Protection and Advocacy Standards





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I. Introduction

The Board of Directors of the National Disability Rights Network (NDRN) and the Chief Executive Officers of its member agencies have adopted these Standards to guide the work of the Protection and Advocacy (P&A) system. The Standards address the philosophy, principles and values that provide a foundation for the work of a P&A system, and the policies and practices relevant to the governance, management, core advocacy activities, and evaluation of a P&A system.

While the Standards generally follow the federal statutes and regulations that guide P&A programs, they extend beyond the regulations, particularly in instances where the regulations do not address core components or provide only minimum guidance on aspects of a P&A system. The Standards are tied to the functions of a P&A identified within the NDRN membership agreement.

These Standards reflect widely accepted norms for an effective P&A system. They are not intended to define best practice. It is the intention of the NDRN Board that the Standards will not to be used to address compliance, nor constitute minimum legal requirements. Compliance issues are specified in law and regulation and the purview of the federal administering agencies.

If a state rule, statute, or regulation requires P&A staff to act in conflict with the Standards herein, NDRN expects the P&A to comply with or, as appropriate, challenge the rule, statute, or regulation in question.

A. Use of the Standards

1. The NDRN Board invites P&A members of the network to use these Standards as a self-assessment instrument. As such, they may assist

- individual P&A systems to identify programmatic and organizational strengths and areas for growth.
- 2. Individual P&As may also use the Standards as a resource in the development of their policies and procedures.
- 3. The Standards may be used by P&A systems as a training and orientation instrument for board and staff.
- 4. NDRN will provide training and technical assistance to support the development of skills and knowledge to implement these Standards, and use the Standards as the basis for voluntary peer organizational reviews.
- Adherence to the Standards by individual P&As may be one way to demonstrate the effectiveness of the P&A's programs to appropriators, federal officials, and other funders and public policy makers.

B. Philosophy Guiding P&A Work

- 1. People with disabilities freely exercise their legal, civil, and human rights in an equitable society.
- 2. People with disabilities are full and equal persons under the law and are entitled to equal access to all the opportunities afforded to others.
- 3. People with disabilities are free from abuse, neglect, exploitation, discrimination, and isolation, and are valued members of our society, treated with respect and dignity.
- 4. People with disabilities have access to age-appropriate services and supports that are shaped by the unique needs and preferences of each individual. Such services and supports are designed to foster an independent, meaningful, and integrated community life.

5. People with disabilities have the right to make choices about all aspects of their life, including daily routines and major life events, without fear of reprisal or loss of liberty.

C. Principles Guiding P&A Work

Advocates use multiple strategies to address the root causes of discrimination, challenge institutional bias, and promote rights enforcement, independence, and inclusion of people with disabilities:

- 1. The primary role of advocates is to establish, expand, protect, and ensure enforcement of the human, legal, and civil rights of people with disabilities, especially those at greatest risk of harm or discrimination, to achieve a more equitable society.
- 2. Advocacy efforts recognize and promote the right to an array of appropriate services and supports.
- 3. P&A services have as their focus the maximization of independence, autonomy, support, and integration of individuals with disabilities, and eradication of systems of inequality.
- 4. Advocacy resources and objectives address the human, legal, and civil rights of individuals and groups of individuals with disabilities, in conformance with established P&A priorities.
- Advocates employ multiple means of action and redress, such as individual and class representation, legislative and other systemic advocacy, monitoring and investigations, training, and public education.
- 6. P&As use collaborative, community-based approaches to legal services to build the power of individuals and communities to challenge and eradicate systems of inequality.

Advocacy services are client directed:

- 1. The client is the person with a disability to whom the P&A provides services. P&A staff take direction from the client.
- 2. When a decision or meaningful choice cannot be or is not expressed by a client, or when consent is not available from or provided by a client or legally authorized substitute, advocates safeguard and advance the human, legal, and civil rights of the person with a disability in a way that promotes the philosophy, principles, and values set forth in these Standards.
- 3. P&As inform their clients about options, assist their clients to express preferences, and ensure that their preferences are heard and vigorously pursued within the scope of the law.
- 4. Advocacy programs are informed by people with disabilities at the greatest risk of discrimination and/or who are multiply marginalized, and are accountable to the people they represent. Such accountability is reflected in the policies and practices of the program as well as in the ethnic, racial, cultural, and disability composition of the governing authority and staff:
- 5. P&As provide their clients with the skills, information, and knowledge that enable the clients to advocate on their own behalf.
- 6. P&As prioritize empowering and being advised by people with disabilities directly affected by the intended activities at all stages of the P&A's action. Intentionally planning partnerships with clients, client communities, and other diverse allies is evident throughout P&A activity.

Protection and Advocacy agencies are leaders on disability issues:

- 1. P&As seek access to, and participate in, forums such as state rulemaking, planning, legislative and policy development processes that affect the rights and opportunities of people with disabilities.
- 2. P&As are leaders in the development of public policy and decisional law that affects people with disabilities.

Advocacy services are independent and accessible to people with disabilities:

- 1. The availability of advocacy services is well known to potential clients. The P&A's name is recognizable and germane to disability rights. Services and location of offices are accessible to people with disabilities, especially those with limited resources.
- 2. All P&A services are offered in physical or virtual settings that are fully accessible to people with disabilities.
- 3. Within the individual P&A's financial resources, P&As use technology to the fullest extent practicable to accomplish their goals and communicate with clients.
- Advocacy programs are administratively independent and physically separate from service providers and state agencies responsible for the provision of services to individuals with disabilities.
- Advocacy priorities include efforts to address the specific concerns of people in segregated settings and promote opportunities for integration.
- 6. Advocacy efforts focus on directing resources to people with disabilities who are systemically marginalized and subject to multiple forms of discrimination, to achieve justice for people who have been most harmed by exclusion and discrimination.

- 7. Advocacy services address the intersectional discrimination that many people with disabilities experience, and the root causes of disparities faced by people with disabilities who have been and remain excluded and discriminated against, including Black, Indigenous, People of Color (BIPOC) and Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual (LGBTQIA+) people, among others.
- 8. P&A services are trauma-informed. Staff are trained on the impact and incidence of trauma and employ trauma-informed approaches when conducting their work.

D. Values Guiding P&A Work

- 1. People with disabilities are included in all activities undertaken by the P&A, including BIPOC, LGBTQIA+ and others who experience multiple marginalization.
- 2. P&As work zealously to protect and advocate for their clients and to advance the rights of people with disabilities in their state to achieve a more equitable society.
- 3. Boards of Directors, PAIMI Councils, and P&A services and staffing reflect the cultural, ethnic, racial, geographic, gender identity, age, and disability diversity in their state.

II. Governance and PAIMI Advisory Council

A. Governance

Each P&A system—whether public or private—is led by a governing entity that provides equitable, effective, independent, and ethical leadership. The

P&A board¹ considers these Standards, along with those it develops internally, and its fiduciary responsibilities to ensure the accountability and stability of the P&A. The board protects the P&A from arbitrary or inappropriate influences that conflict with its mission or that interfere with its responsibility to represent client concerns. The board bears the ultimate responsibility to provide the foundation for a well-run organization, ensure the P&A's efforts are mission and community driven, think strategically about the P&A's future, and make certain the P&A achieves desired outcomes for individuals with disabilities within its state or territory.

Board members receive necessary supports, including staff assistance, reasonable accommodations, payment for related expenses, relevant materials and information, orientation, and training to facilitate their full and informed participation.

The following Governance Standards apply to public and private P&A systems:

- 1. Members of the governing board are aligned with the mission, vision, and values of the P&A, and work on behalf of its interests, including by following their fiduciary duties of loyalty, obedience, and care.
 - a) Members of the board develop and regularly evaluate the mission and vision of the P&A to ensure alignment with the needs of the people served by the P&A and the disability community at large, with a specific focus on individuals experiencing the greatest degree of discrimination or marginalization.
 - b) The governing board uses the mission, vision, and values of the P&A system to guide its work and the work of the P&A.

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¹ In this section, the term "Board of Directors" or "Board" is used throughout, although it is recognized that the governing authority of P&As based in state agencies is an entity other than a board of directors.

- c) The mission, vision, and values are consistent with federal mandates and overarching P&A values and principles as presented in these Standards.
- d) The board is committed to addressing the root causes of individual and systemic discrimination, challenging institutional bias, and promoting rights enforcement, independence, and inclusion for people with disabilities to create a more equitable society.
- The governing board ensures that the P&A demonstrates compliance with applicable federal and state laws for P&As and non-profit organizations.
- The governing board adopts, and regularly reviews, bylaws and other governance documents that define board member responsibility and activity.
- 4. The governing board is composed of members who share a commitment to advance and defend the rights of all people eligible for P&A services as defined by the organization's mission, and has the skills and abilities needed to carry out its roles and responsibilities.
 - a) The board represents the diverse cultural, ethnic, racial, and disability diversity in its state and is connected to the BIPOC, LGBTQIA2+ and other highly impacted and significantly marginalized communities.
 - b) The board membership satisfies the requirements of relevant funding sources.
- 5. The governing board understands its roles and responsibilities as specified in governance documents, and it:
 - a) Determines the organization's mission and purpose
 - Selects, supports, and annually evaluates the chief executive's performance, and takes corrective action when the performance is found to be unsatisfactory

- c) Takes all steps necessary to ensure compliance with federal regulations governing P&As, and state or federal regulations governing non-profit organizations where applicable
- d) Provides proper financial and programmatic oversight, and ensures legal and ethical accountability
- e) Ensures sufficient financial and human resources are available to adequately work toward achieving the mission
- f) Determines and strengthens the organization's programs and services and ensures effective organizational planning, including priority setting and strategic planning
- g) Ensures the P&A has the capacity to perform the core functions of a P&A as described in the NDRN membership agreement
- 6. The governing board acts in a transparent manner.
 - a) Governance documents are available to the public when required by state or federal law
 - b) Minutes are an accurate reflection of board activity and decisions
 - c) All board meetings are accessible to people with disabilities, including linguistic accessibility where necessary
- 7. The governing board provides fiscal oversight and accountability, ensures the use of sound financial practices, and:
 - a) Ensures that the allocation of financial resources is based on a formal budget and is consistent with program mission, values, and priorities
 - b) Retains external independent auditors, commissions an annual OMB A-133 audit (Single Audit), and carefully reviews the audit findings
 - c) Ensures the P&A uses Generally Accepted Accounting Principles (GAAP) in all appropriate accounting and financial reporting and follows regulations and guidelines required by each funding agency (see fiscal section for definitions and additional information).

- 8. The governing board adopts the annual priorities and participates in organizational planning and priority setting with the help of stakeholders and public input that reflects the needs of diverse individuals with disabilities across the state, and ensures client direction. The board:
 - a) Obtains significant public input and advisory council recommendations in setting priorities
 - b) Develops the PAIMI priorities jointly with the PAIMI Advisory Council
 - Actively seeks input to identify the needs of the disability community, with a focus on unserved and underserved communities
 - d) Ensures that program development and goal setting reflect the input of those with the greatest need for services
 - e) Adopts the annual goals and priorities for the system with quantifiable performance measures associated with the outcomes. Intentional planning partnerships with authentic stakeholder communities are evident throughout P&A activity
- 9. The governing board members contribute meaningfully to advance the mission of the P&A, including a commitment of time and financial resources within their individual means.

B. PAIMI Advisory Council

Every P&A shall maintain a PAIMI Advisory Council that meets the following Standards:

- 1. The Advisory Council membership meets the diverse membership requirements of the PAIMI Act.
 - a) Council members include attorneys; mental health professionals; individuals from the public who are knowledgeable about mental

- illness and the advocacy needs of persons with mental illness, and who have demonstrated a substantial commitment to improving mental health services; a provider of mental health services; individuals who have received or are receiving mental health services, and family members of such individuals.
- b) At least 60% of the membership of the Council is comprised of individuals who have received or are receiving mental health services, or who are family members of such individuals. At least one family member shall be a primary caregiver for a minor child or youth who is receiving or has received mental health services.
- c) Membership reflects the racial, ethnic, and geographic composition of the state.
- d) The Council Chairperson is an individual who has received or is receiving mental health services, or a family member of such individual.
- 2. The Advisory Council advises the P&A on priorities to be carried out in protecting and advocating the rights of people with mental illness.
 - a) The Council develops its recommendations for PAIMI priorities for and with the Governing Board.
 - b) The Council works jointly with the Governing Board to develop P&A priorities.
 - c) The P&A shares its goals, priorities, advocacy activities, and budgets with the Council.
 - d) The Council has a mechanism to gather information and feedback from individuals with mental illness.
 - e) The Council submits an Advisory Council Report on its activities with the P&A's annual Program Performance Report.
- 3. If the P&A is a non-profit organization, the Chairperson of the Advisory Council serves as a voting member of the governing board.
- 4. Advisory Council meetings and other events are accessible to people with disabilities.

III. Leadership and Management

A. Leadership and Overall Management

- The P&A leadership envisions and implements the philosophy, principles, and values contained in the Standards. The vision is integrated into all P&A operations, activities, policies, and procedures.
- 2. The P&A is a leader in the disability rights movement in its state or territory. Authentic and diverse stakeholder community partnerships are evident throughout the work of the P&A.
- 3. The P&A is a leader in the vigorous enforcement of laws protecting the civil, legal, and human rights of people with disabilities in its state/territory, with a particular focus on individuals experiencing the greatest degree of discrimination and marginalization.
- 4. The P&A puts forward a vision of an equitable society where people with disabilities have equality of opportunity and are able to participate fully in community life by exercising choice and self-determination.
- 5. The P&A is a leader in its community in terms of hiring, retaining, and promoting individuals with disabilities that represent the diversity of the state, and is connected to the BIPOC, LGBTQIA+ and other significantly marginalized communities.
- The P&A leadership is actively involved in priority-setting, and the advocacy priorities are driven by the needs of people with disabilities in the state/territory.
- 7. Management works with the governing authority to ensure that the P&A:

- a) Meets all the federal requirements of a P&A
- b) Possesses resources necessary to protect and advocate for the human, legal, and civil rights of all people with disabilities in the state
- c) Has the capacity to provide all the functions of a P&A outlined in P&A Standards
- d) Maintains its independence from service-providing agencies
- e) Periodically assesses risk related to governance, employees, volunteers, fiscal operations, grants management, and related matters
- f) Develops diverse funding sources to support its work
- The P&A programs are structured to support effective and equitable legal and rights advocacy.
- Supervisory relationships are well-defined, with a clear division and distribution of authority and responsibility within the P&A.
- 10. Management staff receives relevant management trainings, including but not limited to training on racial equity and prevention of sexual harassment.
- 11. The P&A establishes and implements policies aligned with federal and state laws and professional responsibility rules to protect the confidentiality of its clients and other individuals who contact the organization.
- 12. Required federal and state reports are submitted accurately and timely to appropriate agencies.
- 13. The P&A establishes and implements fiscal, personnel, communications, and other policies consistent with these Standards. Such policies comply with federal and state requirements. The program maintains a written manual(s) that outlines agency policies and procedures.

- 14. Nonprofit P&As maintain property insurance, professional liability insurance, including Errors and Omissions fidelity bond coverage for all employees, and directors' and officers' insurance covering the board of directors.
- 15. The P&A has written policies regarding conflicts of interest and client confidentiality pertinent to governing board members, advisory council members, staff, volunteers, and contract workers.

B. Fiscal Management

The program is managed by sound fiscal principles, experienced fiscal staff, and follows federal guidelines required by each funding agency. Accurate fiscal information and documentation of revenues, expenses, and staff time is maintained for purposes of proper allocation, analysis, and required financial reporting.

Accurate financial information is available to assist the governing authority and management in maintaining financial soundness and achieving programmatic objectives. Management and the governing authority ensure that program funds are spent and accounted for in an equitable manner that fully meets the P&A's responsibility to its clients, funding sources, and the public.

The P&A's compliance with the following statements ensures fiduciary responsibility and internal controls:

1. The P&A uses Generally Accepted Accounting Principles (GAAP) in all appropriate accounting and financial reporting. The P&A may choose to prepare internal tracking and other reports on the cash basis or other non-GAAP basis. Applicable Federal OMB Circulars, IRS regulations, and state rules are understood and followed.

- 2. The governing authority and executive director ensure the financial integrity of the program by:
 - a) Adopting a board-approved budget that utilizes recurring revenues, keeps carryover funding to reasonable levels, maintains adequate cash flow reserves, and avoids any reversion of unspent funds.
 - b) Monitoring spending in relation to the approved budget by reviewing, at least quarterly, financial reports that reflect cumulative expenditures by grant and cost category; and reviewing analysis of any material variances and action plans as necessary.
 - c) Maintaining adequate internal controls and procedures to ensure no one individual has complete authority over an entire financial transaction (segregation of duties).
 - d) Allocating and tracking funds consistent with federal mandates, and ensuring that P&A grant money is spent on the program for which it was intended.
 - e) Ensuring that the use of financial resources is consistent with program mission, values, and priorities; and that neither the program's current funding nor pursuit of new funding compromises the program's independence or represents a conflict with the goals of the program.
 - f) Maintaining a written accounting manual that describes policies and procedures covering all fiscal transactions, including financial records, informational reports, payroll, purchasing, draw downs, and financial statements. The policies and procedures are in accord with federal fiscal policies, and reviewed and updated regularly.

- g) Using an adequate accounting system for maintaining a chart of accounts that ensures receipts and allowable expenditures of the program are recorded in appropriate line-items. The chart of accounts must separate activity by funding source.
- h) Ensuring the review of the annual tax return (990) by the board of directors (for non-profit organizations).
- i) Ensuring the annual performance of an external Single Audit, if required by 45 CFR (which may include a simultaneous program-specific audit), and that the auditor reports activities and findings directly to the governing body.
- j) Ensuring that staff responsible for fiscal oversight understand federal financial guidelines, IRS regulations, and grant specific requirements.
- k) Implementing and maintaining a timekeeping system that allows accurate recording of time, and having procedures for supervisors to validate this process.
- I) Maintaining proper training for all P&A staff on internal procedures relating to fiscal activities, such as completing purchase requests and timesheets, to include a basic understanding by all P&A staff of eligibility and funding requirements for the P&A and its grants.

C. Personnel Practices

The most valuable resource of a P&A organization is its people. The leadership and management of the organization demonstrates a concern and respect for personnel consistent with the overall values of P&As. Leadership and management are committed to creating and maintaining a diverse, inclusive workplace in which all staff and volunteers have opportunities to participate and contribute to the success of the organization and are valued for their skills, experience, and unique

perspectives.

- 1. P&A recruitment implements equal opportunity employment practices, especially regarding people with disabilities. Recruitment practices incorporate strategies to intentionally seek out applicants from underrepresented communities, including people with disabilities, BIPOC, LGBTQIA+ individuals, and others. Recruitment practices are free of barriers (disabilities, language/LEP, plain language) and provide accommodations as needed.
- The P&A maintains an inclusive workplace where staff feel welcomed, supported, and valued. Staff treat one another with dignity and respect in a culturally and disability competent manner. The organization consistently provides training and resources to ensure this.
- 3. The P&A has a written personnel policy manual that is consistent with federal and state law, and addresses diversity, equity, and inclusion goals. A copy of the manual is provided to all employees, and each employee should sign an acknowledgement that they have received and read the manual.
- 4. The P&A provides employees opportunities for professional development. Staff are encouraged to seek training that increases their knowledge and skills in all areas of their work. The P&A encourages and provides opportunities for staff to exercise self-care and avoid burnout.
- 5. P&A practices include coaching and mentoring activities, approached from a perspective of diversity, equity, and inclusion, that build a diverse and inclusive workplace.
- The P&A has written job descriptions for every position in the program that include essential functions of the job duties an employee must be able to perform, with or without reasonable

accommodation(s). Each position is examined to determine which functions or tasks are essential to performance. The job descriptions also include the qualifications needed for the position, and where indicated, the requisite level of experience required.

- 7. The P&A will have standardized, accessible on-boarding for all employees that includes P&A core values and principles, and information about effectively working with varied disability populations.
- 8. The program has an interactive process for conducting employee evaluations and goal-setting on a regular basis. The evaluation process includes feedback from employees and management.
- 9. The P&A provides Equal Employment Opportunity training to all staff and volunteers on a variety of topics including, but not limited to, workplace harassment, the Americans with Disabilities Act as well as discrimination based on religion, race, pregnancy, and age. Additional training around cultural awareness is also recommended.
- 10. The P&A has a process in place to recruit, select, train, and supervise volunteers. Volunteer participation complies with state laws and relevant professional Standards, such as those relating to labor and insurance.
- 11. The P&A has a policy regarding staff conduct that creates an actual or apparent conflict of interest, or that may be inappropriate, unprofessional and/or reflect poorly on the P&A or its mission.

D. Recordkeeping and Data Collection

Proper recordkeeping and data collection allows a program to know whether a diverse client population is being served and through what methods. It also improves the program's efficiency and legal compliance by providing a database from which to assess the program's performance and

compliance. Good practice dictates the method, quality, and retention protocols of recordkeeping.

- 1. The P&A has a uniform system for maintaining client files that conforms to legal standards and that links the client to the appropriate funding source. Client files are reviewed regularly by supervisors.
- 2. Case records include information regarding the nature of the client's disability, the client's complaint or problem and goal(s), the advocacy strategies employed and final disposition, and other relevant data required by the federal funding agency.
- 3. P&As have a policy and procedure for maintaining confidentiality and security of all files, including but not limited to electronic records.
- 4. The P&A prepares and submits all federal grant reporting forms in a timely manner documenting the activities, accomplishments, and expenditures of the program as required.
- 5. There is a written procedure for determining what is an active, inactive, and closed case, and a protocol for file management in all categories of cases.
- 6. The P&A has a system of secure filing/storage retention and destruction that complies with federal and state laws. (Federal or state regulations may dictate retention periods. For grant- or contractrelated record keeping, the grant/contract documents may dictate the record retention requirements.)
- 7. The P&A has a process for collecting and analyzing data concerning client characteristics and program activities, and utilizes the data in program evaluation and priority-setting.
- 8. P&As have a method to ensure quality assurance for client files that includes a review of eligibility for federal programs.

IV. Access, Presence, Outreach and Training

Access, presence, outreach, and training are essential for P&A programs to ensure timely, open and equitable availability of assistance to all persons with disabilities; and that the program's systems advocacy and other efforts are informed by people with disabilities, and take into account the input and needs of the various constituencies throughout the state or territory served. P&A access, presence, outreach, and training (APOT) is trauma-informed and intentional about connecting with BIPOC, non-English speaking, immigrant, LGBTQIA+, and other disabled people with intersectional identities.

- 1. The P&A promotes and facilitates public awareness, visibility, and access to the program by ensuring that:
 - a) The P&A has accessible, plain language methods for indicating that it is the designated Protection and Advocacy system for that state or territory.
 - b) It is easy to locate the P&A's web page on the internet, to contact the P&A, and to find and visit the program's physical office(s) using public (if available) or private transportation. The P&A ensures that its website, phone system, and physical office(s) are accessible, and provides for communication with non-English speakers and people unable to contact the P&A during its regular business hours.
 - c) The P&A is readily distinguishable from service provider agencies and other advocacy groups or agencies. The P&A uses multiple strategies to expand public awareness of the P&A and its services, including media appearances, distribution of brochures or other materials, participation at public events, and social media. These strategies include intentional outreach to the intersectional and diverse communities served by the P&A.

- 2. The P&A makes reasonable efforts to ensure that its services are available throughout the state or territory served. These efforts may involve the use of regional offices, a toll-free phone number, contracts with local advocacy agencies, community partnerships, staffing that reflects the diversity of the communities being served, regular staff visits to various communities and facilities, web-based intake, and other methods.
- 3. The P&A ensures that it accommodates, is accessible, and is culturally responsive to all persons with disabilities. Accommodations may include the use of interpreters (including sign language interpreters), telephone or video relay, materials in Braille, large print or electronic format, translation of materials or correspondence into additional languages, and employment of staff, use of contractors/vendors or use of volunteers who are reflective of the diverse community and speak languages commonly used in the state/territory served.
- 4. The P&A undertakes outreach to potential clients, with a focus on the most adversely impacted and marginalized communities (ethnic, racial, disability, rural or other populations) by:
 - a) Planning and conducting activities to reach populations unserved or underserved by the P&A program. A population is underserved by the P&A when its percentage of the state's population is significantly greater than its percentage of clients served by the P&A.
 - b) Collaborating with organizations that represent and/or provide services to unserved and underserved populations.
 - c) Recognizing the importance of having staff who reflect the diversity of the communities being served, demonstrate an understanding of the impact of racism and structural inequities, and exhibit a passion for/knowledge regarding disability rights.
 - d) Ensuring accessibility standards are met in all outreach and training efforts.

- 5. The P&A establishes a presence in identified facilities and settings where diverse persons with disabilities live, work, or receive services, to the extent feasible and consistent with the P&A's annual priorities and resources. Facilities and settings could include institutions, hospitals, schools, residential facilities, group homes, nursing facilities, jails and prisons, juvenile justice, and immigration detention facilities.
- 6. The P&A regularly provides community education and advocacy training for individuals with disabilities and family members of persons with disabilities by:
 - a) Providing training to individuals with disabilities in settings convenient and accessible to them, and that takes into consideration intersectional identities, and is responsive to their needs.
 - b) Providing referral and rights publications or materials in formats and languages that are accessible (e.g., digital accessibility, plain language) and reflect the diversity of the community being served.
 - c) Providing information about P&A goals and priorities and ways in which to access P&A services.
 - d) Distributing information about laws and policies that affect individuals with disabilities.
 - e) Conducting community outreach and education activities based on the needs of the disability community, as resources permit, with a priority on reaching diverse audiences, considering intersectional identities, and ensuring trainings are culturally responsive.
 - f) Ensuring that its in-person and virtual events and trainings are fully accessible to people with all types of disabilities. Trainings and events are provided in an accessible format, live-streamed whenever possible, materials meet accessibility standards, a method is provided to request accommodations as part of the registration process and in informational materials, and ASL

- interpreter and/or CART services are available. The P&A shall also seek to ensure that events in which it is participating are fully accessible to people with disabilities.
- g) The P&As shall consider paying people with disabilities at trainings, panel discussions, and events where they are sharing their expertise and are not being paid by another source.

V. Information, Referral, and Intake

As the entry point for assistance, the Information, Referral, and Intake staff are key to accessing P&A services. I&R staff must have a baseline level of competency that includes knowledge of disabilities; an ability to engage a trauma-informed approach; a perspective that recognizes the intersectionality of disability and diverse identities; an understanding of P&A programs, eligibility requirements, and priorities; a comprehensive knowledge of resources for a variety of needs; and an understanding of the P&A's grievance policy and procedures.

Some P&As have I&R as a separate function from Intake, while others have them combined. Some separated I&R teams provide basic I&R, while others add a certain level of technical assistance. Some P&As' I&R/Intake functions are conducted by non-attorneys. Though each P&A is structured differently, the functions of I&R and Intake must be in place.

A. Process and Workflow

- 1. The P&A offers a variety of mechanisms that meet the communication needs of individuals with any disability. These might include:
 - a) A dedicated email address
 - b) A confidential online service request form
 - c) Toll free, or 1-800 phone numbers
 - d) Text capability, mail, and other forms of confidential, accessible communication used and preferred by people with disabilities

- e) A mechanism to provide language interpretation that is available immediately when needed
- f) The ability to offer in person meetings
- g) A policy/procedure to surmount the various barriers faced by callers in institutions, including collect or costly calls
- h) A policy/procedure to overcome other communication barriers, such as clients without internet access, privacy, etc.
- Timeline standards are in place for call returns and follow ups.
 Procedures are in place for handling situations where people are difficult to reach, including requirements for number of call attempts or follow up using an alternative communication method.
- I&R staff maintain a referral list to relevant external organizations and agencies that is up to date and includes resources for common issues that fall outside the P&A's priorities and expertise.
- 4. I&R staff have a method to make a warm referral (transfer) for situations in which it might be difficult for a caller to seek additional or other assistance.
- 5. The P&A has a written procedure for responding to emergency situations. This includes a policy that addresses the process staff follow to address individuals who are threatening, suicidal, or in dangerous situation.
- 6. The P&A has standard intake questions to solicit the information needed to guide the intake process.
- 7. The P&A has clear workflows and processes for moving service requests from I&R/Intake to advocates or attorneys, and to ensure follow ups and responses have been made.
- 8. The P&A has back-up systems in place for times when primary I&R/Intake staff are not available.

- 9. A protocol is in place to guide and support I&R/Intake staff on dealing with callers who are verbally abusive or who abuse the intake system.
- 10. Safeguards are in place to protect people with disabilities who identify as BIPOC, LGBTQIA+, and/or older adults from implicit bias.
- 11. Clear direction and procedures are in place to instruct I&R/Intake staff on assessing whether callers can speak confidentially and not under duress or control of a third party on the call.

B. Legal Oversight

- I&R/Intake staff have the ability to recognize legal issues and comply with relevant legal ethics. I&R/Intake staff who are not attorneys disclose this fact to callers when circumstances dictate that it is necessary and appropriate.
- 2. I&R/Intake staff receive clear direction and training on what is and is not considered legal advice, including:
 - a) Parameters around the unauthorized practice of law; and
 - b) At what point an attorney-client relationship is created.
- 3. A licensed attorney provides oversight over intake processes and decision-making, and over all intake-related legal matters.
- 4. A procedure is in place to conduct conflicts checks early in the process, before staff receive confidential information. Intake staff know how to identify the "client" as opposed to an adverse party.
- 5. The P&A has a written procedure for receipt and review of service requests that includes:
 - a) Regular review of intake calls for potential case selection.

- b) Confirmation of case compliance with P&A priorities and/or case selection criteria.
- c) Assignment of cases that is timely and appropriate for staff expertise.
- d) Regular review of service request denials to verify that proper information, advice, and referrals are being given.

C. Informative Materials

- 1. The P&A develops informative resources and materials to address issues appropriate for P&A assistance. P&As should strive to have the following resources available:
 - a) General information about the agency, including a description of priorities.
 - b) Materials that promote self-advocacy and provide technical assistance, written in plain language. Topics might include:
 - i. Rights under particular laws (e.g., ADA, Section 504, IDEA, Fair Housing Amendments Act).
 - ii. Steps to take to file formal complaints (patient rights, residential provider quality, etc.).
 - iii. Information based on frequent requests that are outside the P&A's priorities (e.g., basic information on Medicaid and/or Social Security eligibility, or explanation of federal and state laws regarding service and support animals).
- 2. These materials supplement, and are not a substitute for, person-to-person I&R assistance.
- 3. The P&A ensures that materials are in accessible formats that consider disabilities, cultural factors, reading proficiency, and languages reflective of the state or territory's ethnic diversity. Intake staff should state that accommodations will be made for callers to access the materials.

D. Grievances

- 1. The P&A has a written client grievance policy in plain language and accessible formats. It is made readily available if a client makes it clear that they are dissatisfied with services.
- The grievance procedure is verbally provided or sent when appropriate to anyone for whom services are denied for any reason, including:
 - a) The request does not meet priorities
 - b) The P&A cannot address the request and is making a referral
 - The P&A does not have the capacity to take the request, even if it meets priorities
 - d) Any other reason for a denial
- 3. Grievances are received and accepted through a number of means, which might include paper form/mail, phone, confidential online form, fax, dedicated email address, and/or other forms of confidential communication.
- 4. Every effort is made to accommodate someone who is attempting to make a grievance, which might include:
 - a) Assisting over the phone
 - b) Assuring language interpretation is available
 - c) Arranging an in-person interview
 - d) Allowing the presence of a support person
 - e) Other means to accommodate
- 5. The P&A tracks grievances and is able to produce a report on them. A report of PAIMI grievances is provided annually to the PAIMI Advisory Council and the Board of Directors.

E. Documentation and Recordkeeping

- 1. The P&A has a standard for documenting I&R calls that is used consistently throughout the agency. Such standard ensures the collection of all necessary information to fulfill federal reporting requirements. The I&R process takes into account confidentiality requirements and the need for a written record of all I&R activity.
- 2. The P&A clearly identifies the appropriate grants for which the caller is eligible. Should the I&R become a case, the P&A has a method to determine the appropriate grant source.
- 3. The P&A has a way to record information about emerging trends. Written data collection procedures are in place and P&A staff analyze trends they identify. I&R staff participate in the analysis. Special attention is paid to trends pertinent to the intersection of disability and other identities.

F. Quality

- 1. I&R/Intake staff receive regular training to maintain and increase competencies.
- 2. P&As have mechanisms in place for soliciting and responding to feedback on services provided. These may include tools such as satisfaction surveys or rating scales.
- 3. I&R/Intake staff receive regular written and ongoing verbal performance reviews.
- 4. I&R/Intake staff should represent the diversity of the population in the P&A's service area.

5. The P&A has a formal mechanism to ensure that materials are updated and that these updates are made consistently across all units and programs of the agency.

VI. Communication Advocacy

Public communications are an important systemic advocacy strategy that all P&As shall endeavor to employ. Communication activities should be goal oriented and may include working with traditional media like newspapers or local television, engaging with the public through social media, producing publications and reports, or maintaining websites and other digital content. P&A communication strategies should consider the following methods:

A. Messaging

- 1. P&A messaging reflects its mission and values and intentionally advances the rights of all people with disabilities.
- 2. P&A messaging uses the language and terms preferred by the communities with which they are working.
- 3. P&As prioritize and elevate the stories and experiences of people with disabilities with diverse backgrounds.
- 4. P&As educate staff, board members, and the community about current events and discourse within and affecting the disability community.
- 5. P&As prioritize stories told from the client perspective and in their own words.

B. Branding and Recognition

1. P&As maintain a strong, identifiable brand that is used consistently across all internal and external facing material and platforms.

- 2. Accessibility must be an integral part of all P&As' brands.
- 3. P&As adopt a mission and vision statement that reflects its values and principles.

C. Media Advocacy

- 1. P&As maintain a written media policy that outlines procedures and protocols for responding to media inquiries.
- P&As use multiple strategies to engage with media outlets including those serving specific, diverse communities. To the best of its ability, P&As should:
 - a) ensure media outlets tell the stories of people with disabilities from their viewpoint
 - b) challenge entrenched stereotypes in the media about disabilities and the people who experience them
 - c) strive to challenge institutional bias
 - d) actively dismantle misperceptions that prevent people with disabilities from fully participating in community life
- 3. P&As should educate media outlets about the context within which the disability rights-related issue occurs taking into consideration culture, class, race, sexual orientation, gender identity, and other intersectional factors or current events.
- 4. P&As have a policy and practice that is consistent with your state rules of professional conduct of disclosing, discussing considerations, and obtaining consent for intended use from people with disabilities and/or clients prior to utilizing their stories, images, or other potentially identifiable information in its public communications.

D. Websites

- P&As each maintain an accessible website using <u>Website Content</u>
 <u>Accessibility Guidelines</u> (WCAG) that supports the agency brand and
 includes images of clients and individuals that reflect the diversity of
 populations served. P&As maintain website accessibility through
 consistent effort and improvement.
- 2. Any image or client story used should be gathered with informed consent best practices. Characteristics of a good website include regular updates, current technology and design standards, content written in plain language, and intuitive navigation.
- 3. P&A websites should have: current priorities; case selection criteria; a procedure for intake and referrals; press/media pages that identify press contact(s); a section with self-advocacy publications and toolkits that educate and empower people with disabilities to advocate for themselves; an accessibility statement that includes a phone number and email to notify the P&A of any access issues; a current list of staff, board members, and PAIMI Council members.

E. Social Media

- 1. P&As connect with the community using social media. Social media use should maintain the agency's brand and adhere to the most upto-date guidelines for accessibility.
- 2. P&As' social media activity should contribute to the P&A's mission and goals; elevate the voices of clients and individuals with disabilities from all backgrounds; be informed about the discourse occurring within the online disability community; and collaborate with various members of the disability community whenever possible.

3. P&As recognize social media use is influenced by race, ethnicity, age, sexual orientation, gender identity, and language, among other factors, and attempts to engage with all communities.

VII. Individual Legal Advocacy

The following standards apply to all individual legal representation, whether provided by the legal advocacy program or an authorized subcontractor.

- 1. The P&A has the capacity to pursue legal, administrative, and other advocacy strategies on behalf of its clients.
 - a) The P&A employs a sufficient number of attorneys and advocates on staff to provide litigation, individual legal advocacy, and training consistent with program priorities.
 - b) P&A capacity includes staff with racial, ethnic and gender diversity as well as lived experience with disability.
 - c) The legal advocacy program is supervised by an attorney who is an active member of the Bar in good standing in the state or territory where the program is situated.
 - d) The P&A strives to conduct outreach to unserved and underserved populations.
- 2. Clients of the P&A are people with disabilities who have experienced rights violations as a result of their disability.
 - a) The P&A provides legal representation to individual clients pursuant to its established priorities. The P&A has a policy regarding representation of a minor or an individual with a quardian.
 - b) The P&A has policies regarding case selection criteria and the development of annual objectives and priorities, consistent with grant terms and conditions that govern cases selected for individual advocacy.

- c) The P&A's established priorities should include a plan to reach underrepresented populations within the disability community.
- 3. Clients of the P&A receive high quality legal representation that safeguards and advances their legal rights.
 - a) Each client is consulted to determine the goals of the representation and possible means for achieving those goals.
 - b) When the client is subject to a guardianship, the P&A should advocate for the client's expressed interests consistent with governing rules of professional conduct.
 - c) When a client's legal file is opened, it documents the objectives and desired outcomes of the representation that have been agreed upon through a written retainer or similar document. In certain cases, involving short-term advocacy, case notes in the file may be used to document agreed-upon objectives.
 - d) The P&A provides skillful, steadfast representation to individual clients consistent with each client's direction and expressed goals and preferences pursuant to the retainer or similar document.
 - e) When a client's legal file is closed, it documents the outcomes attained through the representation.
 - f) Individual cases are reviewed periodically by the attorney(s) who supervise the legal program to ensure clients receive high- quality representation.
- 4. All client representation is provided consistent with applicable rules of professional conduct, including rules regarding ethics and requirements for continuing education.
- 5. Attorneys and advocates receive training on working respectfully with individuals with a diverse range of disabilities and cultures, particularly clients with mental health disabilities. Training on properly accommodating people with various types of disabilities should be explicitly provided (e.g., how to accommodate clients with autism spectrum disorders and sensory disabilities). Attorneys and

- advocates receive training in cultural awareness and humility, diversity, equity, and inclusion.
- 6. The P&A ensures there is no unreasonable interference with the attorney or advocate's conducting their professional responsibilities on behalf of each client. Supervisory management by authorized agency staff does not constitute interference.
- 7. Each client is provided high-quality representation that is properly documented.
 - a) Legal file notes demonstrate the attorney/advocate thoroughly and timely addresses agreed goals of the representation. There are specific time lengths set forth in each P&A manual for timely determinations of case representation and reaching the goals of a client during the representation.
 - b) Legal file notes demonstrate the attorney/advocate strives to ensure that each client is provided adequate time between consultation and the time when any decision must be made to enhance the client's ability to provide direction and participate in the case.
- 8. When a client cannot provide direction or consent, the attorney/advocate should ensure that the client's legal rights are safeguarded and advanced, and that any intervention or service proposed by another is consistent with the client's rights.
 - a) The program has policies and procedures to guide representation where a decision or meaningful choice cannot be or is not expressed by a client, or where consent is not available or provided by a client.
 - b) The policies/procedures address the criteria that will be used by the attorney/advocate to ensure the intervention or service is consistent with the client's rights.

- 9. Each client is regularly informed, in a manner consistent with the client's preferred means of communication, of the status of ongoing representation in their case. Attorneys and advocates have access to, and use as needed, interpreters, translators, and other experts, language lines, and alternative forms of communication to facilitate communication with their clients.
- 10. The P&A ensures attorney-client confidentiality.
- 11. Attorneys and advocates have access to, and use as needed, adequate resources that have been budgeted to support representation of their clients such as, but not limited to, supports for legal research, fact investigation, and expert witnesses.
- 12. The P&A carries malpractice insurance adequate to cover legal representation the program provides to its clients.
- 13. The attorney(s) who supervise the legal program ensure that the program's employees do not engage in the unauthorized practice of law.
- 14. When a P&A contracts with another entity to represent a client, the P&A: offers appropriate support, training, and oversight; includes the P&A's official policies by reference; requires compliance with these Standards; ensures that the entity carries adequate malpractice insurance; and monitors such compliance.
- 15. The P&A has a written client grievance policy and notifies clients of its policy at key points in the representation, in accordance with the policy and through a variety of formats. This information should be mentioned and made readily available to clients who make it clear that they are dissatisfied with services. A reasonable accommodation for filing a grievance should always be offered (e.g., if someone is not able to fill out the grievance form in a traditional way).

VIII. Monitoring

The following standards apply to all P&A monitoring activities, whether provided by the Protection and Advocacy system or an authorized subcontractor.

"Monitoring," as described in federal law, is access to public and private facilities and community service providers for the purpose of (1) providing information and training on, and referral to programs that benefit people with disabilities; and providing information and training about individual rights and services available from the protection and advocacy network; (2) monitoring compliance regarding the rights and safety of people with disabilities; and (3) inspecting viewing, and photographing/ videotaping all areas of the facility that are used by, or accessible to residents/program participants. Monitoring is best accomplished in-person, but can be virtual when resources or conditions warrant.

- Scope: The P&A monitors locations where people with disabilities reside or receive services. The extent to which P&As conduct monitoring activities is based on a P&A's annual priorities and resources.
- Protocols: The P&A has protocols regarding how to conduct its monitoring activities. The P&A should develop written policies or procedures to document and guide its monitoring activities:
 - a) to reflect the diversity of the community being monitored;
 - b) to ensure the use of trauma-informed practices; and
 - c) to ensure understanding of the intersectionality of various groups.
- 3. **Training**: P&A staff are trained to conduct monitoring. The P&A should consider the following topics in designing effective monitoring training: the P&A enabling statutes and regulations, the P&A's annual priorities and goals, addressing complaints received, responding to

requests for assistance, utilizing communication and interviewing techniques that reflect the diversity of the community being served, trauma-informed practices, health and safety concerns, and facility and licensing standards.

- 4. **Education**: During monitoring, P&As provide training and plain language education to people with disabilities and others within the setting. The P&A should consider the following when designing effective educational materials: the cultural and linguistic needs of the audience, education on the P&A system, information about the civil and legal rights of those residing or receiving services, and the intersectionality of race, ethnicity, gender identity, age, and religious affiliation.
- 5. **Notice and Communication.** The P&As should ensure that its contact information is posted in facilities and available to people with disabilities, that people with disabilities can contact the P&A as needed and can speak privately with P&A staff in-person and over the telephone.
- 6. Identification of Settings: The P&A identifies and prioritizes settings based upon annual priorities and resources. P&As should develop policies or practices for monitoring selection. This may include: reviewing internal or public data, outreach or other community surveying, referrals or complaints, or designing other selection criteria. Policies or practices should identify how the P&A will ensure that locations with large populations of BIPOC and with lower incomes are identified for monitoring. P&As should also monitor a mix of urban and rural settings in various parts of the state as resources allow.
- 7. **Remote monitoring**: P&As should develop policies or procedures on conducting remote monitoring. The P&A should consider: the technology needs for remote monitoring, the training needs of the P&A staff, the selection process for using remote monitoring, and the

ability of the P&A to have effective confidential communication with those residing or receiving services within the setting being monitored. P&A policies should include accommodations for those with communication disabilities. Remote monitoring supplements but does not replace the P&A's in-person monitoring activities.

- 8. **Access Authority**: The P&A must ensure that it has the resources to challenge any denials of its access authority to conduct monitoring by a service provider.
- 9. **Advocacy Requests**: If an individual requests the P&A monitor to advocate on the individual's behalf, the P&A may provide advocacy in accordance with the Standards under Section VII, Individual Legal Advocacy (above).
- 10. **Post-Monitoring Activities**: The P&A should notify the service provider of any issues discovered that need to be immediately addressed, and follow up after the visit to address other concerns.
- 11. **Confidentiality**: All information gained from monitoring will remain confidential to the extent required by the P&A statutes and regulations.

IX. Investigations of Alleged Abuse/Neglect

P&As have the authority to investigate abuse and neglect of individuals with disabilities if the incidents are reported to the system or there is probable cause to believe the incidents occurred. These standards cover investigations the P&A conducts in response to a complaint, or a determination of probable cause of abuse or neglect.

For purposes of investigations, the P&A uses definitions of "abuse," "neglect," "complaint", and "probable cause" consistent with federal and/or relevant state law.

- 1. **Scope**: The P&A conducts investigations in locations where people with disabilities reside or receive services.
- 2. Reports of Abuse and Neglect from Providers and Other Sources: The P&A identifies the providers and government organizations required to submit reports to the P&A pursuant to state and federal law. The P&A has the capacity to remedy any lack of compliance and to process reports received.
- 3. **Genesis of Investigation**: P&A investigations are conducted on behalf of the P&A. Any other investigation conducted on behalf of an individual or group will be in accordance with Section VII of these Standards.
- 4. Investigation Files: The P&A maintains electronic or paper files for each investigation it conducts. The P&A has policies or procedures for maintaining confidentiality of investigative files. Where the P&A is providing advocacy services to an individual or group in accordance with Section VII, the P&A must ensure that the investigative file is distinct from any advocacy file.
- 5. Initiating Investigations: The P&A has a policy or procedure for determining how to triage complaints and make probable cause determinations, to determine which complaints or issues will be investigated, and to define the scope or extent of the investigation.
- Access Authority: The P&A must ensure that it has the resources to challenge any denials of its access authority to conduct investigations by a service provider.
- 7. **Protocol**: The P&A has written protocols regarding how to conduct its investigations. The P&A should develop policies or procedures to

ensure that investigations are conducted:

- in a culturally and linguistically competent manner
- using trauma-informed practices
- with an understanding of the intersectionality of various groups
- 8. **Advocacy**: If an individual requests the P&A investigator to advocate on the individual's behalf, the P&A may provide advocacy to the individual as long as the P&A conforms to the Standards outlined in Section VII. P&As may assign a different staff member to do the investigation and provide advocacy.
- 9. **Confidentiality:** The P&A shall keep information and records confidential in accordance with applicable federal and state laws.
- 10. Potential Reporting to Other Enforcement and Oversight Agencies: The P&A has a policy on when and how to report abuse and/or neglect to law enforcement, protective services and/or other enforcement or oversight agencies such as licensing authorities consistent with and balancing confidentiality and attorney/client privilege.

X. Systemic Advocacy

Systemic/Impact Advocacy is action by the P&As that promotes change in policies, rules, and laws that affect people with disabilities. The essence of systemic/impact advocacy is its focus on activities intended to address issues and barriers that benefit a number of individuals with disabilities, rather than one or few individuals. P&As engage in advocacy activities that have the potential to advance reforms for large numbers of people with disabilities in areas critical to achieving social justice. Due to its potential to improve the lives of significant numbers of people with disabilities, and

because it is a core function, systemic/impact advocacy work should be a substantial component of each P&A's activities.

To address the intersectional nature of discrimination that many people with disabilities encounter, P&As should focus their systemic/impact advocacy efforts on multiply marginalized individuals with disabilities, to achieve justice for people who have been most harmed by exclusion and discrimination.

Systemic/impact advocacy typically addresses the establishment, support, improvement, or expansion of:

- 1. programs that provide services or benefits to people with disabilities, and
- 2. the legal rights, protections, and entitlements of people with disabilities.

Systemic/impact advocacy includes opposing efforts to prevent, weaken, reduce or eliminate existing services or rights; supporting self-determination; and improving or protecting quality of life. The goal of systemic/impact advocacy is removing barriers that prevent or impede people with disabilities from leading fulfilling lives of their own interest, culture and choosing in the community, or that deny them equal access to services and rights, including when they are incarcerated or institutionalized.

Systemic/impact advocacy challenges systems and structures, and is integral to the work of the P&As. It is essential to leveraging our finite resources, securing the broadest possible impact, and achieving advancements in law or policy to benefit large numbers of people with disabilities. Systemic/impact advocacy should be pursued utilizing the full spectrum of available P&A strategies, including individual advocacy undertaken with an eye toward a systemic impact.

Systemic/impact advocacy comprises a number of effective strategies, including: systemic/impact litigation, policy advocacy and education, investigations, amicus activity, coalition work, community lawyering, communications advocacy, outreach and training.

- The P&A has the capacity and authority to pursue the full range of systemic/ impact advocacy strategies on behalf of its clients and/or potential clients.
 - a) The P&A complies with applicable state and federal rules, but imposes no organizational barriers on itself that would prohibit it from engaging in systemic/ impact advocacy strategies that are allowable under the P&A authorizing statutes.
 - b) The P&A is not expected or required to engage in every potential systemic/ impact advocacy strategy every year, but should not be solely engaged in individual advocacy that does not have a systemic/impact goal.
- 2. The P&A annually identifies goals and objectives for systemic/impact change in its overall annual goals and objectives.
 - a) Systemic/impact advocacy goals and objectives are selected based on the P&A's knowledge and experience in representing individual clients, its expertise or awareness of systemic issues needing to be addressed, and public input received as part of the priority-setting process.
 - b) The P&A has a process whereby a newly identified systemic/impact issue that is not part of the program's annual goals and objectives may be considered for action.
 - c) The systemic/impact goals and objectives, and the strategies adopted to implement or achieve them, are consistent with the P&A's mission, values, and principles.
 - d) The P&A allocates sufficient staff and fiscal resources to accomplish the systemic/impact advocacy priorities it adopts. These resources constitute a significant portion of the P&A's

- overall resources and do not conflict with any IRS rules and regulations.
- e) Any interagency collaborative arrangements reflect program priorities.
- P&As prioritize empowering and being advised by people with disabilities directly affected by the intended systemic activities at all stages. Intentionally planning partnerships with clients, client communities, and other diverse allies should be an evident focus for systemic advocacy activities.
- 4. P&As seek to addresses the intersectional discrimination that many people with disabilities experience, and the root causes of disparities faced by disabled people who have been and remain excluded and discriminated against, including BIPOC, LGBTQIA+ people, and other oppressed groups.
- 5. The P&A takes a role in its state on the systemic issue(s) of its choice, as identified in annual goals and priorities and/or strategic planning, and is a presence or resource in the public policy arena on these issues.
- 6. The P&A has a policy or procedure regarding cases in which it is a named plaintiff in systemic reform/impact litigation, that addresses issues such as who authorizes such litigation on behalf of the P&A and who makes decisions for the P&A in its role as the legal client.
- Staff are trained to identify systemic and legal impact issues, including seeing the impact from a racial and intersectionality lens, throughout all levels of intervention at the P&A.
- 8. The P&A is informed by, and seeks to represent and/or work in concert with, a variety of clients and allies, including BIPOC communities.

SYSTEMIC ADVOCACY APPENDIX: FEDERAL GRANT TERMS AND DEFINITIONS

Systemic Litigation – One PPR and PAIMI

Systemic litigation is a concerted action to reform the policies or mode of operations of a system of services. It attempts to address a systemic issue raised by many individuals, through class action litigation, multi-plaintiff litigation, or in some cases individual litigation when the relief sought has the potential of affecting many people with disabilities.

Group Advocacy Services - PAIMI

Group advocacy is defined as work on behalf of groups of people with disabilities pursued through the interventions of systemic litigation, legislative and regulatory advocacy, and systemic advocacy (non-litigious and non-legislative). It is concerted action to reform the policies or mode of operations of a system of services such as the disability service system or the policies and practices of private actors.

One PPR addition: Report the intervention strategy (abuse and neglect investigation, systemic litigation, educating policymakers, and other systemic advocacy) used in each case/project. You may select more than one per project.

Other Systemic Advocacy – One PPR

Other Systems Advocacy refers to concerted action by the P&A agency to promote and effectuate changes in the policies, rules, and laws that impact groups of people with disabilities, and to remove the barriers that prevent or impede them from leading full, productive lives in the community that does not fit elsewhere in the form. Systems advocacy typically addresses the establishment, support, improvement, or expansion of (1) programs that provide services or benefits to persons with disabilities, and (2) the legal rights, protections, and entitlements of persons with disabilities; and may involve opposition to efforts to weaken, reduce or eliminate existing services or rights.

Systemic Advocacy – PAIMI

Systemic Advocacy Activities are efforts taken to implement changes in policies and practices of systems that impact persons with mental illness. These "systems" include, but are not limited to, state agencies, various public and private residential care and treatment facilities, and other service providers, etc. [PAIMI Rules at 42 CFR 51.24(a) state that systemic activities shall be addressed in the development and implementation of program priorities.]

Educating Policy Makers – One PPR

A critical strategy used to achieve systems change. Policymakers may include individuals in both the executive and legislative branches of government who make or interpret policies (legislation, regulations, rules or practices) that impact the lives of people with disabilities. Advocacy efforts might be directed at the local, state, or federal level. Educating these individuals makes them aware of how their actions may impact people with disabilities. Information reported should only include work done in accordance with the limit on federal funding.

Educating Policy Makers – PAIMI

Educating Policy Makers are efforts directed to local, state or federal level individuals or entities, providing information about disability laws, regulations and policies. Information reported should only include work done in accordance with the limit on federal funding.

Investigation - One PPR and PAIMI

An investigation is a systematic and thorough examination of information, records, evidence and circumstances surrounding an allegation of abuse and neglect.

One PPR addition: Investigations are distinct from advocacy and require a significant allocation of time and resources, including such activities as interviewing witnesses, gathering evidence and generating a written report, which may or may not be made public.

PAIMI - Abuse/Neglect Investigation (A/NI) addition: Investigations are undertaken to determine if there is a basis for administrative or legal action on behalf of the client. Investigations require a significant allocation of time to interview witnesses, gather factual information, and to issue a written report of findings.