



SDS Network-Mapping



Tukena

Organising the SDS network

The current network

- Operates on three continents: Asia-Pacific Region, Europe-Africa Region, America Region
- has its roots in the global North. Important work will be necessary to grow connections with the global South and to learn from people in other countries.
- is primarily a professional expertise-based network, drawing together people who have spent decades of time working on improving social systems. This is only one kind of expertise and the lived expertise and voices of people who use long-term care and support become central to the development of the network.

Governance, active key people

- Simon Duffy, Citizen Network – Global
- Bevin Croft, Human Services Research Institute - USA
- Marsha Marshall, Manawanui - New Zealand
- Markus Vähälä, Citizen Network - Global
- Chris Watson, Self Directed Futures – England
- Tim Stainton, Canadian Institute for Inclusion and Citizenship - Canada
- Leanne Pearman, Western Australia Individualised Services – Australia
- Petteri Kukkaniemi, Suunta/Tukena – Finland
- Heidi Hautala, Suunta/Tukena – Finland

SDS network goals

1. Understand progress on SDS globally
2. Clarify key terms and standards
3. Set out key principles of good SDS
4. Identity good practice and obstacles to progress
5. Share information across the whole community
6. Support ongoing network development globally
7. Support advocacy locally, nationally and globally

Global Standards

- Essential elements of a self-directed support system
- <https://selfdirectedsupport.org/sds-standards>

State of play

- Mapping the system globally
- the survey will be published soon

Join the network

- <https://selfdirectedsupport.org/subscribe>

Mapping: the testing phase

- 13 responds
- United States (4), Canada, UK, Belgium, Ireland, Slovakia, Netherlands
- 4 national, 9 regional responds

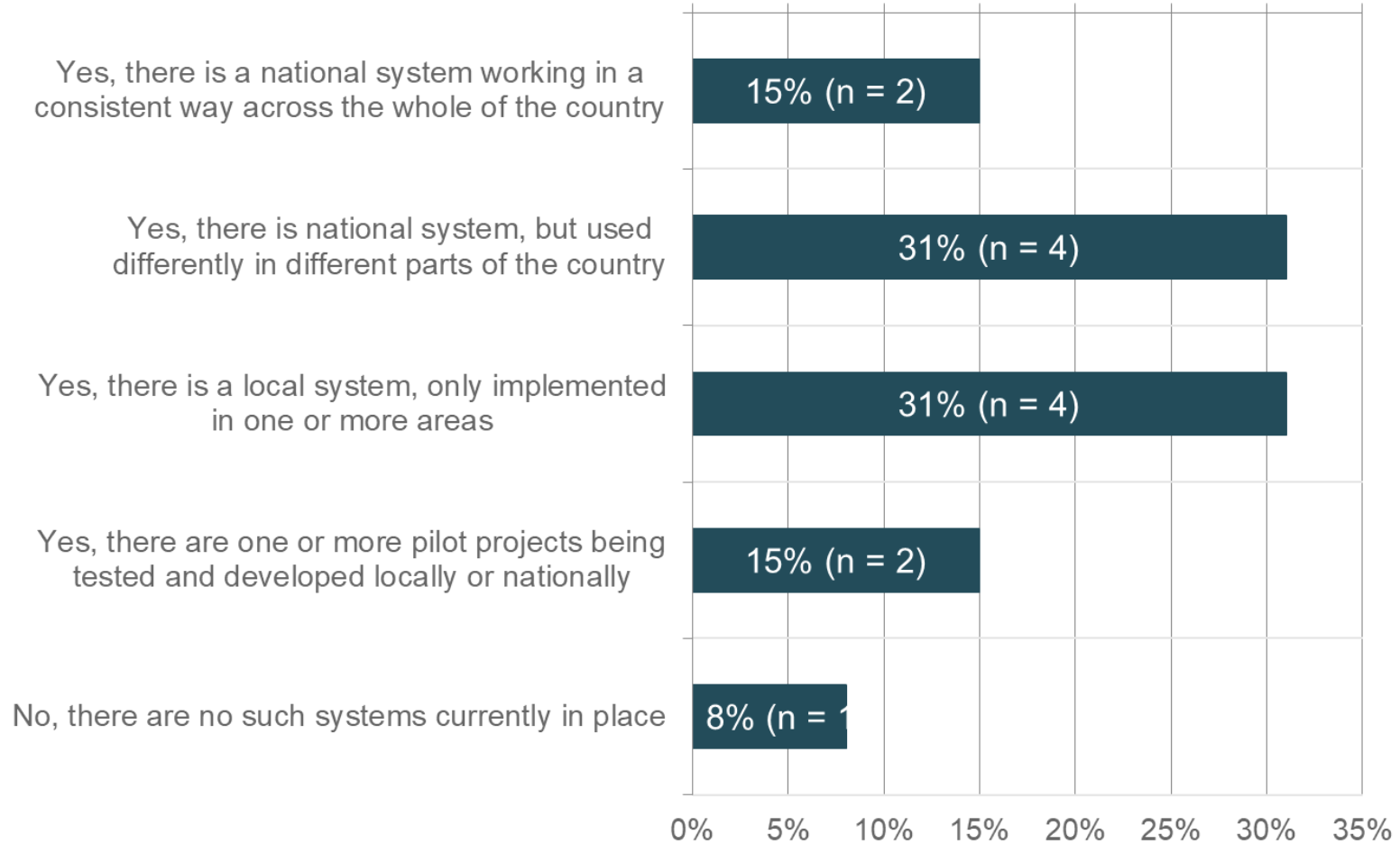
Number of people using SDS in long-term care

- According to responds varies from minimal number to all of the people using long-term care services

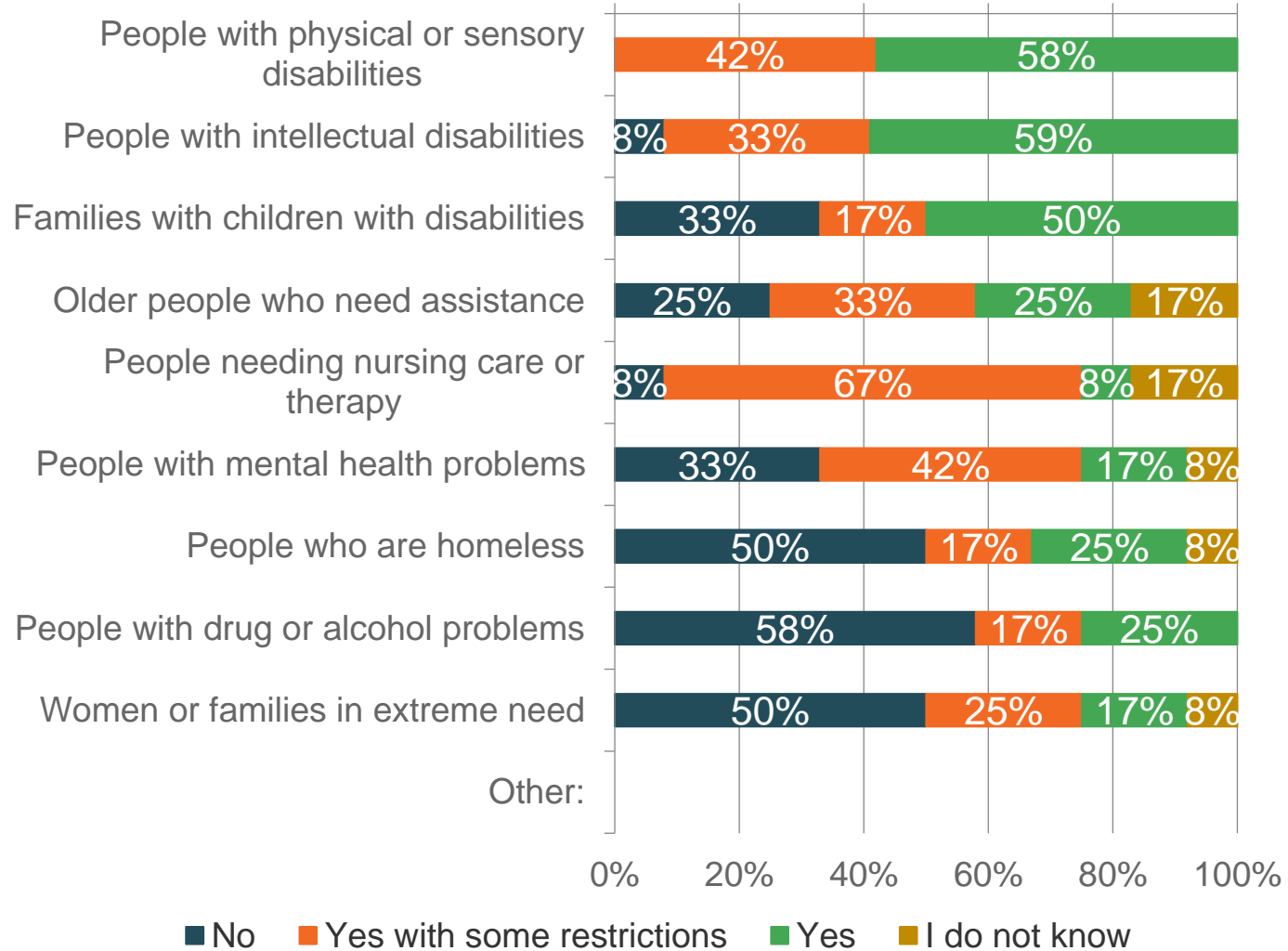
Challenges for developing SDS and barriers to implementation

- Strong institutional culture
- Lack of willingness to reform the system
- Lack of financial and personal resources
- Attitudes towards people with disabilities and weak understanding of human rights
- Complexity of administrative systems and obligations
- Achieving a balance between individual rights community expectations/management of scheme costs
- Self-direction for people with psychiatric disabilities is not commonly understood
- A fragmented system which treats different populations differently
- A limited notion of self-direction that often does not maximize individual choice
- Negative assumptions about the capacity of people to make good choices about their lives
- Trusting people to spend what they need and not more. Fraud has occurred, but mainly by in between organisations
- Only direct care is paid, everything else to do with organising care is not
- The major barrier is access: being eligible and being able to go through a complicated eligibility process

Existing SDS systems?



SDS system can be used by



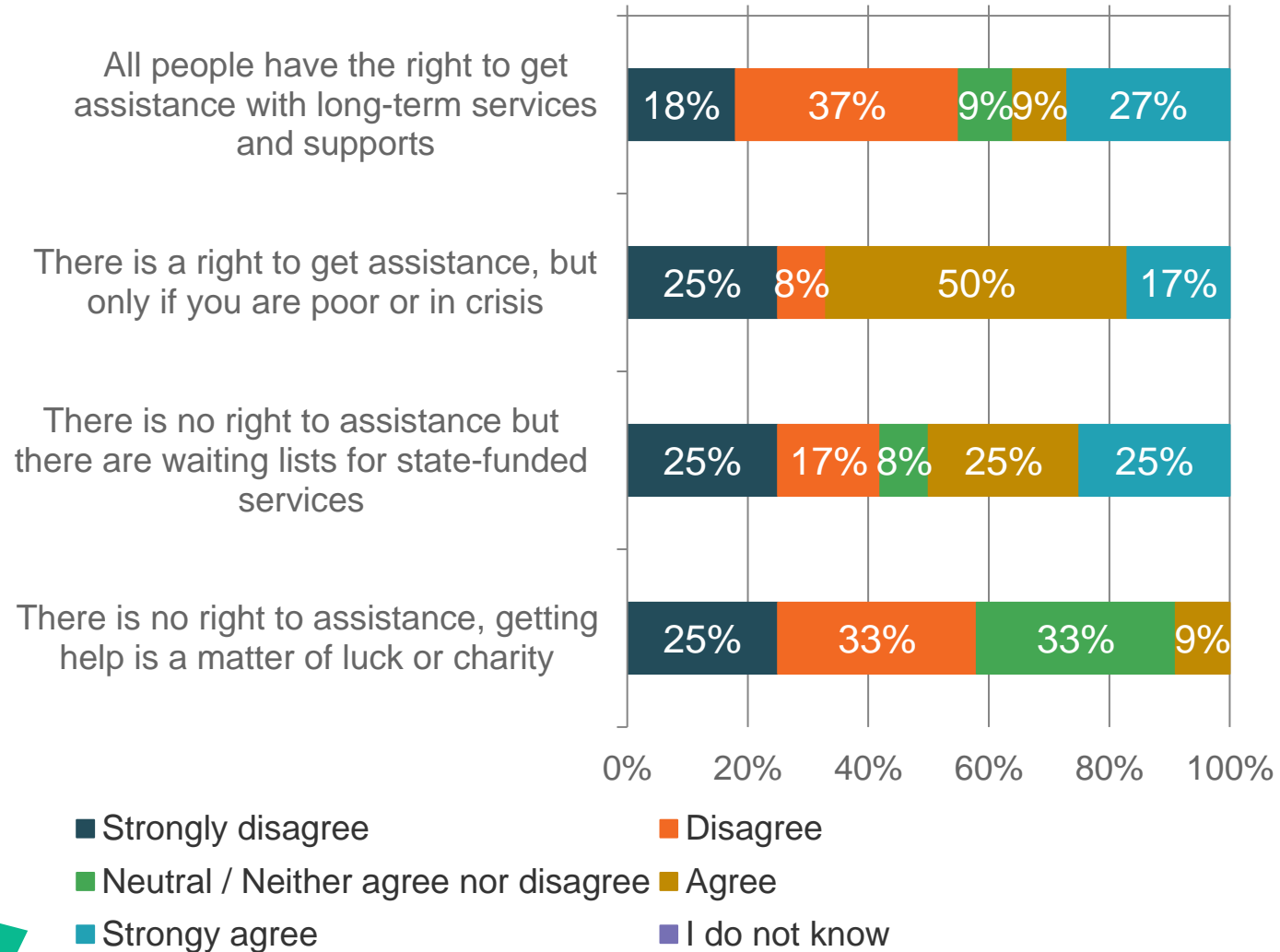
SDS system can be used for

	No	Yes with some restrictions	Yes	I do not know	Average	Median
Residential support services	45.4%	9.1%	45.5%	0.0%	2.0	2.0
Personal assistance	0.0%	41.7%	58.3%	0.0%	2.6	3.0
Support with work	8.3%	41.7%	50.0%	0.0%	2.4	2.5
Support with daytime activities	0.0%	33.3%	66.7%	0.0%	2.7	3.0
Support with leisure	8.3%	25.0%	66.7%	0.0%	2.6	3.0
Therapy	16.6%	50.0%	16.7%	16.7%	2.0	2.0
Training	0.0%	66.7%	25.0%	8.3%	2.3	2.0
Nursing care	16.7%	58.3%	8.3%	16.7%	1.9	2.0
Other medical services	66.6%	16.7%	0.0%	16.7%	1.2	1.0
Childcare	75.0%	8.4%	8.3%	8.3%	1.3	1.0
Family caregiver supports	25.0%	50.0%	25.0%	0.0%	2.0	2.0

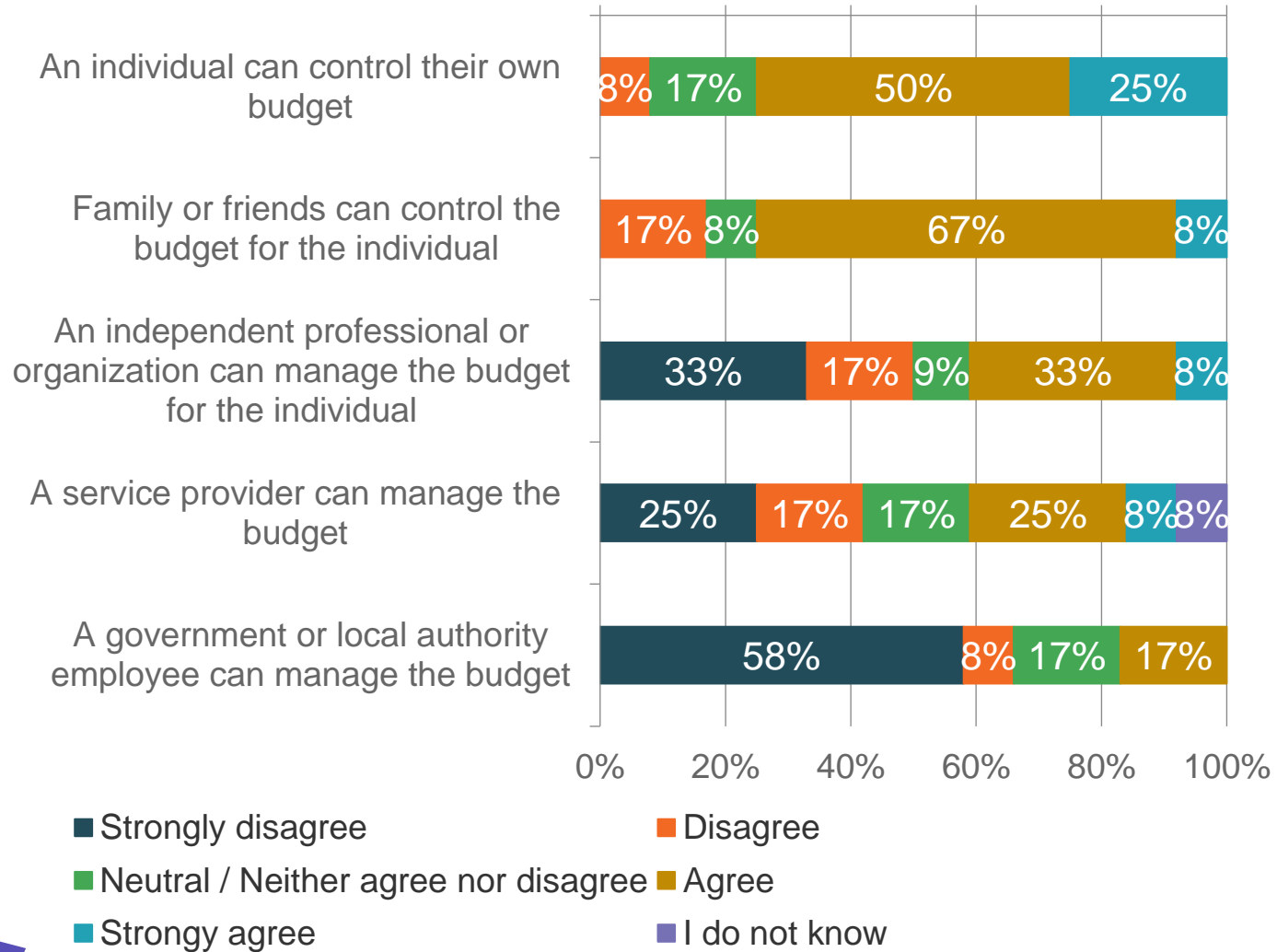
SDS system can be used by

	No	Yes with some restrictions	Yes	I do not know	Average	Median
Schooling (education from birth to 18)	75.0%	16.7%	0.0%	8.3%	1.2	1.0
College (education after 18)	58.4%	33.3%	8.3%	0.0%	1.5	1.0
Transport	8.3%	41.7%	50.0%	0.0%	2.4	2.5
Holidays or respite	16.6%	41.7%	41.7%	0.0%	2.3	2.0
Community action	41.7%	8.3%	41.7%	8.3%	2.0	2.0
Housing-related expenses (home modification, purchaser, or lease)	27.3%	72.7%	0.0%	0.0%	1.7	2.0
Other:	-	-	-	-	-	-
Total	27.2%	34.2%	28.5%	4.6%	2.0	2.0

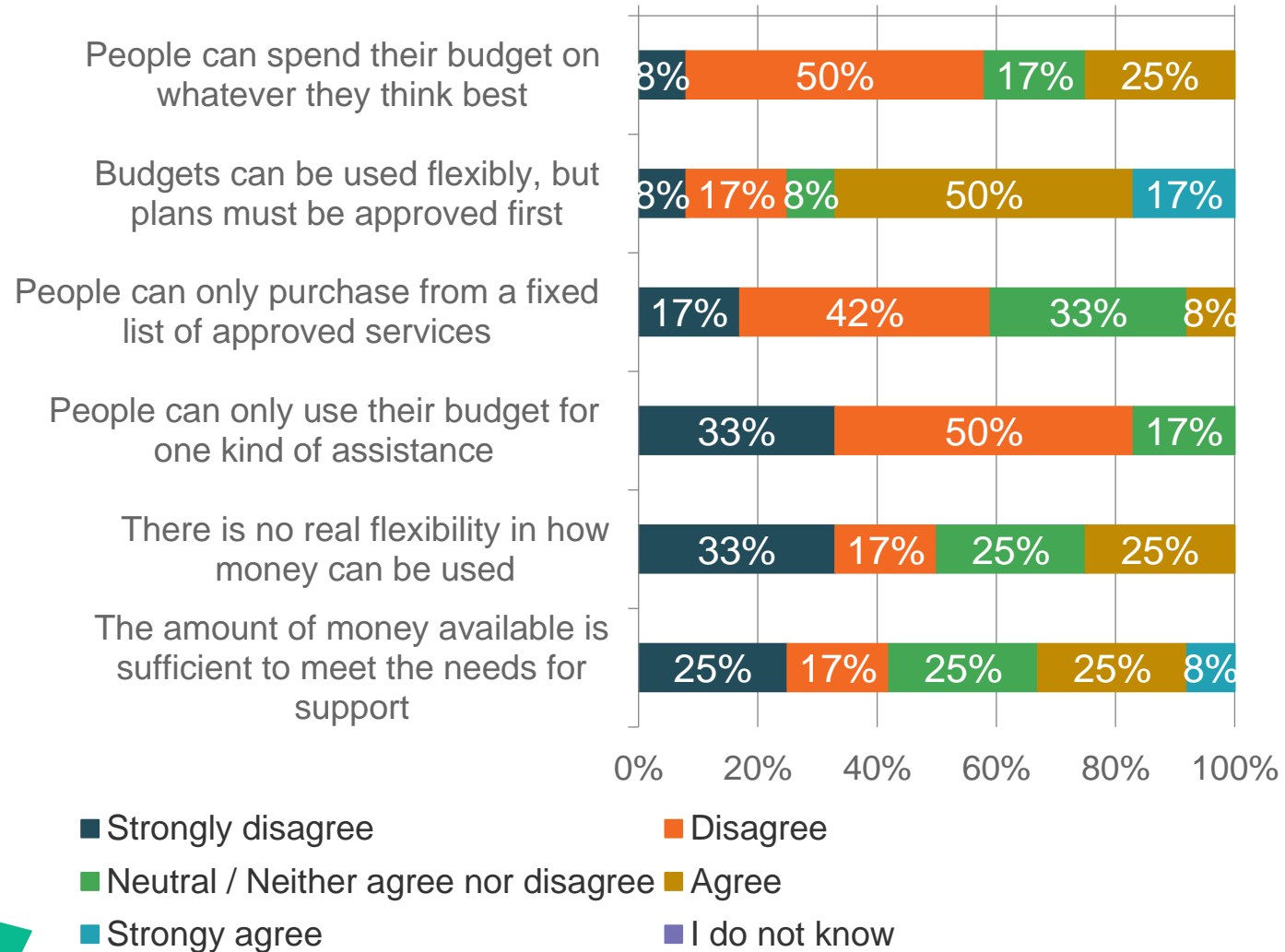
Do you agree or disagree with the following statements regarding the system in your country or region?



Do you agree or disagree with the following statements regarding the system in your country or region?



Do you agree or disagree with the following statements describing the flexibility and sufficiency of this system in your country or region (in theory)?



Do you agree or disagree with the following statements about personalised assistance in your country or region's system?



The SDS Network has developed a set of global standards for best practice in self-directed support. To the best of your knowledge, indicate the extent to which each standard is present in your system:

	Not at all present	Partially present	Mostly present	Fully present	I no not know	Average	Median
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	0.0%	58.4%	33.3%	8.3%	0.0%	2.5	2.0

Present = practices, realized, implemented, applied.

	Not at all present	Partially present	Mostly present	Fully present	I no not know	Average	Median
2) Access to legally recognized supported decision-making that minimizes substitute decision-making and the loss of legal agency	16.7%	50.0%	8.3%	16.7%	8.3%	2.3	2.0
3) Outreach and education on self-directed supports, beginning in early childhood	50.0%	50.0%	0.0%	0.0%	0.0%	1.5	1.5

	Not at all present	Partially present	Mostly present	Fully present	I no not know	Average	Median
4) Clear and simple information on self-directed supports, widely available in the mainstream, tailored for cultural responsiveness and relevance, and fully accessible	33.3%	58.4%	8.3%	0.0%	0.0%	1.8	2.0
5) Practical administrative processes that minimize participant burden	41.7%	33.3%	8.3%	16.7%	0.0%	2.0	2.0

	Not at all present	Partially present	Mostly present	Fully present	I no not know	Average	Median
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	0.0%	33.3%	58.4%	8.3%	0.0%	2.8	3.0

	Not at all present	Partially present	Mostly present	Fully present	I no not know	Average	Median
7) No cost assistance with technical aspects of self-directed supports, including help meeting program requirements and assistance with locating, hiring, and managing staff	41.7%	16.6%	41.7%	0.0%	0.0%	2.0	2.0
8) Information and resources for families, friends, and other allies to support the person	8.3%	66.7%	25.0%	0.0%	0.0%	2.2	2.0

	Not at all present	Partially present	Mostly present	Fully present	I no not know	Average	Median
9) Respectful employment practices that recognize the rights of staff to a fair wage and to be free from exploitation	16.7%	33.3%	33.3%	16.7%	0.0%	2.5	2.5
10) Peer support – mutual aid for wellbeing and navigating the system – bolsters participation, promotes equitable access, and drives innovation	16.7%	83.3%	0.0%	0.0%	0.0%	1.8	2.0

	Not at all present	Partially present	Mostly present	Fully present	I no not know	Average	Median
11) Transparent, sufficient, fair resource allocation based on a person's priorities and needs	16.7%	33.3%	41.7%	0.0%	8.3%	2.3	2.0
12) Portability of self-directed funding and eligibility across jurisdictions within a country	75.0%	8.3%	0.0%	16.7%	0.0%	1.6	1.0

	Not at all present	Partially present	Mostly present	Fully present	I no not know	Average	Median
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	25.0%	50.0%	16.7%	8.3%	0.0%	2.1	2.0

	Not at all present	Partially present	Mostly present	Fully present	I no not know	Average	Median
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	25.0%	25.0%	41.7%	0.0%	8.3%	2.2	2.0
15) Quality practices and outcomes measurement that support continuous learning and improvement and hold systems accountable to the principles of self-directed support	25.0%	50.0%	25.0%	0.0%	0.0%	2.0	2.0

	Not at all present	Partially present	Mostly present	Fully present	I no not know	Average	Median
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	8.3%	75.0%	16.7%	0.0%	0.0%	2.1	2.0

	Not at all present	Partially present	Mostly present	Fully present	I no not know	Average	Median
17) Disabled people and those with chronic illnesses are fundamentally trusted and have principal roles in the oversight, governance, and administration of support systems	33.3%	41.7%	25.0%	0.0%	0.0%	1.9	2.0
Total	25.5%	45.1%	22.6%	5.4%	1.5%	2.1	2.0