

From the Human Services Research Institute – a workgroup of 30 participants from New Zealand, Australia, the United States, Canada, Ireland, Finland, and England. The JBC needs to have copies of this. It needs to go out to the PPDDC. And all decisions must be measured against the global standards. We are moving backwards.

Global Standards on Self-Directed Services

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 disability or chronic illness. To ensure human rights for all, we must organize systems that maximize autonomy of the person to make choices and exercise control over their supports.

Essential Elements of a Robust Self-Directed Support System

1. A dedicated budget, individualized and controlled by the person with any support they choose, used flexibly and creatively to promote 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 on self-directed supports, beginning in early childhood
4. Clear and simple information on self-directed supports, 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 demonstrates a commitment to peoples' capacity and value
7. No cost assistance with technical aspects of self-directed supports, including help meeting program requirements and assistance with locating, hiring, and managing staff
8. Information and resources for families, friends, and other allies to support the person
9. Respectful employment practices that recognize the rights of staff to a fair wage and to be free from exploitation
10. Peer support – mutual aid for wellbeing and navigating the system – bolsters participation, promotes equitable access, and drives innovation

11. Transparent, sufficient, fair resource allocation based on a person's priorities and needs
12. Portability of self-directed funding and eligibility across jurisdictions within a country
13. Comprehensive and genuinely independent advocacy to protect human rights, privacy of personal information, freedom to make big and small life decisions, and safeguarding from harm
14. 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
15. Quality practices and outcomes measurement that support continuous learning and improvement and hold systems accountable to the principles of self-directed support
16. An orientation toward equity in access, respect for people's cultural identities, and positive outcomes with particular attention to groups that are historically marginalized and underserved
17. Disabled people and those with chronic illnesses are fundamentally trusted and have principal roles in the oversight, governance, and administration of support system