# The Importance and Use of Person-centered Principles in Adult Protective Services

**July 2024** 

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## **Background and Purpose**

#### **Overview of the Brief**

In the recently published federal regulations of adult protective service (APS) programs (referred to as "<u>Final Rule</u>" hereafter), the Administration for Community Living (ACL) emphasized the importance of the person-centered principles self-determination, person-centered planning, and use of least restrictive alternatives. These serve as guiding principles for APS policy and practice in the Final Rule.

The purpose of this brief is to better understand the person-centered principles in theory, in the ACL Final Rule, and in current application in APS programs. Specifically, this brief:

- Defines and describes the person-centered principles as established in federal law including the Olmstead U.S. Supreme Court decision and in other resource material from ACL and other organizations
- Provides an overview of the application of the person-centered principles in the Final Rule requirements
- Examines current policy and practice related to the person-centered principles based on data from the National APS Process Evaluation
- Provides a brief list of references for further information on the person-centered principles

#### A Tension Inherent in APS

In the ACL-sponsored <u>National APS Process Evaluation</u>, the Adult Protective Services Technical Assistance Resource Center (APS TARC) identified the following legal/ethical tension in APS: "APS provides 'protection' while ensuring individual rights are upheld, sometimes for individuals who may lack the ability to make decisions for themselves."

In the recently published Final Rule preface, ACL described this tension in APS casework this way: "In supporting the dignity of risk of older adults and adults with disabilities to make decisions to support their autonomy, APS programs should balance the risk with ensuring the person's health and welfare. Such circumstances are fact specific and are best assessed carefully by individual programs."

APS programs provide protection from harm and may address causes of maltreatment when adults are vulnerable to maltreatment because of decline in cognitive ability and/or physical health due to aging or disability. Protection often requires APS programs to intrude in the lives of individuals and their communities of support.

If not done appropriately, this intrusion can run contrary to the core philosophy of ACL. ACL was created around the fundamental principle that older adults and people of all ages with disabilities should be able to live where they choose, with the people they choose, and with the ability to participate fully in their

communities. Every person should have the right to make choices and control the decisions in their lives. Within ACL, the Office of Elder Justice and Adult Protective Services leads the development and implementation of comprehensive APS systems for helping adult victims of abuse and to prevent abuse before it happens. ACL's vision for elder justice is of a "comprehensive, multidisciplinary approach that effectively supports older adults and adults with disabilities so they can exercise their right to live where they choose, with the people they choose, and fully participate in their communities without threat of abuse, neglect, or financial exploitation."

How, then, do APS programs balance the tension of intrusion with respecting individual rights? The answer is application in APS policy and practice of the following person-centered principles focused on clients' rights: self-determination, person-centered (or directed) care or planning, and use of least restrictive alternatives.

#### Why Person-centered Principles Matter in APS

The vulnerability of APS clients is demonstrated by the change in living settings for "victims" of maltreatment. As shown in Exhibit A, based on National Adult Maltreatment Reporting System (NAMRS) 2023 data, the percentage of APS victims living in their own residence decreases from 60.6% to 50.1% from the start to close of an APS investigation. Many of these victims end up in residential settings. While the common idea that nursing home placement is a predominant response of APS is not supported by this data, it does show the need for person-centered principles to help find appropriate responses for APS victims whose home environment no longer meets their needs that are consistent with their personal preferences.

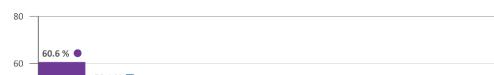
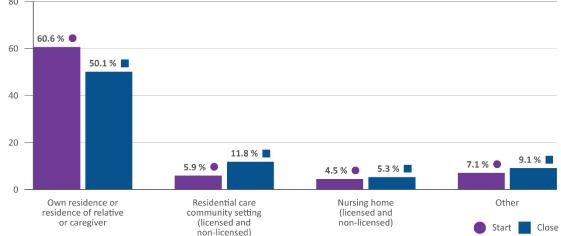


Exhibit A – Victim Living Setting at Start and Close of Investigation



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<sup>&</sup>lt;sup>1</sup> The term "victim" is the label used in the NAMRS system for the subject of APS investigation with a substantiated allegation.

**Note:** Based on data from only 18 states and 76,465 victims, with missing or unknown data in over 20% of records. This data is illustrative but should not be considered a representative sample of APS programs nationally.

How do person-centered principles help address this tension in APS? A guiding principle is commonly understood as a fundamental truth, law, guideline, code of conduct, or driving force that serves as a basis for behaviors or practices. It is a rule or standard by which other judgments can be made. The role of a guiding principle is like that of a **blueprint or architectural plan**; it helps ensure services are built upon a foundation that all stakeholders — administrators, caseworkers, recipients — can use to evaluate whether the program is consistent with its mission and vision and is producing the intended results in people's lives. Guiding principles are also like a **compass or moral North Star** to provide directional guidance and an unwavering point of reference — fixed coordinates — that caseworkers, administrators, and policymakers can continually reorient themselves toward when facing difficult decisions or ethical dilemmas. Finally, guiding principles serve as an **anchor or ballast** to provide stability and steady the organization and keep it upright amidst the churning currents of societal challenges and prevent ethical drift.

All three of these metaphors point to the benefits of person-centered principles for APS caseworkers. These principles provide a foundation on which ethical decisions can be made; they serve as a reference point to determine if correct decisions are being made; and hopefully they provide an assurance to clients, partners, and APS staff of both the efficacy and ethical nature of APS casework.

The role of APS is often misunderstood by clients, community partners, collaterals, and the public. Articulation and application of guiding principles can communicate an understanding and acceptance of the difficult decisions that APS staff must make, regardless of which side of the tension scale (intrusion or rights) a decision may fall on. Use of person-centered principles to make decisions will increase the credibility of the APS program, improving opportunities for advocacy for clients and the program overall. By reinforcing the mission of APS, person-centered principles create a culture that will improve the morale of program staff.

## Understanding the Principles

This section or the brief provides a background to understand the foundation of the person-centered principles, their importance to the ethics of APS practice, and, finally, a definition of them. The person-centered principles are all based in federal law. Support for them is also established in the Final Rule and ethical frameworks of professional organizations related to APS.

The person-centered principles are set forth in the Older Americans Act, Rehabilitation Act of 1973, Americans with Disabilities Act, Elder Justice Act, and Affordable Care Act, among other laws, as well as in the Supreme Court decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999). These requirements are summarized in Exhibit B.

Exhibit B – Person-centered Principles Foundation in Federal Law

Legal Precedent	Description
Older Americans Act (OAA)	An objective of the OAA is "Freedom, independence, and the free exercise of individual initiative in planning and managing their own lives, full participation in the planning and operation of community-based services and programs provided for their benefit, and protection against abuse, neglect, and exploitation." OAA section 101(10), 42 U.S.C. 3001(10).
The Rehabilitation Act of 1973	The purpose of the act is to "promote a philosophy of independent living including a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy, in order to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society." 29 U.S.C. 796.
Americans with Disability Act (ADA)	Congress stated in the ADA's statutory findings that "the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency."
Elder Justice Act (EJA)/Affordable Care Act	Elder justice to mean "efforts to [] protect elders with diminished capacity while maximizing their autonomy, and [] the recognition of an elder's rights[.]" EJA section 2011, 42 U.S.C. 1397(5). Section 2402(a) requires removal of barriers to providing home and community-based services through strategies to maximize the independence of individuals, including through support and coordination for an individual to design a self-directed, community-supported life.
Olmstead U.S. Supreme Court Decision	Requires services for individuals with disabilities be provided in the "most integrated," least restrictive community setting appropriate to an individual's needs.
Affordable Care Act 2010	Contains provisions that promote person-centered approaches. These provisions include: community first living setting; availability of services to meet individual need; person-centered services and supports based on functional need and agreed by or on behalf of individual; individual choice and control; coordinated delivery of services and supports.

In the preface to Final Rule, ACL notes that the laws discussed above "establish separate and independent legal obligations for covered entities; while this final rule is intended to ensure APS policies

and practices are consistent with the principles of person-directedness, self-determination, and integration that are foundational to the statutes listed above ...".

Professional organizations values systems are grounded in person-centered principles. The nearby box outlines the person-centered principles from the <u>code of ethics for the National Adult Protective Services</u> <u>Association</u> (NAPSA).

#### **NAPSA Code of Ethics**

#### **Guiding Value**

Every action taken by adult protective services must balance the duty to protect the safety of the vulnerable adult with the adult's right to self-determination.

#### **Principles**

- Adults have the right to make decisions that do not conform with societal norms as long as these decisions do not harm others
- Adults have the right to accept or refuse services

#### **Practice Guidelines**

- Recognize that the interests of the adult are the first concern of any intervention
- Honor the right of adults to receive information about their choices and options in a form or manner that they can understand
- To the best of your ability, involve the adult as much as possible in developing the service plan
- Focus on case planning that maximizes the vulnerable adult's independence and choice to the extent possible based on the adult's capacity.
- Use the least restrictive services first community-based services rather than institutionally-based services whenever possible
- Use family and informal support systems first as long as this is in the best interest of the adult

Similarly, <u>the code of ethics for the National Association of Social Workers</u> states "Social workers respect and promote the right of clients to self-determination and assist clients in their efforts to identify and clarify their goals. Social workers may limit clients' right to self-determination when, in the social

workers' professional judgment, clients' actions or potential actions pose a serious, foreseeable, and imminent risk to themselves or others."

Self-direction, self-determination, and least restrictive alternatives are self-referring and self-reinforcing concepts. The terms are defined differently by different organizations. One resource with a consistent set of definitions/descriptions for all three terms is the ACL/Center for Medicare and Medicaid Services-funded National Center on Advancing Person-Centered Practices and Systems (NCAPPS). The nearby text box provides a definition/description for each principle based on information from the NCAPPS website, which also contains definitions for "person-centered thinking", "person-centered planning", and person-centered practices.

#### **NCAPPS Description of Person-centered Principles**

#### **Self-determination**

# A fundamental principle of enabling individuals to make choices about their own lives, with the right mix of formal and informal supports. Maximizing independence, autonomy, and control over one's life decisions and services.

#### **Person-directed Planning**

Core philosophy is empowering individuals to direct their own services and supports based on their own preferences, values, and life goals. Putting the person at the center.

#### **Least Restrictive Alternative**

Aligns with providing services and supports in the most integrated, community-based setting possible without unnecessarily limiting self-determination and rights. Avoiding unnecessary institutionalization or restrictions.

# Applying the Principles in Rule and Current Policy and Practice

ACL published the Final Rule, effective June 7, 2024, to oversee state APS systems that receive federal EJA funding. The purpose of the Final Rule is "to codify and clarify a set of mandatory minimum national standards to ensure uniformity across APS programs and to promote high quality service delivery that thus far has not been achieved under the current [Voluntary] Consensus Guidelines [for APS Systems]." ACL called the person-centered principles "foundational" to both "this rule" and "to the protection of the rights of adults," emphasizing the importance of both terminology and requirements, and describing the principles "at the heart of effective APS practice...."

This section of the brief reviews the Final Rule requirements from four perspectives: 1) what does the rule require, 2) what additional insight does the discussion in the preface provide on the requirement, 3) what is current (as of 2021) policy and practice based on data from the *National APS Process Evaluation*, and, in some cases 4) 2023 data from the National Adult Maltreatment Report System (NAMRS).

Appendix A provides the complete language from the Final Rule that is summarized below. For reference, the *National APS Process Evaluation* reported on data from 54 state APS programs; the data presented below indicates the percentage of these programs that have implemented a particular policy or practice covered in the Final Rule as of 2021 when the evaluation data was collected.

The following is divided into sections of the rule, beginning with Program Administration.

#### **Program Administration**

In § 1324.402, two requirements establish the broad baseline expectation for APS systems. The Final Rule requires APS systems to:

- Implement policies and procedures that, at a minimum, "incorporate principles of persondirected services and planning and reliance upon least restrictive alternatives."
- Provide, upon first contact, to potential APS clients an explanation of their APS-related rights under law, including:
  - The right to confidentiality of personal information;
  - The right to refuse to speak to APS; and
  - The right to refuse APS services.

In the Final Rule preface, ACL indicates that adults must be presumed to have decisional capability and notes that most state laws establish the right to refuse services, decline participation in an investigation, and make decisions which others may disagree with about their lives.

In the *National APS Process Evaluation* practice survey, 69% of APS programs indicated that they were guided by a set of guiding principles or core values. More specifically, although the exact number is not known, the policy profiles in the evaluation indicated that confidentiality laws are common in APS programs. The evaluation did not analyze the "right to refuse to speak to APS" in those terms but did find, assuming the client has decision-making capacity, that APS will conclude an investigation in 33% of programs if the client refused to participate and 100% of programs will not provide services if the client refuses them. NAMRS 2023 data indicates that case closure reasons for 6.5% of clients were attributed to "investigation unable to be completed due to refusal of client."

#### **Definitions**

Two of the definitions in the Final Rule relate to the person-centered principles.

In § 1324.401, self-neglect is defined as "a serious risk of imminent harm to oneself or other created by an adult's inability, due to a physical or mental impairment or diminished capacity, to perform essential self-care tasks, including at least one of the following: (1) Obtaining essential food, clothing, shelter, and medical care; (2) Obtaining goods and services necessary to maintain physical health, mental health, or general safety; or, (3) Managing one's own financial affairs."

The preface explains that a key consideration in the self-neglect definition was to "advance the goal of APS in promoting self-determination and person-directedness and supporting adults in making their own decisions in line with their values and wishes." ACL indicated that APS programs should start from the presumption that an adult has the capability to choose to live how they desire. ACL also emphasized the importance of the level of risk since an eligible adult who may require services and supports to perform essential self-care tasks is not, in and of itself, a justification for APS intervention and APS should focus resources on cases with the highest need.

In § 1324.401, Emergency Protective Action is defined as "immediate access to petition the court for temporary or emergency orders or emergency out-of-home placement." Emergency protective actions are the most intrusive actions that an APS system can take to restrict a client's rights, either through placement or ultimately seeking guardianship. As explained in the Final Rule preface, the definition of emergency protective action was changed from the proposed rule to "permit emergency protective action only as appropriate and necessary as a measure of last resort to protect the life and safety of the client from harm from others or self-harm."

The evaluation asked APS programs about their authority to seek different types of emergency protective actions. Exhibit C shows the percentage of programs that answered "yes" statewide or in a majority of the state. Over a quarter of APS programs responded that they did not have authority to take any type of action. For programs with authority, most can purchase goods (69%) and petition probate courts for emergency orders (69%). Slightly over half of all programs (57%) have authority for out-of-home placement.

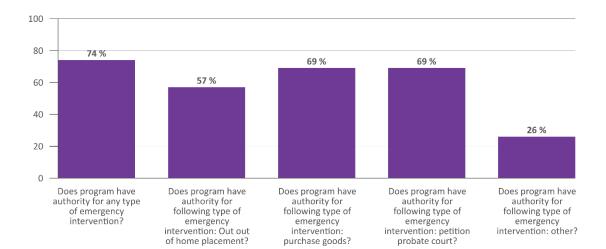


Exhibit C - Percentage of APS Programs with Authority to Seek Emergency Protective Action

#### **APS Response: Investigation and Service Planning**

In § 1324.403, ACL requires APS systems, when conducting investigation and service planning, to recognize that acceptance of APS services is voluntary, except where mandated by state law, to:

- Ensure the preservation of a client's rights
- Integrate principles of person-directedness
- Maximize engagement with the APS client
- Permit APS to seek emergency protective action only as appropriate and necessary as a measure
  of last resort to protect the life and safety of the client

The Final Rule preface indicates that potential clients must be informed of their APS related rights *under state law*, including the right to decline to participate in an investigation, to decline services, to refuse entry to their home, or any rights provided in state law.

The preface indicates that person-directedness is focused on the experiences, values, and preferences of the adult. Person-directed approaches involve the adult in all aspects of intake, investigation, service planning, and delivery, to the greatest extent possible. A person-directed APS response respects the adult's right to self-determination. The adult takes an active role and determines the goals. Examples of person-directed strategies include empowering and assisting the adult to identify and access the desired interventions and services, and emphasizing to the adult that they have a voice — this is their case.

Evaluation data on the voluntary nature of services and emergency protection are provided above. The evaluation did not examine preservation of client's rights per se, only indirectly through the question on use of guiding principles discussed above. The evaluation did examine how APS programs engage with clients, particularly for service planning. As shown in Exhibit D, almost all programs use some method of

client and family input to develop service plans, consistent with the person-centered principles. There is less consistency in the way this is accomplished, although 57% of programs indicated that they have a structured approach for the client to help identify the factors that influence intervention risk and needs.

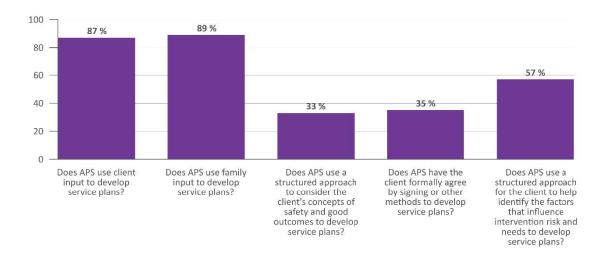


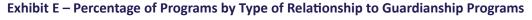
Exhibit D - Percentage of Programs That Use Client and Family Input in Service Planning

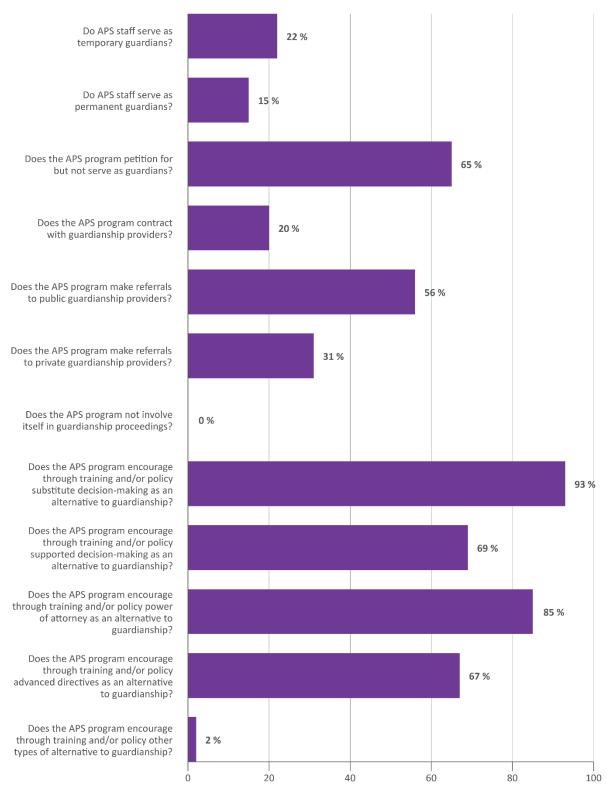
#### **Guardianship Conflict of Interest**

In § 1324.404, the Final Rule requires APS systems to consider less restrictive alternatives to guardianship. If APS must serve as a guardian because of court appointment or lack of other alternative, APS is required to document the dual relationship in the case record and describe the mitigation strategies it will take to address the conflict of interest. The Final Rule preface explains that "client self-determination is of primary importance, and that guardianship and conservatorship should be a last resort" and that "all less restrictive alternatives to guardianship [be] considered" through "holistic case planning and service provision."

The evaluation examined several questions regarding APS relationship to guardianship services. As shown in Exhibit E, every APS program is involved in guardianship in some way. The most frequent way is by petitioning but not serving as guardian (65% of programs). Most APS programs do not serve as guardians. There are 12 programs (22%) where APS staff can serve as temporary guardians. Among these, in eight programs (15% of all programs) APS can also serve as permanent guardians. There are no programs where they can only serve as permanent but not temporary, so overall, APS can serve as guardian in 22% of programs.

Most (93%) APS programs encourage and support alternatives to guardianship. This is accomplished through training and policy related to use of substitute decision-makers (93%), supported decision-making (69%), power of attorney (85%), and advance directives (67%).





#### Conclusion

The tension of the inherent intrusiveness of APS casework with respect for client rights/wishes can be resolved, at least in part, through articulation and application in policy and practice of the personcentered principles of self-determination, self-direction, and least restrictive alternatives. Data from the *National APS Process Evaluation* and NAMRS show that most — but not all — APS programs already apply these person-centered principles in one form or another. The Final Rule by ACL requires their universal application.

The APS TARC will continue to assist APS programs with meeting this goal through development of additional technical assistance materials and consultation with individual programs. We would welcome feedback on what type of additional assistance — such as a detailed how-to practice toolkit expanding on this toolkit or webinar — programs would like to help resolve the tension of protection and rights inherent in APS casework.

# Appendix A: Rule Requirements Related to Person-centered Principles

#### § 1324.402 Program administration.

•••

- (b) The State entity shall create, publish, and implement policies and procedures for APS systems to receive and respond to reports of adult maltreatment and self-neglect in a standardized fashion. Such policies and procedures, at a minimum, shall:
- (1) Incorporate principles of person-directed services and planning and reliance upon least restrictive alternatives;

...

- (c) Upon first contact, APS systems shall provide to potential APS clients an explanation of their APS-related rights to the extent they exist under State law, including:
- (1) The right to confidentiality of personal information;
- (2) The right to refuse to speak to APS; and
- (3) The right to refuse APS services;
- (d) Information shall be provided in a format and language understandable by the adult, and in alternative formats as needed.

#### § 1324.401 Definitions.

...

Self-neglect means a serious risk of imminent harm to oneself or other created by an adult's inability, due to a physical or mental impairment or diminished capacity, to perform essential self-care tasks, including at least one of the following:

- (1) Obtaining essential food, clothing, shelter, and medical care;
- (2) Obtaining goods and services necessary to maintain physical health, mental health, or general safety; or,
- (3) Managing one's own financial affairs.

#### § 1324.403 APS response.

- (c) Practices during investigations to collect information and evidence to support findings on allegations, and service planning that will:
- (1) Recognize that acceptance of APS services is voluntary, except where mandated by State law;
- (2) Ensure the safety of APS client and worker;
- (3) Ensure the preservation of a client's rights;
- (4) Integrate principles of person-directedness and trauma-informed approaches;
- (5) Maximize engagement with the APS client, and;

#### § 1324.404 Conflict of interest.

...

- (1) In the case of an APS program petitioning for or serving as guardian, it is an unavoidable dual relationship only if all less restrictive alternatives to guardianship have been considered and either:
- (i) A Court has instructed the APS program to petition for or serve as guardian; or
- (ii) There is no other qualified individual or entity available to petition for or serve as guardian;
- (2) For all dual relationships, the APS program must document the dual relationship in the case record and describe the mitigation strategies it will take to address the conflict of interest.

#### § 1324.403 APS response.

The State entity shall adopt standardized and systematic policies and procedures for APS response across and within the State including, at a minimum:

...

- (c) Practices during investigations to collect information and evidence to support findings on allegations, and service planning that will:
- (1) Recognize that acceptance of APS services is voluntary, except where mandated by State law;
- (2) Ensure the safety of APS client and worker;
- (3) Ensure the preservation of a client's rights;
- (4) Integrate principles of person-directedness and trauma-informed approaches;
- (5) Maximize engagement with the APS client, and;
- (6) Permit APS the emergency use of APS funds to buy goods and services;
- (7) Permit APS to seek emergency protective action only as appropriate and necessary as a measure of last resort to protect the life and safety of the client.