



**Report on Survey of the  
Protection and Advocacy Network on  
Involvement in Guardianship and Conservatorship  
Issues**

**National Disability Rights Network**

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Please direct questions or comments regarding this report to David Hutt, Senior Staff Attorney at [david.hutt@ndrn.org](mailto:david.hutt@ndrn.org).

## Summary of Key Findings

National Disability Rights Network (NDRN) completed a short survey of the Protection and Advocacy (P&A) Network to determine the overall involvement of the P&As in guardianship and conservatorship issues. The survey results indicate that a large majority of P&A agencies have been, currently are, or could within the next year become involved in representing individuals with disabilities in guardianship cases. A large majority of P&As are also engaged in various guardianship reform efforts within their state.

Several key findings from the survey, in which fifty out of the fifty-seven P&A agencies responded, are as follows:

- 94% of P&A respondents provide at least information and referral services to individuals with disabilities about guardianship or conservatorship issues.
- 84% of P&A respondents currently represent or could represent an individual with a disability in a case involving a guardianship or conservatorship issue. Of these forty-two P&As, 86% or thirty-six P&As currently represent or could represent an individual with a disability in efforts to terminate a guardianship or conservatorship and restore the individual's rights.
- 61% of P&A respondents who have or could represent individuals in guardianship issues have utilized the concept of supported decision making in an attempt to avoid the guardianship or conservatorship.
- 82% of P&A respondents have been engaged in guardianship reform efforts, with at least twenty-three P&As active at some level in promoting the use of supported decision making as an alternative to a guardianship or conservatorship.

# P&A Involvement in Guardianship Issues

## I. Introduction

The Protection and Advocacy (P&A) Network is a system of congressionally mandated agencies established in the mid-1970s originally to protect and advocate for individuals with developmental disabilities. Over the years the P&A program has expanded to include protection and advocacy services for individuals with many different disabilities.

Today the P&A Network includes eight federal funding sources.<sup>1</sup> In addition to federal funds, a number of P&As also receive state, local, and/or private funds to complement their federally funded mandate or to engage in additional work to protect the rights of individuals with disabilities.

The P&A Network is comprised of fifty-seven individual P&A agencies, one for each of the fifty states, the District of Columbia, the five United States territories<sup>2</sup>, and for a consortium of Native American tribes in the Four Corners region. As of this report the P&A is designated to a non-profit organization in forty-five states, the District of Columbia, three of the five U.S. territories, and for the Native American consortium. The remaining P&As are independent state or territorial agencies.<sup>3</sup> Collectively, P&A organizations are the largest providers of legal services to individuals with disabilities in the United States.

Though some of the eight federal funding sources cover individuals with different disabilities, or differ in the scope of work to be performed, the overall mandate of the P&A system is to investigate allegations of abuse and neglect of individuals with disabilities, and to pursue “administrative, legal and other appropriate remedies” to protect the rights of individuals with disabilities.<sup>4</sup> Representation by a P&A may include cases involving an individual with a disability facing imposition of a guardianship or conservatorship, or who is under a guardianship or conservatorship order but who seeks to make changes or to terminate the guardianship.

Given limited resources, each P&A agency is required under federal law to undergo an annual priority setting process. The priority setting process must include input from the public and an advisory council on mental health services.<sup>5</sup> Therefore, even though the federal statutes mandate that P&A organizations investigate and address potential abuse and neglect of individuals with disabilities, and

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<sup>1</sup> The P&A programs, in order of enactment, are the Protection and Advocacy for Individuals with Developmental Disabilities, Protection and Advocacy for Individuals with Mental Illness, Protection and Advocacy for Individual Rights, Protection and Advocacy for Assistive Technology, Protection and Advocacy for Beneficiaries of Social Security, Protection and Advocacy for Traumatic Brain Injury, and Protection and Advocacy for Voting Rights. Congress also created the Client Assistance Program (CAP) to assist individuals with disabilities involving services under the Rehabilitation Act of 1973, as amended. While unlike the P&A programs CAP is not required to be housed within the P&A agency, in 37 out of the 57 jurisdictions the CAP is designated to the P&A agency. CAP programs, however, would not be involved in guardianship work.

<sup>2</sup> American Samoa, Guam, Puerto Rico, Northern Mariana Islands, and the Virgin Islands.

<sup>3</sup> The P&A agency for Connecticut is currently an independent state agency, however, the state passed legislation which requires that the P&A be transferred to a non-profit organization by the summer of 2017.

<sup>4</sup> See 42 U.S.C. § 15043(a)(2)(A) & (B), § 10801(b), § 10805(a)(1); 29 U.S.C. § 794e(f)(3).

<sup>5</sup> See 42 U.S.C. § 15043(a)(2)(D); 42 U.S.C. § 10805(c)(2)(B); 29 U.S.C. § 794e(f)(5). See also, e.g., 45 C.F.R. § 1326.22(c)(2) (a P&A may turn down requests for assistance from individuals with developmental disabilities when outside the priorities set for that program).

advocate for individuals with disabilities through legal and non-legal advocacy, the contours and extent of P&A work on individual issues differs across the P&As based on the annual priorities set by each P&A agency. Consequently through the priority setting process, which includes public input, a P&A agency may or may not include guardianship issues as an offered service, or may limit representation to certain types of guardianship or conservatorship cases. In addition, P&As may only accept cases for representation based on the individual legal merits of the case, and must consider the complexity of the case, the case load and expertise of the P&A advocates and attorneys, as well as other relevant factors before accepting an individual case.

A number of opportunities and discussions have unfolded in recent years about guardianship and conservatorship issues and reform efforts. The Uniform Law Commission is currently completing a revision of the Uniform Guardianship and Protective Proceedings Act, and the United States Administration on Community Living is funding projects which involve efforts to improve state guardianship systems and on the use of supported decision making as an alternative to guardianship.<sup>6</sup> Several organizations, including P&A agencies, are further involved in supported decision making pilot projects. Meanwhile, Texas enacted sweeping guardianship reform legislation in 2015.

These recent opportunities and discussions warranted a better understanding of the work of the P&As on guardianship and conservatorship issues, especially in light of possible variation in involvement with such issues across the P&A agencies due to the P&A priority setting process. National Disability Rights Network (NDRN) therefore surveyed the P&A Network to shed more light on the extent of P&A involvement as a whole in guardianship and conservatorship issues. NDRN is the membership organization and training and technical assistance provider to the P&As. To encourage a high response rate, the survey scope was limited to assessing P&A engagement in providing information and referral to, or representation of, individuals with disabilities in guardianship and conservatorship issues, as well as any P&A efforts in guardianship reform.

## **II. Survey Design and Response Rate**

In November 2016 NDRN created a short survey for the P&A Network to determine how many individual P&A agencies have been involved in guardianship or conservatorship work either in the past, at the time of survey, and/or could be in the future.

The survey used both the terms “guardianship” and “conservatorship” given varied use of these terms across the jurisdictions. To simplify the current analysis, however, the term “guardianship” is used throughout the remainder of this report to encompass both guardianships and conservatorships.

Whether P&As are engaged in guardianship issues, and if so what type of issues, were the two central questions for the design of the survey. To keep the survey brief in order to increase the response rate, the purpose of the survey focused on determining P&A involvement in 1) providing information and referral on guardianship issues, 2) representing individuals with disabilities in cases directly involving guardianship issues, 3) utilizing supported decision making as an alternative to guardianship, and 4)

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<sup>6</sup> See [Uniform Law Commission Guardianship and Protective Proceedings Act Committee](#); [U.S. Administration for Community Living Elder Justice Innovation Grant Program](#); [U.S. Administration for Community Living Supported Decision Making Program](#).

participating in guardianship reform efforts. The specific questions are reproduced in the Appendix. NDRN created the survey on-line through the use of Survey Gizmo, and informed the P&A Network about the survey through e-mail announcements to several P&A list serves.

The survey was not designed to determine the breadth or depth of each P&A organization's work in guardianship issues, but more basic, whether P&As are or could become involved in guardianship issues, and on which guardianship issues this involvement does or might entail. For example, questions such as how many guardianship cases a P&A accepts in a given year, the number of information and referrals related to guardianship provided by the P&A, or how many plenary guardianships were mitigated through the use of more limited guardianships was beyond the scope of this short survey and is left for another day.

Fifty of the fifty-seven P&A organizations submitted a completed survey, which represents an 87.7% response rate.

### **III. Overall P&A Involvement in Guardianship Issues**

The survey responses show clearly that P&As are engaged in guardianship work. Forty-seven P&A respondents, or 94% of total respondents, provide at least information and referral services to individuals with disabilities on guardianship issues.<sup>7</sup> Information and referral services are considered the lowest level of service activity which P&As are required to track.

The vast majority of P&A organizations indicate they currently represent or could represent an individual with a disability in an issue related to guardianship. Specifically, 84% of P&A survey respondents indicated they currently represent or could represent within the next twelve months an individual in a guardianship issue. Making the statistically most conservative assumption that the seven P&As who did not respond to the survey do not and will not represent individuals within the next twelve months in guardianship cases, then at a minimum 73.6% of the nationwide P&A Network currently represents or could represent an individual in a guardianship issue.

Eight P&As, representing 16% of survey respondents, stated they do not represent or plan to represent individuals with guardianship issues. Of these eight respondents, three P&As indicated they provided such representation on guardianship issues in the past, but no longer offer representation in such cases. Resource limitations and lack of demand were mentioned as reasons for no longer providing representation in guardianship cases. One P&A which has provided representation in guardianship cases in the past, is unsure if this will continue because of major organizational changes. The remaining four P&As who do not plan to offer representation in guardianship cases in the next twelve months responded they have not provided such representation in the past. These four P&As were not asked to respond to any further questions in the survey.

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<sup>7</sup> One respondent did not answer this question.

## IV. Issues of Guardianship Representation

### A. Type of Guardianship Case

P&As who responded that they currently represent or could represent individuals in guardianship cases were asked to indicate the type of guardianship issues, phrased in relation to the outcome sought, for which the P&A currently is or could in the future provide representation. The P&As were offered six possible non-exclusive issue areas from which to choose, as indicated in Table 1, as well as an open ended option to add other issue areas. Table 1 presents the results based on the percentage of P&As who responded to the question.<sup>8</sup> This question did not address, nor did the survey, the number of cases accepted by a P&A for representation nor the success rate of any representation.

The two largest areas for which the P&As reported involvement in representing individuals with guardianship concerns are working to terminate an existing guardianship and restore full rights to the individual (36 of the 42 P&As responding to the question, or 86%), followed by representation to achieve partial restoration of the rights of the individual (33 of the 42 P&As responding to the question or 78.5%). Slightly fewer P&As reported they presently do or could represent individuals with disabilities who seek to limit the powers of the guardian at the time of establishment, or to replace the person or entity who serves as the guardian, however, almost three-quarters of the forty-two P&As responding to the question still accept such cases.

**TABLE 1 - Percentage of P&A respondents who currently are, or could within the next 12 months, represent an individual with a disability by type of outcome sought**

Seek to prevent the establishment of a guardianship	76.19%
Seek to limit the powers of a guardian at the time of establishment	73.81%
Seek to replace the individual or entity who serves as a guardian	73.81%
Seek to reduce the powers of a guardian with partial restoration of rights at some point after establishment	80.95%
Seek to terminate a guardianship with full restoration of rights	85.71%
Assist a petitioner establish a guardianship for an individual with a disability	9.52%
Other: Explain:	28.50%

n = 42<sup>9</sup>

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<sup>8</sup> The question was asked of P&As who in the past, currently, or could within the next twelve months provide representation in the guardianship areas listed in Table 1. The responses of the four P&As who reported they represented individuals in the past, but now longer do so, were removed from the analysis of responses to this question to allow for a better assessment of the current status of P&A representation in guardianship cases. One P&A responded in a comment that they are unlikely to provide representation in guardianship cases, but often provide technical assistance in a number of points during the process. This P&A however, did respond affirmatively that they could represent an individual “seek to reduce the powers of a guardian with partial restoration of rights at some point after establishment,” and therefore this P&A’s response is included in Table 1. Removing the P&As response to that question would reduce the percentage from 80.95% to 78.57%.

<sup>9</sup> *Ibid.*

Several P&A agencies expressed differing approaches on whether they have or would represent an individual to obtain a guardianship. Four P&As responded they have or would assist a petitioner establish a guardianship, but one P&A commented further that they would only assist in such a case if the guardianship reflected the will of the individual with a disability as the client of the P&A. A fifth P&A which did not respond that they have or would assist an individual obtain a guardianship, did state in a comment that the P&A agency once assisted with obtaining a guardianship for a person with a disability so the individual could secure Medicaid waiver benefits and avoid becoming homeless. Another P&A commented that as a policy they would not assist in the establishment of a guardianship.

Four P&As under “other” mentioned representation to avoid guardianship through the use of alternatives such as supported decision making, a topic addressed further below. Two P&As stated they are challenging the constitutionality of a state guardianship statute.

### B. Individuals Represented

The P&As were asked whether their representation in guardianship cases was limited to individuals with certain disabilities. All of the forty-two P&As who stated they currently do or could represent individuals in guardianship cases replied this would include representation of individuals with developmental or intellectual disabilities. A slightly smaller number, 88% of P&A respondents reported they are or could represent individuals with mental health disabilities, followed by 81% who are or could represent an individual with a traumatic brain injury in a guardianship case. Almost 67% of P&As who responded to the question reported they are or could represent an individual with another type of disability other than a developmental/intellectual disability, mental health disability, or a traumatic brain injury in a guardianship case.

## **V. Involvement in Supported Decision Making**

The concept of supported decision making to provide supports to individuals with disabilities to understand and make decisions in order to avoid the imposition of, or to terminate, a guardianship has received increased attention over the past several years.<sup>10</sup> The P&As were asked whether they have used supported decision making while representing an individual with a disability in a guardianship case. Table 2 presents the full results of P&A responses regarding use of supported decision making as part of representation during different points in the guardianship process.

Despite the more recent interest in supported decision making in the United States, 61% of the forty-six P&As<sup>11</sup> who responded to the question have used the concept to seek to prevent the establishment of a guardianship. Furthermore, assuming very conservatively that the seven P&As who did not respond to the survey have not used supported decision making, at least twenty-eight of the fifty-seven P&As, or

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<sup>10</sup> For more information on the concept of supported decision making, see the webpages of the [Supported Decision-Making Pilot Project](#) initiative of the Center for Public Representation and Nonotuck Resource Associates, Inc., and the [National Resource Center for Supported-Decision Making](#), a project of Quality Trust for Individuals with Disabilities, Burton Blatt Institute of Syracuse University, and the Beach Center on Disability at Kansas University.

<sup>11</sup> The responses of the four P&As who reported they represented individuals in the past, but now longer do so, were included in the analysis of responses to this question. *C.f.* note 8.

almost half at 49% of all P&As nationwide have used supported decision making to seek to prevent a guardianship. Fewer P&As have used supported decision making in other situations, about 45% of all P&As who responded to the question, such as to reduce the power of a guardian or to terminate a guardianship.

**TABLE 2 - Percentage of P&A respondents who have or currently use Supported Decision Making (SDM) during representation of an individual with a disability by type of outcome sought**

Seek to use SDM to prevent the establishment of a guardianship	<b>60.9%</b>
Seek to use SDM to limit the powers of a guardian at the time of establishment	<b>47.8%</b>
Seek to use SDM to replace the individual or entity who serves as a guardian	<b>43.5%</b>
Seek to reduce the powers of a guardian with partial restoration of rights at some point after establishment	<b>45.7%</b>
Seek to terminate a guardianship with full restoration of rights	<b>45.7%</b>
Other, Explain:	<b>23.9%</b>
P&A has not used supported decision making	<b>28.3%</b>

n = 46<sup>12</sup>

The responses under the open ended question of “other” were wide ranging and do not suggest any common trends. The individual P&A comments ranged from expression of interest in the concept of supported decision making, current engagement in a pilot project, representation of youths with disabilities to use supported decision making to avoid guardianship, and plans to use supported decision making as part of a constitutional challenge to a state guardianship statute. Use of supported decision making in systemic reform is discussed in the next section.

## **VI. Systemic Work in Guardianship Issues**

In order to best utilize limited resources, P&As are encouraged to work for systemic improvement and changes in advocating for the rights of persons with disabilities. The survey thus sought to capture a sense of P&A systemic work to improve the guardianship system for individuals with disabilities within their jurisdiction. In addition, given the increased interest in alternatives to prevent guardianships, especially the use of supported decision making, the survey also asked about P&A systemic reform efforts which involved supported decision making.

A large majority of P&As are involved in guardianship reform efforts. Eighty-nine percent of P&As who responded to the question, which represents 82% of P&A organizations who completed the survey, have

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<sup>12</sup> *Ibid.*



been involved in guardianship reform efforts.<sup>13</sup> P&As were then asked to identify the type of reform work and whether these reform efforts included supported decision making.

Six P&As identified involvement in state Working Interdisciplinary Networks of Guardianship Stakeholders (WINGS) groups, either an already functioning WINGS group or in discussions to establish a new WINGS. WINGS are ongoing court-stakeholder partnerships that aim to use their collective impact to drive changes that will affect the way courts and guardians practice, and improve the lives of people who have or may need a guardian.<sup>14</sup> The National Guardianship Network, with funding from the State Justice Institute (SJI), coordinated the launching of WINGS pilots in 2013 and additional WINGS groups in 2015, and a mandatory stakeholder was either the P&A or the state Council on Developmental Disabilities. A number of states have independently developed WINGS or similar interdisciplinary groups and there are currently 17 state WINGS groups.

Nine P&As specifically mentioned working with groups such as the state Council on Developmental Disabilities, University Centers for Excellence in Developmental Disabilities, self-advocates, and other groups in seeking systemic improvements in the state guardianship system. Eleven P&As reported work with the public guardian, or serving on a task force, subcommittee, or workgroup to address guardianship issues or to seek reform. A number of these task forces or subcommittees were established by the state court system.

Several P&As are engaged in training or presentations as part of their systemic work, mostly to discuss supported decision making. Fifteen P&As indicated involvement in guardianship legislative efforts, or provided comments on state guardianship regulations. Four P&As have either in the past or are currently utilizing litigation to advance alternatives to guardianship, including supported decision making.

Twenty-three P&As who mentioned work on guardianship reform specifically stated that this work included advancement of the use of supported decision making. Of these twenty-three, fifteen P&As are working with other groups, which may include the court system, other advocacy groups, WINGS projects, or serving on task forces or committees to increase the use of supported decision making. In one case the P&A involvement in establishing a supported decision making network led to the creation of a WINGS project. Several other P&As stated their reform efforts included encouraging the use of less restrictive measures instead of a guardianship. Six P&As indicated engagement at some level in legislative work around supported decision making.

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<sup>13</sup> Only P&As who have or could represent individuals with disabilities in guardianship cases were asked about involvement in guardianship reform efforts. Therefore forty-six out of the fifty survey respondents were asked this question, of which forty-one P&As replied they have participated in guardianship reform efforts.

<sup>14</sup> See National Guardianship Network, 2014, [WINGS Tips: State Replication Guide For Working Interdisciplinary Networks of Guardianship Stakeholders](#); Duizend, Richard and Brenda Uekert, July 2015, [Assessment of the Impact and Efficacy of Working Interdisciplinary Networks of Guardianship Stakeholders \(WINGS\): Final Report](#).

## VII. Conclusion

The majority of the P&A Network offers representation to individuals with disabilities who face issues related to guardianship. Most P&A organizations also participate in efforts to improve state guardianship systems.

Though the decision of a P&A to represent an individual in a guardianship case is dependent on a number of factors, such as the merit and complexity of the case, the current obligations of the P&A, and available staff resources, the results of the survey shows that at a minimum about two-thirds of all P&A agencies, and 84% of P&A respondents to the survey, offer the potential to represent an individual with a disability in a guardianship case. All P&As involved in guardianship representation who responded to the survey offer such services to individuals with developmental or intellectual disabilities, while slightly fewer, though still a strong majority of P&A respondents, could represent individuals with other disabilities in guardianship cases.

Despite the individual P&A priority setting process, taken as a whole a large portion of the P&A Network is involved in guardianship representation and reform work, while at a minimum just shy of a majority of all P&A agencies are also involved in the use or advancement of supported decision making. Certainly differences exist among individual P&As in terms of the depth of focus on guardianship and supported decision making issues, a question not specifically explored through this survey, but at a base level most P&As are clearly a player in guardianship issues within their jurisdiction.

## Appendix

### Survey Questions

1. State
2. Does your P&A provide information or referral to individuals with disabilities on guardianship / conservatorship issues short of providing representation?
- 3a. Does your P&A currently represent, or could represent within the next 12 months, individuals with disabilities in cases involving guardianship / conservatorship issues?
- 3b. If you answered no to question 3a, has your P&A in the past, but no longer plans to during the next 12 months, represented individuals with disabilities in cases involving guardianship / conservatorship issues?
- 3c. If you answered yes to 3b, please explain why your P&A no longer represents or plans to represent during the next 12 months, individuals with disabilities in guardianship / conservatorship issues?
4. On which of the following guardianship / conservatorship issues has your P&A in the past, currently does, or could within the next 12 months, provide representation (check all that apply):
  - a. To seek to prevent the establishment of a guardianship / conservatorship
  - b. To seek to limit the powers of a guardian / conservator at the time of establishment
  - c. To seek to replace the individual or entity who serves as a guardian or conservator
  - d. To seek to reduce the powers of a guardian / conservator with partial restoration of rights at some point after establishment
  - e. To seek to terminate a guardianship / conservatorship with full restoration of rights
  - f. To assist a petitioner establish a guardianship / conservatorship for an individual with a disability
  - g. Other: Explain:
5. Which of the following individuals has your P&A in the past, currently does, or may within the next 12 months, provide representation to on guardianship / conservatorship issues (check all that apply):
  - a. Individuals with a mental health disability
  - b. Individuals with an intellectual or developmental disability
  - c. Individuals with a traumatic brain injury
  - d. Individuals with any other disability not listed above
  - e. Other individuals not within the above categories: Explain

6. Has your P&A in the past ever used, or does your P&A currently use, the concept of supported decision making during representation of an individual with a disability in any of the following circumstances, whether successful or not (check all that apply)?

- a. To seek to prevent the establishment of a guardianship / conservatorship
- b. To seek to limit the powers of a guardian / conservator at the time of establishment
- c. To seek to replace the individual or entity who serves as a guardian or conservator
- d. To seek to reduce the powers of a guardian / conservator with partial restoration of rights at some point after establishment
- e. To seek to terminate a guardianship / conservatorship with full restoration of rights
- f. Other, Explain:
- g. P&A has not used supported decision making

7a. Has your P&A been involved in guardianship reform efforts?

7b. If you answered yes to question 7a, please describe those efforts, including whom your P&A has worked and whether the effort has involved supported decision making:

8. Is there is any information related to your P&A's involvement in guardianship / conservatorship issues you would like to share?