What We Heard in Ottawa

Common themes from the Self-Directed Support Network Learning Exchange

August 2026

Self-Directed Support Network

About the Self-Directed Support Network

The Self-Directed Support (SDS) Network is a global community working to define and improve best practice in self-directed support. The network has hubs in 12 countries (Australia, England, Finland, France, Ireland, Korea, New Zealand, Northern Ireland, Scotland, Slovakia, Spain and the USA) plus the SDS Research Hub based at the Human Services Research Institute.

The SDS Network developed out of the 2015 Vancouver Conference on self-determination and is hosted by Citizen Network. It is the publisher of the **17 Global Standards for Self-Directed Support** which were launched at the Global Leadership Exchange in Brussels in 2024.

Stay in touch by joining our **mailing list** and get in touch if you wish to develop a hub for self-directed support in your country.

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Self-Directed Support Network

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Introduction

In June 2026, 33 people from nine countries gathered for two days in Ottawa to connect and exchange ideas about self-directed support. The convening was organized through the Global Leadership Exchange, hosted by Karis Disability Services, and facilitated by members of the Self-Directed Support Network. This summary provides an overview of the main ideas that participants came back to throughout their two days together.[1]

Disabled people, advocates, researchers, government colleagues, providers and people working in community organisations all brought different perspectives, yet the same message kept coming through: **Self-directed support is about people having more say over their own lives.** It is not just about budgets, forms, policies, services or clever system design. Those things matter, but only if they help people live a life that makes sense to them. The language of choice and control has travelled a long way, but the reality is still patchy. In some places there are strong laws but weak practice. In others there are good pilots but no real route to scale. In others there are individual budgets, but not enough help for people to use them well.

The Big Message

> Self-directed support works best when people are trusted, when they have flexible resources, and when the right help sits around them. That means clear information, planning support, peer support, advocacy, supported decision making, good providers, accessible communities, transport, housing, communication support, and safeguards that protect people without taking over their lives.
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> Without those things, self direction can easily become a promise on paper. People may technically have a budget, but still have to fit into old service menus. They may be told they have choice, but only from a short list of approved options. They may be given responsibility, but not the practical backup to make good decisions, employ people, challenge poor practice or try something different.

[1]Source Note: The meeting was transcribed, and participants documented their ideas in notes through various activities. This summary is based on the meeting transcripts, table notes, notes from a debrief held at the Global Leadership Exchange after the two-day meeting, and the personal stories and reflections from participants Mo Ahmad, Ray Ellis, Dr. Clenton Farquharson, Fionn and Jonathan Angus, and Joe Kingdom. It was generated using AI with review and revision by the SDS Network facilitators Chris Watson, Simon Duffy, and Bevin Croft.

The Global Picture: Regional Snapshots

During the morning of day one, participants reported on the state of self-directed support in their respective countries. The countries are different, but the pattern is familiar: the idea of Self-directed support has travelled further than the practical conditions needed to make it real for everyone. Many places now use the language of choice, control, personal budgets, direct payments or individualised funding. But that does not always mean people actually have power over their lives. People kept describing the same pattern in different systems. There are good laws, good policy words, committed people and some brilliant examples. Then there are the old system habits that keep pulling things backwards: eligibility rules, block contracts, risk systems, underfunding, waiting lists, narrow purchasing rules, professional control and a lack of practical help around the person.

So the morning was not really asking, “does Self-directed support exist?” In most places, something like it exists. The deeper question was: does it have integrity? Does it really move power towards disabled people and families? Does it help people build a good life, or has it just become another funding process?

Canada

Good intentions, but the infrastructure is not strong enough yet

The Canadian discussion was a good reminder that Canada is not one simple system. Disability support is organised differently across provinces, so the picture changes depending on where you are. The group talked mostly about Ontario, British Columbia and Saskatchewan, with some wider points about Canada as a whole.

In Ontario, people described a system with good intentions. There are organisations trying to listen better, document how people want to be supported, and work with families in a more individualised way. But people also talked about the limits. The system is still heavily shaped by shared block funding, waiting lists, resource pressures and risk. In practice, choice can become quite narrow.

One of the clearest points was that individualising money is not enough if the service itself does not change. If a person is still living in a group setting, still sharing staff, still having decisions made around them, and still unable to choose who supports them, then the budget may be more individualised on paper, but the person may not feel much more in control.

British Columbia seemed to have some stronger self-directed routes, including individualised funding, host agencies, navigator roles and micro boards. People can sometimes use funding in a much fuller way, including support to live in their own apartment. But the striking point was how few people use it. The figure discussed was around 5% of people self-direct their supports. That raises a big question: if the option is good, why is it not reaching more people? Is it lack of awareness, lack of advice, lack of confidence, shortage of host agencies, workforce pressure, or the fact that it works best for people who already have strong support around them?

Saskatchewan brought a different lesson. People talked about a caseworker role that can follow the person and support planning and decision making. That sounded important, because one of the big missing pieces in many systems is a trusted person who stays with the person, helps them understand choices, and does not just disappear once the plan is written.

The simple Canadian takeaway is this: there is real interest in self-directed support, and there are useful things to learn from different provinces. But the big missing piece is infrastructure. People need planning, advice, navigation, supported decision making, portable funding, flexible providers, workforce stability and practical help. Without that, choice and control remain too dependent on where someone lives, who they know and how hard they can fight.

England

The right ideas are there, but they need watering again

England was described as a garden with the right seeds, but not enough watering. The law, policy language and tools are there. Direct payments, personal budgets, individual service funds, strengths-based practice, peer support and personal assistant models all exist. But the energy has faded in many places, and practice is very uneven.

The group talked about direct payment numbers falling from previous highs and about self-directed support not being properly extended to people who need more support to use it. Too often, it still works best for people who are already confident, informed and able to navigate the system. People with learning disabilities, autistic people, people with complex support needs, people without strong family advocacy and people who need help with decision making can still be left with less real control.

The hopeful bit is that the spirit has not gone. There are still places trying to return to the roots of self-directed support. Individual Service Funds are being talked

about again. Peer support and community led support still matter. Some areas are beginning to see that self-directed support can be more efficient, not because it cuts support, but because it uses resources around real life rather than fixed service slots.

The English lesson is that having the legal framework is not enough. If there is no energy, no leadership, no practical support, no provider development and no pressure on local systems, the model slowly becomes smaller than it was meant to be.

Ireland

People are creating their own routes because the system is too slow

Ireland was described as a “lottery”. In plain English, people’s chances depend far too much on where they live and who they happen to speak to. Advice can be limited and confusing. Personal budget legislation exists, and there has been some piloting, but progress is slow.

The group talked about a pilot that was meant to involve many more people than it actually reached. People want flexibility, but the system can still pull funding back towards quite narrow personal assistance arrangements. That makes it harder for people to use support creatively to build a fuller life.

The hopeful story from Ireland was Fionn and Jonathan and Fionnathan Productions (shared below). Their work showed that people sometimes have to create a workaround when the official system does not give them the right route.

The Irish lesson is that people should not have to invent a whole workaround to live a self-directed life. But when they do, we should pay attention, because those workarounds often show the system what it should have made possible in the first place.

Scotland

Strong law, but people are still too often pushed towards traditional services

Scotland has one of the clearest legal frameworks, with four options under its self-directed support legislation. In theory, people can manage their own budget, have an Individual Service Fund, use traditional services, or mix these approaches. That framework is strong and is still important.

But the group was honest that the law has not been fully delivered. Too many people are still steered towards Option 3, the traditional service route. Local areas interpret the legislation differently. Money is tight. Eligibility is being narrowed. People worried that human rights language can be strong at national level, but weaker in everyday local practice.

At the same time, Scotland gave one of the strongest examples of provider innovation. ENABLE, Scotland's personal assistant model, was discussed as a way of giving people more control over staff without forcing everyone to become an employer. Staff are recruited around the person, their life, relationships, values and interests. The provider still carries some of the employment and regulatory responsibility, but the support is shaped much more around the individual.

The Scottish lesson is that good law matters, but culture and implementation matter just as much. Providers can either pull people back into old service models, or they can help people direct their lives without carrying every administrative burden themselves.

Slovakia

New personal budgets, but also pressure back towards institutions

Slovakia brought a very important warning. New personal budget legislation is emerging, but it is likely to be gradual and limited. It may mainly cover home-based care and may not reach people who need more support. At the same time, there are pressures pushing the system back towards institutional responses.

People talked about private companies taking over parts of social care and lobbying for more institutional models. There were also concerns about assessment changes being used to reduce support. That is a real danger for self-directed support everywhere: the language of reform can exist at the same time as financial and provider pressures that move people away from ordinary life and back towards institutions.

But Slovakia also had some really hopeful examples. The Support for Independent Living project was described as flexible and person-centred. There is work to use the SDS Standards. People with lived experience are being trained as service quality inspectors. Inclusive researchers with learning disabilities are teaching government and providers how to create Easy Read materials.
The Slovakian lesson is that lived experience leadership is not a nice extra. It is part of how we protect quality and stop systems drifting back towards institutional thinking.

New Zealand

A good vision has been knocked backwards by policy change

New Zealand was one of the clearest examples of frustration and loss of trust. People talked about the Enabling Good Lives approach as a really strong vision. It created hope, language and direction around choice and control. There were pilots and real momentum.

But people also said that progress has stalled. The clock has been wound back. The Ministry for Disabled People gave people hope, but then commissioning was moved away from it, leaving it with less power to change what actually happens. People described caps, no referrals, tighter purchasing rules and reforms being described as “stabilisation” or “consistency”.

The concern is that stabilisation can sound sensible from inside government but feel very different to disabled people and families. It can mean less flexibility, less trust, more reliance on family and friends, and more worry about means testing or restrictions. People were particularly concerned that natural support could be defined so broadly that government support becomes something people only get after family and friends have been stretched further.

The New Zealand lesson is about durability. A good vision is not enough if it can be weakened by changes in government, commissioning structures or fiscal pressure. Self-directed support needs political protection, public understanding and infrastructure strong enough to survive policy swings.

Australia

The NDIS changed the world, but also created new problems

Australia was described as contested. The National Disability Insurance Scheme or NDIS has made individualised funding part of the mainstream in a way few countries have achieved. It gave many people access to support and the possibility of more control. But the discussion was very clear that scale has brought serious problems too.

People talked about public narratives around cost, fraud and provider capture. Families, especially parents of children, can be portrayed as taking too much from the system. There were worries about particular groups being carved out of the NDIS, including autistic children and children with developmental delay, with

psychosocial disability possibly next. People also talked about social and community supports being taken out, which makes it harder for people to use support to build a good life.

A big theme was the market. The NDIS created a market, but not enough guardrails. People talked about providers entering too easily, support becoming siloed, incentives not rewarding coordinated support, and vulnerable people being exposed to poor or exploitative practice. The system gave people self-direction in theory, but it did not always build the support people need to direct well.

The children's space was a particular concern. Families may have to chase labels, assessments and disability system routes to get help that previously might have come through schools or community supports. That can medicalise children and make families jump through more hoops.

The Australian lesson is not that national schemes are wrong. It is that scale without values, evidence, local connection and good infrastructure can create new harms. The NDIS shows both the promise and the risk of making individualised funding mainstream.

United States

Self-direction exists almost everywhere, but it is still too uneven

The United States discussion showed a different kind of problem. Self-direction has been around for a long time and is available in every state in some form. Person-centred language is built into guidance and regulation. On paper, the idea is well established.

But people also said implementation is hugely uneven. One way of saying it is: if you have seen one self direction programme in the US, you have seen one self direction programme in the US. It can look very different from state to state. It is also not portable. If someone moves states, they may have to start again, and there may not be an equivalent option available.

People described self-direction as still feeling boutique in many places. Many people do not know about it, or do not have the knowledge, confidence or support to use it. This creates an equity problem. The people most able to fight their way through the system are often the people most likely to benefit.

There were also worries about fraud narratives, especially around paying family caregivers. People did not say there is evidence of widespread fraud, but they did say the political story is powerful. Once fraud becomes the main story, flexibility can quickly be replaced by suspicion and control.

The United States lesson is that spreading a model across many systems is not the same as making it easy, fair or understandable. Self-direction needs data, public explanation, portability, practical support and a stronger story about why it matters.

Personal Stories and Reflections

During the afternoon of the first day, disabled participants shared from their direct lived experience. This session gave the whole Match its human centre. It reminded everyone that self-directed support is not mainly about funding routes or service models. It is about how people are treated, whether they are listened to, and whether support helps them live the life they want.

Mo Ahmad: Ask me, explain why, treat me with respect

Mo's reflections show that good support is built through ordinary actions: ask me, listen to me, explain things to me, include me, plan with me, respect me, and do not talk about me without me. For Mo, choice and control are not only about services or systems. They are about how people treat him every day. Good support means seeing him as a person with his own views, needs, relationships, judgement and wisdom. It means making sure his voice is at the centre of decisions about his own life.

Choice starts with being asked. Mo was clear that choice means being asked what he wants to do. As he put it, choice is about "what I would like to do". He does not want people to tell him what he is doing, or what time things will happen, without involving him. For Mo, that feels controlling. Good support starts when people ask him, listen to him, and take his answer seriously.

Support is about relationships. Mo came back again and again to "respect, love and kindness". He said that staff can become like family. The relationship matters because support is not just a task. It is something built through time, trust, good moments and difficult moments. Mo said he tries to focus on the now and on what comes next, while still remembering what has happened before.

He also spoke about mutual respect. If staff have an idea, he wants to listen to it. If he has an idea, he wants staff to listen too. For Mo, good support means respecting each other's ideas and opinions. It is not staff on one side and the person being supported on the other. It is people working together.

Do not talk around me. When Mo talked about lacking choice and control, one of the clearest examples was being talked about as if he was not there. He does not like people whispering, talking about his care, or making decisions around him without including him. Mo's message was simple: "ask the person". Do not only ask staff or

caregivers, because they only know part of him. They learn over time what he likes and does not like, but that does not mean they should speak for him without him. Mo said communication is about "trust, respect, and honesty".

Practical barriers affect real choice. Mo also talked about the practical things that can make choice and control harder. He spoke about washrooms, personal care, accessible spaces, transport, vehicles, walking routes, staff availability, and whether staff are able to drive. These things may sound small to a service system, but they are not small to Mo. They shape whether he can go out, where he can go, how safe he feels, and whether his dignity is protected. He gave the example of needing to use a washroom in the community and not wanting to be told no because of staff gender, access rules, or the lack of a family or accessible washroom. For Mo, the basic point is that he is human and should be treated with the same respect as anyone else.

Mo also described a programme where there was no safe walkway into the building. People had to go along the road, with staff guiding them. He spoke about how transport can limit choice too. If there is only one vehicle, or if no staff member can drive, then the choice to go somewhere may disappear.

Because Mo has vision difficulties, walking safely in the community also depends on staff understanding him, knowing how to support him, respecting boundaries, and having experience of working with people with disabilities.

Do not just say no. The change Mo most wants to see is that people should not simply say no without explaining why. If staff are not available, he wants to know. If another staff member can be called, he wants that to be tried. If something cannot happen, he wants the reason and the details. Mo wants to be part of decisions. He said, "I want to know why" and "I want more details". One of the strongest lines from his contribution was that he wants to be part of decisions because he is pretty wise. His message was: "just ask me".

Ray Ellis: Communication, belonging and real choice

Ray Ellis spoke about choice and control in very practical terms. For Ray, self-directed support is about where he lives, who he lives with, whether people can communicate with him, whether he can get out, and whether he can be part of his community.

Ray's message is clear: learn how to communicate with me, give me enough support, make places accessible, improve transport, create real employment opportunities, and let me have more choice about where and with whom I live. For Ray, good support is support that helps him belong.

Still looking for the right place to live. Ray began by explaining how much effort he has put into finding a living situation that works for him. He wanted to know what places in Ottawa would be right for him. He first moved into a group home model, which worked well because his housemates were at a similar support level. Later, when that home was due to be replaced by apartments, Ray tried apartment living. He said it was very difficult, isolating and lonely.

Ray then advocated to move back into a group home. He wrote to his local politician, John Fraser, and even went to his barbecue. That advocacy helped him move to Karis. At first, Ray lived in an apartment in the same building as Mo, which is how they became friends. But the apartment was still isolating, and fire code was also a problem. Ray moved again, hoping roommates would make him less lonely. That did not work either: the house was loud, and he did not connect with the people there. Ray is now in a different group home, but he said it is still not exactly what he wants. What he really wants is to live with his friend Mo, just the two of them.

Communication comes first. One of Ray's strongest messages was about communication. When staff are not able to communicate with him, and when his talker is not set up, he feels 'lonely and sad', 'upset and frustrated'. He said he does not like feeling like a burden on staff.

Ray wants staff to be trained to communicate with him and to help him find places to go and things to do. When things go well, people communicate with him using the board on his wheelchair tray. Staff take the time to sit and talk with him. When that happens, Ray said he feels 'happy and good' and 'like I belong'.

Being part of community. Ray gave church as an example of what belonging looks like. He said he loves going to church because he can see friends and people in his community. He also enjoys singing there. This was a simple but powerful example

of what good support makes possible: not just receiving care, but being present, known, connected and included.

The barriers Ray wants people to understand. Ray named communication as one of the biggest barriers. Without his talker, communication is not good. Too often, people only ask yes or no questions. Ray said only one staff member in his home currently knows how to use his board. Training has happened, but staff turnover means the learning does not always stay in place. Ray understands that people are still learning, but he wants at least a few people around him who know how to use his board.

Ray also spoke about funding and care. He said there is not enough money and that he needs more care so he can do the things he wants to do. He wants more choice in who he lives with. He said he does not want to have to live with people whose disabilities are very different from his. When someone yells unexpectedly, his body jumps because of his startle reflex. Having to keep his defences up every day is, in his words, 'very, very, very tiring'.

Accessibility, transport and work. When asked about the change he most wanted to see, Ray talked about accessible places and better public transportation. He said buses can be very late, which means people miss appointments. He also said he wants to work because he really likes to be busy and wants to be part of his community. Ray said many places are not accessible, and employers do not always want to employ disabled people because they think accessibility takes too much time and money. He said government should bring employment back into law so employers have to consider disabled people.

Rules should not trap people. Ray also raised fire code and housing choice. Because Ray receives support from an agency, rules about fire safety and self-evacuation can limit where he is allowed to live. This means he may have to live in a group home, even if he would rather live in an apartment or in a home with one chosen person.

Dr Clenton Farquharson: From service-shaped lives to life-shaped support

The following is a narrative prepared by Dr. Farquharson for the event.

For me, self-directed support is very, very personal. My life changed in February 1995. I was intervening to stop a young woman from being raped, and I was attacked and stabbed 26 times. That moment changed everything.

I've said before to people who know me: the NHS saved my life, but social care changed my life. Social care, personal assistance, equipment, adaptations, income support and wider community support helped determine the life I could live afterwards. That distinction matters.

Sometimes we get wrapped up in services and we don't ask the question: what makes your life worth living? The issue is not simply whether a service was delivered. The issue is whether a life was enlarged.

Self direction changes the question from, 'What service can we offer?' to, 'What life does this person want to lead?' It is not just about paperwork. It is about power in the hands of the person. It is the difference between standing outside the door of your own life and being given the keys.

I am not a care package. I am not a form to be filled. I am not a risk to worry about. I am a person with work to do, relationships to build, places to be and contributions to make.

One of the biggest things I have always fought against is the narrative of disability. When I acquired my disability, I was told I would never work again. I was told I would never parent again. I would be looked after. I know that was said with the best intentions, but it scared the living daylights out of me. Everyone was telling me I should be grateful that I was alive. That lasted about four weeks. After that, I wanted to have a life.

Before the accident I used to play rugby at a pretty good standard. That all went overnight. Then the NHS and social care became two tribes, arguing about who would fund me getting back to my Victorian house, with steps to the door, another flight inside, and a bathroom that wasn't accessible. For two and a half years, my family and friends carried me up and down the stairs. That is not dignity.

When choice and control are missing, life gets smaller. It can feel like standing in a corridor with separate doors: adult social care, NHS services, benefits, housing

adaptations, equipment, transport, employment support, advocacy and voluntary sector support. Each door has its own form, assessment, threshold, language, evidence requirement and waiting time.

On paper these are separate systems, but people do not live in systems. People live lives. In real life it is one body, one home, one bank account, one family and one future. The biggest issue is not just that the system is complex. It is that the person has to carry the complexity.

When I have real choice and control, life opens up. The walls move back. I feel more human, more trusted and more able to contribute. I have personal assistants who enable me to parent, work and do everyday activities. But I still have to navigate different forms of funding and learn legal language and financial complexity because information and advice are not always treated as a right.

For me, a gloriously ordinary life means being able to get out of bed when I want, leave my home, see people I love, work, contribute, take risks, be safe, take part and belong. That is not sentiment. That is infrastructure, rights and power: housing, personal assistance, transport, equipment, income, advocacy, peer support, employment, education and access to the environment.

Advocacy, for me, is about making good trouble. We also have to remember that support is not only about personal care. That is one pillar. If one pillar is missing, the whole structure becomes unstable. You can have everything else, but if you cannot leave your door because of public transport, it all falls down.

At its best, self-directed support helps people stop asking for permission to live.

The change I most want to see is a move from service-shaped lives to life-shaped support. That means asking once and sharing properly, so people do not have to keep repeating the most personal parts of their lives to prove what has already been proven. It means assessing the whole life, not just service eligibility. And it means funding outcomes that matter, not just outputs and activities.

We talk about key performance indicators, but we do not measure key human indicators. The person should not have to join the system together because the system has failed to join itself together.

For me, the policy test is simple: does the decision you make increase or reduce the person's choice, control, dignity, safety, participation and ability to live in the community of their choice?

Fionn and Jonathan: From ‘none of the above’ to abundance

Fionn and Jonathan are a son-and-father team with an ambition to change the world. Fionn and Jonathan's message was one of abundance. Their presentation was not a conventional life story. It was a quick journey through the work they have built together: self-directed support, creative collaboration, inclusive research, advocacy, travel, film, art and supported entrepreneurship. Their presentation showed self-directed support as more than a choice between existing services.

Choosing ‘none of the above’. Their starting point was Fionn leaving secondary school. Before that point, they had already been learning about social role valorisation, personal budgets, inclusive research, human rights and citizenship. So when Fionn was offered a menu of day services, his answer was simple: 'none of the above'.

Instead of choosing an existing service, Fionn and Jonathan asked whether the money that would have gone to a service provider could be used by Fionn to build the life he wanted. The answer at first was no. They kept asking. Eventually, a workaround was found: the state would not give funding directly to an individual, but it could fund a company. So they created a company - effectively a service provider for one person. What began as an awkward workaround became the foundation for Fionnathan Productions.

Support as a platform for contribution. The point of the company was not simply to arrange support differently. It was to make possible a different kind of life. Fionn did not want to be 'cooped up in one place'. He wanted to travel the world, learn about wildlife and the natural world, share stories, make art and collaborate with others. The presentation included examples of creative work in different places, including travel, music, comedy, art and performance.
Their message was that self-directed support should not end with a person being looked after. It should help people discover and share their gifts. For Fionn and Jonathan, choice and control are closely tied to contribution: the chance to make things, meet people, ask questions, tell stories, and be part of work that matters.

More than ‘self advocacy’. Fionn and Jonathan also challenged the way people use the term 'self advocate'. They were clear that advocacy matters, but they questioned why people with intellectual disabilities are so often described only through that label. The examples they shared included community, peer, legislative and international advocacy. Their point was not that self advocacy is wrong, but that people should not be reduced to it.

I**nclusive research and asking better questions.** Their work in inclusive research carries the same message. They argued that people with intellectual anddevelopmental disabilities should not be brought into research late in the process, or only given a small role. They should be involved from the beginning - before the grant application, through design, delivery and presentation. Their own long-running research asks people a simple question: 'What do you love about your life?'

That question captures a lot of what Fionnathan stands for. It begins with what matters to people, not with what is wrong. It invites people to speak about meaning, identity, joy, contribution and the good life. It also makes space for people who communicate in different ways, including people who use boards or other forms of supported communication.

A place in the room. Fionn and Jonathan reflected on being in rooms such as the GLE and the United Nations. They said they can feel overwhelmed by the professional status of others, but then realise that they have a place there too: 'they need us' and 'we need them'. Lived experience is not an optional extra in conversations about systems, research or policy. It is part of the knowledge those rooms need.

Supported entrepreneurship and abundance. The final part of the presentation focused on their new initiative Abundant Enterprises and supported entrepreneurship. Fionn and Jonathan described co-designing a course with people with Down syndrome or intellectual disabilities and supporters about starting a business. The course is rooted in citizenship: knowing your rights, understanding your responsibilities, discovering your gifts and finding the support needed to make a meaningful contribution.

They also described how they have 'hacked' different forms of support. Fionn hired Jonathan as his first personal assistant, but they soon realised that running self-directed support involves work that often goes unpaid: planning, administration, paperwork, coordination and advocacy. Their view is clear: people should be paid for running their own supports. They have also looked for different funding streams, so that self-direction is not dependent on one fragile pot of money.

Joe Kingdom: Right support, right time, real opportunities

The following is a narrative prepared by Joe Kingdom for the event

Before I start, I want to thank all my co-panelists for sharing their stories. They have been powerful, and I hope I can follow with my story.

When I talk about choice, you have to look at where I started. I have a disability that affects my motor skills, my speech and the pace at which I work. Back in 2017, I was involved in a course, but honestly the support just was not right for me. I felt completely stuck. My future felt very bleak.

The turning point for me was making the choice to join ENABLE's Breaking Barriers programme in the summer of 2018. That involved studying at the University of Strathclyde Business School and getting a work placement at ScottishPower. More importantly, it allowed me to learn in a way that worked for me. Because I was given ways to learn that worked for me, I built confidence in my own abilities. I took control of my career.

Now I work full-time in a legal department at ENABLE. I also got the opportunity to study to become a paralegal, which was something I was nervous yet eager to do. ENABLE encouraged and supported me throughout. As of February this year, I am officially a trainee paralegal. I feel proud, not only for accomplishing a personal goal, but for showing what becomes possible when disabled young people get the right support and opportunity.

My story is deeply personal to me, but it reflects a much bigger challenge. Many young people want to contribute to society, but struggle to access the right opportunities and support. The difference for me was having access to the right support at the right time, from people who believed in my potential. Having that choice did not just give me a job; it gave me a career path, confidence, independence and a future.

When you do not have choice and control, it feels like doors are locked before you even get a chance to knock on them. When systems did not listen to me, I felt completely underestimated. People saw my disability first, rather than looking at what I was actually capable of. When you are not given a say in how you are supported, or when there are no accessible options available, you lose your independence. You begin to doubt yourself because other people are doubting you. You can end up isolated, feeling like you do not have a future or a purpose.

When you finally get to exercise choice and control, it completely changes. You can do anything as long as you set your mind to it. Having control over my career and my support gives me a reason to get out of bed every morning. When I am in control, my confidence skyrockets. I went from being a nervous wreck with very low confidence to standing on a stage at the United Nations, opening the Zero Project Conference in Vienna. I have also cycled from London to Paris, raising money for charity.

What changes is how you see yourself and how the world sees you. You stop being someone who just receives care, and become a professional who contributes to society and helps others. Having choice and control has allowed me to build a career, contribute to my community, and hopefully inspire others to aim higher.

The biggest barrier I face has not even been my disability. It is other people's low expectations. Too often, employers or educators look at the label and assume you cannot do the work before they even give you the chance to try. Another barrier is the lack of opportunities to get your foot in the door. If workplaces do not offer accessible internships, placements or entry routes, you get trapped in a loop of needing experience, but never getting the chance to get that experience.

Communication is also a major barrier. Mainstream environments often do not know how to adapt. If information is not shared at the right pace or in an accessible format that lets me process it properly, I am locked out of making informed decisions.

The one change I want to see is for the Breaking Barriers programme to become the standard everywhere. We need public sector organisations, universities and private businesses working together in real partnerships to create accessible routes into education and employment. It should not be a one-off project or lucky opportunity.

Self-directed support is not a luxury or an afterthought. It is a basic human right. When you give us the right support and the power to choose our own path, we do not just survive. We thrive. We work. We contribute. We lead. I would challenge leaders not simply to talk about the barriers disabled people face, but to invest in and scale solutions that work.

Strategies for Change

The first day was about orienting one another to the current state and grounding the meeting in lived experience perspectives. The second day built from that foundation of shared understanding and values by focusing on how change happens. The group used a simple innovation curve to think about different stages of development. For each stage of development, the group asked: what kind of strategy is needed at this stage?

The same strategy will not work everywhere. A country with no real self-directed support system needs something different from a country with a pilot. A country with a working law but poor uptake needs something different again. And a country trying to make self-directed support normal for everyone has a different challenge: how to keep the values alive when the system gets bigger, more regulated and more political.

Stage 1. Make the Idea Visible

This is the stage where there is little or no self-directed support, or where people do not see it as relevant. The system may be built around institutions, block contracts, fixed services or professional control. Disabled people and families may not have heard of self-directed support, or they may have been told it would not work for them.

At this stage, the job is to make the idea real. The question is: can we show what becomes possible when support is shaped around a person instead of a service? People need to see it, feel it and recognise it. Stories matter here. Small examples matter. Champions matter. Peer networks matter.

Useful strategies at this stage include sharing powerful lived experience stories, finding early champions, creating small practical examples, using simple language, connecting the idea to human rights and citizenship, and building a small community of people who believe this can work. The aim is to move self-directed support from being invisible to being imaginable.

Stage 2. Build Trust around Early Practice

This is the stage where pilots exist, or a few people have individual packages, but people are still nervous. Governments may worry about risk, fraud or cost. Providers may worry about losing control or income. Families may worry about being left with more responsibility. Disabled people may worry that the offer is not real, or that they will have to fight too hard to use it.

At this stage, the job is to build trust. That means being honest about what is working and what is not. It means not pretending that pilots solve everything. It also means showing that self-directed support is not chaos. It can be values led, safe, accountable and practical, if people have the right support.

Useful strategies include independent evaluation, plain English learning from pilots, honest stories from disabled people and families, clear guidance for practitioners, support for providers to change their role, early economic evidence, and communities of practice where people can learn together. The aim is to move self-directed support from being a risky experiment to being a serious route for change.

Stage 3. Simplify to Make it Usable for Ordinary People

This is the stage where self-directed support exists, but only a minority of people use it well. There may be laws, policies, personal budgets, direct payments, individualised funding or self-direction programmes. But the process may be hard work. People may need confidence, time, paperwork skills, family support and system knowledge to make it work.

This is where many systems get stuck. Self-directed support becomes technically available, but practically exhausting. The people who benefit most may be the people who already have strong networks and good advocates. That is not good enough.

At this stage, the strategy is simplification. Make the system easier to understand. Reduce paperwork. Provide independent advice, brokerage, peer support and navigation. Make information accessible. Offer practical help with payroll, recruitment, employment and administration. Develop Individual Service Funds, host agencies and provider models that reduce burden while keeping power with the person. Train workers and managers so they do not quietly pull people back into old service thinking.

The aim is to move self-directed support from being available only to determined people to being usable by ordinary people, including people with communication support needs, people without family advocates, people with higher support needs and people who have been excluded from earlier models.

Stage 4. Make Self-Directed Support the Norm

This is the stage where there is appetite for bigger change, or where individualised funding has already become a large part of the system. Once self-directed support gets big, the system often tries to control it. Rules multiply. Flexibility narrows. Markets grow without enough values. Cost and fraud stories become louder. People can end up with a national programme that still does not feel personal.

At this stage, the task is integration with integrity. Self-directed support has to be built into legislation, funding, assessment, planning, information, workforce, quality assurance, research, provider culture and community development. It cannot sit as an add-on next to the old system. But it also cannot become so bureaucratic that it loses its heart.

Useful strategies include aligning funding streams, protecting flexibility, using standards or scorecards to test whether choice and control are real, investing in lived experience leadership, building strong safeguards that protect people without controlling their lives, developing provider accountability, making outcome data about real life, and keeping local community connections alive. The aim is to move self-directed support from being a programme to being the normal expectation of how support should work.

How this Connects to the Participating Countries

The stages are not neat labels. A country can be in more than one stage at the same time. One part of a system may be mature, while another group of people has almost no access to self-directed support at all.

Ireland, Slovakia and some Canadian contexts show why the first and second stages matter. There are powerful examples and emerging laws or pilots, but people still need clearer routes, better information, trust and practical proof.

England, Scotland, British Columbia and parts of the United States show why simplification (stage 3) matters. The mechanisms exist, but the experience can still

depend too much on where someone lives, who they know, whether they have family support, and how much energy they have to fight the system.

Australia and New Zealand are examples of why stage 4 matters. Both have had big visions and significant scale. But bigger systems bring bigger risks: loss of flexibility, public anxiety about cost, tightening rules, market problems, and the danger that the original values get buried under system management.

Canada probably shows the whole picture at once. Some provinces are still trying to work out how to individualise support from block funded systems. Some have individualised funding routes that only a small number of people use. Some have useful planning or caseworker roles. The lesson is that national conversations need to respect provincial difference, while still asking the same human question: what does the person actually experience?

Practical Actions and Proposed Next Steps

In the afternoon of the second day, the group reviewed the current research on self-directed support and then built a working to-do list. The two days created a lot of energy, but the next step is to turn that energy into a small number of useful actions that people can actually carry forward.

Action cannot just mean more meetings. Action means useful products, clearer learning, stronger connections, better local practice, and a more sustainable SDS Network. It also means making sure disabled people and families are not just consulted, but involved in leading, testing and shaping the work.

Future next steps will need to be refined and planned, but for now, this list covers the main practical next steps that came through the conversations.

1. Keep lived experience at the centre

The strongest parts of the two days were not abstract. They came from people speaking about their lives. Mo reminded people to ask, listen and explain. Ray showed how communication, home and belonging are practical issues, not extras. Clenton talked about moving from service-shaped lives to life-shaped support. Fionn and Jonathan showed what happens when support is built around contribution and abundance. Joe showed how the right support at the right time can unlock work, confidence and leadership.

So one practical action is simple: do not let the lived experience pieces become a nice emotional section at the front of the report and then disappear. They should shape the standards, the evidence work, the provider conversations, the strategy work and the next meetings. Practical next steps could include:

- confirming any remaining permissions and final wording before wider publication;
- using stories as teaching and discussion material;
- inviting people with lived experience to help shape the next products;
- paying disabled people and family leaders for research, facilitation, review and public speaking roles wherever possible;
- making sure people with communication support needs and people with high support needs are not left out of future work.

2. Turn the SDS Network Standards into something people can use

The standards give the movement a useful centre of gravity. They help us say what good self-directed support should look like without pretending every country has to use exactly the same model. The next step is to make the standards practical. They should not sit on a website as a nice statement of values. They should help people ask: is this real in everyday life? Do disabled people actually see it, feel it and experience it? Possible actions include:

- creating a simple self-assessment tool or scorecard based on the standards;
- testing the scorecard with disabled people, families, providers and public bodies;
- using plain English questions such as “am I asked first?”, “do I understand my options?”, and “can I use support in a way that fits my life?”;
- using the standards for learning and improvement, not just compliance;
- developing simple examples of what each standard looks like in real life.

3. Make research useful, not hidden away

A really important message from the research review was that there is already a lot of research on self-directed support. The problem is that too much of it is hard to find, hidden behind paywalls, written in academic language, or not translated into practical tools. This gives the SDS Network and partners a clear job: translate knowledge into action. Practical next steps could include:

- creating a small online evidence hub;
- starting with plain English summaries of key research;
- producing Easy Read or visual versions where possible;
- creating short policy briefings on live issues such as flexibility, safeguarding, cost, administrative burden and provider culture;
- linking academic evidence with lived experience and local practice;
- asking researchers to include a “what this means for action” section in anything they produce.

This does not have to start big. A small, useful collection of evidence that people can actually use would be better than a huge library that takes a lot of work to maintain or that nobody knows how to navigate.

4. Build learning circles and communities of practice

One of the clearest messages was that people do not want to keep solving the same problems alone. Countries, regions and organisations are facing similar issues: low uptake, poor information, provider resistance, budget anxiety, bureaucracy, workforce problems, weak evidence and loss of flexibility. The SDS Network can help by creating spaces where people facing similar issues can learn together. Possible actions include:

- regular online learning circles by theme or stage of development;
- groups for people with lived experience, families, providers, researchers, policy people and advocates;
- international sessions where one country brings a live problem and others help think it through;
- short webinars focused on practical tools, not just presentations;
- sharing failures and problems as well as good news.

The tone matters. This should not be a polished conference machine. It should feel like a movement helping itself think, learn and act.

5. Support local action and visible examples

Global learning only matters if it changes what people experience locally. The conversations kept coming back to the same point: local culture, local providers, local government, local workers and local relationships can make or break self-directed support.

One useful next step would be to support a small number of local demonstrations or action sites. These do not need to be huge pilots. They could be focused pieces of work where partners agree to test one thing properly and share the learning. Examples could include:

- a local area simplifying its SDS pathway;
- a provider redesigning support around individual budgets or Individuaised Service Funds;
- a peer network helping people understand their options;
- a region testing the standards survey;
- a research partner working with disabled people to document what changes in real life;
- a local government using its current powers to make support more flexible.

The important thing is to document what happens in ordinary language: what was tried, what helped, what got in the way, what changed for people, and what others could learn.

6. Work with providers on culture, not just contracts

People were rightly worried about provider capture, profiteering, weak regulation and systems that pretend people are empowered consumers when the market is not really fair. At the same time, good providers can be part of the solution. Some of the strongest examples came from organisations trying to do support differently: personal assistant models, host agencies, micro boards, support for independent living, peer led quality work, and providers who see their role as helping a person build a life. Good providers should move power closer to the person, not pull it back into the organisation.

The next phase should include some provider-facing work. This should not just be about procurement or compliance. It should ask what kind of culture helps people have more power. Practical actions could include:

- creating a provider reflection tool based on the SDS standards;
- asking providers how they share power with people;
- collecting examples of providers using Individualised Service Funds, host agency models, personal assistance and flexible support well;
- creating a provider learning circle;
- linking provider participation to transparency, values and willingness to be challenged by disabled people and families.

The aim is to help providers become part of the solution rather than just another part of the system people have to navigate.

7. Protect flexibity and reduce the burden on people

Flexibility came through as one of the heart issues. If support cannot flex around real life, it stops being self-directed support and becomes another service menu. But flexibility on its own is not enough. If people are left with all the paperwork, employment duties, audit anxiety, recruitment problems and system navigation, then choice can become another burden. Problems should lead to better support and better safeguards, not automatic restriction. Practical next steps include:

- identifying where forms, rules and delays are making self-directed support too hard;
- developing practical support for payroll, recruitment, employment and administration;
- creating independent navigation or brokerage roles;
- protecting the right to use support creatively, while having sensible safeguards;
- developing short briefings that explain why flexibility matters and how to manage risk without removing control.

8. Build a sustainability and finance framework for the SDS Network

One of the nicest things about the Match was the sense that people are not fighting these battles alone. Different countries are facing the same patterns: progress, pushback, austerity, confusion, missing infrastructure, good local practice, weak national learning, and the constant risk that the values get watered down.

The SDS Network can help with that. It can connect people, share practical examples, support local hubs, amplify lived experience, translate research, protect the standards, and help build a stronger public argument for choice, control, rights and citizenship.

The SDS Network has grown because people have given time, energy, relationships and goodwill. That is powerful, but it is not enough if the network is now being asked to hold standards, support hubs, translate research, host learning, produce resources and help countries learn from each other.

The next step is for the SDS Network to continue to strengthen its capacity in a sustainable way.

Final Thought

People left Ottawa with relationships, ideas and energy. The work now is to keep the spirit of Ottawa alive without turning it into another heavy process. The best next step is not to do everything. It is to do a few things well: share the learning, protect the values, support real examples, make research usable, strengthen the network, and keep asking whether disabled people have more choice, more control and a better chance of living the life they choose.

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