Global Standards for Self-Directed Supports

Draft for comment October 27, 2022

We all have the right to live a life of freedom and full community inclusion. These fundamental rights were articulated in the Universal Declaration of Human Rights in 1948. The 2006 Convention on the Rights of Persons with Disabilities underscored that human rights apply to all people regardless of the challenges they face. To ensure human rights for all, we must organize systems that maximize autonomy, choice, and control. The following are essential elements of a robust self-directed support system:

- Dedicated resources, individualized and controlled by the person, used flexibly and creatively to support the person's best life
- 2. Access to legally recognized supported decision-making that minimizes substitute decision-making and the loss of legal agency
- 3. Outreach and education, beginning in early childhood
- 4. Clear and simple information, widely available in the mainstream, tailored for cultural responsiveness and relevance, and fully accessible
- 5. Practical administrative processes that minimize participant burden
- 6. Person-centered planning a process of identifying what is important to a person with strategies to support what's important that supports a commitment to peoples' capacity and value
- 7. Freely available assistance with technical aspects of self-directed supports, including assistance to ensure good employer/employee relationships, fair and rewarding work, and effective hiring and retention practices
- 8. Peer support mutual aid in understanding and navigating the system at the person, community, and system levels that bolsters participation, drives innovation, and holds the system accountable to its values
- 9. Transparent, fair resource allocation based on a person's priorities and needs
- 10. Portability of self-directed funding and eligibility across jurisdictions within a country
- 11. Comprehensive and genuinely independent systems of advocacy to protect human rights, privacy of personal information, freedom to make big and small life decisions, and the prevention and safeguarding from harm
- 12. Practices that ensure all people have the option to control as much or as little of their supports as they choose, based on the presumption of personal capacity
- 13. Quality practices and outcomes measurement that support continuous learning and improvement and hold systems accountable to the principles of self-directed support
- 14. An orientation toward equity in access and respect for people's cultural identities, with particular attention to groups that are historically marginalized and underserved
- 15. People with lived experience of disability or ill health have principal roles in the oversight, governance, and administration of support systems