



Joint Committee to Examine the Activities of the State's Protection and Advocacy
System and Client Assistance Program

Joint Committee Recommendations

April 11, 2023



To: Mike DeWine, Governor
Matt Huffman, President of the Senate
Jason Stephens, Speaker of the House of Representatives
Jada Brady, Executive Director, Joint Medicaid Oversight Committee

From: State Representative Scott Lipps, Chairman

Date: April 11, 2023

RE: Recommendations of the Joint Committee to Examine the Activities of the State's Protection and Advocacy System and Client Assistance Program

Introduction

The Fiscal Year 2022-2023 biennial budget (HB 110), under Ohio Revised Code (ORC) section 5123.603, requires the establishment of a joint committee to examine the activities of the state's Protection and Advocacy (P&A) system and Client Assistance Program (CAP).¹ The statute requires the joint committee to submit recommendations to the Governor, the President of the Senate, the Speaker of the House, and to the Joint Medicaid Oversight Committee.² The joint committee consisted of six members of the General Assembly, which included three members appointed by the Speaker of the House of Representatives, and three members appointed by the President of the Senate. The joint committee was chaired State Representative Scott Lipps and consisted of the following members:

House Appointments	Senate Appointments
Representative Scott Lipps (R), Chairman	Senator Mark Romanchuk (R)
Representative Marilyn John (R)	Senator Andrew Brenner (R)
Representative Tavia Galonski (D)	Senator Vernon Sykes (D)

¹ FY 2022-FY 2023 biennial budget provision (ORC section 5123.603), see page 1580, HB 110 text, as enrolled, <https://www.legislature.ohio.gov/legislation/legislation-documents?id=GA134-HB-110>

² Ibid.

Section 1

Overview of the Joint Committee Hearings

The Joint Committee to Examine the Activities of the State’s Protection and Advocacy System and Client Assistance Program held two hearings. The first hearing was held on November 1, 2022 and the second hearing was held on November 15, 2022.³ Over this period, the joint committee was provided an overview of the duties, responsibilities, and authorities of Disability Rights Ohio (DRO), the state’s designated P&A system, from the organization’s executive leadership, including DRO’s Executive Director, board members, caregivers, and individuals with disabilities. Additionally, the joint committee received testimony highlighting DRO’s legal actions, advocacy, and investigations of abuse and neglect, as well as ensuring access to services and supports.

At the same time, the joint committee accepted testimony from families of individuals with disabilities who receive critical care and support in Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF), sheltered workshops, and facility-based day programs.

Despite being Ohio’s P&A and CAP, with the responsibility to protect the rights of individuals with disabilities, the testimony given by parents, guardians, and family members expressed concerns over DRO’s administration of its service system. Specifically, the testimony described DRO’s excessive litigation against the State to which families objected. It also described DRO’s efforts to promote transfers of residents out of ICFs, sheltered workshops, and facility-based day programs into community settings without regard to individual choice and parental rights.⁴ Those efforts included DRO staff meeting privately with ICF residents without their guardians or parents present to encourage them to leave their ICF placement.

Furthermore, the testimony indicated unilateral actions taken by DRO to target ICF settings, day programs, and workshops, without seeking cooperation from families and ignoring families’ advocacy to preserve these settings. Witnesses stated DRO’s actions run counter to health and safety needs and disregard the informed decision-making of families. Moreover, witnesses emphasized the importance of the specialized services and expertise offered in ICFs to support individuals with complex physical, medical and/or behavioral needs.

The witnesses also touched on the issue of aging caregivers, and the importance that families have access to intermediate care facilities to appropriately address the needs of their loved ones when they are no longer able to provide that care. In addition, witnesses stated that it is vital for policymakers to underscore and promote a multi-dimensional strategy, which includes access to ICFs, sheltered workshops, facility-based day programs, and community-based residential and

³ Joint Committee to Examine the Protection and Advocacy System and the Client Assistance Program (November 1, 2022 and November 15, 2022), <https://www.ohiochannel.org/video/ohio-joint-committee-to-examine-the-protection-and-advocacy-system-11-1-2022>; and <https://www.ohiochannel.org/video/ohio-joint-committee-to-examine-the-protection-and-advocacy-system-11-15-2022>

⁴ Ibid.

work settings. However, witnesses stressed that DRO takes a one-size-fits-all approach preferring community settings to the detriment of other options. In its adherence to this approach, families are concerned that DRO acts adversely to their disabled family members' interests who require higher levels of specialized care.

Finally, families expressed concern regarding DRO's treatment toward guardianship. Parents and family members of adults with intellectual disabilities often serve as guardian for their adult child. These family members typically have the most intimate knowledge of their loved ones' needs and are most motivated to ensure that the individual's health, safety, and welfare is protected. DRO's website reflects an antagonistic attitude toward guardianship as does DRO's actions when it advocates against residential (ICF) and vocational service options guardians have carefully chosen.

The opportunity to conduct oversight hearings of the state's P&A system afforded members of the joint committee the opportunity to hear perspectives from DRO's leadership, as well as from individuals with disabilities, family members, and caregivers. Although DRO's duties, authorities, and responsibilities are outlined in federal statute, it is clear from the testimony that actions of the state's P&A lack accountability, proper coordination, engagement, notification, and communication with families and caregivers.

Section 2

History of the Protection and Advocacy System

Under the Developmental Disabilities Assistance and the Bill of Rights Act of 2000 (DD Act), each state and territory must have a P&A designated by the state's governor. The DD Act and other authorizing statutes give the P&A the authority to advocate for the rights of individuals with disabilities.

According to the U.S. Department of Health and Human Services' Administration for Community Living (ACL), P&As work at the state level to protect individuals with disabilities, and advocate on their behalf. ACL notes that there are 57 P&A systems in the U.S. and its territories. Each operates independently and may partner with agencies that provide other services.⁵ Overall, P&As have the legal authority to: (1) investigate suspected abuse or neglect; (2) have access to records and facilities necessary to investigate abuse or neglect or to monitor the treatment and safety of residents; (3) pursue litigation and all other appropriate remedies under federal, state, and local law; (4) provide information and referrals regarding entitlements to services and other legal rights; and (5) educate policymakers on needed reforms to disability-related laws and services.⁶ As noted above, Ohio's P&A system is DRO. It is designated by the Governor and charged by federal law "to advocate the rights of individuals with developmental disabilities," under 42 U.S.C. § 15043.

⁵ U.S. Department of Health and Human Services' Administration for Community Living, July 27, 2022, <https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems>

⁶ Ibid

In addition, HB 153 of the 129th General Assembly required the transition from the Ohio Legal Rights Service (OLRS), a state entity, to a nonprofit entity to serve as Ohio's P&A system.⁷ On October 1, 2012, OLRS was abolished, and DRO was designated as the state's P&A system.⁸ The transition was made after a feasibility study was completed. The feasibility study was required under HB 1 of the 128th General Assembly, the FY 2010-FY 2011 biennial budget.⁹ Furthermore, there are four requirements under federal law that must be satisfied before a state may redesignate the agency responsible for implementing its P&A system. A P&A system may not be redesignated unless:

1. There is good cause for the redesignation;
2. The state has given the agency both notice of the intention and an opportunity to respond to the assertion that good cause has been shown for the redesignation;
3. The state has given timely notice and an opportunity for public comment in an accessible format to individuals with developmental disabilities or their representatives; and
4. The system has an opportunity to appeal the redesignation to the U.S. Secretary of Health and Human Services, on the basis that the redesignation was not for good cause.¹⁰

Finally, as referenced under Section 2, there are 57 P&A systems. Moreover, 52 are Governor designated nonprofits, such as DRO. Five are state operated, similar to an independent state agency, which include: Alabama, American Samoa, Kentucky, North Dakota, Puerto Rico.

Section 3

Summary of Individuals Living in ICFs and Participating in Sheltered Workshops & Facility-based Day Programs

On November 29, 2022 and February 3, 2023 the Ohio Department of Developmental Disabilities (DODD) provided the following information regarding individuals living in an ICF, as well as participating in a sheltered workshop or day program. Below is a summary of recent data:

- Number of individuals living in an ICF: **4,280**
- Number of individuals who are in a sheltered workshop (total number of people who receive services in sheltered workshops): **4,870**
- Number of individuals who are non-verbal (system-wide): **20,311** (this includes both limited verbal abilities and non-verbal individuals ages 10 and above)

⁷ HB 153, 129th General Assembly (2011-2012), p. 2849

http://archives.legislature.state.oh.us/analyses.cfm?ID=129_HB_153&ACT=As%20Enrolled

⁸ Executive Order 2012-15K, Designation of the Ohio Disability Law and Policy Center, Inc., as the Client Assistance Program.

⁹ HB 1, 128th General Assembly (2009-2010), p. 2909,

http://archives.legislature.state.oh.us/BillText128/128_HB_1_EN_N.pdf

¹⁰ 42 U.S.C. 15043(a)(4).

- Number of individuals in facility-based, non-work (day programs) services: **19,368**
- Number of individuals with some level of legal guardianship (system-wide): **14,728**

The DODD data above reinforces the vulnerability of the population affected by the P&A system and the need for careful consideration to be given to the decision-making of families, guardians, and caregivers. Open and transparent dialogue, through collaboration, notification, and coordination, is important in ensuring the health, safety and well-being of individuals who need and choose care in an ICF, sheltered workshop, or facility-based day program as opposed to a community setting. Testimony from DRO and the public reveals that DRO does not support these programs and actively seeks to limit and close them. This adverse treatment of respected service options is concerning as it reflects a marginalization by the P&A of the interests of highly vulnerable people in the P&A service system.

Section 4

Joint Committee Recommendations

1. Redesignate the current P&A agency for intentionally not protecting and advocating for *all individuals with disabilities*. In particular, the current P&A is not protecting or advocating for individuals residing in ICFs and/or accessing sheltered workshops, and facility-based work and day programs. When the joint committee questioned DRO about this concern, DRO indicated it does not have the resources to help everyone.¹¹ The joint committee understands that DRO cannot provide individual legal representation to every individual served by the system, but it can protect all interests by promoting all service options through its advocacy with policymakers and by respecting the diverse choices made by individuals and families in the system.
2. Explore changes to Ohio law, to the extent permissible under federal regulations, that apply to the P&A system. For example:
 - Aligning Ohio law with federal regulations regarding the P&A system's access to records.
 - Requiring the P&A system to obtain authorization from the individuals or the individual's legal guardian, conservator, or other legal representative for ICF visitation for reasons other than abuse and neglect
 - Requiring the presence of, or a waiver from, the individual's legal guardian or parent when discussing an individual's setting or services for reasons other than abuse and neglect.

¹¹ <http://ohiochannel.org/video/ohio-joint-committee-to-examine-the-protection-and-advocacy-system-11-1-2022>, see 36:25 minute mark

- Requiring the P&A system to show cause to the legal guardian to discuss an individual's setting or services for reasons other than abuse and neglect.
3. Explore having multiple P&A systems. For example, establishing one P&A system for individuals residing in an ICF, or accessing sheltered workshops and facility-based day program.
 4. Explore having a separate P&A system from the CAP.
 5. Explore establishing clear guidelines, parameters, and notifications when the P&A system investigates or goes in to interview an individual with a disability. Legal guardians should be afforded reasonable notification, unless abuse or neglect is alleged.
 6. Explore establishing criteria when the P&A system enters individuals into a class action lawsuit. Ensure there is verification and understanding by the individual or the individual's parent(s) or guardian(s).
 7. Explore creating a better system of accountability to allow ICFs, and vocational centers to report issues, abuses, and inaccuracies by the state P&A system.
 8. Explore requiring the P&A system to adopt a posture of individuals and families having the right to an ICF setting. That right should not be infringed upon. Under Medicaid law and Ohio's state plan, individuals have a right to an ICF placement. If individuals want a community placement, Medicaid law requires that they "waive" that right, thus the term "waivers". Medicaid law requires that service information is provided to individuals and families so that they can make an informed choice between these two options. DRO in its capacity as the legal advocate for people with developmental disabilities should respect and support the laws and benefits that protect the DD population and aid in the implementation of them – such as those options that make up Ohio's Medicaid State Plan.
 9. Explore using an advisory council or board of willing family members to advise the P&A system about the needs of individuals living in an ICF setting, sheltered workshop, and facility-based program.
 10. Explore using a state entity, as in the case of the OLRs.
 11. Develop a plan to engage with stakeholders to make recommendations for amending federal law.