2022 Match Summary

Name of Match: Advances in Self-Direction

Location of Match: virtual

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1. Describe the **purpose** of the match: (Maximum 500 words)

This exchange was aimed at taking the next steps following on from an exchange that occurred in Boston in September 2019. Whilst there was a wide range of self-direction models and implementation approaches, there was unanimous agreement in 2019 on the benefits and positive outcomes achieved with self-directed support models. Lessons learned and future directions were also discussed, with common themes emerging related to equity in outreach, person-centred planning, the role of advocacy and peers, the use of data, and the adequacy of the workforce.

This exchange extended learnings from 2019. We further explored advances and progress from participants/countries since then and facilitated agreement on an international declaration on self-direction. The intent was to advance self-direction from an "allowable" option for support to the default position as a fundamental human right in health and disability support services.

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2. Describe the **leaders** who participated in the match (for example, were some of them peers, youth, family/caregivers, practitioners, policy makers, clinicians? Were they from community settings, government, NGOs, clinical settings?):   (Maximum 500 words)

There were approximately 30 participants across the multiple virtual meetings hailing from New Zealand, Australia, the United States, Canada, Ireland, Finland, and England. Participants included disabled people who self-direct, loved ones of people who self-direct, researchers, technical assistance providers, service providers, self-direction information and assistance providers, and fiscal intermediaries from community and NGO organizations.

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3. What do you see as the **game changer** for this match topic? (Game changer is defined as: a newly introduced element or factor that changes an existing situation or activity in a significant way.)   (Max 500 words)

The group supported the development of the following draft statement:

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 of supports. The following are essential elements of a robust self-directed support system:

1. *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. *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, respect for people's cultural identities, quality, and positive outcomes 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*

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4. How will the match **support inclusion, resilience and growth** for this match topic and for the leaders who attended: (Maximum 500 words)

The group was keen to stay connected and to continue to find ways to collaborate and learn from one another in the years to come. We are exploring options and platforms to stay connected over the long-term.

The virtual nature of the group facilitated inclusivity, with several disabled people noting that their participation was greatly supported by not having to travel. On the other hand, scheduling convenings across many different time zones was nearly impossible. To ameliorate this issue, we held a set of convenings by region (North America, Europe, and NZ/AUS) so that more people could attend. Still, this limited the possibility for sharing and collaborating across time zones.