of mortality shortly after release<sup>132</sup> as those diagnosed with cancer within the first-year post-incarceration are often already in advanced, terminal stages of the illness.<sup>133</sup>

<sup>124</sup> Maria Polletta, *Arizona Governor Picks Federal Bureau of Prisons Official David Shinn to Lead State Corrections Agency*, ARIZ. CENT. (Oct. 7, 2019, 5:58 PM), <https://www.azcentral.com/story/news/politics/arizona/2019/0/07/david-shinn-appointed-director-arizona-department-corrections/3900413002/>; See Rothschild, *supra* note 85, at 956.

<sup>125</sup> See Rothschild, *supra* note 85, at 961–62.

<sup>126</sup> *Id.* (citing Jacques Billeaud, *Expert Picked in Lawsuit Over Inmates’ Health Care in Arizona*, WASH. TIMES (Dec. 6, 2018, 4:39 PM)).

<sup>127</sup> See Rothschild, *supra* note 85, at 965.

<sup>128</sup> PEW CHARITABLE TR., PRISON HEALTH CARE: COSTS AND QUALITY (Oct. 18, 2017), <https://www.pewtrusts.org/en/research-and-analysis/reports/2017/10/prison-health-care-costs-and-quality>.

<sup>129</sup> Timothy Hughes & Doris James Wilson, *Reentry Trends in the United States*, BUREAU OF JUST. STATS. (Apr. 14, 2004), <https://bjs.ojp.gov/content/pub/pdf/reentry.pdf>.

<sup>130</sup> Backman, *supra* note 43.

<sup>131</sup> *Id.*

<sup>132</sup> Oladeru, Aminawung, Lin, Gonsalves, Puglisi, Mun, Gallagher, Soulos, Gross & Wang, *supra* note 31; Megha Ramaswamy, Christopher Manz, Fiona Kouyoumdijan, Noel Vest, Lisa Puglisi, Emily Wang, Chelsea Salyer, Beverly Osei, Nick Zaller & Timothy R. Rebbeck, *Cancer Equity for Those Impacted by Mass Incarceration*, 115 J. NAT’L CANCER INST. 1128, 1128–130 (2023).

<sup>133</sup> See *supra* notes 42–58 and accompanying text.

This is largely attributed to the fact that, while in prisons, individuals are not getting screened.<sup>134</sup>

These delays in cancer diagnoses and treatment significantly increases healthcare costs. For example, treating breast cancer averages \$82,121 in stages one and two, but rises to \$129,387 in stage three.<sup>135</sup> Similarly, cervical cancer, a common diagnosis during the post-release period,<sup>136</sup> costs approximately \$15,722 in its early stages, but escalates to over \$52,539 in its terminal stages.<sup>137</sup> These late-stage costs are transferred to the public health system when prisoners are released, but could be avoided if addressed earlier on.

### III. PROPOSED SOLUTIONS

To address the access issues and associated harms outlined above, this paper proposes two solutions. First, it advocates for the repeal of the Federal Medicaid and Medicare Inmate Exclusion Policy to enable these services to be utilized within correctional facilities. Second, it recommends the implementation of regular screenings within prisons. Together, these measures aim to improve health outcomes and mitigate the challenges faced by incarcerated individuals.

#### *A. Repeal Medicaid/Medicare Inmate Exclusion Policy to Allow Such Services in Prisons*

Pursuant to the Social Security Act of 1965, incarcerated people are excluded from Medicaid and Medicare coverage, except for hospital stays longer than twenty-four hours.<sup>138</sup> The Medicaid/Medicare Inmate Exclusion Policy (MIEP) is predicated on the idea that “carceral systems are traditionally a state concern”<sup>139</sup> and that inmates constitute the “undeserving poor” and thus should be shut-out from government benefits.<sup>140</sup> These

<sup>134</sup> Backman, *supra* note 43.

<sup>135</sup> Erin L. Boyle, *What's the Average Cost of Breast Cancer Treatment?*, HEALTH CENT. (Sept. 10, 2024), <https://www.healthcentral.com/patientpower/breast-cancer/cost-of-treatment>.

<sup>136</sup> Backman, *supra* note 43.

<sup>137</sup> Ning Liu, Nicole Mittmann, Peter C. Coyte, Rebecca Hancock-Howard, Soo Jin Seung & Craig C. Earle, *Phase-Specific Healthcare Costs of Cervical Cancer: Estimates from a Population-Based Study*, AM. J. OBSTETRICS & GYNECOLOGY 615 (2016).

<sup>138</sup> 42 U.S.C. § 1396d(a)(32)(A) (2006); Wurcel, London, Crable, Cocchi, Koutoujian & Winkelman, *supra* note 61, at 95.

<sup>139</sup> Kim Herbert, *Improving Healthcare Quality and Access for People Experiencing Incarceration Through Repealing the Medicaid Inmate Exclusion Policy*, GEO. J. POVERTY L. & POL'Y, Feb. 5, 2024, <https://www.law.georgetown.edu/poverty-journal/blog/improving-healthcare-quality-and-access-for-people-experiencing-incarceration-through-repealing-the-medicare-inmate-exclusion-policy/>; see also Mira Edmonds, *The Reincorporation of Prisoners into the Body Politic: Eliminating the Medicaid Inmate Exclusion Policy*, 28 GEO. J. ON POVERTY L. & POL'Y 279, 285 (2021).

<sup>140</sup> Nicole Huberfeld, *Federalism in Health Care Reform*, in HOLES IN THE SAFETY NET: FEDERALISM AND POVERTY 197, 203, 205 (Ezra Rosser ed. 2019); Edmonds, *supra* note 139, at 286



aforementioned purposes of MIEP are not being realized as (1) the post-release period creates higher costs for the public health system when prisoners are not cared for during incarceration,<sup>141</sup> and (2) the concept of prisoners as “undeserving poor” directly contradicts the principles announced in *Estelle v. Gamble*.<sup>142</sup> Repealing MIEP to allow Medicaid and Medicare services to cover carceral facilities offers a viable solution for fostering a healthier, and less costly prison population.

### 1. The Federal Government Should Repeal MIEP

Repealing MIEP is, in fact, a more appropriate path towards achieving the legislation’s intended purpose of saving federal Medicaid funds.<sup>143</sup> Furthermore, a repeal would help ensure that correctional facilities remain in compliance with constitutional principles as prisoners would no longer be considered *un-deserving poor*.

The primary purpose of MIEP was that federal Medicaid Funds should “not be used to finance care for institutionalized individuals who have traditionally been the responsibility of State and local governments.”<sup>144</sup> This goal is fundamentally flawed, as MIEP balloons healthcare costs during the post-prison-release period for both state and federal governments. As discussed in Part I.C., to manage healthcare costs, correctional facilities “charge prisoners unaffordable co-pays . . . and offer low-quality care that inadequately follows established clinical guidelines,” including regular cancer screenings.<sup>145</sup> This lack of care frequently results in individuals re-entering society sicker, and consequently, more expensive to treat.<sup>146</sup> In other words, the expenses that MIEP aims to mitigate (*i.e.*, costs of prisoners while they are incarcerated) are merely deferred until release when prisoners re-enroll in Medicaid and Medicare. It is predicted that if MIEP is repealed,

---

(first citing LESLIE ACOCA, JESSICA STEPHENS & AMANDA VAN VLEET, HEALTH COVERAGE AND CARE FOR YOUTH IN THE JUVENILE JUSTICE SYSTEM: THE ROLE OF MEDICAID AND CHIP 13 (2014); and then citing COMMITTEE ON ECONOMIC SECURITY, OLD AGE SECURITY STAFF REPORT (Jan. 1935) (including a survey of state old age assistance laws and their focus on ensuring that “recipients of relief are ‘deserving’ citizens” and may have formed the basis for the inmate exclusion in 1935 Social Security Act)).

<sup>141</sup> See *supra* Part I.C (discussing increased public healthcare costs).

<sup>142</sup> See *supra* Part II.B (discussing *Estelle v. Gamble* and its progeny).

<sup>143</sup> 50 Fed. Reg. 13196 (Apr. 3, 1985) (“As explained in the preamble to the NPRM, we decided to change our regulations and ensure that Medicaid funds are not used to finance care for institutionalized individuals who have traditionally been the responsibility of State and local governments.”); see also Herbert, *supra* note 139; see also Edmonds, *supra* note 139.

<sup>144</sup> 50 Fed. Reg. 13196 (Apr. 3, 1985) (“As explained in the preamble to the NPRM, we decided to change our regulations and ensure that Medicaid funds are not used to finance care for institutionalized individuals who have traditionally been the responsibility of State and local governments.”); see also Herbert, *supra* note 139; see also Edmonds, *supra* note 139.

<sup>145</sup> See Sarah Wang, *Prison Health Care is Broken Under the Medicaid Inmate Exclusion Policy*, HARV. L. PETRIE-FLOM CTR. (Jan. 26, 2022), <https://blog.petrieflom.law.harvard.edu/2022/01/26/medicaid-inmate-exclusion-policy/>.

<sup>146</sup> See discussion *supra* Part II.C and footnotes 136–38 (discussing costs of cancer treatment depending on stage).

Medicaid expansion states could save \$4.7 billion each year.<sup>147</sup> The current high-cost reality is likely to be exacerbated with the bipartisan passage of the Consolidated Appropriations Act of 2024 (CAA), which “requires states to suspend, rather than terminate,<sup>148</sup> Medicaid coverage when people are incarcerated.”<sup>149</sup> With the passage, starting in 2026, newly released inmates will automatically be re-enrolled in Medicaid and Medicare,<sup>150</sup> and will likely utilize its services immediately to front the costs of their worsened illnesses.<sup>151</sup>

Furthermore, a repeal of MIEP would help bring correctional facilities into compliance with constitutional obligations and likely reduce litigation. *Estelle v. Gamble* “affirmed that incarcerated individuals have the constitutional right to health care.”<sup>152</sup> Yet, the current prison healthcare system—in part because of MIEP—is falling short of that obligation.<sup>153</sup> MIEP reflects a Medicaid principle that government-issued benefits belong “only to those deemed worthy, or *deserving* poor.”<sup>154</sup> Because of the crimes prisoners have committed, they are categorized—in the government’s eyes—as *un-deserving*, and shut out from benefits.<sup>155</sup> Consequently, prison systems have to look elsewhere for healthcare delivery which typically results in privatizing healthcare and contracting with or outsourcing to providers.<sup>156</sup> This system is expensive,<sup>157</sup> which dissuades prisons from utilizing healthcare. However, if Medicaid and Medicare were available in prisons, correctional facilities could “offset[] [their healthcare] costs with the federal assistance provided.”<sup>158</sup> Also, federal prisons would be able to tap into Medicaid’s negotiation power “which can reduce healthcare costs by

<sup>147</sup> See Wang, *supra* note 145, at 4.

<sup>148</sup> Prior to the passage of the Consolidated Appropriations Act, prisoners were automatically disenrolled from Medicaid upon incarceration. So, when they were released, they were without insurance until they re-applied and re-enrolled. This new legislation will ensure that upon release prisoners are automatically re-enrolled. See Sarah E. Wakeman, Margaret E. McKinney & Josiah D. Rich, *Filling the Gap: The Importance of Medicaid Continuity for Former Inmates*, 24 J. GEN. INTERNAL MED. 860, 860 (2009).

<sup>149</sup> Consolidated Appropriations Act, 2024, Pub. L. No. 118–42, 138 Stat., 25, 407; John Sawyer, Vikki Wachino, Silicia Lomax & Margot Cronin-Furman, *New Bipartisan Legislation Uses Changes to Medicaid Policy to Help Support Healthy Transitions Between Corrections and Community*, COMMONWEALTH FUND (Mar. 14, 2024), <https://www.commonwealthfund.org/blog/2024/new-bipartisan-legislation-uses-changes-medicaid-policy-help-support-healthy-transitions> [hereinafter COMMONWEALTH FUND].

<sup>150</sup> Provided that they are eligible.

<sup>151</sup> COMMONWEALTH FUND, *supra* note 149.

<sup>152</sup> Wang, *supra* note 145, at 3; See *Estelle v. Gamble*, 429 U.S. 97, 104 (1976).

<sup>153</sup> See *supra* Part I.B (discussing MIEP) and Part II.B (discussing constitutional violations).

<sup>154</sup> Elenore Wade, *The Undeserving Poor and the Marketization of Medicaid*, 72 BUFF. L. REV. 875, 877 (forthcoming 2025).

<sup>155</sup> See Edmonds, *supra* note 139, at 282–83.

<sup>156</sup> See Sabeena Bali, Comment, *The Economic Advantage of Preventative Health Care in Prisons*, 453 SANTA CLARA L. REV. 453, 461, 469 (2017).

<sup>157</sup> Departments of Corrections collectively spent \$8.1 billion on prison health care services for incarcerated individuals in fiscal year 2015. See PEW CHARITABLE TR., *supra* note 128.

<sup>158</sup> See Bali, *supra* note 156, at 471.

lowering beneficiary rates.”<sup>159</sup> Through these payment and coverage systems, Medicaid “encourages using cost-effective services such as preventative care . . . chart[ing] a path for more funding to preventative care programs in carceral institutions.”<sup>160</sup> Such improvements would better equip prisons to respond to medical concerns, decreasing the risk that prisoners suffer and die from preventable or treatable cancers in violation of *Gamble*.

Repealing MIEP will, of course, require some political will. However, with the passage of the CAA, it seems that Congress may be moving in the right direction. This passage reflects a congressional interest to “improve access to health care at re-entry . . . [and] improve both health and safety outcomes for people and communities.”<sup>161</sup>

## 2. Avenues to Getting Medicaid/Medicare Services into Prisons

Once MIEP is repealed, the next step to this solution will be getting Medicare and Medicaid services into prisons. This could happen in three primary ways: (1) prisons can become Medicaid and Medicare providers; (2) prisons can do fee-for-service billing through Medicaid and Medicare; or (3) prisons can contract with Medicaid and Medicare managed care organizations.

Prisons could first consider becoming Medicare and Medicaid providers. Provider requirements vary by state,<sup>162</sup> but once a prison becomes enrolled, the institutions can contract with providers and bill them on a fee-for-service basis.<sup>163</sup> Alternatively, prisons could forgo the provider enrollment process, and instead offer Medicaid benefits through either a fee-for-service (FFS) basis or through managed care plans.<sup>164</sup> With respect to managed care plans, prisons would enroll eligible prisoners in a plan,<sup>165</sup> then providers from that plan could enter the prison and provide services to enrollees.<sup>166</sup> Such managed care systems “provide[] states with some control and predictability over future costs,” give “greater accountability for outcomes[,] and can better support systematic efforts to measure [and] monitor performance, access, and quality.”<sup>167</sup>

Regardless of the path chosen, repealing MIEP would result in the cost of prison healthcare not falling wholly on correctional facility budgets, and

---

<sup>159</sup> See Herbert, *supra* note 139.

<sup>160</sup> *Id.*

<sup>161</sup> COMMONWEALTH FUND, *supra* note 149, at 2.

<sup>162</sup> 42 C.F.R. § 455(B)&(E) (2024); CTRS. FOR MEDICAID MEDICARE SERVS., MEDICAID PROVIDER ENROLLMENT REQUIREMENTS, <https://www.cms.gov/files/document/mpe-faqs082616pdf> (last visited Dec. 16, 2024).

<sup>163</sup> CTR. FOR MEDICAID AND MEDICARE SERVS., *supra* note 162.

<sup>164</sup> *Provider Payment and Delivery Systems*, MACPAC, <https://www.macpac.gov/medicaid-101/provider-payment-and-delivery-systems/> (last visited Dec. 16, 2024).

<sup>165</sup> *Enrollment Process for Medicaid Managed Care*, MACPAC (last visited Apr. 12, 2025), [https://www.macpac.gov/topic/managed-care/?post\\_type=subtopic](https://www.macpac.gov/topic/managed-care/?post_type=subtopic).

<sup>166</sup> *Id.*

<sup>167</sup> *Id.*

instead, “enable[] states to offer more comprehensive coverage to more people.” Additionally, the Center for Medicaid and Medicare Services (CMS) “sets quality standards to which institutions accessing federal funds must adhere.” Although the National Commission on Correctional Health Care sets accreditation standards for carceral facilities, compliance is optional.<sup>168</sup> Ultimately, healthcare funded by Medicaid and CMS standards would incentivize and make it easier for prisons to actually provide the quality care that is currently lacking.

### *B. Increase Regular Screenings*

It is well-established that prisoners have higher rates of cancer incidence,<sup>169</sup> and that early cancer detection saves lives.<sup>170</sup> Yet in prison, “early cancer symptoms are often missed altogether or misdiagnosed” because of the current system of “rushed discretionary screenings” or no screenings at all.<sup>171</sup> Following a repeal of MIEP, the next crucial step for prisons is to eliminate discretionary-only screenings and adopt regular inmate cancer screenings in-line with recommendations by the American Cancer Society.<sup>172</sup>

Evidence suggests the effectiveness of prisons increasing screening programs. For instance, Connecticut prisons faced criticism after researchers observed “a trend toward diagnosis of late-stage cancers in the post-incarceration period,”<sup>173</sup> which was attributed to the lack of regular screenings during incarceration. In response, Connecticut introduced a prison on-site colon cancer screening program.<sup>174</sup> The program has garnered “national attention,” with results showing that nearly half of the participants “were found to have pre-cancerous polyps” that were able to be addressed.<sup>175</sup> Without this increased screening, the prisoners with polyps may have faced the same fate of so many before them who missed an early diagnosis. Connecticut’s approach represents a step in the right direction and offers a strong model for other carceral facilities across the nation.

<sup>168</sup> Currently, only seventeen percent of United States prisons and jails are accredited. *See Facility Accreditation*, NAT’L COMM’N ON CORR. HEALTH CARE, <https://www.ncchc.org/accreditation> (last visited Dec. 14, 2024); McCann, *supra* note 82.

<sup>169</sup> See Manz, Odayar & Schrag, *supra* note 7, at 7278.

<sup>170</sup> See DAVID, *supra* note 29.

<sup>171</sup> See Aziz, Ackah, Whitson, Oppong, Obeng-Gyasi, Sims & Pawlik, *supra* note 17, at 968.

<sup>172</sup> *American Cancer Society Guidelines for the Early Detection of Cancer*, AM. CANCER SOC’Y, <https://www.cancer.org/cancer/screening/american-cancer-society-guidelines-for-the-early-detection-of-cancer.html> (last visited Dec. 16, 2024).

<sup>173</sup> Sujata Srinivasan, *Study Raises Questions About Cancer Screening in Prisons*, CONN. PUB. RADIO (Dec. 1, 2023, 1:36 PM), <https://www.ctpublic.org/news/2023-12-01/connecticut-prisons-likely-under-screen-under-diagnose-cancer-study-finds>.

<sup>174</sup> Sujata Srinivasan, *A Program to Screen for Colon Cancers in CT prisons is Attracting National Attention*, CONN. PUB. RADIO (May 10, 2024, 3:04 PM), <https://www.ctpublic.org/2024-05-10/a-program-to-screen-for-colon-cancers-in-ct-prisons-is-attracting-national-attention>.

<sup>175</sup> *Id.*

Interesting new data also reveals that prisoners would be responsive to the availability of screenings. One study found an overall 69% willingness to be screened—88% of the female sample were willing to be tested while incarcerated and 56% of the sample was willing to undergo a colonoscopy.<sup>176</sup> The study concluded by finding that “the correctional population may be an excellent group to target for screening efforts.”<sup>177</sup> Similarly, a study conducted by the World Health Organization in Europe found that “many people living in prisons are strongly willing to be screened for cancer.”<sup>178</sup> If this data proves universally true, increasing screenings would be viable for early diagnosis, and in turn, lower mortalities and lower costs.

With a repeal of MIEP, increasing regular screenings would be easier and less expensive with the entry of Medicare and Medicaid providers into the institutions. Ultimately, prisons must prioritize screening their inmates in order to thwart the cancer that is plaguing the population.

#### CONCLUSION

In a nation grappling with widespread healthcare challenges,<sup>179</sup> it is unsurprising that the needs of incarcerated individuals have received low priority.<sup>180</sup> However, these prison healthcare disparities should no longer remain in the shadows. Of the limited research on health outcomes in prison, it is well-established that access to cancer diagnostics and health insurance are limited. Consequently, cancer is the leading cause of mortality among the incarcerated population, public health costs are increasing, and prisoner’s rights are being violated and left unvindicated. Two viable solutions to this issue are repealing MIEP and increasing regular screenings in carceral facilities. While there remains a lot of work to be done to improve the health of this hidden population, this paper proposes a promising way to start enacting change.

---

<sup>176</sup> Ingrid Binswanger, Mary C. White, Eliseo J. Pérez-Stable, Joe Goldenson & Jacqueline Peterson Tulskey, *Cancer Screening Among Jail Inmates: Frequency, Knowledge, and Willingness*, 95 AM. J. PUB. HEALTH 1781, 1781, 1783–84 (2005).

<sup>177</sup> *Id.* at 1785.

<sup>178</sup> Although WHO is based on European prisons, many studies suggest that European prisons are dealing with the same challenges as American prisons. *Prisons Can Bring Health to Vulnerable People*, WHO (July 18, 2022, 8:40 AM), <https://www.who.int/europe/news-room/17-07-2022-protecting-prisoners-from-cancer--new-who-report-explains-how-to-fight-health-inequities>.

<sup>179</sup> Christopher J.L. Murray, Sandeep Kulkarni & Majid Ezzati, *Eight Americas: New Perspectives on U.S. Health Disparities*, 29 AM. J. PREVENTATIVE MED. 4 (2005) (exploring “the consistent gap in all measures of mortality, particularly between black and white Americans, as well as in “insurance coverage, access and utilization of care” and quality of care).

<sup>180</sup> E. Bernadette McKinney, *Hard Time and Health Care: The Squeeze on Medicine Behind Bars*, 10 AM. MED. ASS’N. J. ETH. 116, 117–18 (2008).