



Balancing the Right to “Access to Food” with Protections for Individuals in Home and Community Based Settings

The Office for People With Developmental Disabilities (OPWDD) and providers in the OPWDD system are in the process of implementing the Centers for Medicare and Medicaid Services' (CMS) requirements for Home and Community Based Services (HCBS) Settings in federal regulations 42 CFR section 441.301(c)(4), and OPWDD Person-Centered Planning regulations in subpart 14 NYCRR 636-1. In accordance with these requirements, all individuals receiving HCBS Waiver services are entitled to have their needs, preferences, and goals met in a way that respects their rights and maximizes their independence, choice and community integration. Efforts must be made to promote and protect individuals' rights when providing services. It is critical that staff be trained regarding individuals' rights and the applicable requirements related to rights modifications as part of the person-centered planning process.

This Health and Safety Alert is designed to address the requirement for “access to food” under the HCBS Settings standards and to provide information to promote this access, while mitigating any individual risk. In accordance with requirements in 42 CFR 441.301(c)(4)(vi), and section 14 NYCRR 636-1.4, individuals are entitled “access to food at any time.” **As stated in OPWDD Administrative Memorandum #2014-04 (which provides interpretation and clarification of these standards):**

“Individuals shall have access to food, meal(s), and storage of food (e.g., individuals may purchase and store their own snacks or special food and keep food for themselves; kitchens, refrigerators, and pantries are not locked or if any safety measures need to be implemented for the needs of a particular individual, the other residents have a means of ready access).”

Concerns have been raised regarding the protection of an individual's right to access food when certain conditions exist, e.g. choking history/risk, medical conditions, a need for a special diet, or a diagnosis of Prader-Willi syndrome. The right to access food should not be misrepresented as a barrier to adequate safeguarding or be a reason to avoid responsible person-centered service planning. As part of the person-centered planning process, the individual and his/her program planning team should collaborate to identify any necessary supports and strategies that are available to the individual to address his/her unique needs and abilities pertaining to food, food types, food access, and supervision while eating.

The person-centered planning process requires the implementation of supports and services based on a hierarchy of approaches from least restrictive (*access to all foods-all the time*) to most restrictive (*limited access to food*). The least restrictive and most supportive approach should be implemented to the extent possible. There are instances when an individual's rights may need to be limited to ensure the health and safety of the individual and others. Limitations on access should only be used in accordance with OPWDD regulations and when least restrictive approaches have been deemed unsuccessful or would be inappropriate given the level of risk to the person.

Efforts to protect the rights of an individual include providing any necessary supports so that the individual can carry out choices as independently as possible. Although an individual may have health and safety needs regarding access to food and dining, providers should still seek to establish a level of autonomy regarding food access that is appropriate for the individual given his or her assessed abilities and risks. When an individual's communication skills are limited,

providers and the program planning team should use their experience and knowledge of the individual to determine food access strategies.

Considerations for appropriate access to food given the individual’s assessed abilities and risks include:

- Facilitating routine access to foods and food portions that the individual can select and eat independently and/or at will. For example, educate the individual and staff on the foods the individual can eat independently and where such foods are stored
- Assisting the individual to create individualized activities and routines that satisfactorily provide him/her access to desired foods, allowing individual choice to the greatest degree possible (e.g. what, when and where to eat) and including necessary staff supports
- Creating conditions and parameters that increase the likelihood for success and engage the individual by helping him/ her demonstrate adaptive and healthy behaviors

Rights Limitations and Modifications

In some cases, an individual cannot safely exercise his or her right to access food and may require modifications or limitations to ensure the health and safety of the individual and others. When least restrictive approaches are deemed ineffective or clinically inappropriate in assuring health and safety, more restrictive approaches can be considered. **Examples of modifications or interventions that may be considered to limit an individual’s right to access food include:**

- Altered food/beverage consistency
- Specific food/beverage restrictions (e.g. due to food allergies, and/or medical/physical conditions such as eating concerns related to Prader-Willi syndrome, uncontrolled diabetes, kidney disease, medical fluid restrictions, etc.)
- Portion control to address health issues or risks
- Conditional supervision/support while eating; for example, support required when eating with others due to risk of choking or eating food that is not appropriate, but not required when eating privately/alone
- Limitations based on location (e.g., dining room vs. bedroom, home vs. restaurant, home vs. work or day program)
- Secure food storage

Careful consideration is required for modifying or limiting an individual’s rights and must be an integral part of an ongoing person-centered planning process.

Access to food may be restricted for clinical purposes in accordance with the documentation and consent requirements contained in the following federal and OPWDD regulations:

- 14 NYCRR section 633.4: *Rights and Responsibilities of Persons Receiving Services*
- 14 NYCRR section 636-1.4: *Documentation of Rights Modifications*
- 42 CFR section 441.301(c)(4)(vi)(F): *Contents of Request for a Waiver*
- 14 NYCRR section 633.16: *Person-Centered Behavioral Intervention*

Additionally, consideration should be given to how an individual’s rights modifications or limitations may impact peers and housemates. Accommodations within the setting should be made based on the needs of other individuals who are not restricted from access to food. (See OPWDD regulations on person-centered planning in 14 NYCRR sub-part 636-1 and guidance in OPWDD Administrative Memorandum #2014-04.)