Protection and Advocacy Agencies and the Needs of Disabled Parents

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Robyn Powell, JD, PhD
Nicole Lomerson, MPH
Linda Long-Bellil, JD, PhD

National Research Center for Parents with Disabilities
Centro Nacional de Investigación para Padres con Discapacidades

Brandeis | THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT
Lurie Institute for Disability Policy

Introduction

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Disabled parents are disproportionately involved in the child welfare system compared to non-disabled parents (National Council on Disability, 2012; Powell & Nicholson, 2019). When involved with state child welfare agencies, they face a higher risk of having their parental rights terminated than their non-disabled peers (Powell, 2023). Although both Section 504 of the Rehabilitation Act of 1974 and Title II of the Americans with Disabilities Act protect the rights of disabled parents within child welfare proceedings, disability discrimination within the court system remains well documented (Powell, 2023).

The Lurie Institute for Disability Policy at Brandeis University conducts multidisciplinary research on the needs, experiences, and policy priorities of people with disabilities. Our work covers a wide range of topics, including the experiences of parents with disabilities; policies addressing long-term services and supports for people with disabilities; and health and healthcare outcomes. Moreover, the Lurie Institute houses four major federally funded programs of research: The National Research Center for Parents with Disabilities the Community Living Policy Center, the National Center for Disability and Pregnancy Research, and the Community Living Equity Center. These programs focus on salient issues affecting people with disabilities and the communities around them to ensure the full integration of people with disabilities into society at large.

In addition to research and training, the National Research Center for Parents with Disabilities provides technical assistance (TA) to parents with disabilities. A significant portion of TA requests are from disabled parents seeking help with child welfare cases. The Center frequently refers these parents to their state’s Protection and Advocacy Organization (P&A), which are federally mandated to provide “legally-based advocacy services for people with disabilities (Administration for Community Living, 2024). However, in our technical assistance efforts, many parents report that their local P&A declined to provide assistance in child welfare cases.

In 2023, the National Research Center for Parents with Disabilities initiated an effort to understand how P&A staff perceive the needs of parents with disabilities within the broader scope of their services. The overarching goal of this effort was to identify gaps in services currently provided by P&As and uncover opportunities to better serve disabled parents.

As part of this initiative, staff from the National Research Center for Parents with Disabilities surveyed P&A Executive and Legal Directors about their experiences providing TA and legal representation to parents with disabilities involved in child welfare cases. The data collection methods included online questionnaires and follow-up interviews. Links to the online survey were distributed, and the respondents could provide their contact information for a follow-up virtual interview, though otherwise, the survey responses remained anonymous.

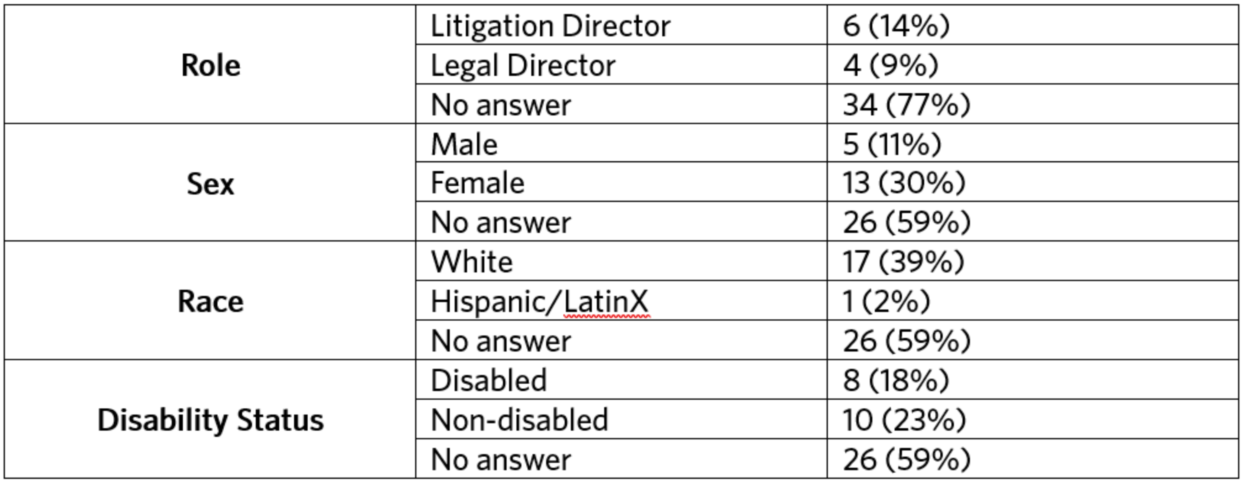
Survey Findings

44 unique respondents completed the survey. However, most responses to the survey were incomplete.

Demographics

Table 1. Demographic Information

All percentages are rounded to whole numbers.



Role	Litigation Director	6 (14%)
	Legal Director	4 (9%)
	No answer	34 (77%)
Sex	Male	5 (11%)
	Female	13 (30%)
	No answer	26 (59%)
Race	White	17 (39%)
	Hispanic/LatinX	1 (2%)
	No answer	26 (59%)
Disability Status	Disabled	8 (18%)
	Non-disabled	10 (23%)
	No answer	26 (59%)

Among those who answered the demographic questions, respondents were more likely to be female, white, and non-disabled. However, a significant majority of respondents did not provide answers to these demographic questions. For example 59% of respondents did not provide information about sex, race or disability status. (Table 1).

Who contacts P&As about Child Welfare?

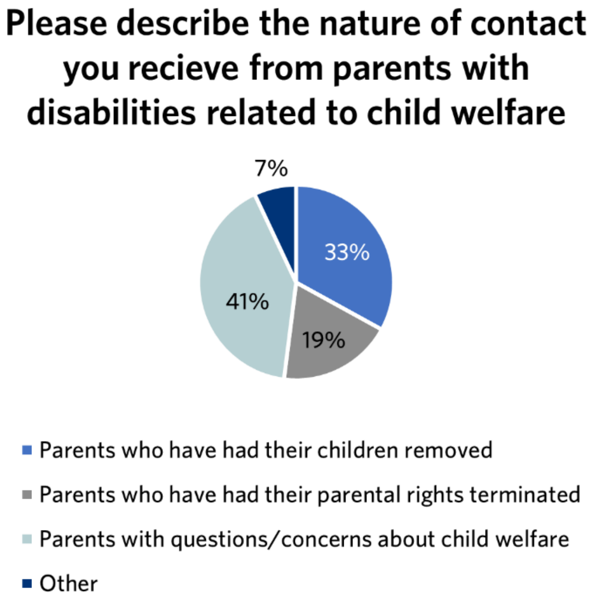
Table 2. Nature of Contact P&As Receive about Disabled Parents and the Child Welfare System.

All percentages are rounded to whole numbers.

Do parents with disabilities contact you for assistance or information regarding child welfare cases?	Yes	29 (66%)
	No	4 (9%)
	No answer	11 (25%)

About 66% of respondents reported that disabled parents contact their P&A organization for help with child welfare cases. Furthermore, around 30% indicated that legal counsel for disabled parents consult their P&A regarding issues related to disabled parents and the child welfare system. It is also crucial to highlight the significant non-response rate for these questions (see Table 2).

Nature of contact with P&A organizations



Respondents discussed the types of contacts they receive from parents with disabilities related to child welfare cases. There were 57 responses to this question, with participants allowed to choose multiple answers. The main issues reported by parents to their P&As involved the removal of their children from custody and the termination of parental rights.

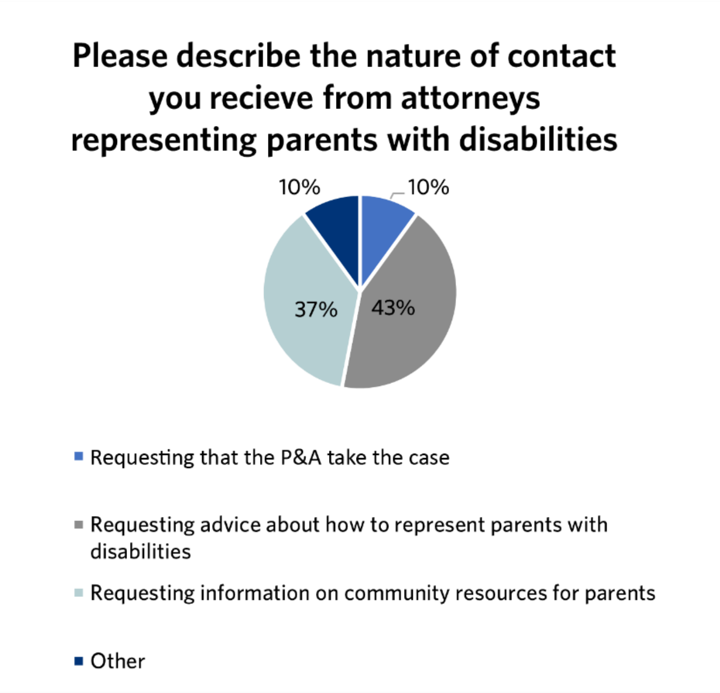
When posed with an open-ended question regarding the annual number of calls they receive from disabled parents concerning the child welfare system, the responses varied significantly, ranging from 0 to 120. The most frequent replies were in the ranges of 0-5 and 0-10.

Table 2 (cont.). Nature of Contact P&As Receive about Disabled Parents and the Child Welfare System.

All percentages are rounded to whole numbers.

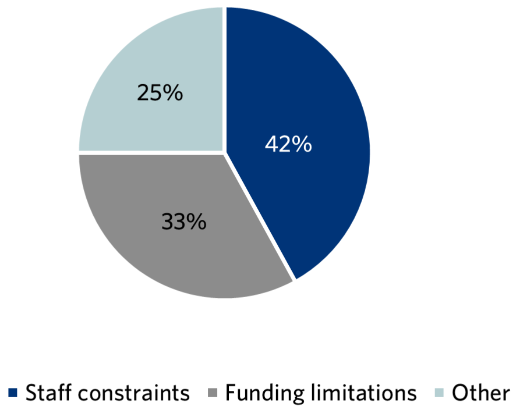
Do attorneys contact you for assistance or information concerning parents with disabilities in child welfare cases?	Yes	13 (30%)
	No	9 (20%)
	No answer	22 (50%)

Nature of contact with P&A organizations, continued



The respondents shared insights about the types of communications they receive from attorneys who represent disabled parents in child welfare cases. A total of 21 responses were gathered, with participants permitted to select multiple options. The predominant requests consisted of asking P&As to handle specific cases and seeking guidance on representation. This underscores the necessity for attorneys to acquire more information on how to effectively advocate for disabled parents in the United States.

Barriers to Assisting Parents with Disabilities



What, if any, are the barriers to providing services to parents with disabilities?

Respondents were identified to identify barriers to assisting parents with disabilities. We received 36 responses to this question, and respondents could select more than one answer. Staffing and funding constraints were the most common barriers mentioned. Additionally, over a quarter of the responses highlighted other issues, including parents seeking outside counsel, potential conflicts of interest disabled parents not being a priority for the P&A. Significantly, none of the respondents indicated that “there are no barriers” in response to this question.

Interest in Assisting Disabled Parents in Child Welfare Cases if More Funding was Available

Table 3. Interest in Assisting Disabled Parents

All percentages are rounded to whole numbers.

If funding were available, would your organization provide services to disabled parents in child welfare cases?	Yes	4 (9%)
	No	1 (2%)
	Unsure	7 (16%)
	No answer	32 (73%)

When asked if their organization would be interested in providing services to disabled parents, the overwhelming majority of respondents chose not to answer the question. The lack of response to this and many other questions in the survey prompted us to conduct follow-up semi-structured interviews with P&A staff. These interviews aimed to gain a better understanding of their experiences with disabled parents in the child welfare system.

Key Findings from Interviews with P&A Staff

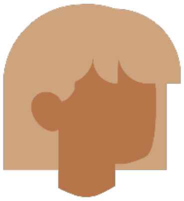
We completed six key informant semi-structured interviews with P&A staff who had given us permission to contact them after completing the online survey. The insights from these interviews provide a clearer perspective of the challenges faced by P&As in supporting and representing disabled parents in the child welfare system. Several common themes emerged from the interviews, as described below:

Limited legal counsel exists for parents with disabilities through Protection and Advocacy organizations:

The responses indicated that P&A support for disabled parents in child welfare settings was minimal. When one respondent was asked if their agency currently assists disabled parents in child welfare cases, they responded: “Yes, but in limited ways.” Another respondent stressed that child welfare cases are not a key focus of their work:

> “Sometimes... that is not an advertised focus of our work. So what we have done up to this point ... is provide information, referral, and some amount of self-advocacy assistance... We are able to deal in generality, but to actually get high quality, meaningful technical assistance where we could be a subject matter expert for them... that's a huge limitation on how much help we can provide"

Despite the limited support of P&As, several respondents recognized the urgent need for increased legal support for disabled parents in the child welfare system, noting that children of disabled parents are often removed from their families:



> “What I have continually witnessed is children being removed and being provided the same services that their parent could have authorized if anybody had given their parents a chance to authorize the services . . . They'll take kids away from parent because ‘parent can't care for them’, quote unquote. But... the parent could have also authorized that facility, like you didn't have to take the kid away to do that.”

Some respondents report providing technical assistance to attorneys representing disabled parents in lieu of supporting parents themselves:

> “We can't provide you with representation because you have an appointed attorney, but that we're happy to talk with that person... to the extent that we can try to point someone in the right direction and give them advice, we want to try to do that.”

> “[I]f lawyers call... sometimes we will provide assistance to lawyers, and how to represent, how to represent...and so we have fielded questions. From CPS-appointed counsel... on how to assert Title II arguments... so from time to time, those questions come in.”

Complex barriers to assisting disabled parents:

Respondents report significant staffing and financial barriers to addressing the issues faced by disabled parents in the child welfare system, echoing the barriers that were mentioned in the survey. While many of these barriers may not be unique to P&As

> “We just don't have the capacity to do that, you know... I just don't have a volume of disabled parents.”

> “Funding is a big one... we get limited funding to do a whole lot of different things potentially that impact people with disabilities."

> “It would be very hard for P&A to suddenly devote resources to this issue without having more funding and having the ability to do that.”

Additionally, the responses highlighted the need for training staff to effectively work with disabled parents, as well as a general lack of interest in representing these parents:

> “If we had additional funding just for high-quality training, that would go a long way, for sure.”

> “I defended parents in termination cases before I started working for the P&A. Personally, I do not think our attorneys have the skills or desire to zealously represent parents with disabilities.”

Another perceived barrier mentioned by several respondents is the potential for conflicts of interest. This includes conflict between the needs of the disabled parent and the needs of their child when the child has a disability, as well as conflict within P&As themselves about how and whether to support disabled parents:

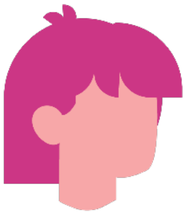
> “It’s true that in any situation when you're representing multiple parties, obviously their interests have to be aligned... if it's at any point become clear that the parent really isn't able to provide with the child needs, then it's not new. I got so much pushback from the lawyers in my office... They feel as though if we represent a parent it would jeopardize our standing in the state representing kids.”

Despite concerns raised by colleagues about conflict of interest, one respondent challenged this perception by noting that the mandate of child welfare agencies is to keep families intact whenever possible:

> “[I]f their child has a disability, there's no conflict because the mandate is to reunite the family and that we have that special expertise to do it, but I have a hard time persuading my colleagues even though I'm the legal director, I get a lot of pushback from my colleagues, and I think it's they're a lot harder cases than representing a kid.”

Potential for Policy Advocacy and Systemic Change:

Despite their hesitancy in representing disabled parents individually due to resource constraints and other barriers, many respondents recognized the need for policy advocacy and systemic change regarding the way disabled parents are treated within the child welfare system:



> “I think from a policy perspective they should be advocating for... what are the processes that are not keeping kids with parent and well, not keeping kids in the community?”

> “We have from time to time been involved at a more systemic level on the failure of DCF and the court system to provide accommodations.”

Finally, respondents recognized the widespread misconceptions regarding disabled parents and how this potentially drives policy and practice:

> “It's an attitude. It's this perception of, well, [disabled parents are] abusers. There's a possible conflict.”

> “There's just a lot of really amazingly narrow-minded beliefs about what parents with disabilities can and can't do... the cultural belief that somehow we'll be doing a better job or provide better services, or somehow improve a child’s life when (instead) the parent could.”

Conclusion

The findings from the online survey and interviews demonstrate that P&A organizations are failing to fulfill their legal mandate to protect the rights of people with disabilities, namely their fundamental right to parent. This data reveals a critical gap between P&As' obligations and their current support for disabled parents.

The barriers to supporting disabled parents are complex and multi-faceted, with several important implications for P&As:

Research implications: To strengthen their service delivery, P&As should consider conducting an internal organizational assessment of their services for disabled parents in child welfare cases. This internal review could yield more detailed insights than our external survey, as staff may feel more comfortable sharing information within their organization. Additionally, documenting and analyzing cases of successful representation of disabled parents would provide valuable guidance for all P&As in serving this population.

Program Implications: This report reveals significant concerns: P&A staff express substantial hesitation about representing disabled parents, creating a barrier for parents seeking knowledgeable legal representation. There is a marked lack of specialized training for P&A staff regarding disabled parents' interactions with child welfare systems. Additionally, many P&A attorneys may be unaware of disabled parents' capabilities and the available supportive services and assistive technologies.

To address these issues, P&As should: Establish clear protocols for handling requests from disabled parents and their counsel

- Develop partnerships with local parent attorneys for training and consultation
- Implement comprehensive training programs about parenting capabilities across different types of disabilities
- Explore funding options for both individual representation and systemic advocacy
- Create collaborative networks with local attorneys who represent disabled parents

Policy Implications: To better serve disabled parents, P&As must address several policy-level challenges. Advocate for increased federal funding specifically designated for assisting disabled parents in child welfare cases. Work to clarify and strengthen the P&A mandate regarding support for disabled parents. Address the perceived conflict of interest between disabled children and their disabled parents through policy reform. By implementing these recommendations, P&As can fulfill their obligation to protect the rights of disabled parents and help ensure that families remain intact, as is their legal right.

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CenterForParents@Brandeis.edu

@DisabilityParentsCenter

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