



INTERNATIONAL ADVANCES IN SELF-DIRECTION

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WHAT WILL WE COVER?

- Description and purpose of the Match on Self-Direction
- Description of self-direction programs in the United States, United Kingdom, New Zealand, and Australia
- Discussion of best practices in self-direction
- Considerations for the future



AN INTERNATIONAL LEARNING
EXCHANGE

ATTENDEES HAILED FROM AUSTRALIA, NEW ZEALAND, ENGLAND, AND THE U.S.

- People with lived experience of disability and self-direction
- Family members and direct support workers
- Program administrators
- Researchers





OVER TWO DAYS WE...

- Shared our home countries' models and developments
- Dialogued with people with lived experience
- Used a world café format to
 - Explore common challenges
 - Brainstorm solutions
 - Strategize how to hold our gains
 - Set an agenda for the future

UNITED STATES

- Self-direction is available in all fifty states
- Self-direction programs vary widely from state to state, but all programs offer either employer authority, budget authority, or both
- Individuals receiving self-directed services report improved quality of life, less unmet personal care needs, and reduced primary caregiver fatigue
- Individuals report self-direction can be complicated initially, particularly related to understanding employer responsibilities and paperwork

SELF-DIRECTION IN THE UNITED STATES

- ~1.2 million people in the U.S. are self-directing
 - Up 17% from 2013
- ~13% of respondents with intellectual and developmental disabilities are self-directing
 - Individuals self-directing mental health needs remain small and are mostly in pilot programs

ENGLAND

- Adult social care policy is set by the Department of Health and Social Care and implemented by locally elected councils
- The Care Act of 2014 required councils to have a self-directed option for everyone meeting national eligibility criteria (based on need and a means test)
- People can choose to:
 - Take their budget as a direct payment
 - Leave it to the council to manage
 - Delegate to a third party through an individual service fund

SELF-DIRECTION IN ENGLAND

- Although direct payments have been an option for over 20 years, only ~28% of individuals receiving long-term support are using direct payment
 - 240,000 of 858,000
- Numbers vary significantly between councils and populations
 - There are more working age adults (18-64) than older adults (65+)
- Improved outcomes are reported, but challenges related inflexibility and excessive monitoring cause concern

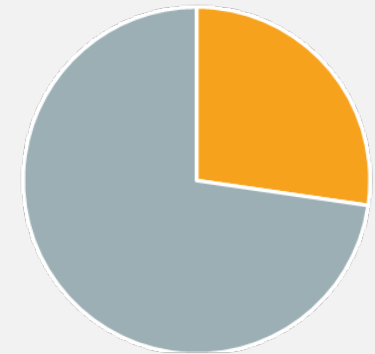
AUSTRALIA

- The National Disability Insurance Scheme (NDIS) passed in 2013
- Put funding in the hands of participants to purchase services, equipment, etc.
- At the time of the match, 300K people enrolled
- Target population: people with disabilities, including psychosocial disabilities

NDIS AND SELF-DIRECTION

- Participants have 3 options to manage NDIS funding: self-managed, plan-managed and agency-managed
- 15.8% fully self-manage; 11.5% partially self-manage
- Self-managing participants are gradually increasing – tend to be younger and have better outcomes
- Sometimes “screened out” by planners

A little over one-quarter of participants fully or partially self-manage their funding



NEW ZEALAND

- 34K people receiving disability supports
 - Of those, 17K receive home and community-based supports
 - Approx. 7K receive self-directed supports
- Majority of people who self-direct are under 65, w/ long-term disabilities

SELF-DIRECTION IN NEW ZEALAND

- 2012: introduction of the “New Model” based on individualized funding and local area coordination
- Initial concerns on fraud, but found to be nonexistent
- Growing concerns on self-direction becoming more bureaucratic

BEST PRACTICES IN SELF-DIRECTION

What have we learned?



EQUITY IN OUTREACH

- Engage with communities to identify resources and supports
- Develop outreach materials that are culturally competent and written in plain language
- Start with “low-hanging fruit” including people dissatisfied with current services
- Target young people and families
- Assume competence to avoid gatekeeping
- Create a trial period
- Make sure people have access to information, advice and support



PERSON-CENTERED PLANNING

- Outlining elements of the person-centered planning process in legislation, policy or regulation
- Striking a balance between flexibility and ensuring the process is somewhat standardized to avoid arbitrary and subjective judgments by others
- Reducing the administrative burden on the person and family
- Making the service “menu” and budget amount available prior to developing the plan



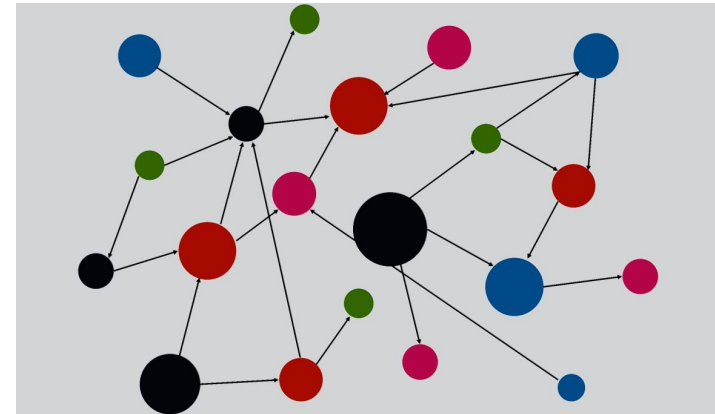
ROLE OF SELF-ADVOCACY, PEERS, AND PEER-RUN ORGANIZATIONS

- Include peer support in policy and regulatory guidance
- Establish partnerships with peer-run and self-advocacy organizations
- Create funding mechanisms to sustain peer-run and self-advocacy organizations
- Provide training and mentorship opportunities for peers and self-advocates
- Compensate peers and self-advocates for their time
- Bring peers and self-advocates into discussions of self-direction policy and practice; when possible, they should lead or co-lead discussions
- Ensure peer supporters play a central role in self-direction



USE OF DATA

- Involve people with lived experience in the design of quality improvement and evaluation efforts
- Make self-direction data publicly available
- Create a stakeholder forum to review the data and suggest improvements
- Be wary of satisfaction surveys that may include sample bias or lack accuracy
- Make sure surveys include questions that address quality of life and other outcomes important to people and communities
- Provide stakeholders opportunities to share feedback beyond structured questions
- Employ multiple, accessible research methods



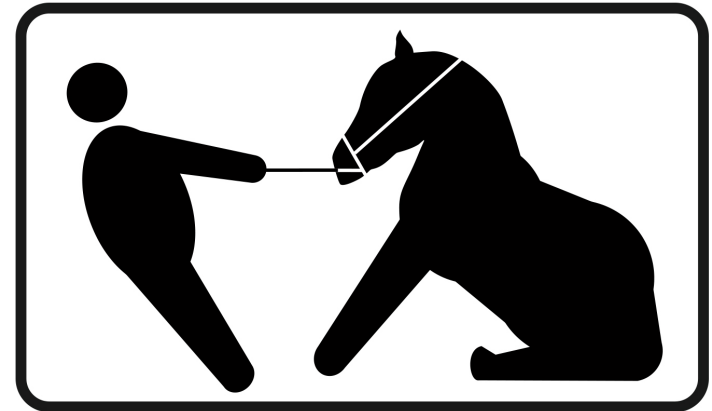
ADEQUACY OF DIRECT SUPPORT WORKFORCE

- Assist the person to recruit staff, customize training (depending on services) and manage the budget
- Ensure budgets include enough funds to attract capable staff
- Develop training on how to be an employer
- Give people the ability to use staff as job coaches
- Expand the pool of potential staff by exploring the person's circle of support
- Anticipate potential workforce unionization



SYSTEM RESISTANCE TO SELF-DIRECTION

- Anticipate resistance and showcase the range of participants successfully self-directing
- Win support from policymakers and others by making the business case for self-direction, including both economic and quality of life benefits
- Be aware of the possibility of fraud but recognize that fraud/misuse is very low and develop proportionate responses
- Support the voices of participants and families demanding self-direction as a right



CONTINUING CONCERNS

- Who should self-direct?
- Who should provide support?
- How should the plan and budget be developed?
- What should be funded?
- What type of support do participants need?



NEXT STEPS

(SLIDE 1 OF 2)

- Do a better job of highlighting the values and outcomes of self-direction including expanded relationships, employment, and community membership.
- Demystify self-direction to demonstrate it is accessible to all.
- People who are self-directing should facilitate conversations and inform their peers as “ambassadors”
- Conferences, webinars and virtual discussion groups can be effective vehicles to spread the word about self-direction.



NEXT STEPS (SLIDE 2 OF 2)

- To help educate and train, clearly spell out the components of self-direction and what has worked and what has not.
- Do more to embed self-direction in the mental health system. Models, examples and research are needed.
- Make self-direction a part of school curricula to prepare students to self-direct when they transition to adulthood.
- IIDL/IIMHL should take the lead in crafting a universal statement on self-direction to reinforce the global value of self-direction and an international compact on self-direction.



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