

# PROTECTION AND ADVOCACY STANDARDS

National Disability Rights Network

900 Second Street, NE, Suite 211 Washington, DC 20002

P: 202-408-9514 ◊ F: 202-408-9520 ◊ TTY: 202-408-9521

www.ndrn.org

# **Table of Contents**

Introduction Use and Values	3
A. Use of the Standards	
i y	
Governance and PAIMI Advisory Council	6
A. Governance	
·	
Access, Presence, Outreach and Training	14
Information, Referral and Intake	16
A. Accessibility of Intake Process:	16
B. Timelines:	
i S	
Individual Legal Advocacy	19
Monitoring	22
Investigations of Alleged Abuse/Neglect	22
Systems Advocacy	24
	A. Use of the Standards B. Philosophy. C. Principles D. Values Governance and PAIMI Advisory Council A. Governance B. PAIMI Advisory Councils Leadership and Management A. Leadership and Overall Management B. Fiscal Management C. Personnel Practices D. Record keeping and Data Collection Access, Presence, Outreach and Training Information, Referral and Intake A. Accessibility of Intake Process: B. Timelines: C. Staff and intake supervision: D. Material development and provision: E. Record Keeping F. Case Selection G. Grievances Individual Legal Advocacy Monitoring Investigations of Alleged Abuse/Neglect

#### I. Introduction

The Board of Directors of the National Disabilities Rights Network (NDRN) has adopted these standards to guide the advocacy work of its member agencies. These standards address the philosophy, principles and values that provide a foundation for the work of a protection and advocacy system. They also address the policies and practices that are relevant to the governance, management, core activities, and evaluation of a P&A system.

These standards closely follow the federal statutes and regulations that guide P&A Programs. However, they go beyond the regulations in instances in which the regulations do not address core features of a P&A or where they provide only minimum guidance on aspects of a P&A system.

These standards reflect the generally accepted norms for an effective protection and advocacy system. They are not meant to define best practice. It is the intention of the Board that these standards are not to be used as a method to address compliance and do not constitute minimum legal requirements. Compliance issues are specified in law and regulation.

If a state rule, statute or regulation requires P&A staff to abide by standards that conflict with the standards herein, NDRN expects the P&A to either comply with the state standard or, as appropriate, challenge it.

The standards are tied to the functions of a P&A identified within the NDRN membership agreement.

#### A. Use of the Standards:

- The Board invites individual 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 weaknesses.
- Individual P&As may also use the standards as a resource in the development of individual P&A policies and procedures.
- The standards may be used by individual P&A systems as a training instrument for board and staff.
- NDRN will use these standards as the basis for voluntary peer organizational reviews.

- Adherence to these standards by individual P&As may be one way to demonstrate the effectiveness of P&A programs to appropriators and to federal officials and policy makers.
- The NDRN Board recognizes that federal administering agencies may also wish
  to use these standards as a basis for the development of evaluation instruments.
  In that event, NDRN is committed to negotiating and developing appropriate
  protocols for their use in promoting quality services. Such protocols will be
  developed with input from the NDRN membership.

#### B. Philosophy that guides P&A work:

- People with disabilities are full and equal persons under the law and are entitled to equal access to the opportunities afforded to all members of American society.
- People with disabilities are entitled to be free from abuse, neglect, exploitation, discrimination, and isolation, and to be treated with respect and dignity.
- People with disabilities have access to age appropriate services and supports that are shaped by the unique needs and preferences of each individual. Such service and supports are designed to foster independent, productive and integrated community life.
- People with disabilities have the right to make choices about all aspects of their life including daily routines and major life events.

#### C. Principles that guide P&A work:

# Advocates use multiple strategies to promote rights enforcement, independence and Inclusion of people with disabilities:

- The primary role of advocates is to establish, expand, protect, and insure enforcement of the human, legal and civil rights of people with disabilities.
- Advocacy efforts recognize and promote the right to an array of appropriate services and supports
- All P&A services have as their focus the maximization of independence, autonomy, productivity, and integration of individuals with disabilities
- Advocacy resources and priorities address the human, legal, and civil rights of individuals and groups of individuals with disabilities in conformance with P&A priorities.

 Advocates employ multiple means of action and redress, such as individual and class representation, legislative and other systemic advocacy, training, and consumer education.

# **Advocacy services are client directed:**

- The client is the person with a disability for whom the P&A provides services and the advocate takes direction from the client.
- 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 as stated in these standards.
- The advocate informs the client about options, assists the client to express preferences, and ensures that these preferences are heard and vigorously pursued within the scope of the law.
- Advocacy programs are accountable to the people they represent and 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.
- The advocate provides the client with the skills and knowledge that enable the client to advocate on his or her own behalf.

#### Protection and Advocacy agencies are leaders on disability issues.

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

# Advocacy services are independent and accessible to people with disabilities

- The availability of advocacy services is well known to potential clients.
- All P&A services are offered in settings that are fully accessible to people with disabilities.
- 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 special concerns of people in segregated settings and promote opportunities for integration.

#### D. Values that guide P&A work

- People with disabilities are included in all activities undertaken by the P&A.
- P&As work zealously to protect and advocate for their clients and people with disabilities in their state.
- Boards of Directors, PAIMI Councils and P&A services reflect the diverse cultural, ethnic, racial, 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 it with effective, independent, and ethical leadership. The Board<sup>1</sup> considers these standards, 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 influences that are in conflict with its mission or that interfere with its responsibility to represent client concerns. The Board of Directors bears the ultimate responsibility to set the stage for a well-run organization, ensure the P&A's efforts are mission driven, thinks strategically about the P&A's future, and makes certain the P&A achieves its desired outcomes for its state's individuals with disabilities.

Board members are given necessary supports, including staff assistance, payment for related expenses, relevant materials and information, orientation, and training to facilitate full participation.

The following standards of Governance apply to both public and private P&A systems.

<sup>&</sup>lt;sup>1</sup> 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.

- Members of the Governing Board are aligned with the mission, vision, and values of the P&A, and they work on behalf of its best interest including following the duty of loyalty to the organization in their role as members of the Governing Board.
  - Members of the board develop and regularly evaluate the mission and vision of the P&A, and ensure that they align with the needs of the people served by the P&A.
  - 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.
  - The mission, values and principles are consistent with federal mandates and overall P&A values and principles as presented in these standards.
- 2. The Governing Board ensures that the P&A demonstrates compliance with applicable federal and state laws for P&As and non-profit organizations.
- 3. The Board of Directors has adopted, and regularly reviews, bylaws and other governance documents that define board member responsibility and activity.
- 4. The Board of Directors is composed of members who share a commitment to the protection of the rights of all people eligible for services as defined by the organization's mission, and has the skills and abilities needed to carry out the mission.
  - The board is inclusive of the diverse cultural, ethnic, racial, and disability diversity in its state.
  - The board membership satisfies the requirements of relevant funding sources.
- 5. The Governing Board understands its roles and responsibilities as specified in governance documents.
  - It determines the organization's mission and purpose.
  - The governing board selects, supports, and annually evaluates the chief executive's performance, and takes corrective action when the performance is found to be unsatisfactory.
  - It takes all steps necessary to ensure compliance with federal regulations governing P&As and state or federal regulations governing non-profit organizations where applicable.

- It provides proper financial oversight and ensures legal and ethical accountability.
- It ensures there are adequate financial and human resources available to adequately work toward achieving the mission.
- It determines and strengthens the organization's programs and services and ensures effective organizational planning including both priority setting and strategic planning.
- It develops and approves policies to ensure compliance with state and federal laws and regulations.
- It ensures that there is adequate guidance for the management and oversight of the organization.
- It ensures that 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.
  - Governance documents are available to the public when required by state or federal law.
  - Minutes are an accurate reflection of board activity and decisions.
  - All board meetings are accessible to people with disabilities.
- 7. The governing board provides fiscal oversight and accountability, and ensures the use of sound financial practices.
  - It ensures the allocation of financial resources is based on a formal budget and is consistent with program mission, values, and priorities.
  - It ensures the P&A uses Generally Accepted Accounting Principles (GAAP) in all appropriate accounting and financial reporting. It ensures the P&A follows federal guidelines required by each funding agency.
  - It ensures the P&A follows all applicable OMB Circulars.
  - It retains external independent auditors, commissions an annual OMB A-133 audit, and carefully reviews the audit findings.
- 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 individuals with disabilities across the state and ensures client direction.
  - It obtains significant public input and advisory council recommendations in setting priorities.

- It actively seeks input to identify the needs of the disability community including unserved and underserved communities.
- It ensures that program development and goal setting reflects the input of those in need of services.
- It adopts the annual goals and priorities for the system. Goals and priorities are accompanied by quantifiable performance measures associated with the outcomes.

## **B. PAIMI Advisory Councils**

The following standards shall apply to PAIMI Advisory Councils:

- 1. The Advisory Council membership meets the diverse membership requirement s of the PAIMI Act.
  - 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 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.
  - 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 an individual who is currently a minor child or youth who is receiving or has received mental health services.
  - Membership reflects the racial, ethnic and geographic composition of the state.
  - The Chair of the Council is an individual who has received or is receiving mental health services or who is a family member of such an 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.
  - The Council develops its recommendations for PAIMI priorities for the Governing Board.

- The Council works jointly with the Governing Board to develop P&A priorities.
- The P&A provides the Council with its goals, priorities, advocacy activities, and budgets.
- The Council has a mechanism to gather information and feedback from individuals with mental illness.
- The Council submits a report of Council 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 member on 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

- 1. The leadership of the P&A envisions and implements the philosophy, principles, and values contained in the Standards. The vision is integrated into all P&A operations. It is reflected throughout agency policies and procedures.
- 2. The P&A is a leader in the disability rights movement in the state.
- 3. The P&A is a leader in the vigorous enforcement of laws protecting the civil and human rights of people with disabilities in its state.
- 4. The P&A puts forward a vision of a 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.
- 6. The P&A leadership is actively involved in priority-setting and the priorities reflect the needs of people with disabilities in the state.
- 7. Management works with the governing authority to ensure that the P&A:
  - possesses resources necessary to protect and advocate for the human, legal and civil rights of people with disabilities in the state,

- has the capacity to provide all the functions of P&A outlined in NDRN membership agreement,
- maintains its independence from service-providing agencies,
- meets all the federal requirements of a P&A,
- periodically assesses risk related to governance, employees, volunteers, fiscal operations, grants management, and related issues,
- develops diverse funding sources to support its work.
- 8. The program is structured to support effective legal and rights advocacy.
- 9. Supervisory relationships are clearly outlined. There is a clear division and distribution of authority and responsibility within the P&A.
- 10. Management staff receives management training.
- 11. The P&A agency has policies in line with federal and state laws to protect the confidentiality of the clients and other individuals that contact the organization.
- 12. Required federal and state reports are submitted accurately and on time to appropriate agencies.
- 13. The P&A maintains a written manual(s) that outlines agency policies and procedures.
- 14. Non-profit P&As maintain property insurance, professional liability insurance, including Error and Omissions fidelity bond coverage for all employees, and Directors and Officers insurance that covers the Board of Directors.
- 15. The program has a written policy regarding conflicts of interest as pertaining to governing board members, advisory council members, staff, volunteers, contract workers and management.

#### **B. Fiscal Management**

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

The availability of financial information assists the governing authority and management to maintain financial soundness and to achieve programmatic objectives. Management and the governing authority assure that program funds are spent and accounted for in ways that fully meet the program'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:

- 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 applicable state rules are understood and followed.
- 2. The governing authority and the Executive Director ensure the financial integrity of the program by:
  - Adopting a budget that utilizes recurring revenues, keeps carryover funding to reasonable levels, maintains adequate cash flow reserves and avoids any reversion of unspent funds.
  - Monitoring spending in relation to the approved budget by reviewing, at least quarterly, financial reports that reflect cumulative expenditures by grant and cost category according to the approved budget.
  - Maintaining a written Accounting Manual that describes policies and procedures covering all fiscal transactions including financial records, reports, payroll, purchasing, and financial statements. The policies and procedures are in accordance with federal fiscal policies and are reviewed and updated regularly. The policies are approved by the governing authority.
  - Maintaining a chart of accounts that insures that receipts and allowable expenditures of the program are recorded separately by funding source.
  - Maintaining adequate internal controls and procedures that assure that no one individual has complete authority over an entire financial transaction.
  - Ensuring the review of the annual tax return (990) by the Board of Directors (for non-profits).
  - Ensuring the performance of an external A-133 audit annually, if applicable. The auditor reports activities and findings directly to the governing body.
  - Ensuring that fiscal staff and those responsible for fiscal oversight understand federal financial guidelines and IRS regulations.
  - Ensuring that all staff are trained to keep time properly, and that procedures are in place for supervisors to validate this process.

- Allocating and tracking funds consistent with federal mandates.
- Ensuring that federal P&A grant money is spent on the program for which it was intended.
- Ensuring that the allocation of financial resources is consistent with program mission, values, and priorities.
- Ensuring that neither the program's current funding nor the pursuit of new funding compromises the program's independence or represents a conflict with the goals of the program.

#### **C. Personnel Practices**

The most valuable resource of an advocacy program is its staff. The leadership and management of the organization demonstrates a concern and respect for the program's personnel consistent with the overall values of P&As.

- 1. The P&A has recruitment policies that implement equal opportunity employment practices, especially with regard to people with disabilities.
- 2. P&A staff treat all individuals with dignity and respect in a culturally and disability competent manner.
- 3. The P&A has a written Personnel Policy Manual that is consistent with federal and state law and is provided to all employees.
- 4. The P&A offers employees opportunities for professional development.
- 5. Written job descriptions exist for every position in the program.
- 6. Orientation of new staff members includes P&A core values and principles, as well as information about effectively working with different disability populations.
- 7. The program has a process for conducting yearly employee evaluations.
- 8. Employees have the qualifications and experience necessary to perform their job duties.
- 9. When programs use volunteers, the program has a process in place to recruit, select, supervise, and train volunteers.

• Volunteer participation complies with state laws and relevant professional standards, such as those relating to labor and insurance.

# D. Record keeping and Data Collection

Proper recordkeeping and data collection allows a program to know who is being served and through what methods. It also improves the program's efficiency by providing a database from which to assess the performance of the program. Good practice dictates both the method and quality 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 funding source. Client files are reviewed regularly by supervisors.
- Case records include information regarding the nature of the client's disability, the client's complaint or problem, the advocacy strategies employed, and final disposition, as well as other relevant data required by the federal funding agency.
- 3. The program prepares and submits Program Performance Reports in a timely manner documenting the activities, accomplishments, and expenditures of the program as required.
- 4. There is a written procedure for determining what is an active, inactive, and closed case; and a protocol for the management of files in all categories of cases.
- 5. The program has a system of secure filing/storage retention and destruction that complies with federal and state laws.
- 6. The program has a uniform and systematic process for collecting and analyzing data concerning client characteristics and program activities and utilizes the data in evaluation, priority-setting.
- 7. P&As have a policy for maintaining confidentiality of all files including but not limited to electronic records.
- 8. P&A has 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 assure prompt, open and equitable availability of assistance to persons with disabilities, and to

assure that the program's systems advocacy and other efforts take into account the needs of the various constituencies throughout the state or territory served by the program.

- 1. The P&A agency promotes and facilitates public awareness, visibility, and access to the program by ensuring that:
  - It is easy to locate the program's web page on the internet, easy to contact the program, and easy to find and get to the program's physical office(s) using local public transportation, if available, or private transportation.
  - The program has methods for indicating that it is the designated Protection and Advocacy system for that state or territory.
  - The program is readily distinguishable from service provider agencies and other advocacy groups or agencies. The program uses multiple strategies to expand public awareness of the program and its services, such as media appearances, distribution of brochures or materials, displays at public events, social media or other methods.
- 2. The program makes reasonable efforts to ensure that its services are made available throughout the state or territory served by the program. These efforts may involve the use of regional offices, a toll-free phone number, contracts with local advocacy agencies, regular staff visits to different communities and facilities, web-based intake, or other methods.
- 3. The program's physical office(s), telephone system and its website are accessible to persons with disabilities, and the program provides an opportunity to leave messages for persons who do not or cannot call during working hours.
- 4. The program assures that it accommodates and is accessible to persons with disabilities and to minority communities. 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 other languages, and employment of staff, use of contractors/vendors or use of volunteers who speak languages commonly used in the state or territory served by the program.
- 5. The program undertakes outreach to potential clients, including unserved and underserved communities (ethnic, racial, disability, rural or other populations) by:
  - Planning and conducting activities to reach populations that are unserved and underserved by the P&A program and populations who are less likely or less capable of actively contacting the program to seek assistance

themselves. An underserved and ethnic minority population is underserved by the P&A when its percentage of the state's population is significantly greater than its percentage of the clients served by the P&A.

- The program collaborates with organizations that represent and/or provide services to unserved and underserved populations.
- 6. The program establishes a presence in targeted facilities and settings where persons with disabilities live, work, or receive services, to the extent feasible and consistent with the program's annual priorities and resources.
  - The program resolves challenges to its access authority as they arise, or proactively addresses access issues in advance.
  - The program maintains a consistent schedule to visit facilities and informs residents of those dates; this does not preclude other, unannounced visits.
- 7. The program regularly provides community education and self advocacy training for individuals with disabilities and family members of persons with disabilities by:
  - providing rights training to individuals with disabilities in settings that are convenient and accessible to them.
  - providing referral and rights publications or materials in formats that are accessible and reflect cultural competence.
  - providing information about P&A goals and priorities and ways in which to access P&A services.
  - distributing information about laws and policies that affect individuals with disabilities.
- 8. The P&A may train additional groups as it determines useful and as resources permit.

#### V. Information, Referral and Intake

Information and referral can entail a wide range of activities, including the provision of brief written or oral information, such as information about the P&A or information about additional programs and resources external to the P&A.

I&R may also include direct assistance such as the provision of information about deadlines for filing complaints. I&R can be provided in the form of phone, mail, e-mail, face-to-face contact, or training.

#### A. Accessibility of Intake Process:

- 1. The P&A has a process by which individuals are able to access P&A services through an intake process and receive referral and rights information.
- 2. The P&A offers a variety of mechanisms for contacting the agency for information or assistance so that its services are accessible to persons with diverse disabilities and communication requirements.

#### **B. Timelines:**

- The P&A has specific and reasonable written timelines for an initial call-back, for an actual response to requests for I&R and for completion of an I&R. P&As have a quality assurance mechanism for meeting these timelines and maintaining accountability.
- 2. The P&A has a written policy for what constitutes a reasonable effort to return an I&R request, for example, how many times a P&A should attempt to return a call after the initial attempt is not answered by either the caller or voice mail.

#### C. Staff and Intake Supervision:

- 1. The P&A employs individuals qualified to provide I&R information to callers.
- 2. I&R staff have the ability to recognize legal issues and comply with relevant legal ethics.
- 3. I&R staff who are not attorneys disclose this information to callers when circumstances dictate that it is necessary and appropriate.
- 4. The P&A has procedures that allow for supervision of all intake work by a licensed attorney.
- 5. The P&A has standard intake questions to solicit the information needed to guide the intake process.
- 6. The P&A has a written procedure for responding to emergency situations. This should include a policy that addresses the process staff follow to address individuals who are threatening or suicidal.
- 7. The P&A has back-up systems in place for times when primary I&R staff are not available.

#### D. Material development and provision:

- 1. The P&A commits resources to identify or develop responsive materials to address issues appropriate for P&A assistance. At a minimum, P&As has the following resources available:
  - General information about the agency including a description of priorities;
  - Referral lists to: disability specific organizations; legal aid providers; and other state and private service agencies.
  - Materials that promote self advocacy. Examples may include easy to understand information about the purpose, scope and enforcement of basic disability rights laws, such as: the PAIMI Act; the DD Act; the IDEA; the ADA; Section 504 of the Rehabilitation Act; and the Fair Housing Act.
- 2. The P&A has a formal mechanism to ensure that materials are updated and these updates are made consistently across all branches and programs of the agency.
- 3. The P&A has a mechanism for the evaluation of I&R materials.
- 4. The P&A ensures that materials developed by the P&A are in an accessible format that considers disabilities, cultural factors, reading proficiency and languages that reflect the ethnic diversity of the state.
- 5. P&A materials supplement and are not a substitute for direct person-toperson I&R assistance.

#### E. Record keeping

- 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.
- The P&A clearly identifies the accounting code or funding category of the call. Should the I&R become a case, the P&A has a mechanism to re-confirm accuracy of funding code.
- 3. The P&A has a mechanism to record information about emerging trends.

#### F. Case Selection

- 1. The P&A has a written procedure for how service requests are received and reviewed.
- 2. The process includes:
  - Regular review of I&R calls for potential case selection
  - Attorney oversight of the process,
  - A confirmation that the case fits into the P&A priorities and/or case selection criteria.
- 3. If a request for assistance is accepted for advocacy or legal representation, the case is assigned on a timely basis to an appropriate staff person or contractor.

#### **G.Grievances**

- 1. The P&A has a written client grievance policy.
- 2. The P&A notifies clients of its policy at key points in the representation in accordance with its written policy.

## VI. 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 program has the capacity to pursue legal, administrative, and other advocacy strategies on behalf of its clients.
  - The program employs a sufficient number of attorneys and advocates preferably on staff – to provide individual legal advocacy consistent with program priorities.
  - 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.
- 2. Clients of the program are people with disabilities whose rights are at issue as a result of their disability. The program provides legal representation to

- individual clients pursuant to its established priorities. The program has a policy regarding representation of minor or an individual with a guardian.
- 3. Clients of the program receive high quality legal representation that safeguards and advances their legal rights.
  - Each client is consulted to determine the goals of the representation and possible means for achieving those goals.
  - 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.
  - The program provides representation to individual clients consistent with each client's direction and expressed goals and preferences pursuant to the retainer or similar document.
  - When a client's legal file is closed, it documents the outcomes attained through the representation.
  - 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.
- 6. The program assures there is no unreasonable interference with the attorney or advocate's carrying out his/her professional responsibilities on behalf of each client. Supervisory management by authorized agency staff does not constitute interference.
- 7. Each client is provided zealous representation.
  - Legal file notes demonstrate the attorney/advocate addresses agreed goals of the representation thoroughly and timely.
  - 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 assure 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.
  - 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.
  - The policies/procedures address the criteria that will be used by the attorney/advocate to assure 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 his/her case. Attorneys and advocates have access to, and use as needed, interpreters and other experts and assistance to facilitate communication with their clients.
- 10. The program assures attorney-client confidentiality.
- 11. Attorneys and advocates have access to, and use as needed, adequate resources that have been budgeted to support their representation of their clients such as, but not limited to, supports for legal research, fact investigation and expert witnesses.
- 12. The program carries malpractice insurance adequate to cover legal representation provided to clients by the program.
- 13. The attorney(s) who supervise the legal program assure that the program's employees do not engage in the unauthorized practice of law.
- 14. When a program contracts with another entity to represent a client the program offers appropriate support and training, includes the program's official policies by reference, requires compliance with these standards including 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 its written policy and through a variety of formats.

#### VII. Monitoring

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

"Monitoring" includes activities in which a P&A evaluates compliance issues and quality of service by providers of services, supports and other assistance. Monitoring may take place in an institutional or community setting by: a) conducting face-to-face interviews with individuals with disabilities in those settings; b) conducting at least one face-to-face interview with a staff member in those settings; c) observing and evaluating the physical conditions of the setting; and d) accessing and reviewing records, where appropriate, in accordance with applicable federal and state laws.

- 1. **Scope.** The P&A monitors different types of institutional and community settings. The extent to which P&As conduct monitoring activities is based on a P&A's annual priorities and resources.
- 2. **Identification of Settings.** The agency has a policy, procedure and/or database for determining how to triage complaints, surveys, referrals and other information in order to determine which settings should be monitored.
- 3. **Reports of Abuse and Neglect.** The P&A takes steps to assure that it receives reports required by federal and state laws
- 4. **Access Authority.** The P&A has, and utilizes as needed, the capacity to challenge in court any denials of access to monitor institutional and community settings.
- 5. **Protocols.** The P&A has written protocols conducting its monitoring activities.
- Advocacy Requests. If an individual requests the P&A monitor to advocate
  on the individual's behalf, the P&A may provide advocacy to the individual as
  long as the P&A communicates to the individual the scope of advocacy to be
  provided.
- 7. **Post Monitoring Activities.** The P&A has a policy or practice that addresses how information acquired through monitoring activities will be used.

#### VIII. 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 if there is probable cause to believe the

incidents occurred. These standards cover: investigations the P&A conducts upon receipt of a complaint; investigations conducted upon determination of probable cause of abuse or neglect; and investigations performed on behalf of a client, pursuant to a retainer agreement.

For purposes of investigations, the agency uses a definition of "abuse," "neglect" and "probable cause" that is consistent with P&A authorizing legislation and the implementing regulations.

- 1. **Scope**. The P&A conducts investigations in different types of institutional and community settings
- Reports of Abuse or Neglect. The P&A takes steps to assure that it is receiving reports that providers and government agencies are required to send to P&As under federal and state laws.
- 3. Genesis of Investigation. The P&A conducts the investigation on its own behalf rather than on behalf of the victim, witnesses or other individuals unless the P&A enters into a written retainer agreement with the victim, witnesses and/or other individuals to represent them in the investigation. If the P&A is conducting an investigation on its own behalf, the P&A informs the victim(s), in writing, that it is not representing him/her/them unless and until the P&A enters into a written retainer agreement with him/her/hem.
- Investigation Files. The P&A maintains electronic and/or paper files for each investigation the P&A conducts. These files are distinct from individual client representation files.
- 5. **Initiating Investigations.** The P&A has a policy and/or procedure for determining how to triage complaints and make probable cause determinations, in order to determine which complaints or issues will be investigated and the scope or extent of the investigation.
- 6. **Access Authority.** The P&A has, and utilizes as needed, the capacity to challenge denial of access to witnesses, including the alleged victim, records, staff, and any persons whom the P&A reasonably believed by the P&A to have knowledge of the investigation.
- 7. **Protocol**. The P&A has a protocol for investigations.
- 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 communicates to the individual in writing what the scope of that advocacy shall be. 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 or neglect to law enforcement, protective services and/or other enforcement or oversight agencies consistent with and balancing confidentiality and attorney/client privilege with any applicable legal requirements.

## IX. Systems Advocacy

**Systems advocacy** refers to concerted action by the P&A agency to promote and effectuate changes in the policies, rules, and laws that impact people with disabilities, and to remove the barriers that prevent or impede them from leading full, productive lives in the community. 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.

Systems advocacy may also include efforts to support self-determination, autonomy, independence and to improve or protect the quality of life for persons with disabilities. Systems advocacy efforts are carried out on behalf of individuals with disabilities, although service providers and others may benefit from such efforts.

The essence of systems advocacy is that it is intended to benefit a number of individuals with disabilities rather than one or a few individuals or their families at a time. Because of its potential to impact the lives of a significant number of persons with disabilities, and because it is a core function, systems advocacy work should be a significant component of each P&A agency's activities.

Systems advocacy strategies include impact litigation (including but not limited to class action); filing amicus briefs in litigation brought by other parties; affecting state or federal legislative action; affecting state or federal agency regulatory action; policy analysis and recommendations; direct negotiation with agencies, service providers, employers or others; participation in advisory committees, task forces, etc.; media/publicity efforts; collaboration with other groups in pursuit of common goals; and other appropriate remedies on behalf of groups or large numbers of persons with disabilities.

- 1. The program has the capacity and authority to pursue the full range of systems advocacy strategies on behalf of the program's clients and/or potential clients, except as specifically limited by applicable law.
  - The program complies with applicable state and federal rules, but imposes no organizational barriers on itself that would prohibit the program from

- engaging in systems advocacy strategies activities that are allowable under the P&A authorizing statutes.
- The program is not expected or required to engage in every potential systems advocacy strategy every year, but should be consistently engaged in key strategies and have the capacity to pursue other strategies as needed.
- 2. The program annually adopts goals and objectives for systemic change that are consistent with its overall annual goals and objectives.
  - Systems advocacy goals and objectives are selected based on the program's knowledge and experience in representing individual clients, the program's expertise or awareness of systems issues needing to be addressed, and public input received as part of the priority-setting process.
  - The program has a process whereby a newly identified systemic issue that is not part of the program's annual goals and objectives may be considered for action.
  - The systemic goals and objectives, and the strategies adopted to implement or achieve them, are consistent with the program's mission, values and principles.
  - The program allocates sufficient staff and fiscal resources to accomplish
    the systemic advocacy priorities adopted by the program. These
    resources constitute a significant portion of the program's overall
    resources and do not put the agency in conflict with any IRS rules and
    regulations.
  - Interagency collaborative arrangements reflect program priorities.
- 3. The program takes a leadership role in its state on the systems issue(s) of its choice, and is a presence or resource in the public policy arena on systemic issues identified in its annual goals and priorities and/or strategic planning.
- 4. The program has a policy or procedure regarding cases in which the program itself is a named plaintiff in system reform litigation, which addresses issues such as who authorizes such litigation on behalf of the program and who makes decisions for the program in its role as the legal client.
- 5. Staff are trained to identify systemic and legal issues throughout all levels of intervention at the P&A.