

1 **Day 1- Tuesday, October 23, 2023**

2
3 **Opening formalities**

4
5 Nancy Jokinen

6 Good morning, everyone. I hope everyone had a restful evening. For those of you who were not
7 here last night, we had an enjoyable dinner. And my name is Nancy Jokinen. I'm a member of
8 the planning committee that planned summit activities. I would like to introduce members of
9 the planning committee. First and foremost, I need to give some thanks to the team from
10 Reena, who were exceedingly helpful. Ziv over there, who's busy taking photographs for us, and
11 welcomed you at the desk. And Gary here, our excellent go between for various activities.
12 Thank you. And there are other members of the Reena team who aren't present at the moment
13 but were very helpful. Who else? Matthew Janicki, Phil McCallion. Excellent sources. Cathy
14 Service down there, Nurse Practitioner on the NTG board. Sandy Stemp, my good friend and
15 colleague from Reena and Dr. Karen Watchman, who joined us via Zoom from many miles
16 away. Between me being on the west coast of Canada, and her in Scotland, it's sort of amazing
17 to try to get people together. But we did it! And I want to thank all the committee members for
18 their help. Right now, I'm going to turn things over to Sandy, who is going to keep us on track
19 today, hopefully.

20
21 Sandy Stemp

22 Thank you, and lovely to be here this morning. For those of you who were not with us at the
23 dinner last night, this is your official welcome to Toronto. I always like to say the most diverse
24 city in the world. So, I am very, very happy to host and also certainly my pleasure as it is Reena's
25 50th year. Reena is a developmental service agency, and we support people in the Greater
26 Toronto Area. And throughout many years, we've had a focus on Aging, so not just sort of
27 within our local region, but provincially as well as nationally and been certainly my incredible
28 pleasure to work with Nancy. So, we wanted to recognize all the incredible people in the room.
29 Where are all the Canadians? Let's see your hands up there. Okay. Woo-hoo for the Canadians!
30 Yeah, tried to spread you around, just like a wedding. Right? I wanted to get you to meet new
31 people. Okay, what about the Americans? Woohoo, there's, oh, there's a bit of a cluster over
32 there. Oh, that's going to be a problem right there. And overseas, all the folks who traveled very
33 far to get here. Wonderful and welcome. So, I did mention last night and it's also worth
34 mentioning this morning that although we are celebrating certainly Reena's 50th, we're also in
35 significant distress related to some of the world events in Israel. Reena really has a lot of strong
36 ties and connections to Israel, we work with a lot of the developmental services agencies there,
37 so you know, just to mention that, as I mentioned, we're here with you at but our hearts are

1 also in Israel with all of those individuals. One of the things, as I mentioned, aging and dementia
2 has been near and dear to our hearts at Reena for almost 24 years and most of that time, it was
3 myself trying to try to lead or co-lead various events and snaffling people like Nancy to assist
4 me, so really such a great match for us to be able to host this event and really our pleasure. To
5 help us with some of the more acknowledgments around sponsorships, and those that we are
6 going to call up to speak, I'm going to call upon Gary Gladstone, the lead for Stakeholder
7 Relations, and also the lead for Reena at 50 activities.

8

9 Gary Gladstone

10 Thank you very much. So, first of all, everybody, welcome to Toronto. Thank you for coming.
11 Can't believe everybody got here. Unbelievable. We are thrilled to be hosting you as part of
12 Reena's 50th anniversary, as Sandy said, and for the important second Summit, so thank you.
13 And we wouldn't be here if it wouldn't be for our incredible sponsors. In addition to Reena, and
14 the Azrieli Foundation, who several of you heard from last night, we have Surrey Place and
15 Temple University's School of Social Work the Butz Family Fund. And our supporters, of course,
16 the National Task Group on Intellectual Disabilities and Dementia Practices, both the US,
17 Canada, the International Association for the scientific study of intellectual and developmental
18 disabilities, the University of Stirling and the Health Matters program of the University of
19 Chicago, Illinois. If we can just have a great round of applause for our sponsors and supporters
20 because we wouldn't be here without them. And thank you very much. When I started with
21 Reena, and I think I'm going on about eight years now, I needed to take people on tours of our
22 intentional community, the initial one would be opened up that's now been renamed the Sandy
23 Keshen Reena Residence. And we thought it was very important that we give the tour from an
24 individual supported individuals perspective, as opposed to my perspective. I met many people
25 there. And there was one individual in particular, Jason Marcovitch, who was an incredible tour
26 guide, who would take us all around, who would be chummy with everyone and was one of the
27 best ambassadors that Reena has. So, it's doubly my pleasure right now to introduce his mom,
28 who also doubles as a Reena board member, to say a few words. Dr. Sharon Marcovitch, if you
29 could please come up and say a few words of welcome.

30

31 Sharon Marcovitch

32 So hello, I'm truly honored to address you today as we kick off the second International Summit
33 on Intellectual Disability and Dementia, building on the success of your inaugural Summit held
34 in Glasgow, Scotland in 2016. My name as Gary said, is Sharon Marcovitch, and I'm a member
35 of the Reena board. I'd like to offer you a glimpse into my personal journey and the profound
36 impact that Reena with its intentional community housing model has had on our family,
37 particularly on our son Jason. When we began the quest to find a supportive and nurturing
38 environment for Jason, who has been a resident of the Reena Community Residence since its

1 inception, probably more than 10 years ago, we were filled with a mix of hope and anxiety. Our
2 search was not without challenges, as we were searching for a place that could provide Jason
3 with the care, compassion and understanding he truly deserved. From the moment we first
4 entered the Sandy Keshen Residence, our concerns quickly transformed into a deep sense of
5 reassurance. The staff's genuine warmth, unwavering dedication, and boundless empathy
6 enveloped us, instantly making us feel like an integral part of the Reena family. Throughout
7 Jason's residency, we have witnessed firsthand the life changing impact of the Sandy Keshen
8 Residence, the commitment to individualized care, the fostering of personal growth and
9 development, and the nurturing of a sense of belonging have all profoundly influenced Jason's
10 life, including becoming a tour guide. When Jason's evolving needs demanded a creative and
11 collaborative approach, the Reena team, in partnership with the Ministry of Community and
12 Social Services, worked with March of Dimes, another agency under the Ministry of Health to
13 develop a coordinated care plan for Jason. It was within the walls of this residence that Jason
14 has thrived, forming deep connections and achieving milestones, which we once believed were
15 unattainable. He, when he lived at home, was an anxious person. He didn't have any
16 connections with any community and was just happy to sit in his room at home and never
17 connect with anyone. And this was about age 33,34,35. So he wasn't ready to move out and
18 moving him to the Reena Residence, just like every day he would say when am I coming home?
19 And that was 12 years ago, and now he is an ambassador and asking when tours can start again.
20 He's actually in a wheelchair now and he wasn't in a wheelchair before. So that's been a very
21 big transformation. But he's actually happier now, less anxious, and much more involved in a
22 community that's important to him. So, Reena has made a huge difference. And this very
23 exciting collaborative model, where health and social services work together and need to work
24 together. And I see that in the future for so many people as they age. It's, it's really an
25 incredible opportunity and not dividing people into silos, separate silos. The other thing that I
26 learned about living in this residence for Jason was the idea of an intentional community. And I
27 remember when we first talked about the intentional community, what was that? And I
28 thought, well, this is just a great place for him to live. And we heard people way back saying,
29 well, intentional community is just another institution. And I remember thinking, oh, my gosh,
30 this certainly is not an institution. So how do we make people understand what an intentional
31 community is. And slowly over time, it's been exciting to see that people are understanding and
32 respecting the idea that you've got so many people with so many things happening and their
33 staff and connections to the community outside that are part of an intentional community. And
34 that really having an intentional community is the way to go for people as they age, and they're
35 in the community and being supported, to be continuing to be part of society, rather than going
36 into hospitals, or long-term care homes, if they don't have to. So, I was pretty excited about the
37 concept of intentional community. And that's been something that I am very thankful to Reena
38 for, that we've been part of that. As we convene here, I wish to express my gratitude to every
39 one of you, who have dedicated your time and effort to advance research, generate reports
40 and peer reviewed articles that will expand clinical knowledge and research in this field. Your
41 unwavering support for Reena, and its mission has my deepest appreciation. Through our

1 collective efforts, we can continue to provide essential support for aging individuals. I extend
2 my thanks as well, to the generous donors and everyone involved, including Reena, Surrey
3 Place the Azrieli Foundation, Temple University's School of Social Work and the Butz Family
4 Fund, as well as the National Task Group on Intellectual Disabilities and Dementia Practices
5 (now we know what NTG stands for), encompassing both the American and Canadian chapters,
6 for their valuable contributions and support towards the Summit. Have a very good two days.
7 Thank you.

8

9 Gary Gladstone

10 Thank you very much, Sharon. If I could also ask those of you who are already seated, you
11 already know who you are, if you can flip your name tags around the other way, so everybody
12 else can see you most have Thank you very much. So now, Minister Kamal Khera, the Minister
13 of Diversity, Inclusion, and Persons with Disabilities Federally, was unable to join us this
14 morning, but is delighted that we're all here and wanted to bring some greetings. So, if I could
15 turn your attention to the screen, thank you very much everyone.

16

17 Kamal Khera

18 Hello everyone. I am Kamal Khera, Minister of Diversity, Inclusion and Persons with Disabilities.
19 Before I begin, I want to acknowledge that I'm speaking to you from the traditional territory of
20 the Algonquin people. I want to thank Reena and the National Task Group on Intellectual
21 Disabilities and Dementia Practices for inviting me to participate in the Second International
22 Summit on Intellectual Disability and Dementia right here in Toronto. Today, academics,
23 researchers and support professionals attending from around the world. I want to start by
24 thanking you for the work that you do. Your research and advocacy are changing the landscape
25 for persons with intellectual disabilities and dementia. My goal as Minister of Diversity,
26 Inclusion and Persons with Disabilities is to lead a whole government approach when it comes
27 to building a more inclusive, accessible, and diverse Canada. Our government has made a lot of
28 progress with a coalition of accessible Canada Act, the launch of the disability inclusion action
29 plan, and most recently, the passage of legislation to create a Canada Disability Benefit. But
30 still, we know that a lot of work needs to be done; work that government cannot do all on its
31 own. That's why I'm so grateful for events like these. They bring the brightest minds together to
32 better share research and results on some of the most pressing issues facing persons with
33 disabilities. Thanks to your work, we're finding new and innovative ways to provide the best
34 possible care and support for persons with intellectual disabilities and dementia. Again, I want
35 to thank Reena, and the National Task Group on Intellectual Disabilities and Dementia Practices
36 for organizing this wonderful event and for your tireless work that you do on behalf of persons
37 with disabilities. Your efforts have lasting impact and help us to build a more acceptable,
38 inclusive Canada, for everyone. Thank you. Merci.

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Gary Gladstone

Thank you, Minister. And I also want to point out that when Canada released their National Housing Strategy about seven years ago now, and the National Dementia Strategy shortly after that, individuals with intellectual and developmental disabilities were included in both, for the first time ever, recognized federally as a vulnerable group that needed extra supports. So, thank you very much Minister and the Government. Last night, Minister Raymond Cho, the provincial Minister of Seniors and Accessibility, came and spoke to us and filled us with laughter as he encouraged everybody to put their hands up, but with a big belly laugh, ha ha, ha, everybody starts their day in a positive way, and keeps them young. He does it much better than I ever will. Now a word from some of our sponsors. In addition to Reena and the Azrieli Foundation, who you heard from last night, I'm honored to call on Terry Hewitt, CEO of Surrey Place and one of our sponsors, to say a few words. Terry.

Terry Hewitt

Thank you. My name is Terry Hewitt, and I'm CEO at Surrey Place. Surrey Place is a clinical service agency. And we provide clinical services in Ontario, mostly in Toronto, but also in the Northwest, in parts of Ontario that are hard to reach and don't get a lot of services. We provide services for individuals from birth all the way through to adulthood. And so, you know, it's really important to us that we look at all ends of the age spectrum and make sure that the clients that we serve are as healthy and well as possible. I've been at Surrey Place now for over 30 years. And when I started, I worked in the adult clinical program as a psychologist, I'm a psychologist by trade. And one of the things that we did regularly at the very start of my career was make sure that we were doing baseline assessments on anyone who had Down syndrome, so that we could ensure that when they were referred back to us querying dementia, we had the ability to sort of have that database of information about the individual to say yes, or no, or maybe depression or whatever. But without that, we couldn't do anything. And so, I can tell you, I have a colleague, I swear that in a mall, if she met someone with Down syndrome, she would invite them in for a baseline assessment. And then as time went by, you know, our program, our adult program grew. And now we have a particular team that is called, Plus 45 Team, that specifically supports individuals who are over the age of 45. And that's really important, and it's important work. We're very excited that everyone here is working on developing more clinical knowledge and more ability for us to support those individuals. Thank you very much for having us as a part of this. And thank you very much for the work you do.

Gary Gladstone

1 Thank you very much, Terry, and keep up the wonderful work. Dr. Phil McCallion, I'm telling
2 you, I was hearing so much about you before I started to get involved with the conference. And
3 our sessions online did not disappoint. It's been a pleasure working with you on the Organizing
4 Committee. And thank you very much for organizing the sponsorship from Temple University
5 School of Social Work, the Butz Family Fund, and if you could say a few words, we'd be
6 delighted.

7

8 Phil McCallion

9 I hope when you say that you enjoyed my participation in the committee that you are not
10 talking about my missing so many meetings. So, I'm the Director of the School of Social Work at
11 Temple University, very pleased to welcome this group here. But I feel I personally need to start
12 with a word of thanks to Susan and Brian Butz, who are donors to our school who established
13 the research fund in aging and health. And it's really their sponsorship that I'm representing
14 here. Their personal interests are around Parkinson's disease, but they have a really interesting
15 perspective, that sort of everything that is good for aging, everything that is good for aging and
16 health will also benefit those who have Parkinson's. So, they've been very generous in allowing
17 me to support activities beyond Parkinson's, although there are some things we're doing in the
18 area of Parkinson's as well. I also bring greetings from the Special Interest Group on Aging, for
19 the International Association for the Scientific Study of Intellectual and Developmental
20 Disabilities. But I'm really looking forward to the discussions today. And thank you all for being
21 here.

22

23 Gary Gladstone

24 Thank you very much. I'd like to add one item that's not on the agenda. And that's this morning
25 at 1015, when we're supposed to have the first coffee break, just before the coffee break, I'd
26 like everyone to come up to the front so we can take a family photo. Must have a family photo.
27 So, if we can do that at 1015, I'd appreciate that. Nancy, back over to you. And thank you very
28 much.

29

30 Nancy Jokinen

31 Thank you, Gary. I'll try to be visible to everybody. So, I get the pleasure of doing housekeeping,
32 which is always just so much fun, right? Name tags are out facing outwards, so everybody can
33 see. One of the suggestions, when we're having the discussions, if you want to make a
34 contribution/comment/ suggestion/question is, if you tilt your name card up like this, we'll be
35 able to track who's sort of next to be acknowledged, okay. Let's see, you all know where the
36 washrooms are, down there. What else, breakfast is here in the morning time. Lunch is here

1 and all the breaks are here. So, you don't have to go anywhere, all right? We're trying to
2 confine you a little bit, I think, but that's okay. Dinner tonight is on your own. So, if you have a
3 couple of people, you want to go out and have dinner with the concierge might make some
4 suggestions where that is in the local area, you might want to decide to meet downstairs in the
5 lobby and go together, it's up to all of us to make our own arrangements. Nancy is not involved
6 in those, just so you know, okay.

7 ***End of formalities***

8

9 **Segment 1 of Day 1 Summit Discussions**

10 Nancy Jokinen

11 You'll see that there are microphones spread around the room, and we're encouraging their use
12 so that everyone can hear everyone's comments or questions. So, they have to be turned on
13 and then turned off afterwards, otherwise, we're probably going to get a lot of feedback or our
14 wonderful AV tech over here is going to cut you off anyway. Okay. We have a very ambitious
15 schedule today and tomorrow, so we're very cognizant of time. And Sandy taskmaster over
16 there is going to try to remind us of the time from time to time to keep us on track. Okay. You
17 have an agenda that gives you an overview of today and tomorrow in your pack, along with
18 some very interesting swag, I have to say, because I had a look in there. Okay, so I think that's
19 everything. Does anybody have any questions for us at this point? Thank you. We'll make that
20 short. So, the way the process works, again, is each of the co-leads from the three topics, will
21 do presentations in turn, each group has been given approximately two hours to do that and
22 have a discussion on their topic area with the group. Then when they're done, the next group
23 does and the next group. So, today is focused on those presentations and discussion. Tomorrow
24 is another whole agenda. Okay. Just so we know what we're doing today, and I don't want to
25 overwhelm anybody with anything else. So, our topic one, Human Rights and Equity, the co-
26 leads are Karen Watchman, and Frode Larsen, from Scotland, Norway, respectively. And they'll
27 start out the day with us. Okay.

28

29 Karen Watchman

30 Thank you very much and hello, everybody! I'm delighted to see you all here. I'm Professor
31 Karen Watchman. I'm from the University of Stirling in Scotland. And I'm delighted to see
32 Summit two happening, fantastic! And also, that there are some familiar faces here, from the
33 first Summit that we held in Glasgow, as well. So that's great, and equally delighted that there's
34 so many new faces, as well and we're bringing fresh perspectives to the table too, which is
35 fantastic. So, I'm speaking today, and Frode will pick up tomorrow. So, we've split it this way in
36 terms of presentations, on behalf of group one. So, Addressing Human Rights and Equity
37 Concerns. And I'll be speaking for around 15 minutes maximum, and then we'll turn it over to

1 you in terms of discussion, presentation. I probably have more questions to leave you with,
2 then statements or anything else.

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5 Nancy Jokinen

6 I'm sorry to bother, but I neglected to mention that the sessions are being audio recorded. The
7 recordings are going to be restricted use, but it's so that we don't miss any of the comments or
8 important ideas people bring forward. Okay? I just needed to do that. Sorry.

9

10 Karen Watchman

11 That's important. And I assume everyone's okay with that? Yeah? Brilliant. Thank you. Thanks,
12 Nancy. So, in terms of the next 15 minutes or so, I'll talk through the process that we went
13 through with group one very briefly, and remind you what our guiding statement is, and the key
14 issues that we identified. And then, as I said, put back to you, in terms of mostly questions for
15 us to talk about rather than particular discussion points. But this is us, would group one just like
16 to raise your hand, so everyone knows who's who in the room? Thank you, excellent. I think
17 almost everyone's made it. And in terms of our process, probably like the other two groups, we
18 worked in a shared area online, so we used SharePoint, OneDrive, where we shared our bios,
19 first of all, because most of us hadn't met each other in person at that point. And then that's
20 where we built up the evidence and the document that was prepared the background
21 document for today, and also the presentation as well. So mostly working remotely. We had
22 two meetings online, and inevitably, not everyone could attend all the meetings. But that was
23 our process for getting to where we are today. And in terms of our guiding statement, that we
24 were asked to produce, as you can see, examining the multifaceted issues of human rights and
25 equity faced by adults with intellectual disabilities affected by dementia and their caregivers.
26 The group were keen that we added "and their caregivers", the care partners as well, to make
27 sure that was upfront to. I'm not going to just repeat what's in our background document,
28 because hopefully, everybody's read that. But I just wanted to pick out a few things. And even
29 before we kind of get into the detail as well, this topic really is going to extend through the
30 entire two days. So, it's not in isolation, it really impacts on the other topics that we're going to
31 be discussing as well. So, it's quite core and central. But particularly, of course, we've tried to
32 keep our focus on ID and dementia. But to be aware that we and possibly you in your groups as
33 well, the evidence that we found was mostly in English, it was primarily from the same group of
34 countries. And there were a whole host of parts of the world that we haven't represented, and
35 possibly, you may be the same as well. So, I think that's really important to be aware of, and so
36 that we don't fall into the trap of getting too caught up in local issues. Now, that's inevitable,
37 we did it in the groups. And it's not because those local issues are not important. But we maybe

1 just need to keep reminding ourselves of the global picture. And actually, you know, we know
2 what we know, in this room, but we shouldn't make assumptions about what else might be
3 known in other parts of the world that are not representative, especially. Just as an example of
4 that, I still come across people on probably too regular basis, whether it's families, staff,
5 commissioners, who are not aware of the link between dementia, early onset dementia, young
6 onset dementia, in people, particularly with Down syndrome, and that's in the UK, and that
7 that's still an issue. So, a lot, we're going to be talking about new areas today, perhaps new
8 directions to go in. I think we still need to not lose sight of that as well, that that's still a really
9 important issue for our Down syndrome societies and organizations and other support and
10 service providers as well. An example of that, I don't know if any of you saw or have read the
11 most recent Alzheimer's Disease International World Alzheimer's report that was launched just
12 a month ago. And the focus for this year's report was on risk, risk reduction, risk awareness,
13 identifying factors that may be risk factors for dementia. And when that was launched, during
14 their launch webinar, the person who wrote the entire report was asked if anything in there
15 had surprised him. And he said one thing, Down syndrome, he wasn't aware of that link, and he
16 wrote the entire report. So, I think we still need to really be mindful that yes, new stuff, we
17 need to be going in new directions as well, but we need to make sure everyone comes along
18 with us too. I tend to go off track, I've done it already. And I've only been here two minutes. But
19 with this in mind, back to the topic. So, the second part of the slide, really, equality is not the
20 same as equity. And you'll have seen that we went into those differences in our background
21 document. And of course, the legislation is intended to be for all, that's not in any question. But
22 the equity comes in when we think about how it's actually applied, or how it can be accessed by
23 different groups, by different individuals, by families, and how it's implemented with different
24 populations as well. So how is it actually equitable, when we have different starting points? And
25 as I say, there are going to be more questions as we go through, that's just the first one.

26 So, we're not just talking about health, obviously, we're talking about dementia, but it's not
27 specific to only health, when we're looking at what equity might actually look like in practice.
28 But equity in terms of where people access information, where people find support, their social
29 support from, how it's accessed, where support services, particularly if we're talking about
30 dementia in younger people. How equitable is that support and that treatment? That goes
31 interventions, be it medical or be it non-pharmacological. How equitable is that when we look
32 at it in practice? For example, in our groups, one of the things that we talked about in
33 preparation, was the equity in terms of access to ventilators, for people with intellectual
34 disability during the pandemic. So that was an example of, okay, there may be equality
35 legislation in place, but how equitable is this, for all the people that we actually support or live
36 with. The four key themes that came out were equality, not equity, non discrimination,
37 participation and inclusion. They had come through strongly in the evidence, but of course,
38 people with ID were very rarely, if at all involved in putting that evidence together. So, we have
39 to keep that in mind as well. Inclusion to a point I think, would be perhaps fairer there. Our
40 topic as given, was addressing human rights and equity concerns. So, I did notice on the NTG

1 page, that there was also a focus on dementia as a disability. It wasn't something we initially
2 looked at, but we did go back and look at that. And just for some context, dementia, as a
3 disability is something that has come through the self advocacy movement of people with
4 dementia, not ID. This is people, self advocates with dementia, who has been pushed over
5 years, over recent years to have dementia recognized as a disability. And we talk in our
6 background document, our briefing document about what the benefits might be, for people
7 with dementia, not intellectual disability. We don't know if that's a benefit or not for people
8 with intellectual and developmental disabilities, because nobody's asked. So, it was very much
9 coming from a different place. But it's something, is it helpful? And for who? Is it helpful to have
10 dementia identified as a disability, when someone already does have a disability, so it's that
11 different starting point again. So that might be something that we want to look out. As
12 someone in the group said, it's not comparing apples with apples, we don't have the same
13 starting point here. Communication is so important that I wrote it three times. Looking at all of
14 the information that's out there, it's often not accessible for people with intellectual disabilities
15 or even for families, or even support staff as well. Just need to think about how it actually
16 reaches the people who need to know what their rights are, before we can start to think about
17 equity in any more detail. And actually, one of the articles that we refer to in our background
18 paper, by Trevor Parmenter, the title of that article is, Rights are necessary, but insufficient for
19 the achievement of the full inclusion of people with intellectual and developmental disabilities.
20 And I think that's perhaps something that is maybe even a starting point, but very succinctly,
21 just brings together some of the challenges that we also saw when looking at the evidence. And
22 that the picture up there is representing silos and that's something that we certainly saw
23 through the evidence. So, we've got legislation around human rights and equality. Separate to
24 that we've got guidance or strategies around dementia, dementia care in different nations.
25 We've got convention the rights of people with disabilities, and similar legislation or guidance
26 for people with intellectual disabilities. And they're separate. And there's very little crossover
27 and there's very little coming together. And there's very little about application, the equity and
28 application of these different approaches, different legislation, different guidance for people
29 with ID and dementia. So those are the key points. So just moving on to some of the discussion
30 questions. Now, we had more questions than this in the actual document, and you can see that,
31 but we've just pulled out some of the things that might be worthy of further discussion. So how
32 do we stop people falling between these gaps, these silos that are either specific to one sector
33 or another? And how do we ensure that rights are translated into practice to best support
34 people, regardless of their settings? Or of where support is provided from? Or who the care
35 provider or care partner is? Should we be looking at something like a charter, a dementia
36 charter for ID and dementia in the way that we have charters in many countries, for dementia?
37 Now, that's not to say that those charters don't apply to people with intellectual disability
38 either, of course they do. But are they equitable in their content, when we've got different
39 starting points, and the pre-existing disability? So that's maybe something that we want to
40 think about as a group, do we have a position on that? So also, how might we actually highlight
41 those specific equity challenges that are affecting people with ID and dementia? Not so much

1 the equality, which is covered in legislation, but actually the equity in how they're
2 implemented. And I've called this a summary, but it's just some more questions, basically. So,
3 the kind of things that we looked at and came out as core from the evidence, how equitable are
4 that the human rights and equality legislation and dementia charters are similar, when applied
5 to people with ID and dementia? How are people with ID and their care partners supported to
6 actually access and know those rights? We heard about some good and strong localized
7 examples through the group development, but how can that be scaled up and shared more
8 widely? And the focus on dementia as a disability has come from and really focuses on people
9 who don't have ID. What does that mean for people with ID, if this is a direction or something
10 that will grow in the future? So, I hope I've done justice, justice to the group. Happy to get us
11 started with some conversations or take any questions. We've got till just before 10:30, I think?
12 10:15? Thank you.

13 So, I'm going to sit back down, but I'll keep talking. Any thoughts or comments or anybody in
14 the group, anything I've missed in particular? Because I'll just keep talking otherwise. Laura?

15

16 Laura LaChance

17 Thank you. Good morning, Laura LaChance from the Canadian Down Syndrome Society. What
18 recommendations would you have, or the groups have with regard to the type of research and
19 providing new evidence moving forward with regard to equity in service provision?

20

21 Karen Watchman

22 I'm going to pass that out to the room.

23

24 Matthew Janicki

25 Laura, could you perhaps expand on your question? I think that, you know, we realize that
26 people with Down syndrome generally have a very strong advocacy system behind them in
27 most countries. So, what are you looking for in terms of a response?

28

29 Laura LaChance

30 Thank you. So, I guess what I'm looking for, and it was secondary to an interview that I had with
31 care providers at the Baycrest community in Toronto last week. Do individuals with Down
32 syndrome, in particular, or expand that to intellectual disability, do they understand their
33 rights? What kind of research, what kind of evidence, how could we expand in gaining the voice
34 from the community?

1

2

3

4 Frode Larsen

5 In the paper, when we worked with the background, we came across the World Health
6 Organization's Toolkit for Human Rights and Intellectual Disability People, and they also did a
7 survey for different countries and we see the differences from some countries, but it's just a
8 small part of the European Union. So, I think, to, dive into that toolkit can be one possibility.

9

10 Mary McCarron

11 Thank you, Karen, for your presentation, really interesting. And I suppose just going back to the
12 point, how can we involve people more. Within the center that we are running, we've
13 employed somebody with Down syndrome within the center. And that person with Down
14 syndrome has set up her own PPI panel. So, she has set up her own panel of people with an
15 intellectual disability within the panel to advise on every project and every idea that we have.
16 So, we have an idea, we're going to set a research question, if we're going to think about
17 something that we're going to do, it must go to that panel at its inception, not after we've
18 decided what we're going to do or how we're going to do things. So, I think that for us all, and
19 I'm only speaking from my own role as somebody who's working in academia, I think that is the
20 starting point in terms of changing the culture. And that was not to try to undertake and to
21 change the culture in university, even to have people implied in the same manner as every
22 other academic, both through the system and probation periods and everything else been
23 similar. So, I think a starting point for me is having people involved at the beginning, in setting
24 the agenda, and in really trying to understand what's important for them.

25

26 Karen Watchman

27 Thanks, Mary. And I think I would agree with that from a university perspective. That what
28 we've done, my team has some core researchers with intellectual disability, not employed on a
29 permanent basis, but for specific funded pieces of work. So, from a university perspective, I
30 think we need to practice what we preach. And I think that's one way of doing that, certainly,
31 and having that involvement from the start. And so, we're with Phil McCallion, and then
32 Matthew Janicki.

33

34 Phil McCallion

1 I'd like to move it beyond universities and beyond research. There are serious inequities in the
2 availability of services. There are inequities based on geography. There are inequities in terms
3 of the people who are already in systems are more likely to get other services. There are huge
4 inequities in terms of the amount of resources that are provided to some people with
5 intellectual disabilities and dementia and that to others, you know, the reality that the majority
6 of people in a number of countries live at home with family and always have, means that, you
7 know, like when I talk with states in the United States, they talk to me about who they know,
8 and who they don't know. And they acknowledge that the majority of people with intellectual
9 disabilities are getting older, they don't know, because they've not received services to this
10 point. And there was a time, and I'm thinking, Matt, of sort of, some of the early work that you
11 did with the administration and community living, where we actively then went out and looked
12 for people who were unknown to the system, our thinking on that has now changed. And it's
13 like, well, when people are doing fine where they are, and we're supporting aging in place,
14 we're not actively looking in the same way because our act of looking was about moving people
15 to group homes and into out of home placements, and now we're sort of questioning all of
16 that. But I do you think that as the population gets older, and grows, we have a growing
17 number of people who are not within the system. And we've not seen budgets grow to the
18 same extent as the population is growing. But we then run in to, and this is true in the general
19 aging population as well, we have groups who are already receiving services and are concerned
20 that if we are going to cut the same small pie up even more, that their share gets smaller as
21 well. And so, the seriousness with which we look to include more people is really dependent
22 upon our ability to increase the size of the pie to be shared. And most countries, particularly
23 post COVID, are not in a position to grow the size of the pie. So, to the question that was raised,
24 I think this is a very fundamental issue that we kind of gloss over. We look at improving the
25 services that we are providing, but are we looking at how do we include more people? And are
26 we looking at that even if programs are demonstrated to be effective, is that actually the most
27 equitable way to share the resources?

28

29 Matthew Janicki

30 Jumping in and sort of just throwing things out. There's a political process too at play here in
31 defining dementia as a disability. I know that we have in the States, I think dementia has not
32 been really recognized as a full-blown disability whether its contentions whether... And we have
33 these Americans with Disabilities Act, whether that really covers people with dementia, or it
34 doesn't cover. And even the national group that represents, the most vested interest in
35 Alzheimer's disease, the Alzheimer's Association, has not really come up forthrightly about that
36 issue. I think part of it is bound into stigma, and the fact that they don't want to create more
37 problems for people with dementia, in terms of being seen as different in society, as a result of
38 having dementia, so characterizing them as having a disability might even go that route. My
39 guess is that's where they're going with this. The other thing is, in terms of equity for services,

1 and I think maybe that's what you were getting at, Laura. In some countries, someone who has
2 a lifelong disability receives support services, either under the health scheme or some other
3 governmental support program, because they do have an intellectual or developmental
4 disability. But as they get older, they are then transferred over into the aged care system, which
5 has a less investment by government into support services. And so, their supports are
6 diminished in many ways. It not so true in the States, because there isn't that nature of
7 supports for older people that there is vested in intellectual disabilities. And then certainly the
8 other aspect is, and maybe talking internationally, I don't know too many countries that have
9 invested a lot of money in long term dementia supports for people, notwithstanding
10 institutional care, nursing home care, home based care. And that is a dilemma in the States as
11 well, where there isn't the same funding mechanisms, and I don't want to say wealth, but at
12 least it's there, some money is there, to provide continual long term care in group settings or
13 individual family settings for people with intellectual disabilities as they age and as they
14 potentially show signs and are diagnosed with dementia. So, there's a value to retaining the
15 identity of the intellectual disability, as opposed to simply the dementia. But again, you know, is
16 there a positive side to having dementia determined to be a disability for ID folks, or is it a
17 negative side? Just kind of throw that out as a maybe a thought point.

18

19 Dawna Mughal

20 Okay, I'm Dawna Mughal. I would like to extend the broad conversation to something more
21 specific, and that is nutrition. In nutrition we have this campaign message, nutrition as a human
22 right. We have many guidelines in nutrition. I'm very familiar with the literature, I'm familiar
23 with the nutrition related to people with IDD and dementia. We have these guidelines, how are
24 they implemented? And there is a difference between guidelines and practice. It's the same
25 with healthcare and people without disability. We have guidelines for diabetes management,
26 how are they implemented? Access to care, access to nutrition, access to food, food and
27 nutrition insecurity is prevalent in the US. It's worse, I think, among the population with
28 disability. So, it's a universal language. So, as we talk about the different issues today, I would
29 like us to remember the importance of food and nutrition. That is a universal language. Without
30 food and good nutrition, caregivers cannot do the work well, right. The clients, the consumers,
31 cannot function well. Medications won't work well. So, I'm biased because I'm a registered
32 dietician. But my practice includes academia, and also research and hands on work, with people
33 who have IDD. So, keep in mind the importance of nutrition. We all ate here. I would like to
34 thank the staff, the culinary staff of the hotel for feeding us. We often neglect the people who
35 clean the rooms, and who serve the food. I would really like to acknowledge them and have
36 thanked them repeatedly. Thank you. The food is good, it's nutritious, it looks good, it tastes
37 good.

38

1 Karen Watchman

2 Thank you. And I think nutrition is certainly one example of where we need to look at equity in
3 terms of information.

4

5

6 Lucy Esralew

7 Okay, hi. I'm Lucy Esralew. Thank you for raising this conversation to the level that you're doing
8 today. I work for the California Department of Developmental Services. And California is
9 unique. And so far, it's the only state that actually has mandated legislated services for
10 individuals with intellectual and developmental disabilities. However, and very interestingly, in
11 thinking about equity for individuals with ID and dementia, I'd have to step back and wonder
12 about equity for individuals with ID who are aging, in general. So, my experience is that it is a
13 very youth- oriented department, very youth focused, most of the funding and activities has
14 been generated around the young, and I have nothing against the young, I like the young.
15 However, there's been no thought about what happens when they age, you know, in a number
16 of ways. So in a sense, my kind of dilemma or challenge, in terms of services in California - and
17 there are many issues that, touch on equity, because we have very great geographical
18 challenges, socio economic challenges, and we have a very diverse state linguistically, culturally,
19 etc. and just kind of making sure that people get access to what they need - is to really kind of
20 help people come along to this idea that people have lifespan issues. And that we have the
21 privilege of seeing a cohort of individuals, who are actually living longer than, you know,
22 preceding generations. I mean, I think the average age for an individual with intellectual
23 disability has doubled since the 1980s. And so that is an amazing phenomenon. But I don't think
24 our thinking, at least in talking about this service system that I'm in, has kept abreast of that
25 changing demographic.

26

27 Karen Watchman

28 Thank you, Lucy.

29

30 Yumi

31 Hey, this is Yumi. And I have a background in university, as well as the practice in the field, and I
32 always felt the gap. I started as a movement therapist, and working physically with the
33 individuals, then went to university with the research. And I'm just going back to Laura's
34 question, how can we really capture it with the research? I think, moving forward, Nancy
35 suggested a fantastic article about building an ethical community. And, that kind of more

1 contextual study, you know, not just relying on the numerical data, what works in terms of
2 intervention. So, smaller studies, equity-based studies may need to come up out from the
3 inclusive research. Right. So, I think it's really the popping out different ideas that really are
4 connected to address Laura's issue to how we can move the field forward is to look at the
5 research from different perspectives. And also federally, we need to really acknowledge, not
6 the numerical base data is important, fix the issues for the world issues. And Karen always
7 acknowledged that this is an international issue, not just the U.S. and developed countries. And
8 can we really learn based on the cultural practice that we haven't really captured, it may be
9 working, may not filled by the governmental supplement, for the support. And I think those
10 kinds of studies have not been well highlighted, or prioritized in the government- supported
11 research, and government has limited funding, and how can we divide those pies? And maybe
12 we need to switch some of the conception of what is the body of research and how we invest in
13 research. So that's kind of from the, all different shelling, I kind of thought of that. Thank you.

14

15 Karen Watchman

16 Thanks, Yumi. And so, Eimear, and then Seth, and then back over, back again.

17

18 Eimear McGlinchey

19 I just wanted to add another issue around equity and compounded inequities within the Down
20 syndrome population. So, particularly around race and socio-economic status. And it's coming
21 back to the point that Phil McCallion and Lucy Esralew both made actually, around access to
22 services, but also around life expectancy. So, there was a meta-analysis done recently that
23 showed that black people with Down syndrome are dying younger than white people with
24 Down syndrome. And that this is around access to services and health care throughout their
25 lives. But I think as if in the future, we're moving towards disease modifying therapies that we
26 think about this and we think about who's going to access it and is there going to be equitable
27 access for people with Down syndrome.

28

29 Seth Keller

30 I'm going to pick up on that comment. I'm Seth Keller. I'm a neurologist with the National Task
31 Group. And I think since this is an international and a global perspective, and equity, equitable
32 care is relative. So certain places, certain countries, how far did they have to go where they're
33 at now to reach equitable care as to other countries. So, I think it's important to take a deep
34 dive into the issue of equity, equitability from place to place to place and not gloss over it and
35 make it like a general conversation about equitable care. Because it really does certainly make a
36 difference if you live in Canada versus Ukraine or other countries that have nothing, you know,

1 they really have nothing. I think it's important to kind of give a deeper perspective on the level
2 of equitability on where people live and what they have. So, I think that's number one. I think
3 those are important to not gloss over. And then the second part of that equitable care is what
4 are we referring to in terms of equitability of care, and I'll just make the reference to like,
5 what's happening now, in terms of the changes in the focus of care standards and practices for
6 this population in research, is the biomarker and the therapeutics, it's huge. It's a huge issue
7 that's happening all around us every day. And that's a major thing that's happening, it's staring
8 us in the face, and we have to really focus on that also, as a very important aspect of issues of
9 equitability. And I know that we're working on that now and in the National Task Group and
10 other things in terms of that. So, I think that's something that we just, we can't stay on the
11 sidelines and watch this happening and outmaneuver external powers and how we can
12 continue to keep up with that. Thank you.

13

14 Janice Barr

15 Morning, everyone. I'm Janice Barr. I'm from Vancouver, BC and the CEO of the organization
16 called Community Living Society. It is interesting thinking about the comments around silos, and
17 I think some of our challenges, certainly in BC are rooted in our structure and rooted in our
18 history. In the 80s, we made a commitment to downside or deinstitutionalization of all people
19 with intellectual disabilities, which is wonderful and hence we see around the world the life
20 expectancy changed significantly, which is wonderful. However, the structure of services for
21 people with intellectual disabilities are often funded and provided through a social care system.
22 And as they age, the services and supports for people with dementia are funded through the
23 health care system. And I know in BC, we are often at the mercy of the health care system
24 trying to be acknowledged or even on the radar of that system. And really, for the most part in
25 the health care system, it's, you have an intellectual disability, you're provided support over
26 there, not over here. But over there in the social care system. There aren't the resources,
27 knowledge, skill, to support diagnosis, treatment, and often nursing and other clinical support
28 for people with intellectual disabilities and dementia. So, I think some of our history and
29 structure prevents us from moving forward in this area.

30

31 Karen Watchman

32 Thank you. I'm trying to see who's out here, is it Brianne?

33

34 Brianne

35 Good morning. I'm Brianne Samson. I'm also from British Columbia, Canada. I work for
36 Community Living B.C, which is like the government service delivery in that province. One thing

1 I reflect on a lot is the ability for us to translate the knowledge that we do have in academia to
2 those that actually need the information. And I think that's something that's really important.
3 So, when we're talking about people with Down syndrome, I think, presenting that information
4 that we do have, whether it be to Donna's point, the high-level issues that we know affect
5 everybody into ways that they understand it, is really important. And I think that's something
6 that we need to work on. I work with Janice quite a bit and there's some strong self advocate
7 community in British Columbia, there's a lot of societies that exist, led by, we call them self
8 advocates, but led by self advocate groups throughout our province. And they really aren't
9 asking for information, they want to be involved. But I think we just need to do also think
10 through how we can translate knowledge into an accessible way. And I think that looks like a lot
11 of different ways. I think people understand, to what Karen had mentioned in terms of
12 communication, I think that's something else that we need to consider in terms of equitability.
13 If it's not equitable information, then, you know, they also need that too.

14

15 Unknown

16 So, I think just listening to these conversations, kind of two ideas popped up. One is the
17 importance of co-design and ensuring that, you know, people who are impacted, and who live
18 that experience, are involved and included at our agency. We actually have three staff who are
19 lived experience staff, and do the translation work for us and, you know, sort of are involved in
20 the development of programs, so that we're sort of kept focused and making sure that we're on
21 target when we're thinking about different programs. But as well, just that idea that, certainly
22 in Toronto, which is a pretty big city, you know, 85% of people with intellectual disability live in
23 their family homes, and don't necessarily know about or get access to the services that people
24 who are well connected and have had the privilege really of connecting to awesome services
25 like Reena are, you know, exposed to. And that's one issue. Many of them, we connect with
26 because their parents, in fact, become ill, break a hip and someone says, oh, this person is
27 actually caring for their parent. And it becomes quite traumatic to change that home
28 environment. But, as complexity increases, so does equity decrease. And I think that's really
29 important. You know, we do a lot of work in the shelter system. Many people in shelter who are
30 homeless, do not have intellectual disability, and certainly would be, it would be hard for us to
31 determine, and we do a lot of screening, where we separate is this person head injured? Is this
32 person, mental health? Is this person, intellectual disability? And often, more than one, right?
33 So, it's really important to recognize that that we rarely hear their voice and rarely are they
34 supported with food, with necessary housing. Also, in Toronto, recently, the respite system for
35 adults ended. I think there's a plan to resume it. But really what was ensured was that the
36 children's respite system is still in place and is coordinated. And I think it's just evidence that
37 the older you get, the less important frankly, the service delivery is from a legislative
38 perspective. And then I think that as you increase in diagnosis, the complexity increases. So, we
39 have many clients who, you know, not just intellectual disability, but also may have autism and

1 then get dementia. And that looks very different, then intellectual disability or Down syndrome
2 and dementia. And the service providers, who are now in Health or Long Term Care, are really
3 stumped in terms of how to support these individuals, who may have been doing very well at
4 home, in a group home, having learned a lot of skill, and yet forgetting it through dementia and
5 becoming quite a handle in terms of putting them in an environment with other individuals
6 with dementia. It's just, it can create chaos. So, just that concept that, you know, the more
7 complex I think the less equitable is really important.

8

9 Karen Watchman

10 Some good points. Thank you. Matt and then is it Leslie?

11

12 Matthew Janicki

13 I guess, throwing something else into the hopper, someone mentioned a comment about
14 disparity, based on race in terms of longevity and Down syndrome. There's a lot of work now
15 being done and so issue of differences between different population groups, and how they
16 access health services or are not able to access health services or have decent nutrition, have
17 food insecurity, etc. The issue is coming up also, in terms of, big effort in the States to look at
18 risk reduction of dementia, that the Centers of Disease Control is funding these major projects.
19 And one of the affiliations that I have is University of Illinois in Chicago, and I apologize, my two
20 colleagues who are supposed to be here, from the University program on Intellectual
21 Disabilities and Risk Reduction, went to Atlanta to participate in a funders program meeting
22 that CDC was running. And they were told that if they didn't show up, that would be
23 problematic. So, they were going to be here, and I suppose they could speak to this issue. But
24 anyway, what I'm trying to get at is one of the things that we're looking at is the disparity of
25 health, and other factors in terms of longevity and potential effect on the increased evidence,
26 excuse me, the expression of dementia in people with intellectual disabilities. And the notion
27 that we're getting at, and Kathy Service might want to talk about this as well, is the issue of
28 weathering. And that's the concept that's now starting to emerge in terms of what other
29 lifelong factors, the stress factors, the lack of access to decent nutrition, sanitation, housing,
30 etc. And particularly for people who may be marginalized with intellectual disability who are
31 not in a very stable situation with care at home families, etc., are affected, and whether that
32 contributes to their earlier aging, obviously, but also to the higher rates of dementia, and how
33 that affects equity, in terms of trying to minimize that through a risk reductions program.
34 Anyway, I'm just throwing that out into the hopper because I think it's something that you
35 might want to think about in terms of long-term effects.

36

37 Leslie

1 Hi, I'm Leslie Udell from the National Task Group Canadian consortium. And there's a couple of
2 points that are just resonating with me, and one of them is around engaging the voice of people
3 who have an intellectual disability, and I think engaging the voices of their families and support
4 networks. And there's a lot of great work out there about how to do that in a meaningful way.
5 But those are very small pockets, we have a long way to go in in helping everyone to
6 understand how you meaningfully engage people. And until we figure that out on a broad-
7 based manner, we're never really truly going to get the voices that are important in all of this.
8 The other point, you know, is that taking that piece of the pie and dividing it, and I know forever
9 that we've talked about silos and working together, but sometimes you can expand that piece
10 of the pie when you invite others in and find ways to work together. So, it's not always about
11 dividing the pie. It's about expanding the pie. And looking at the gifts and ideas that come from
12 other sectors and finding ways to come. We do and we've always talked about this in our
13 sector, we've always, we've often come as beggars, right? Rather than coming to say, here's
14 what we have to offer. And if we can come from that perspective, then maybe those pieces of
15 the pie see that it's advantageous to invite in people who have an intellectual disability and
16 their families and the people that are important to them.

17

18 Karen Watchman

19 Thanks, Leslie. We'll go Kathy Service, Lucy, Frode Larsen and Dawna Mughal. And I apologize if
20 I'm not getting you all in the right order, feel free to interrupt.

21

22 Kathy Service

23 Yeah. Hi, everybody. I'm Kathy Service. Initially, I thought about bringing up the notions that are
24 big in the States on DEIA, Diversity, Inclusion, Equity, and Accessibility. Accessibility goes back
25 to what you're talking about in terms of getting information out to those who need to know
26 and those who matter. But then the other thing that is big in the field of dementia, is including
27 people with ID in the discussion. It's going back to the pieces of the pie, and making sure that
28 people, and we look at other diverse groups of people, and how their voices when they're
29 hurting the field of dementia. But making sure as we've done, and it's having a member in
30 Napa, is making sure that people with intellectual disabilities are included in the big picture of
31 when we talk about dementia capable care. But the other thing is a notion that is gaining much
32 more acknowledgement in the States is intersectionality. And that's the point that people with
33 ID also are parts of other groups and what does that mean in terms of access to services and
34 care. And I agree with Leslie, there's only so much in the pie, how are we going to partner with
35 other people in working together for that? And I also wanted to kind of add a little bit more
36 about that notion of weathering, and this is a topic that came up in the late 1990s with a social
37 scientist, Arline Geronimus, and she talked about how these microaggressions in a way because
38 of discrimination, fear, you know, not just in terms of some of the physical issues, but in terms

1 of how people are regarded in their own social settings, and how that wears at people and they
2 can cause what we call allostatic load, which is actually physically stress hormones that then
3 actually go down and continue on to do such effects on the body such as increased blood
4 pressure, diabetes, etc. And then when we look at risk factors, what does it mean for our
5 population? And where can we affect some change? And we don't know right now, I mean, it
6 may be some of these stressful things, and in fact, when we look at different groups of people,
7 for instance, people with cerebral palsy, or autism, what are these allostatic loads? What does
8 that mean for these groups of people, in terms of being at risk for developing a dementia of
9 some sort? So, those are a lot of important notions, I think we need to kind of keep involved
10 with our discussion. Thank you.

11

12 Lucy Esralew

13 Thank you, Lucy Esralew here again. So, there are three kinds of things I've been thinking about
14 as I listened to everybody. One is building on this idea of risk reduction, and thinking about how
15 when we look at what leads to dementia in individuals with ID or in dementia in general, we're
16 needing to take kind of a backward glance to what has happened earlier in a person's life. And
17 also think about equity for early intervention services. And what might that mean in terms of
18 people then having the resources coping individuals and their families that then lessens the risk
19 later down the road? So, I always like to say, what did we learn about this person with
20 dementia and ID that would help us understand where we could have intervened a little bit
21 earlier and understood and again, I take the perspective of a clinician, I'm not a researcher, I'm
22 a clinician and to me, I'm like, what it has clinical utility here? Where can I kind of understand
23 how to intervene? The other thing, and again, not being a researcher, but what would be
24 beneficial is to have more funded qualitative research in which we are involving individuals with
25 intellectual disability and dementia and their caregivers, their families, in really understanding
26 what their life, their lived experience is with regards to having dementia, and unfortunately,
27 you know, qualitative research is not well funded. And it would be really nice to be able to put
28 ourselves behind that with this understanding that qualitative research often leads us in a
29 direction that can be followed up with more empirical practices. And the last thing, related to
30 systems use, that was said before, was that many of the individuals with whom I work are cross
31 systems users. So, they're using that intersectionality multiple systems. And there is a concept
32 in the States, I don't know how well it's implemented, but it could be useful to be built upon
33 about, this notion of No Wrong Door. So, if systems are working together collaboratively, it
34 doesn't matter where they've entered, presumably they can get information about all the
35 relevant services for the individual and for the family, it often does not work that way.
36 However, that model, I think, is a very good one to keep in mind and to strengthen, because I
37 think it has potential.

38

1 Frode Larsen

2 Yes, just to go back, you mentioned that the family should be involved. When we were working
3 in Norway with the National Dementia Plan, then the relatives were invited to engage in this
4 plan. All this work, it was all around in Norway. And now we're talking about dementia in
5 general. But here we also have work for people with intellectual disability, and there were
6 nearly no family members that were engaged in these activities. So, we tried to get family
7 members to engage in this work, but it seems there's something we don't know why they are
8 not engaged, when the kids are growing up and then the parents, maybe they are exhausted
9 from the grown up parenting, I don't know, but they're not engaged in the aging process.
10 They're more afraid they're going behind, so that's, that's struggling, because as a professional
11 that is working with the government about the need for people with intellectual disability, we
12 don't hear a voice from the people themselves. So maybe it's cultural differences between
13 Europe, Norway, and other countries. And just the last comment about this financing of the
14 welfare in the future. I only know the figures in Norway, but I know that it is also similar in
15 other European countries. But in Norway in three years from now, we are more aging group
16 than younger group. So, we have huge challenges in the future to get financed the welfare
17 system. And we know that people with intellectual disability are behind the line, struggling for
18 money.

19

20 Dawna Mughal

21 Four points on my list, but I'll be brief. Number one, I work with a group that uses also
22 Inclusion, Diversity, and Equity, but we add 'A', accessibility. So, it's an idea. Now if you
23 abbreviate diversity, inclusion, and equality is DIE. There's a difference, right? DIE versus IDEA.
24 Point number two, you mentioned the complexity of the care and the more complex, the less
25 equity. Correct? So, I see a problem, care coordination. It's a huge problem, even in people who
26 do not have this ability is huge. So how do we promote better care coordination, better
27 interdisciplinary communication? I cannot emphasize enough the importance of
28 communication; among us, between us, with our audience. I do not use the word 'to', use
29 'with'. Communicating with, talking with, rather than talking 'to', so words matter. Point three,
30 Lucy mentioned 'participated research', that has pros and cons. We know the barriers and we
31 know the benefits of doing that participated research, where we involve the community, the
32 family and also the clients. Lilian Thorpe and I presented that research, I think in Norway, Frode
33 was there. And I heard three terms; one is culture, the other one is system and the other one is
34 structure. So, what is our problem? Cultural, systemic, structural. We need to think about this,
35 what are we talking about? What kinds of problems are we talking about? Words? What is
36 culture? Define culture. System? I know how to define system. Structure? I know how to do
37 that. Culture is something very different. What is the culture of NTG? Good question. What is
38 the culture of your organization? Does everybody buy into it? How do you translate that culture
39 into actions? Broad questions, but very important. How do we translate these big ideas into

1 actions that are practical and relevant? We do not want to be irrelevant. Being relevant is
2 important to the clients. I'm done.

3

4 Karen Watchman

5 And then Mary McCarron.

6 Yona

7 Well, you took my "communication, communication, communication". I loved that, Dawna! And
8 I do think with a lot of the things we're talking about here, if we think about equity, with
9 communication, we have to be thinking within intellectual disability, how we vary the way
10 we're doing our communication, right? So not just about at the end what we figured out, but
11 even just how to help people understand what the heck we're going to be doing. And that we
12 have to explain it not only for people with ID, but differently within the ID population, which we
13 do through a lot of the partnerships and ideas that have come out. And then a tiny comment,
14 just to react to one of the things you said Frode, about parents and use the word parents and I
15 totally understand it, and we all do. But I think when we think about intellectual disability,
16 because we start thinking about children, we're always thinking about parents. And so, parents
17 get older as their children get older. Right? And, sometimes burnt out, but sometimes they're
18 actually not alive or not around, and we need to be thinking about family. And, of course, a
19 really important group that gets more involved as people age are siblings. So, not to critique
20 you or anything, but just for all of us to be thinking about, it's one of these biases or culture
21 things that we've just all sort of inherited, which is thinking about it from a parent perspective.
22 We need to be thinking about how we bring in siblings who aren't necessarily, like when you
23 talked about the leader not knowing around Down syndrome and aging and those issues on the
24 World Health Organization report, you know, I think that happens as well with families that
25 sometimes siblings don't have this information. So, communication, again, just keeping in mind
26 the family perspective, I agree.

27

28 Frode Larsen

29 Just a short comment about communication, as I'm not native to English. So, sorry. But when
30 I'm talking about parents, I also mean, the organizations for people with intellectual disability
31 that were silent in this work, because all the organizations for dementia care in the general day
32 was very, very active in this work, but not the organization for family members.

33

34 Yona

1 Yeah. And just that its parents. So, in the dementia organizations, it's often children of people,
2 most often, right? Or perhaps spouses. But, in the disability sector, in our sector, it's often the
3 parent organizations that have started all this work, and they're involved. We haven't figured
4 out the sibling group is kind of a yeah, when other people aren't around, it becomes siblings,
5 but I do understand the language. Thanks for highlighting that.

6

7

8 Frode Larsen

9 Yes, but there are also younger people in this organization that are working for the
10 organization, so it's a very mix of people both in the dementia organization and an organization
11 for people with intellectual disability.

12

13 Mary McCarron

14 Thank you. I just want to follow up on Yona's point, and I met with Yona's group yesterday and
15 spoke about the issue for sibling carers and certainly in Ireland we're conducting, as part of the
16 longitudinal aging study, we interview a lot of family units. And really, you're talking about most
17 of the care being given by sibling carers and there are unique and very different issues for
18 sibling carers. That's the first thing. But we are running a longitudinal study on aging in Ireland
19 on people with intellectual disability an add on supplement to the Irish longitudinal study on
20 aging. But there's many longitudinal studies in aging happening all around the world and people
21 with intellectual disability have never been included in those studies. So that's one thing I think
22 it's really important to, are to actually be able to understand the differences and determinants
23 of health and well being between both populations. And I think I would encourage that we've
24 shown it can work, we've shown how it can happen. But we then need to be taking the data
25 from the studies and getting it into policy. Because when policy is written, the train has left the
26 station, and it's too late. So, when Ireland was developing the National Policy on Dementia, we
27 made sure we got the data that we had into the policy. So now when they have now how we're
28 going to implement a strategy, people with intellectual disability are included within the
29 national model of dementia care in Ireland. So, funding well follow that. And we've just got
30 significant funding. But when they're developing the obesity strategy, the nutritional strategy,
31 the women's health strategy, we need to be at the table to make sure that people are in. So
32 that's where the intersectionality of all of these services will happen. But we need to be in at
33 the policy level. And that's something I really think is just so critical and key. And the other
34 important thing I do want to mention is I think we had a very firm mandate, and a philosophy
35 that drove the deinstitutionalization of people with an intellectual disability. And that was really
36 important and really good, which we don't have the same moral compass in some ways to help
37 us to understand how we support people who are aging. And my concern, really, from what I

1 see that is happening, there is very little money in countries to support changing needs. There is
2 money maybe for new services, but not to support changing needs. And we have
3 institutionalized people with an intellectual disability in the past, we have moved people into
4 institutions. When we knew better, we did better, and we moved them back out into
5 community-based alternatives or supportive people to live at home. And now at a time in
6 people's life, when they are most vulnerable, when they're developing a memory impairment
7 and decline, they're running the risk, because we lacked that moral compass to be moved back
8 into a bigger institution than they ever left in the first place. And I think for this group, we need
9 to cost services. We're doing a big costing study at the moment. It's going to cost money and
10 we have no information on cost, or very little information on cost. So, I think the books on how
11 successful we were with respect to deinstitutionalisation, the last chapters have to be yet
12 written, because we have not understood how we have been able to successfully engage
13 people to enable people to engage in the community of their choice.

14

15 Karen Watchman

16 Thank you. We're heading towards the break. We have three more cards up. If we don't get
17 around everybody, don't worry, we'll pick up again after the break.

18

19 Vikram Palanisamy

20 Thank you, I'm Vikram Palanisamy, I'm a psychiatrist. So, speaking about equity, from a clinical
21 perspective. When I think about equity, I look at people with intellectual disability with
22 dementia, how comparable are the services they receive, compared to people without
23 intellectual disability. So, in most situations, people without intellectual disabilities have better
24 access earlier, the waiting times are lower, access to medication, everything is better. But in
25 some situations, I don't want patients with intellectual disability to access generic services. So,
26 some examples are I don't want people with intellectual disability with dementia, when they
27 develop psychiatric services to be admitted to geriatric psychiatric units because, they're really
28 struggling to manage the situation. And Brianne gave an example, I think, somebody from
29 Community Living Services gave an example of how people with intellectual disability, when
30 they become dementia, their access to long term care facilities is less than adequate. And in
31 fact, I actually don't promote that they be referred to long term care because staffing levels are
32 hugely disproportionately lower compared to community living services. So, we sort of think
33 okay, in certain situations, services for people with intellectual disability is better. But we're
34 missing the perspective that that means that we are restricting access to better inpatient
35 services respect and access to better long-term services. So, this is where the concept of
36 reasonable adjustments, which is quite popular in England, reasonable adjustments and people
37 buy into this. So why do we have to accept that long term care homes are not good? Because
38 they're reduced staffing levels? So why should they not accommodate the intellectual disability

1 needs on top of dementia services? So, I think, as a Summit, we could do with defining what a
2 reasonable adjustment looks like in this population. So, at the patient level, so what would a
3 reasonable adjustment look like when a person with intellectual disabilities with dementia? So,
4 there are good practice guidelines, you know. MMSE is not good. So, the sort of assessments in
5 NTG, based on assessment too. So those are reasonable adjustments at personal level. I think
6 we need to define what are the reasonable adjustments at a service level, you know, make it
7 mandatory for family caregivers and support agencies to be invited and to make sure that they
8 don't discriminate, and people with intellectual disability can readily access dementia clinic.
9 And what are the reasonable adjustments at an agency level? So, what are the, for example,
10 any organization dealing with aging services should have training about dementia. So, if we can
11 come up with some practical definitions, I think it will be that will give us a lot of mileage. Thank
12 you.

13

14 Karen Watchman

15 Thank you, Nancy said she'll go after the break. Phil, do you want to take us into the break?

16

17 Phil McCallion

18 Sure, I'll borrow from Dawna Mughal, and I'll have a short list. So, as much as anything, I
19 wanted to pick up on a couple of things that were said in the presentation that haven't been
20 addressed yet. I think this issue of either creating our own charter or getting into charters, and I
21 don't want to take away from the value of that. But I want to emphasize what Mary McCarron
22 raised and what I see other people in this room doing that it's much more important that we be
23 at the table in the development of primary legislation than that we write these charters that we
24 all read and get very excited about, but other people don't read them. And so, I think we need
25 to, that equity is probably going to happen more, if we get involved. But in getting involved, we
26 have to think about how we want to change too. You know, broken record, Lucille sitting here
27 next to me, she's going to, you know, hit me for saying this one more time. But screening for
28 dementia. In the general population, screening is about, at least in the United States now, it's
29 about an eight-item scale. And we keep saying to people, no, you've got to spend hours doing
30 screening. We're not spending hours doing screening, we spend hours doing a diagnosis. We
31 have to start thinking about and sort of take that all the way through the dementia journey. We
32 have to think about where is it, for example, that we could make change, that we give up some
33 of our sacred cars that we've developed for really good reasons, but are resulting in people with
34 dementia and intellectual disabilities not receiving services because they can't fit into some of
35 the community-based models. And then one area that I think, again, started thinking just about
36 the whole assessment issue, saw this really great example recently, in the area of autism.
37 Clearly, if children are diagnosed very early, we have great opportunities to do really good
38 programs for them. Yet, in a lot of places, that assessment takes years, in terms of waiting lists.

1 So, Vanderbilt University in Tennessee, developed a virtual assessment, and within six months
2 had wiped out the backlog in the state of Tennessee. We did a lot of stuff during COVID online. I
3 understand the dangers in that and the limitations of that. But are we willing to start, as we
4 think again about these equity issues, about geographic inequities, about black and brown
5 inequities, socioeconomic inequities? Expanding the opportunities for access is how you change
6 inequities, not saying we need to address inequities. And so, I think that there's a requirement
7 on us to be willing to move in directions that sort of actually produce results and get people to
8 want to work with us. And again, I think there are examples already in several countries where
9 when we have stepped in, and we have talked the same language as everyone else, that we've
10 had much greater openness to change. Still a lot of barriers, but much greater openness to
11 change. Thank you.

12

13 Karen Watchman

14 I'm keen to hear some of those examples, but we'll save that for after the after the break.

15

16 Sandy

17 I think that now would be great. So, before everybody runs off, we're going to have you, as
18 Gary has said, we have to get the family photo while everybody is here. So, if you wouldn't
19 mind coming up to the front of the screen, and then we'll get our photo and then we'll have a
20 break till just a little bit past 10:30.

21 Karen Watchman

22 We're just going to get started again, I'm just conscious of time. We're going now to 1130 and
23 we'll pick up where we left off with Nancy.

24

25 Nancy Jokinen

26 Thank you, everyone for such great comments and ideas and thought-provoking things. My
27 mind is going like a million miles an hour right now. And I know I'm supposed to be thinking
28 globally, but I'm thinking locally, being Canada, and about what we've accomplished here in
29 Canada. At this point, we're in the National Strategy, we've been funded on a national basis.
30 But I'm already thinking much to Sandy's displeasure, probably about five months from now,
31 and where we go from here. Because the project isn't the end. Sorry, Leslie. One of the things
32 that I heard mentioned several times is "communication, communication, communication", and
33 how we need to communicate with family members, staff and people with intellectual
34 disability. But I don't want to forget that there's a small group of people with intellectual
35 disability with dementia that we need to communicate with too, and how our communication

1 strategies need another twist to do that appropriately, and in a timely fashion. So, that's where
2 I'm sitting right at this moment, thinking about those kinds of things. One of the project's aims
3 that we're on, is to provide communication in various formats. And I'm not sure we're at the
4 format of how to communicate for people with intellectual disability and dementia at various
5 stages, because it will change with stage.

6

7

8 Lucy Esralew

9 Nancy, I'm glad you brought that up, because, and this is kind of getting back to a conversation
10 that Karen and I had before the conference. And that is this issue of pulling the person with IDD
11 and dementia into the situation as fully as possible. And I think that's a notion that hasn't even
12 occurred to a lot of individuals that that would be even a conversation that one would have,
13 you know, so I think back to the wonderful work, Karen, you've done in Scotland, in terms of
14 Jenny's diary. And, you know, I use that, I utilize it quite a bit in my training. And it is often eye
15 opening to staff and family members to even think about how you would have a conversation
16 with a person with IDD and dementia, with their significant other, in the case of Jenny's diary,
17 her boyfriend, or with housemates of the individual or co workers of the individual who have
18 ID. And then I think you mentioned Karen, there was somebody who was actually involved with
19 counseling individuals with ID and dementia, which I thought was brilliant. I just still think it is
20 brilliant today. And I think that's the kind of thing that I will take back with me to California as
21 ideas that I would like to strengthen and promote. So, thank you for Nancy for bringing that up.

22

23 Shahin Shooshtari

24 Hello, everyone, Shahin Shooshtari from University of Manitoba, in Winnipeg, Canada. As a
25 researcher, Mary McCarron said it well, but I just want to emphasize the importance of
26 including people with intellectual disability in large scale, national studies. In Canada, we do
27 have the Canadian longitudinal study on aging, but people with intellectual disability are
28 excluded. So, when it comes to understanding the experience of people with intellectual
29 disabilities aging, that's of no use to us. We have the Canadian survey on disability. It doesn't
30 have that much health-related information or things about cognitive functioning. We have the
31 Canadian Community Health Survey, which collects a wealth of information on health, but it
32 doesn't allow us to identify people with intellectual disability. So, when it when we talk about
33 the disconnection of disability and health sectors, that's also very clear in the way that we
34 collect data. And I believe it's essential to have the data to understand the aging experience of
35 people with intellectual disability. So, it was well said, but I just want to emphasize that.

36

1

2 Mary McCarron

3 I just want to comment and say, we're very happy to share all our experiences, all our materials
4 and support any country in the world that wants to develop a longitudinal study on aging, in
5 comparison to your own studies. So go for it.

6

7

8 Kathy Service

9 Yeah, hi, it's Kathy Service again, Service. And I just wanted to call a couple notions that are
10 really important towards this conversation, because we were talking about families and
11 siblings, etc. But this whole notion that, you know, I first heard in the UK, in the gerontological,
12 nursing field, and, and of course, we're involved with person centered care, we need to do that.
13 But then what about relationship centered care? And how does that figure in with, you know,
14 supporting people who are living with dementia, and their care partners and everybody in the
15 picture? So, I think it's important, you know, and bringing in the other notions of lifespan and
16 life story, when we're looking at people so, and we're getting back to people, because in terms
17 of doing education with people and supporting people, we need to have this to help guide us in
18 terms of how we work and support people.

19

20 Karen Watchman

21 Thank you, keep going along your table. Is that Ivan? I can't quite work out who.

22

23 Ivan

24 Ivan Brown here, from Toronto. I just want to add to the conversation here, I've heard so many
25 ideas, I wasn't quite sure what to respond to. But I like to add to the conversation point about
26 siblings and how we need to support them. And I like this think of siblings in kind of a broad
27 sense, not just brothers and sisters, but sometimes their nieces and nephews or aunts and
28 uncles and so on, or even nonblood related people. But these kinds of relationships often start
29 in childhood, within a family. And it's really, really important, I think for us as a field to
30 remember that. Brothers and sisters, when they're children, and growing up, are going to form
31 relationships that will last a lifetime. And if those relationships are not ones that are supportive
32 in childhood, then the likelihood of them being supportive when the person gets older, and
33 develops dementia are probably not going to be there. Many years ago, I interviewed a woman
34 in Toronto here, while I was interviewing people about family quality of life. And she was

1 talking about her two daughters, one daughter had an intellectual disability, and the other
2 daughter did not, she was a professional woman. And she said, my daughter who is a
3 professional, moved to Vancouver on purpose, so she wouldn't have to look after her sister.
4 And I found that very, very sad. Because the relationship that woman had with her sister had
5 somehow not developed in childhood, and to the point where she actually moved across the
6 country to get away from her. And when I look at the literature in our field, I don't see as much
7 emphasis as I think we need to put on developing relationships among children, with their
8 siblings, which will carry on through life. And when we talk about equity, it's those people who
9 are closest who will try to work towards ensuring equity. And a final point on that is sometimes
10 in our field, and sometimes governments and so on in our society in general, we assume that
11 family members are both capable and willing to be advocates and to provide good care. And
12 that's simply not the case. Sometimes people are don't have the skills, they don't have the
13 knowledge and they don't have the willingness to do it. And our field, I believe, has not
14 addressed that very well. We haven't really understood that some families are not able or
15 willing to be advocates and to ensure equity when we assume that they will, and we don't seem
16 to have a way to deal with that. So that's all I have to say.

17

18 Karen Watchman

19 Thanks, Ivan. We'll just work down the table, in the order.

20

21 Alyt Oppewal

22 Alyt Oppewal, from Rotterdam, the Netherlands. Linking into the longitudinal studies, in the
23 Netherlands, we also have a longitudinal healthy aging study for people with an intellectual
24 disability. And also linking into how research can help policy, we also had a good number of
25 samples that our research results really got into the policy making in the Netherlands, which
26 really helps people with an intellectual disability. So, Mary McCarron raised that, I think that's a
27 very important route that we need to think of. And also, with regard to the community of
28 communication, and including people with an intellectual disability, in the like the last couple of
29 years, we are really including the wishes of people with an intellectual disability, but also their
30 whole support network. So, if that's family, siblings, or carers or volunteers, in which issues they
31 run into, and which issues they want us to study in our Healthy Aging study. And I think that's a
32 very important route to take. So, I totally agree with everybody saying that we really need to
33 include the network of people around them. And the same goes for the communication. And
34 actually, in the Netherlands, with all our funding schemes, we are now obligated to write a
35 piece on how we include people with an intellectual disability themselves and how we
36 communicate it back to them as well. So, I think that's a really good development in really
37 getting some improvement on that aspect.

1

2 Karen Watchman

3 Absolutely. And that is becoming a funder requirement in a number of places now, which can
4 only be a good thing.

5

6

7

8 Janice

9 Excellent points. I think in BC anyways, we lack the connection between research and policy
10 development, and we certainly could do a whole lot better. I just wanted to pick up on
11 something that Vikram Palanisamy had said. My comment's around structural problems, with
12 respect to the social care system and the health care system. And certainly, the social care
13 system has done an exceptionally good job in supporting people, in BC anyways, post
14 deinstitutionalisation. But that system doesn't have the knowledge, at this point and the clinical
15 skills to support people as they age. I think that the system can learn and as long as the system
16 can get access and carers can get access to outpatient supports, diagnostic, treatment. But I
17 would absolutely agree, what we don't want to get access to for the people we serve is long
18 term care, or the long-term care system because the healthcare system has not done well in
19 terms of supporting people as they age in that long term care system. And that would really
20 harken back to the institutions from which the people we support came from. So, I couldn't
21 agree more.

22

23 Dawna Mughal

24 I'm Dawna Mughal again. The context of my comment is "communications, communications,
25 communications". Let me tell you about myself. I retired in 2017. But I'm Associate Professor
26 Emerita at a university. And since then, I have taken courses in health communications, media,
27 strategic, public relations, organizational, but not for another PhD. It's just for intellectual
28 stimulation, because I believe that intellectual stimulation is good for the brain. And my social
29 network at school is another pillar of brain health. So, it's very important to do that. But going
30 back to my context is communications. Many factors affect communications. And my
31 experience is that we really have to have the ability, as a care provider, to individualize the
32 guideline to that person. If we're talking about person centered care, education is very
33 individualized. You talk about dietary guidelines; those are only guidelines. We modify them to
34 suit the client, according to health goals, cultural preferences, and resources. So, I had the
35 privilege of counseling family members and people with intellectual disability. And luckily, food
36 is a good language, they may not be able to tell me in complete sentences, but there's I like

1 potato, or I like this fruit, they understand food. So really, individualizing the method of
2 communication is so important, I don't care about the guidelines, how I am able to translate
3 that to something that is practical and useful to that person at that person's level, I have to
4 have the ability to assess the communication ability of that person and personalize my way, my
5 language. And another problem in professional communication is too much gobbledegook. You
6 know, plain language is very important to follow. There are so many resources for writing in
7 plain language. Government language is not plain language. And so, it's very good to translate
8 the professional language that we use to plain language. If you analyze your sentences, you
9 subject your sentences, a smog test, I predict that you're using too many words. Too many poly
10 syllables, too many long sentences, right? So, it's very, very important to do that. And language,
11 verbal, nonverbal, my body language, am I smiling at you or with you? That makes a difference.
12 My position on my body, am I doing that, or I'm not really paying attention to you? So, it's really
13 very important. My brain is swirling around listening to all the issues here, and I'm trying to
14 filter it down to something that will give some meaning to me. That is really bad to the clients
15 and relevant also to my ability. Knowledge is not enough. I can tell you that when you teach
16 care providers, knowledge is not enough. My research on diabetes is on self efficacy, meaning
17 my ability to be able to do something because I'm skill building, makes a difference. So,
18 knowledge plus training, education to build the skills for that person to continue the behavior
19 and support along the way, their support system to maintain the behavioral change that
20 occurred is very important, because if you don't support my new behavior, it will decay back to
21 baseline. It's very complicated. Communication is very complicated. I predict that it will be an
22 ongoing discussion, because it's been ongoing for a long, long time. Communications is really a
23 problem. And there's a difference between communication and communications. I learned that
24 in school.

25

26 Karen Watchman

27 And hopefully that's exactly what we'll do tomorrow, which is to distill everything that we're
28 talking about today and decide what we're going to do with it. And in what format.

29

30 Lucy Esralew

31 So hello, again, Lucy Esralew here. So again, I'm coming from the perspective of being a clinical
32 neuropsychologist, who is interested in brain behavior relationship, but also is a family systems
33 practitioner. And I wanted to get back to something that Kathy Service said, and something that
34 Ivan said. I loved the fact that you talked about relationship centered care, because for me, the
35 paradigm shift is I think we've kind of gotten a pretty good sense of person-centered care, but
36 we have a less good sense of relationship centered care. And that's what I would like to have as
37 kind of a focus of my activity a little bit more so. And I agree with Ivan, I mean, one of the things
38 I've noticed in working with families is sometimes the individual or couple who've been

1 caregivers to their child, their adult child with ID and dementia has presumed that another child
2 or offspring of theirs will take on the care, without having that conversation. You know, and
3 then when things happen that the family is no longer able to provide care in the same way, as
4 had been traditionally, it is really a struggle for that child, the adult child who has been basically
5 elected by default, to take over the care of their sibling with dementia. And those conversations
6 and that advanced planning has to happen a lot sooner. I think the same thing happens in the
7 general population. I don't think it's specific to the population of individuals with ID and
8 dementia, I think that is true generically the case, at least in my experience. So, I'd like to see us
9 promote advanced planning, in terms of just the family understanding and embracing what it is
10 that they're dynamic, in terms of what happens when the caregiving situation changes, because
11 of the illness or death of the primary caregivers.

12 Colleen

13 Hi, everyone, Colleen Hatcher, from the National Down Syndrome Society in the US. I think to
14 provide some context and talk a little bit about siblings. First, I have a best friend who I grew up
15 with who has Down syndrome. She's the same age and was born almost the same time as my
16 little sister. So, I grew up with her. I think of her as a sister, but I'm not technically defined as a
17 sibling. And if you ask Gina, is her name, she'll tell me I'm not her sister. But I think that that
18 context is really important, as we talk about this family and not family being necessarily
19 biological, but this group of people who supports loved ones with Down syndrome or other
20 disabilities, because Gina only has one sister and her sister has sort of known her whole life, at
21 some point, Gina will become her responsibility. But at the end of the day, I am happy to be
22 part of that group that provides care, so it's not on just one person. But I think Lucy, you said it
23 really nicely. We have conversations at work with siblings of. How do you have these
24 conversations, so it's not necessarily just put on a sibling, right? Or if you have four siblings, or
25 there's four children and one has Down syndrome, how do you have conversations about who
26 supports what, so it's not just put on one sibling who maybe doesn't want it? And that's fine,
27 right? But how do you have those conversations? We are diving, as an organization, a little bit
28 more into that sibling space to figure some of that out. So hopefully, we'll have resources for
29 you all shortly to share with families, on the sibling piece. One other thing I want to talk about
30 is, is health care access and equity there. This is not my area of expertise. But as an
31 organization, we do a lot of work, or have been doing a lot of work recently, to look into the
32 Down Syndrome clinics that are available in the United States. The majority of those clinics only
33 support people with Down Syndrome till either 18 or 21 and then it's sort of like a free for all of
34 where do you go. And so, I think one conversation that we are having, and that, as a society, we
35 need to continue having, and I'm sure the United States is not the only place where this is
36 happening, is how do we provide equitable access to clinicians who understand Down
37 Syndrome and aging generally, but also Down syndrome and Alzheimer's disease? A lot of our
38 families are coming to us and saying, well, we went to a neurologist, but the neurologist doesn't
39 understand or the neurologist says that my 25-year-old son has Alzheimer's and giving them
40 that diagnosis because the doctor doesn't understand that it will talk about co-occurring

1 conditions, right, but any of the other pieces that could be going into some of that regressive
2 behavior. And so, I think that there's that conversation that needs to continue to happen is how
3 do we take all the minds in this room and share them with the clinicians on the ground who
4 maybe don't focus on the IDD community, but are seeing patients with IDD, so that everybody
5 has access to good health care.

6

7 Karen Watchman

8 Thank you, I think is that Leslie along the table? And then Seth and Brianne.

9

10 Leslie

11 I just wanted to echo something about relationships. But, you know, I see a lot of people that
12 really are not known to the system. I mean, I'll see people in my neighborhood all the time and
13 etc. So, what about people who don't have any kin, kinship, and how do we support those
14 people where they are? I mean, they come into the system when they go into the hospital and
15 then you know, in the States, there's this, this system called PASA, where they get assessed
16 whether they have an intellectual or developmental disability, and then they become known to
17 us. And neighbors and friends help to support a lot of people. And then what do we do about
18 that? And then going in another direction, is looking at paid providers, people who provide
19 direct support, get paid terribly. And so, we're always struggling, that even we're trying to
20 provide supports for people, whether it be in group homes, or helping families and other
21 people, people who are in shared living, etc., getting support for respite and stuff like that, you
22 cannot find staff. Many of the staff are marginalized themselves and work two and three jobs.
23 So how can we address that and in terms of our conversations, that people deserve to have
24 trained care providers, we provide all the care, but there's always a turnover of staff, you can
25 train one person, and then they're gone. So how do how do we understand those kinds of
26 things? I think we need to be able to kind of call attention to people who provide hands on
27 support. How can they get compensated decently and be able to provide the kind of care that
28 any of us want for any of our family members, and people and friends in our community? I
29 think notions like that, that we, you know, it's a big like, the monkey on the person's back. We
30 don't talk about that. I mean, we always talk about it, but it's, it's just overwhelming, because
31 even in terms of equity, how can we keep people in homes and etc.

32

33 Seth Keller

34 I just want to add to a comment of the drivers of care that are different from one country to
35 another country. In the United States, it's for profit. I mean, the economics that drive care for
36 me as a neurologist, my own practice, is money, it's really very money based. I will see a

1 patient, that I can say make money, but that's kind of really how it is. My practices survive as a,
2 in my private practice, it's the economics. So, for me to even see a lot of people with
3 developmental disabilities, unfortunately, it's like a money loser based on the complexities and
4 time and their insurance that they have. So that's one thing about what drives a good quality
5 care in the United States. And I use the United States as an example, because a lot of you are
6 not for the United States, or you have your own issue or in good things that might be more
7 socialized systems of care, which is very different. When you also then look at long term care,
8 or actually what happens to individuals when they age and they need more long-term care
9 supports, live at home and bring in more care supports. But again, in the United States, we have
10 a cottage industry in the United States, that's popping up every corner, of units that are
11 basically meant for assisted care, long term care, and it's these business models that actually
12 are pushing where the future of long-term care should be. And does that mean that that's
13 right? Does that mean that's wrong? So, I think there's the driver that really pushes the reality,
14 sort of realities of where people want to be. And then also, from a cultural standpoint, what
15 does that mean for us as people, so like, for me, Oh, I don't want to, I'm growing up, and I don't
16 want to have my mother and father and care how to care for them. And I'm not going to say I'm
17 going to move 1000s of miles away. But that's an expectation that a lot of people are going to
18 have. And then there's, of course, different cultures of your nationality, and what culture you
19 have as an individual, and what's going to drive it. So, these nuances, you know, obviously make
20 a difference. It's certainly not a black and white issue. So that's kind of why when we think
21 about these, it's interesting to kind of pare down and think this through and what's right or
22 wrong, you know. And I would never want to be very judgmental. So, you know, when I say to a
23 family member, that, Oh, I don't want to bring care supports into my home, aging in place and
24 I'm really looking to get them out into a care facility. And I'm thinking like, what do I think is
25 right? And try not to be judgmental to them and say, what would I think for them, and I don't
26 want to do that. It's also very important to be very broad and open minded about how I think,
27 or we should think about what the so-called right thing is for people.

28

29 Brianne

30 I just wanted to touch a little more on the family systems and the sibling relationships. I think
31 one thing that is, in the province of British Columbia and Canada that is getting a bit of
32 momentum is around better advanced care planning, because I think those are good
33 opportunities to start early. We hear a lot from the family networks that drive actually a lot of
34 the systems in our province that they want to plan not when they're older, but when they're
35 young, which means that their child is probably in their 20s or their 30s. So, I think using
36 advanced care planning and there's an advanced care planning framework in Canada, which
37 targets legal, financial and health. And so similar to any of us, as we're also involved in our own
38 planning, I think the equitability of looking at those models is a valuable way to sort of start
39 planning earlier. And particularly if we're talking about someone with Down syndrome, we

1 know that the odds of them aging younger are very high. So, what we can do earlier on to
2 address some of the changes that we know are going to happen, is something that could be a
3 valuable approach, I think, as we learn more. The second thing I wanted to touch on is what
4 Vikram said before the break. I liked what you said about reasonable adjustments. I think what
5 we see a little bit in British Columbia is we do have some policy. And it's more around, it's kind
6 of guidelines, and they're meant to be the roles and responsibilities between our health sector
7 and our community living sector. And I have to say, they've probably created more conflict than
8 they have actual support between the two. So, I think a good sort of ground, in the middle,
9 would be something related to reasonable adjustments, because I think that's where a lot of
10 the conflict is happening right now. Sort of, whose role is what? Anyway, so I just appreciate
11 that comment. I think it's something to explore a little bit more.

12

13 Karen Watchman

14 Yeah, I think so too. Thank you, Mary and then Lucy Esralew.

15

16 Mary McCarron

17 Just to comment again on the sibling carers and Ivan, what you have said. One question we are
18 asking is, where does the locus of care responsibility lie? I mean, that's the fundamental
19 question that we need to consider. And from our work with family carers and sibling carers, like
20 many siblings in Ireland are working, they have their own children, mortgages and property,
21 and everything else is extremely expensive, so it's often not realistic. I do think there has to be a
22 conversation around that. We have developed, as people can access, a future planning tool,
23 which is very accessible, it's on the site. And there's also because we also have advanced care
24 planning tool, which is kind of a little bit different, because it more deals with people maybe
25 who are new and at a more advanced stage of their lives or just future planning tool is much
26 more geared for people to discuss what's about to happen. And in that way, it brings in, who is
27 their extended friends and friendships that they want to be involved in their lives. So, they're all
28 free, they're accessible. And you can download both of those sets of tools from the website.
29 And then just come back to Karen's point, I think one of the most fundamental things, and I
30 know we've had a discussion in the center around this, is relationship-based care and person-
31 centered care. I think one of the most fundamental human rights, and I know we can differ
32 about this is the right of human security. And people very often working in, living in these care
33 settings, have a constant movement of staff. So tomorrow, they wake up and there's a different
34 person looking after them, there's a different person there than was there the previous week,
35 and different expectations. People are struggling with memory issues, or even without memory
36 issues, and they have a disability in care. This is a fundamental issue is the constant movement
37 of staff into people's lives and out of people's lives. And I don't know what we need to do at the
38 system level, to address that issue, and keep people because I do think it impacts hugely. And

1 any of us that have anyone who was ever in care, oftentimes, were going in thinking, Oh, I
2 wonder what staff is on? I went into a fantastic care setting that we have developed, that I'm
3 supporting, and out of nine staff on duty, there was two permanent staff and seven agency.
4 And that has major impact on the lives of the people living there. And we can do all the training
5 we like but it's a revolving door in terms of training.

6

7 Lucy Esralew

8 I wanted to comment on something that you just said, and then kind of go back to something
9 else I was thinking about. And what occurs to me, Mary is this idea of equity for staff who are
10 carers. And that kind of goes back to what Kathy Service said, until we have that moral
11 compass, thank you for introducing that into the discussion, in which we value individuals who
12 provide supports and care and show that value by paying them a living wage. Now I'm talking
13 about the United States, I don't know what the Canadian situation is, although I can't imagine
14 it's much different. And so until we do that, and we have equity for those individuals who are
15 their formal caregivers, not family or you know, caregivers or until we kind of recompense
16 family members so that they are not burdened with the care financially of individuals with
17 dementia, then we're going to, you know, be missing a very important piece of that stabilization
18 and safety for all concerned in this equation. Then the other thing, you know, just kind of
19 thinking out loud about this is, I think one of the equity issues is, at least in the States, we are
20 very confused about what dementia is. Is it a medical condition? Is it a psychiatric condition? Is
21 it a social or a disability issue? And depending on how we define what dementia is, will
22 determine what kind of services get pulled in, or even who the person sees, who will eventually
23 give a diagnosis or determination that they meet criteria. So, it was also kind of that arcs back
24 to what Colleen was talking about in terms of, I think educating the practitioner, the primary
25 care physician, most of the people that I work with, are not going to go to a psychiatrist, they're
26 not going to go to a neurologist, they're going to go to their family care practitioner. And to the
27 extent that that practitioner knows, or does not know, what they're looking at, that person may
28 or may not get a diagnosis or be diagnosed with having one or another neurocognitive disorder.
29 And then, Seth had mentioned earlier about equity for the therapeutics, that NTG is working
30 very hard, in terms of making sure that individuals with ID have access to these therapeutics, if
31 and when that would be available to them in some way. The problem is, we need to determine
32 who has mild cognitive impairment. I have never, in my multiple decades of practice, seen
33 anybody with ID with an MCI diagnosis. Never. I mean, I've given that as a diagnosis, but I have
34 not seen that given by anybody else. So, this idea of just how do you access something when
35 we're not even talking about things in the same language? We don't have a common way of
36 referring to whatever it is that we want to access. So again, are we medicalizing dementia? Is it
37 a medical condition? It's in the DSM-5 and the DM-ID-2, is it a psychiatric condition? We're very
38 ambivalent, I think about how we understand what we're even talking about with regards to
39 dementia, and I think we have to come to some better consensus, if we're going to really have

1 some equity around whatever services can be developed to support individuals with ID and
2 dementia.

3

4 Karen Watchman

5 Thank you, Phil. And then Leslie.

6

7 Phil McCallion

8 I want to comment on several things. I want to comment, first of all, on the sibling issue. And, I
9 was struck by Ivan, when you told your story that simply because that sibling had moved away,
10 does not mean that that person may not at a future time, be the caregiver. And it's a reality of
11 our world, that no matter what we do, we still fundamentally place responsibility on families.
12 And because so many people are not known to the service system, and it's very hard to get into
13 services when you're not already part of those systems, that that's the reality that happens. The
14 fastest growth that we see in family caregiving is in long distance caregiving. I always think that
15 we have a choice when we see those things, we can rail against it or we can look at, okay, if this
16 is the reality, how do we better support that? I'm struck the same way in terms of direct care
17 staff. I ran an agency 40 years ago. The things that people are talking about today, we talked
18 about 40 years ago, nothing has really changed. Well, some things have changed. There are
19 other countries that pay their direct care staff a lot better than is true, certainly in the United
20 States. And for a long time, those countries seem to have a much more stable workforce. But
21 over time, what I'm seeing, when I look at the data, is that they are also experiencing the same
22 issues with turnover. Perhaps not as great an extent as some parts of the United States, but it's
23 happening. The other thing that I find really interesting, and this is more anecdotal than firm
24 data, is that post COVID, a lot of salaries in areas like direct care came up substantially. And so
25 just even talking to my own students, who most of my students work, and many of them work
26 full time. And they were the group that you talked about as having two to three jobs. Post
27 COVID, they didn't need to have two to three jobs, because hourly rates went up so much, so
28 the job they gave up was the direct care job. When you look at all of the research around how
29 we support staff and care positions, the staff themselves say yeah, I'd like to be paid more, but
30 that's not the real issue. And I think there's a fundamental issue as to whether or not we can
31 solve the turnover in direct care, because none of the things that we've thrown at it have
32 worked. As I said, I remember what it was like 40 years ago, it's still the same today, in many,
33 many ways. So, the definition of madness is we do the same thing over and over again and
34 expecting a different result. As we think about the organization of long-term care, not just for
35 people with intellectual disabilities and dementia, but everyone, are we continuing to do the
36 same things over and over again, argue for the same solutions, and then get the same results?
37 And then the last thing is, again, future planning has been something we have talked about in
38 this field for a very, very long time. There are two things that happen. One, most people don't

1 participate. If you look at the published studies, they're always based on very small numbers.
2 And that's true too in the general population, we don't get a lot of people participating. But
3 then the other piece is, what happens after you've developed your plan? Is it actually possible
4 to implement the plan? My favorite story is a story from my own family, I have a cousin with
5 Down syndrome, she's the same age as I am, and her father thought that he had it all worked
6 out. What he did was, and remember, this is like going back a very, very long time ago, without
7 acknowledging my age. And he said, Okay, he told his other two daughters, whichever one of
8 you will assume the responsibility to care, I'll leave the house to you. Okay, and that's what he
9 did, with the best of intentions. And in his lifetime, he came to the realization that both of his
10 other daughters got married, both of his other daughters, who were working together with
11 their spouses, bought their own houses, bigger houses and better houses than his. But the most
12 important thing that happened, was that his daughter with Down syndrome turned around to
13 her two sisters and said, "This is my house, and when you move in here, I'm the boss". And so,
14 if we form future plans, will the future plans be realized? And there is a skepticism among
15 families. And the denial sometimes, of the intent of a sibling to say, I'm going to provide care, is
16 because it's actually quite functional and I don't have to do it right now. I'm not going to deal
17 with that right now. But when the time comes, it turns out that many of them will. But the real
18 concern is that there just aren't that many siblings anymore. The literature on caregiving talks
19 about that there's always one family member, there's they're the one that you always turn to in
20 the family, when there's a crisis, and they'll take care of it, and that's the person that will
21 become the caregiver. Well, that kind of thinking works when there's four to seven siblings, as
22 some of us experienced growing up in our lives. When it's just you, it's the luck of the draw,
23 whether you're that person who can be the scheme. So, i'm going to argue again that we need
24 to be thinking about new and different models and not trying to fix things that don't work.

25

26 Karen Watchman

27 Leslie, and then we'll go around the table if we can, but keep it really, really tight, because of
28 the time.

29

30 Leslie

31 Quick story. Lucy, I actually supported a lady who received a diagnosis of mild cognitive
32 impairment. But I'm going to say that there are a whole lot of healthcare practitioners out there
33 who don't even understand what MCI is. And so, they said she has mild cognitive impairment,
34 which I agreed with, and I know everything, right? But then they said it's dementia. And I had
35 such a time trying to work through this, like, no, this isn't a type of dementia. It may always
36 remain stable, it may eventually progress, but it's not a diagnosis of dementia right now. So,
37 getting somebody diagnosed with mild cognitive impairment was not a helpful process. The
38 other piece I just want to speak to very quickly, when I talk about relationships, I think that

1 organizations, in particular, suck totally at recognizing the importance of peer relationships for
2 the people that they provide supports to. And there's such a discontinuity, and people get
3 moved and shifted, and there's never a thought about who gets left behind and how do we
4 maintain connections and relationships? And I think that peers are such a significant piece for
5 advocacy for dealing with grief and loss, for sharing historical perspective, and organizations
6 decimate those relationships.

7

8 Karen Watchman

9 Thank you. Is it Ivan that's along? No? I can't see. One minute.

10

11 Alyt Oppewal

12 Hi, I just want to go back to what Lucy alluded to earlier on. So, I work with the National
13 Intellectual Disability Memory Service in Dublin, Ireland, which was set up in 2020. And Lucy
14 just alluded to the fact that often GP is the first point of contact. And GPs, I find, are very
15 reluctant to diagnose dementia in people with intellectual disability, they're afraid. So, what
16 we're doing now is we're supporting GPs, we meet with them, we help them and look at their
17 neuro imaging, look at supports that they can provide for people with intellectual disability.
18 And this is working well. We are also diagnosing MCI earlier on. And at that point in time, we're
19 drip-feeding information to family members and staff members about what's coming down the
20 road. We're providing information to services, we're providing information to families, and
21 we're also providing easy read information to people with, perhaps the diagnosis of MCI, which
22 has been made a consensus diagnosis, and allowing them to read around what MCI means for
23 them?

24

25 Karen Watchman

26 Thank you. And we've got two more cards up. So, one minute each.

27

28 Arianna Esposito

29 Hi, Arianna Esposito, Autism Speaks U.S. I just wanted to go back and comment on the piece
30 about the adult service providers and the lack of equity that really exists, especially in the US
31 system, where you have mostly a well resourced, in comparison to the adult service system,
32 and usually highly trained professionals. And you enter the world of adult services, and the cliff
33 is there, and it's called a cliff for a reason. Not just because funding changes, but really from the
34 staff perspective. And it really has me kind of thinking about, okay, to the point that was raised

1 earlier about, well, we've looked at increasing wages, and the turnover is still there. And part of
2 me thinks when you're looking at profession, and I used to do this before joining Autism Speaks,
3 was training future behavior technicians at the undergraduate and graduate level. And there's
4 no sense of professionalization in adult services that exists in younger, in school aged, K to 12 in
5 the US, or 0 to 21. And part of me thinks, if we look at are there other models, other types of
6 training models that we can learn? Perhaps it's not in special needs or disabilities at all, that we
7 could think about can we take any of the successful findings that exist out there and apply it
8 within this population? I think there's a, speaking for the U.S., there's a de-incentivizing about
9 solving this piece, because the more professionalization and the higher rates, the higher hourly
10 rates, which put pressure on an already incredibly strange service system, than the public
11 service system. And then the other piece just about looking at successful models overall, trying
12 to solve some of these larger problems, that often we couldn't look to whether it's another
13 disability category or perhaps another industry and see those well paved paths. And
14 straightening out to Kathy's point earlier about increasing the pie, are there other avenues that
15 we can really learn from here and apply?

16

17 Karen Watchman

18 Brilliant, thank you. Last word from Donna.

19

20 Dawna Mughal

21 Yeah, one sentence. This model emerged in my head while listening to you. And that is
22 research, education practice, and public policy and digitalization are all interrelated. So, we
23 identify the issues under each category, they're all interrelated. So, organizing the stuff I heard
24 today into this model. To repeat, I hear research, education, practice, and legislation. I was told
25 before that if it's not legislated, it may not happen.

26

27 Karen Watchman

28 Thank you all very much. And beat that for timing, Hey Sandy?

29

30 Nancy Jokinen

31 Well, that was most interesting. And I have been writing away like crazy during this whole
32 discussion. So, I want to thank Karen and group one members for a very interesting
33 conversation. And, of course, to all of you for contributing your thoughts and ideas. Stay tuned
34 to group one, topic one tomorrow, for a synopsis and moving forward, on our agenda. We're

1 going to move on now, I think I'm looking at the co-leads. Phil McCallion and Mary McCarron
2 will do on topic two, which, if I'm not mistaken, is brain health and risk reduction. So, thank you
3 again, Karen.

4

5 Phil McCallion

6 I thought it was a great discussion and a great presentation, I want to thank the organizers,
7 again. I will admit that I missed some of the organizing meetings, so the rest of the committee
8 should take more credit for the program than I should. But I also want to really recognize our
9 committee. I put everyone's names up here. There were two things that we tried to do. We
10 certainly tried, in our meeting, to really discuss all of the issues. But the other thing that in our
11 background paper that we tried to do, was to reflect a variety of literatures. A variety in terms
12 of disciplines, but also a variety in terms of countries. And so, I really appreciate the work that
13 the committee did, in bringing those materials together. Mary and I are co-leading. Mary said
14 I had to present because she's never seen me present before with a set of slides that were
15 developed a week ago. Usually, my thoughts have moved way on, but I'm going to try to be
16 good. I'm going to start off that as we think about these issues of prevention and risk reduction.
17 We're a field that started with a medical model, and we're still very influenced by medical
18 models. So, when we think about this in a medical model way, we tend to think about, okay, we
19 know things work. As Donna said to me at one point, what you should do and what you
20 shouldn't do. And we've got the research evidence for it, and we lay that out. But we tend to do
21 those studies in very controlled situations, then we think that these things will then move out
22 beyond the clinical setting, and they'll be equally effective. Kate Lorig, who developed the
23 Chronic Disease Self Management program, talks about that we act as if either the people will
24 just believe us and do it. Or we start acting as if what we should do is that we should be
25 standing next to you in the kitchen and in your bathroom, and sort of telling you what to do.
26 And clearly, we can't do that. So, we need to move forward in a different way. And so instead,
27 the way in which we advance brain health, the way in which we advance, a risk reduction is
28 really about turning this into something that just becomes part of life. I know, the idea that I'm
29 going to have to give up all these things is never great. However, I was really pleased to see
30 and, I think this was Dawna's influence, I found in my bag dark chocolate, acai and blueberry.
31 Thank you, Dawna. So that actually is not too bad in terms of if that's all I'm allowed to eat. But
32 for people with intellectual disabilities and dementia, started to think about how we move this.
33 But when we think about it from a population perspective, we're not just talking about when
34 you're 40, 50, 60, we're talking about decisions that are made over a lifespan. When Mary and I
35 were talking, as we were preparing this presentation, she was talking to me about someone
36 that she works with who talked about that, in many ways, what you end up eating, particularly
37 as a person with an intellectual disability, when other people are preparing food and giving you
38 food, is it's probably decided by the time you're two and a half. And then, we rely so much
39 upon food as a motivator, as a reward, that we build up these habits that then become lifetime

1 habits. And so, we can think about that for people with intellectual disabilities. But probably,
2 this has worked the same for most of us. So then, when we start thinking about the
3 determinants of health, of brain health across the life course, and this is from the World Health
4 Organization, we think about modifiable and non modifiable issues. But an awful lot of the
5 modifiable issues are not necessarily issues that are under our own control. So really, if we're
6 interested in brain health and the reduction of risk, we probably should be climate change
7 warriors. Because that's going to really influence things. We should be talking about pollutants.
8 We should be talking about the management of our communities to be walkable communities.
9 These are kinds of things that will really influence, without saying to us, you 'should', or you
10 'shouldn't'. Suddenly, you're in a walkable community and you're able to walk around. Several
11 people asked me about things I like about being at Temple University, and it's an urban campus.
12 And I always say that when I arrive on campus, I'm guaranteed 5000 steps, whether I want to
13 do it or not, because that's the way life is there to get around the campus. So, to me, that's sort
14 of the ways in which modifiable factors can be modified. But you know what, then there's the
15 other things that you do. And so, Mary's a great cyclist, and even Mary admits to me that there
16 are some mornings she gets up in the morning and she's like, "it's too cold", or "it's too wet, I'm
17 not going to cycle this morning". Then she tells herself, "Yes, but here are all the reasons why I
18 should do it" and she gets out on the bike. The 'Yes, but' conversation doesn't happen for many
19 people with intellectual disabilities. They're going out to walk or they're going out to cycle or
20 whatever, because someone is telling them that they have to do it. And that's the Kate Lorig
21 model, that somebody stands behind you and tells you that you have to do it. And if it doesn't
22 work for the general population, it doesn't work for people with intellectual disabilities. And
23 then there is that idea again about when does this need to start? For none of us, should it be
24 discovered when we're age 60 and we're getting ready to retire and it's like, Oh, I've lived this
25 great life. I've really, really enjoyed all these things but now I'm going to give them up. That
26 doesn't work. So, how does this then become part of what we're doing? But when it's not part
27 of what I understand to be of value to me, but somebody else, it makes for not a particularly
28 nice life, to be required to do these things. That's why I liked the dark chocolate and acai and
29 blueberry, because that seemed nice. As we talked, we were very influenced by something that
30 was put out by the Lancet, talking about that, beyond dementia, risk reduction, a consensus
31 statement on brain health, that it really is about a life course perspective, that it's more than
32 just dementia. We should be really looking at how we integrate the strategies that we want for
33 brain health, with the strategies that we want just for good health, the strategies that we want
34 for a good quality of life, and that all of those things then contribute. And then we start
35 addressing some of those risk factors. But again, the Lancet report talked about, that
36 addressing the risk factors may prevent or delay up to 40% of dementia cases. But how many of
37 those things does an individual have an opportunity to directly modify themselves? So again, it
38 sort of takes this much more holistic approach, it takes this more organizational systems, or as
39 Dawna said, structures. All of these things come into play as things that we need to influence, if
40 we're going to improve brain health and reduce risk. We looked at, I pulled together from all
41 the literature that people had sent to me, I looked at everybody's list. What are the things that

1 are demonstrated to make a difference? I know I'm going to put this up, and somebody's going
2 to say, "well, what about..." and they didn't make the list, but they are all important. But there
3 are some things that met a lot of people's lists. Mental stimulation, you know, there's a science
4 behind that, in terms of connections between nerve cells, and perhaps even to help the brain
5 generate new cells. We talked a lot about plasticity. We talked about the building of reserves.
6 And so, it seems like pretty straightforward things - reading, taking courses, word puzzles, math
7 problems, and also a manual dexterity aspect to this as well. So, when I did presentations at
8 senior centers in the United States, I'm talking about dementia issues, one of the things that
9 people always ask me is, well, what can we do? What can we do to avoid it? And so, I would
10 encourage, particularly these mental stimulation aspects, because they don't want to hear
11 about modifying their diet or walking more. But again, it's that idea that if I explain it, and I'm
12 pretty upfront and honest, about the amount of evidence there is around these things, people
13 want to do something. They want to feel some agency in the midst of this, and so many people
14 will do these things. Again, for not all, but for many people with an intellectual disability,
15 there's not necessarily that commitment to attending that kind of agency, or even to
16 understanding what that agency is. So how do you create a situation where people will increase
17 the things that they're doing, that contribute to mental stimulation, without it being you
18 'should' or you 'should not'? I think actually, in the area of mental stimulation, at the end of the
19 day, it's often about habits that people have developed. And so, for many people with
20 intellectual disabilities, that's probably the easiest one to do, is it's about encouraging people to
21 continue to do things that they've always done, figuring out what adaptations that you can
22 make. But we also have examples, and one of the articles that we cited was Eimear
23 McGlinchey's article were sort of purposeful mental stimulation interventions, people with
24 intellectual disabilities will participate in those and more importantly, will get benefit from
25 them. So that encourages us to think about those things. Physical exercise, again, all kinds of
26 things, but we move into physical exercise, and we move into improving diet. One of the things
27 that we talked about was that here are multiple benefits from that. There are benefits in terms
28 of reduction of other health conditions that potentially increase risk for dementia. And so,
29 thinking about how these things then, the increases in physical activity, improvements in diet. I
30 always think of it like, you know, people say eating a healthy diet. I remember, one of our local
31 TV stations did a piece about, they went into, I don't know if people have a TGIFs. Okay, and
32 they went in there and they had the fried onion bloom and they walked around the tables and
33 they talked to people about how many calories that represented. Until they got to this one guy,
34 and he looked at them, and he said, "Yeah, you're so right. The only reason I ordered that was
35 because I thought it was the healthiest item on the on the menu". Like sometimes we just like
36 those things, but we know that there are things that will really be of benefit. Blood Pressure.
37 Clearly, the management of blood pressure makes a difference not only for cognitive decline
38 but makes a difference for risk of heart disease. The data from IDS-TILDA doesn't support that
39 there is as higher rate of blood pressure or as higher rate of cardiovascular disease in people
40 with intellectual disabilities. But there is a percentage to do. And so, perhaps if it's not showing
41 up in that way, perhaps it contributes to cognitive decline as well. Diabetes, and really just the

1 improvement of blood sugar is also one of the ones that's very high. The improvement in your
2 cholesterol. There has been so much work done on cholesterol, so many things supposedly
3 demonstrated in terms of cholesterol, so much evidence then overturned on cholesterol. But
4 on balance, it's still an issue to be followed. Some of the guidances that we reviewed, also
5 talked about the use of low dose aspirin. With the physicians in the house, let me say you
6 should not do that without consulting with your physician. But we have such an emphasis now,
7 and Mary, we've contributed to this. We have such an emphasis now on reducing
8 polypharmacy. Are we depriving people of potentially beneficial things, because say, we don't
9 identify a disease specific treatment option? And so, I get to decide, do I want my vitamin E? Do
10 I want my low dose aspirin? You know, there's all manner of things that I'm often encouraged
11 to try. And very quickly, you could be up over five of those things and people who say, "Well,
12 that's polypharmacy", and you combine it with medications that you're taking, well, that's
13 hyper polypharmacy. But yet some of these things are therapeutic. So, I always think we also
14 have to think about what are the purposes of things. Avoiding tobacco and avoiding alcohol are
15 two other things. There are lower rates, for most people with an intellectual disability, but that
16 doesn't mean to say we shouldn't be paying attention to them. I'm always a little concerned
17 when they say, "*no more than two drinks*", but I'm doing my best. But then, caring for your
18 emotions, the importance of the potential contributions of anxiety, depression, sleep
19 deprivation. But to what extent is that about scoring poorly on tests, versus actually
20 representing cognitive decline? And so, I don't think we've done enough in terms of looking at
21 that. Protecting your head. I think we have a much higher appreciation of this because of what's
22 happening with sports celebrities, in later life. But you don't have to be a running back to have
23 lots of head injuries, including head injuries that may not have a diagnosed concussion that can
24 increase the risk of cognitive impairment. To what extent are we really monitoring for that and
25 encouraging that? To what extent are we accepting that people who have gait problems just
26 fall? And then, the whole issue of building social networks, and I think that, the benefits of
27 building social networks are really well demonstrated. But as has been said already, the
28 numbers of people that a person with an intellectual disability has within their social network is
29 compromised because they don't have children, they don't have spouses. They may not have a
30 lot of contact with other family members. But if we are devaluing their peer relationships, as
31 someone talked about, if we're devaluing their relationships with staff, we're actually
32 interfering with social networks that may be important for brain health. So, some of the other
33 modifiable factors, it was interesting to me that they didn't always make all of the lists, were
34 maintaining a healthy weight. And our definitions of a healthy weight have changed over time.
35 But actually, we're still talking about the general population, what is a healthy weight for a
36 person with an intellectual disability? Particularly when we're seeing lower rates of
37 cardiovascular disease, even though we may see higher rates of overweight and obesity.
38 Treating hearing problems is an issue that we are talking about a lot for the general population.
39 Several studies came out recently that are talking about how critical that is, and how many
40 people with an intellectual disability are receiving regular hearing screenings? I can personally
41 vouch for that as you get older, your hearing gets worse. And why isn't that true for people with

1 intellectual disability? Simply because they had a hearing screening 10 years ago, that is not
2 speaking to their hearing today. And then this issue, again, of sleeping well. There was a study
3 done in the U.S., they convened the consensus panel, and they find that there was encouraging,
4 but inconclusive evidence for three types of behavioral changes: increase in physical activity,
5 better blood pressure control, and the impact of cognitive training. Encouraging, but
6 inconclusive. So, some of that is about there just haven't been enough studies done, to be able
7 to say conclusively that something works, there's definitely a lot to be said for doing things that
8 at least have good evidence, even if it's not... I remember once, for an intervention that I was
9 working on, talking with someone from the Centers for Disease Control. And a new study had
10 come out on that particular intervention. It was the 32nd study that said that there were
11 positive effects. And I said to her, so what do you think that means? And she said, there's 32
12 studies. Now, she still wasn't ready to say, there was convincing evidence. When we have a
13 population that is excluded from a lot of studies, and we're struggling to get them included,
14 how many studies does it take for us to decide that this is an evidence-based intervention, and
15 we should try it, particularly something that doesn't do harm? We had some discussion already
16 today about MCI and both its measurement and sort of what it means. And so, some of the
17 more recent studies are really looking, as is true for the general population, been looking at
18 MCI and really sort of looking, for example, at the impact of physical activity in the conversion
19 from MCI to dementia. But even there, they, take this systematic review that I mentioned here,
20 they said that their recommendations were based on a very low or low certainty of evidence.
21 So, I think that as we present some of the interventions that are likely to reduce risk, we're
22 often working with things that don't have a lot of evidence. Nevertheless, things are changing.
23 There's a piece that came out this year, on the memory clinic as a future. And you can see here
24 that what they now see as one of the pillars for memory clinics, is the building of cognitive
25 enhancement. For people with intellectual and developmental disabilities. I looked for a study
26 that had more than 36 subjects... 36 subjects is my favorite, because there was a study on the
27 effects of dark chocolate. And people came up to me and they said, "This looks really good, this
28 must be the answer". And I was like, okay, there were 36 subjects in it. And I said, and who
29 funded the study? Nestle. But the statistics are very good. So, this is a cross sectional,
30 multicenter study that was completed in Japan with 1831 participants. We've talked already
31 about the importance of cross-national studies or cross center studies, which give us evidence
32 that we can utilize. So, hypertension, depression, head trauma and stroke, all associated with
33 the risk. Although diabetes and hearing disorders were clearly identified as risks in the general
34 population, they didn't find that they were risks for people with ID. Higher baseline severity of
35 ID may increase the risk. But actually, if we prevented head trauma and stroke, if we treated
36 hypertension and depression, they concluded we probably could reduce that risk. So, these are
37 interventions that will work for every person, potentially, with an intellectual disability. Now, of
38 course, we always have to talk about the limitations of studies. This was facility based, so it was
39 not a community-based sample. Nobody smoked, nobody drank alcohol, which I thought we're
40 guilty everywhere of this, they all at the same thing. It really helps you to control for outliers,
41 but it speaks to not a great variety in people's lives. And then there was also this concern that

1 hearing loss was not well screened. So, they couldn't really conclude that hearing loss didn't
2 work. So again, because we were really anxious to include studies from a variety of countries, I
3 was really pleased that we had come across this study from Carmeli and Imam. I know Carmeli
4 quite well. In talking about health promotion and disease prevention and intellectual and
5 developmental disabilities in general, and again, we're thinking about this from a lifetime
6 perspective, their review really found that it was about attending to cardiovascular and
7 respiratory concerns, addressing digestive problems, preventing falls, more focused on primary
8 prevention, physical activity, improve nutrition. But they pointed out that interventions require
9 reinforcing factors and joint effort among health professionals, organizations, policymakers,
10 volunteers, community leaders. Brain Health is not going to happen unless we're all working
11 together to make this happen. Again, just want to highlight the study by Eimear McGlinchey on
12 examining the effects of computerized cognitive training on levels of executive function in
13 adults with Down syndrome. I also think about well what exactly do we mean by brain health?
14 What aspects of the brain are we influencing? Eimear targeted executive function, but do we
15 need to be doing more to try to understand what it is that we're actually influencing? And then
16 I just want to bring in self determination, my life by choice, my voice. Self determination, I
17 think, as we think about the things that are likely to be influential on brain health and reduction
18 of risks, and again, Mary, and I talked about this quite a bit, that it becomes an excuse for not
19 doing something. We say, well, the person has the ability to say, and they do, that "I don't want
20 to do this". But to me, that's the conversation of you 'should', you 'shouldn't'. And if I say to
21 you, you should or you shouldn't, you get to say back to me, "I don't want to." But it speaks to
22 that we need to do so much more, that this becomes something that people want to do for
23 themselves. Okay. So that's kind of what we considered, what you'll see in the background
24 paper, but we have a series of questions. When should brain health programming begin for
25 people with intellectual disabilities? And who should manage it? Are the brain health materials
26 for the general population suitable for people with intellectual disabilities? And if they're not,
27 what do we need to do, what additional is needed? Is a separate, evidence base for people with
28 intellectual and developmental disabilities needed on brain health interventions? And what
29 would that look like? And how our autonomy and self determination issues, balanced with
30 encouraged brain health, when we know so little about the actual efficacy for people with
31 intellectual disabilities, of the interventions? And in thinking about all of those things, where
32 should the research and the practice agendas begin? I'm going to leave those up and we can
33 start the discussion. I understand this is all being recorded. So, for our group, we will have
34 access to that tape. But nevertheless, I'd ask the members of the committee, if they would also
35 just take some notes because I think it will really enrich our discussion afterwards that we
36 capture what is clearly going to be a really great discussion, because there's dark chocolate as a
37 reinforcer.

38

39 Mary McCarron

1 Yes, I'm being told. Okay, so great. And thanks, Phillip for that, and I'm going to roll it open for
2 some questions and comments. Great, lovely. Thank you, Lucy.

3

4 Lucy Esralew

5 Yeah. So, thank you very much. I really appreciated the presentation. I thought about a number
6 of things. One of the things I thought about is how do you build the habit of doing those things
7 that are not only good for the brain health of individuals with ID, but all of us, essentially? I
8 mean, what you mentioned is not specific to the population of individuals with intellectual
9 disability. So, I'm thinking that it becomes a family affair, of kind of convincing people brain
10 health is something they should be concerned about, from the very beginning. And the same
11 thing is for staff. So, I'll just give you a very brief vignette, when I worked in a developmental
12 center in New Jersey, several decades ago, I had a colleague, who was a psychologist, she was
13 my counterpart. I was in the all-female unit; she was in an all-male unit. And every day, she
14 took a walk with individuals who are capable of being outside on the grounds of, we were at
15 North Princeton Developmental Center in New Jersey (in the States)... very lovely grounds. And
16 she took staff with her on that walk. One reason is that she needed to take staff with her for
17 supervision purposes. But the other thing is that one of the reasons she had the idea of taking
18 everybody on the walk was she was a walker, that was something that she did on a daily basis
19 as part of her habit and routine. And she got the staff involved. So, it was built into their
20 program day, that every day at a certain time, you could see them circulating around the
21 campus. And they took a very healthy walk. And it was really good for everybody. And one of
22 the things that I've done, when I've consulted with group home agencies, etc. I've talked to
23 them about how do you build in some of these activities into the day, which are good for staff,
24 as well as for the individuals with intellectual disability whom they serve? The other thing, and
25 to convince families of course of that. So, we're talking about lifestyle modifications and
26 changes. The other thing that I didn't see as much stressed, and maybe it does not appear in
27 the literature, is the value of stress reduction and modifying the level of stress experience. I
28 know that Kathy Service is going to talk about weathering. Yes, you are. So, I'm not going to
29 steal that from her. But this idea of helping people of all ages build skills, in terms of being able
30 to manage stressors and reduce stressors. Two things that are kind of more IDD specific, in my
31 thinking, is the high incidence of sleep apnea among individuals who have, particularly Down
32 syndrome. I don't know how much that figures into their overall brain health, how well that has
33 been studied? But I do know how difficult it is sometimes to get people to cooperate with the
34 use of a CPAP or other kinds of interventions. And I have to be fully transparent, I have sleep
35 apnea. And it took me close to a year to become accustomed to using a CPAP. I had to submit
36 myself to a gradual exposure, desensitization program in order to accept that, and I can imagine
37 how much more difficult it might be for some of the individuals whom we work with and serve.
38 The other thing that occurs to me is among a certain portion of the population, the degree of
39 self injurious behavior that might result in concussion, which might result in head injury. That

1 may not even be acknowledged, reported, investigated, that we know very little about. And
2 what might the cumulative effect, over time be, for such individuals who have that within their
3 behavioral repertoire, that has been very difficult to manage? What is the ultimate outcome, in
4 terms of that for their brain health and their adaptive functioning? Two more things. So, COVID,
5 kind of highlighted for a number of us the issue of social isolation, and the disruption in social
6 networks, and how important consideration of loneliness, and disruption of those connections
7 might be for overall well being. One of the things is to marry this idea of brain health to overall
8 well being, it's not a separate thing. Brain is not separate from rest of the body, in terms of just
9 overall functioning. And so, really are being more cognizant of just the importance of
10 maintaining social connectivity, as people age, we all age, but certainly the people with whom
11 we work. The last thing is really kind of my puzzlement as a neuropsychologist. I'm aware of
12 cognitive training in the general population and I have actually done some cognitive rehab or
13 training for people who have been identified as mildly, intellectually disabled. And I don't know
14 really what that totally looks like, an agenda of mental stimulation or cognitive training. We
15 would talk about executive functioning, which refers to a set of skills. So, are we talking about
16 attention and attention training? Are we talking about working memory and working memory
17 training? Are we talking about problem solving? There are any number of things that kind of go
18 under this general category of executive function. So, I would be really curious if any of our
19 colleagues here have experience with a cognitive training routine, because I personally would
20 be very interested in that, and what's the data to support it? I've spoken enough. Okay.

21

22 Mary McCarron

23 Thank you so much and they are really important points. And just to say, certainly, post COVID
24 in the memory clinic, we've seen a lot of cognitive and social frailty. And I think that is
25 something that we needed to unwrap, was this dementia? Was it cognitive or social frailty? So
26 yes, that is something that we are really interested in. We can certainly come back to you in
27 relation to that. And I must say, in terms of sleep apnea, I just met a lady coming out from the
28 clinic the other day with Down syndrome with our carers. And I said, "Hello, and how are you?"
29 She looked at me and said, "I am wonderful, I got that machine, and I am back to normal" and
30 everyone would probably support that. And this lady had regressed so much, like there's such a
31 problem with both overdiagnosis and underdiagnosis. She had regressed so much that anyone
32 would have sworn that she had dementia. But we decided to look at sleep apnea and do the full
33 diagnostic workup and six months later, she came back a completely different woman. So, I just
34 wanted to highlight that, and we can talk offline a little bit more about that. But it's really
35 timely for me to hand over to my colleague, Dr. Eimear McGlinchey to speak next. And she will
36 probably pick up on some of those points as well that Lucy Esralew has raised. Great, lovely
37 Eimear McGlinchey.

38

1 Eimear McGlinchey

2 Thanks so much. Lucy, just on your question around executive function and what was
3 measured. So, within that study, it looked at attention working memory inhibition. Now, it was
4 Phillip who talked about 36 participants. It wasn't many more, it was 40 participants in that
5 study, so it was a very small sample. And it was a feasibility study. Is computerized cognitive
6 training feasible for people with an intellectual disability? And it was, so people enjoyed it,
7 people completed it. It was an eight-week training program, 20 minutes a day, five days a week.
8 Adherence was really good, and people did complete the program. It was a very small sample,
9 but there appear to be some benefits in terms of some of the assessments, so inhibition and
10 working memory. We also then looked at do these translate to day-to-day activities? And it
11 didn't, in that sample, but again, it was a small sample in a relatively short time. I know of two
12 other studies looking at cognitive training and intellectual disability, so I can share some of
13 those with you, if that's helpful. In terms of some of the other questions that you put up, Phillip,
14 I think in terms of is, is separate evidence base needed? I think certainly there is. I think even
15 when we talk about the Lancet Commission, and we talk about the 40% modifiable risk factors,
16 there's been some work done on population attributable fractions, with other, say, with low,
17 middle-income countries and the differences that these modifiable risk factors may be within
18 different populations. And there may be a focus on different factors depending on the
19 population. I think this work hasn't been done yet in people with an intellectual disability, but I
20 think it's something that would be, knowing what are the areas that will benefit most and will
21 be most helpful to target would be really important. We've recently got a grant from JPND to
22 bring a working group together to develop a framework for multimodal interventions for
23 people with an intellectual disability. That is part of the worldwide FINGER study. So, to develop
24 a finger, Down syndrome study. And whenever we're talking about brain health, I think, and as
25 my work with Mary McCarron and Phil McCallion in Trinity Center for Aging and Intellectual
26 Disability, I'm also faculty at the Global Brain Health Institute, so I am a real proponent of brain
27 health. But I am also always conscious, particularly when we're talking about people with Down
28 syndrome. When we are talking about brain health, research hasn't been done on the effects of
29 brain health, related to cognition, specifically, in people with a genetic risk for Alzheimer's
30 disease. So, either ADAD or DSAD, and I think it's really important that we think of that when
31 we're discussing brain health. I absolutely agree that the benefits of brain health are beyond
32 just cognition. So that has benefits around quality of life, many other health benefits and I
33 absolutely agree, it's something that we should work on, work with. But in terms of the
34 messaging to people with Down syndrome and to their family members, we're conscious that I
35 think this is a community, that for a long time, have wanted some kind of hope in terms of
36 dementia, been aware of this risk of dementia and Down syndrome. And I guess that we're
37 sensitive in what we're saying this will do, if we do exercise, if we do diet, if we do all of these
38 things. We're not saying that you won't get dementia, we're not saying it's going to delay
39 dementia. I think it's just the messaging is important.

40

1 Mary McCarron

2 Thank you very much, Eimear. And Eimear has eked out on a whole body of work around brain
3 health, so we're really pleased to have her leading out on that. So, thank you. Kathy, I think it
4 was you that's next?

5 Kathy Service

6 As a nurse practitioner, I found over the years that no matter, you can write an order, you can
7 tell people what the science is, but the reality is how are we going to make it work? And I think
8 that that's the other thing, the motivation and working together. Over the years, you can look
9 at the person's lifespan and life history, but partnership, how can we work together on it? I
10 must admit that the older I get, the more important, the fun factor is, for me, in terms of any of
11 these kinds of activities I do, it's important to enjoy them. And that's going to be a motivating,
12 not just for myself, I mean, when I get on the treadmill, almost daily, but keeps me going, I
13 watch my British and my Polish TV shows. Figuring out these kinds of interventions, partnering
14 with people, working together with people, what kinds of things that they want to do. When I
15 think about some of the cognitive work but looking at the social aspects and making it again,
16 you know, I think a lot of these multimodal kinds of interventions are really the things that work
17 for a lot of people. And, of course, stress reduction. I've already talked about weathering and
18 allostatic load and there's a researcher in Arizona, Blair Braden, who's working with people with
19 autism. And granted, they are people with ID, but she's doing mindfulness with a group of
20 women with autism and finding that it's working for them. So, looking at what can we do
21 around some of the stress reduction, because as I said, around weathering and allostatic load,
22 stress is dangerous for us all. But then, also in the big picture, looking at social determinants of
23 health and cultural. My parents, I mean, "*eat the fat on your meat, it lubricates your joints*".
24 That's what I grew up with. So, how do I understand that? What does love and food, and Dawna
25 Mughal can attest to, what does all this mean for all of us growing up? And then lastly, this
26 notion of well being, and I really want to stress that even when somebody is living with
27 dementia, we really need to pay attention to what wellbeing is for people. People can live for
28 years with dementia. In fact, there's a lot of people with Down syndrome, because of well being
29 and what staff and families do, that have kind of gone off and on, believe it or not, hospice, a
30 couple times. So, I think we need to pay attention that just because a person has been
31 diagnosed with dementia, that doesn't mean the value of their life is any less. And so, I think
32 part of what we need to do is look at either the pillars of health, or what was used in the UIC
33 Healthy Brain Initiative, is the Six Pillars of Health. But calling attention to how are we going to
34 support these kinds of notion when somebody's living with dementia?

35

36 Mary McCarron

37 Can you hear me now? Yeah, perfect, lovely. I'm standing here because I can't see people on
38 this end. Please go ahead.

1

2 Vikram Palanisamy

3 Thank you for the presentation. Excellent review. I find, to define all those factors that you
4 described, it's like reading a textbook, summarizing all the things that are available. This is more
5 like questions. You talk about blood pressure, cholesterol, and blood sugar. So, there are two
6 ways to look at it. Right? Keeping it as close to the normal range, and then targeting when
7 they're significantly outside the normal range. From your review, do you find any indicators
8 that this works when your target, high blood sugars, hypertension, which is causing other
9 problems, significantly high cholesterol levels? Or do you find that even, if there are no
10 significant problems, keeping these values close to the normal range prevents dementia?

11

12 Phil McCallion

13 I think that in the literature that we reviewed and just from other literatures, it is it is much
14 more about, well, if you're thinking about prevention and reduction of risk, it's much more
15 about general management. But on the other hand, if people have elevated blood pressure, I
16 think clearly that would be a group that you would particularly want to target. But I'm just
17 being a little careful because I'm looking at the physicians in the room and I don't want to step
18 over too many lines. But I think that that really though, that's what the literature is really
19 saying.

20

21 Mary McCarron

22 Yeah, and there may be different risk factors as well for people with intellectual disability and
23 for those with Down syndrome. Eimear did a mapping exercise, looking at the IDS-TILDA data,
24 to the general risk factors for the Lancet. And we might show that slide in the afternoon,
25 because that was interesting to just look at the difference in terms of those risk factors. But
26 yeah, I think that that's great. Okay, I think this gentleman down at the end, I can't see the
27 name. Yeah, thank you.

28

29 Ashok Krishnamoorthy

30 Thank you. I'm Ashok Krishnamoorthy. I'm a geriatric psychiatrist, I'm a practitioner and I do
31 memory clinic and dementia-related work in the community as well as the hospital. It's very
32 interesting, our overview of this and I just thought I would try to take a little bit of a population-
33 based view to start with what we need to address, whether the brain health recommendations
34 need to be different, compared to the general population. It's good to start with what applies
35 to the general population should also apply to intellectually disabled population. Apart from the

1 fact that there is another layer of specific risk factors, which are more closely related to the
2 broader Down syndrome and intellectually disabled population. I was thinking in terms of
3 differentiating between brain health, where we talk about a population-based brain health
4 recommendations, which includes avoiding concussions, protecting your brain. And in that line
5 of thinking, stress, and related oxidative distress to the brain is a significant factor, which is not
6 often talked about. I'm sure that there is evidence which you can highlight into that as well. And
7 then if you funnel that a little bit into a risk factor, risk prediction model, then we need to be
8 more specific in terms of the current longitudinal cohort studies across the world, in at least
9 two sites, which we have learned now, Ireland and Netherlands, as to which of those risk factor
10 reduction models talks about? In the general population, dementia, there are studies that are
11 machine learning models, which automatically would start doing prediction towards dementia.
12 If you want to push it a little bit, we should probably go further and talk, or at least make a
13 reference into the machine learning artificial intelligence models as well. There are certain
14 other basic elements, which have been highlighted, I really want to repeat it again. So, hearing
15 issues, sleep issues or sleep apnea. When we do a recommendation through this kind of a
16 Summit, it carries a lot of weight to take it to the primary care practitioners, family physicians
17 and nurse practitioners as well. And one other thing is, treatment of psychiatric disorders,
18 especially anxiety and depression, carries a lot of weight in preventing or improving brain
19 health, as well as preventing dementia progression. With regards to cognitive, we talked a lot
20 about cognitive training, but in general population, mild cognitive impairment, we talk a lot
21 about cognitive stimulation training. So, I presume we are probably using this very
22 interchangeably. But the cognitive stimulation training in the mild cognitive impairment stage
23 does address attention working memory, executed functions, agnosia, and all those kinds of
24 stuff as well. So, it is found to have evidence. While pre-MCI stage in the general population-
25 based suggestion, we can talk about those activities which are stimulating for the brain, like
26 how it's been pointed out in the presentation. From mild cognitive impairment progression, we
27 can also suggest things like cognitive stimulation as a form of brain protective mechanisms to
28 help with the brain, as with the reduction of stress and mindfulness-based recommendation.
29 So, I don't know if all these things have a level 1a evidence, but sometimes you need to come
30 up with a consensus, if you don't have the highest level of evidence. And what is applicable to
31 general population, should also apply to this population, but need to add another layer of
32 recommendations to this.

33

34 Mary McCarron

35 Excellent, thank you so much for that. There's a huge amount in that. That's lovely. I'm going to
36 hand over to Seth Keller.

37

38 Seth Keller

1 Aside from my work in dementia care, I am a stroke neurologist. I see vascular disease like
2 every day, it's kind of mainly what I do, aside from the dementia care. So definitely the
3 appreciation of vascular risk factors is huge. I mean, it's a huge thing. And often in the general
4 population, the dementias are really mixed. There's a mixture between, so called vascular
5 dementia and neurodegenerative disorders and I often see a patient that had a stroke and then
6 shortly thereafter, the stroke progressive decline. So, it seems there's definitely a correlation
7 with and that's true. And those with Down syndrome, I don't see as many strokes and that
8 definitely happens. So definitely the appreciation of the vascular risk factors, and many patients
9 that I see with stroke, they're already smoking, their blood pressure, the weight, their sleep
10 apnea is already there, and may not be fair, but I use that as a motive for that motivation. I
11 actually use it as a fear factor as the motivation for them to say this is not an inevitability that
12 they're going to have another stroke, there is not inevitability they will develop a disability. I
13 use almost like a fear basically of how do you get motivation to do anything? You can get into it,
14 or you can be scared to death. And I really think that people develop like a PTSD sometime,
15 when they have some kind of complication of some sort. I don't want to get a stroke again, I'm
16 worried. Okay, well use it to your advantage. So, it's almost like flipping the coin, that kind of
17 take the fear of what brought him into that health issue and use it to what proactive approach
18 to get them motivated. So how do you do that in someone with, say Down syndrome, that has
19 a lifelong, high prevalence of getting Alzheimer's disease? And I think, that is the other issue
20 about the issue of ambivalence or lack of motivation, and really to use the nature, the fact that
21 there is a high prevalence of Alzheimer's and Down syndrome, to use the advantage of almost
22 motivating people to do that. And I really think that goes to the psychology of the messaging of
23 people with Down syndrome early on. And when you start bringing up the conversation, when
24 do you start talking about it? And when the families and carers really start talking about the
25 issue of Alzheimer's, and it's often a denial at something kind of people don't really want to get
26 their mind wrapped around, until they start showing signs of decline, and it's almost late. So,
27 where's that middle ground between someone that's 20 years old and say 40 years old? I think
28 it really has to be marketed, in terms of really talking about, we should start thinking about this.
29 And the issue of that also, rather than denial and not wanting to think about and talk about it is
30 really useful. And I think, to be honest with reality that is very highly prevalent in people with
31 Down syndrome, that most of them will be getting it at a relatively young, early age. And I think
32 it's a marketing approach, how do you do it in a very positive way of getting yourself motivated
33 to care for yourself in your life? And just finally, the issues about factors, you can treat the
34 hearing loss and the sleep apnea. And I love Lucy, takes you a year - you're motivated, you're
35 very motivated to do it. And I think it's the motivation and self discipline you only do, so what
36 does that mean for those with, you know, IDD and Down syndrome, and how they do it. And it's
37 not only them and their carers, but also what about the experts, the so-called sleep apnea
38 doctors or the audiologists or ENT doctors? So, you bring the individual with IDD to the
39 specialist and what is the specialist going to do? Do you think they know enough about this
40 population to do the motivation? And they give up. They wave the white flag after one
41 therapeutic or one trial, and that happens, I'm sure all the time. So, trying to find the experts

1 and what is our role and responsibility to help the experts to become better experts? I really
2 think there's roles, responsibility that all of us have to help each other.

3

4 Mary McCarron

5 Okay great. So, I'm going to ask people now, we're going to rush through these next comments.
6 I have Alyt Oppewal next, then I have Dawna Mughal, and this lady here then. We'll get through
7 those three in the next five minutes. Okay, so Alyt.

8

9 Alyt Oppewal

10 Okay, I will make it very quick. It's also pretty in line with what other people already said, I think
11 it's looking at the questions, do we need a separate evidence-base for people with an
12 intellectual disability? When to start brain health programming? I think what's really needed in
13 this population is that we get more insights in the early signs of MCI and dementia. Also, to
14 know when we should start with prevention programs or some sort of treatment. And I think
15 the longitudinal studies can help really well in that, so it would be really interesting to look at
16 early signs. And also, I'm a sports scientist by background, also very interested in the mobility
17 signs that may precede the whole MCI and dementia part. And in addition, with the whole
18 motivation, and how can we get people to change their lifestyle for a healthy brain? I think we
19 need to think about how to include the whole system in that, because we can look at the clients
20 themselves with an intellectual disability, but it also needs to include, again, the whole support
21 system, the care systems that they are in. Because from experience, I know if you don't do that,
22 it won't last and it won't work. I think motivation and fun is a factor that we hear very often
23 that helps, but also including the whole system around it.

24

25 Mary McCarron

26 Okay, lovely. Yeah, I'm just going to take one more comment, because I don't want the only
27 thing between you and your lunch is me and hosting questions. I'm going to ask Dawna then
28 next and after that, we'll break for lunch. I will resume with questions. People keep their names
29 up and I'll resume there when we come back.

30

31 Dawna Mughal

32 All right, a few points on my long list. Number one, for sure that treatment for the prevention
33 for dementia doesn't come in a pill. And number two, Phil, you missed the gut microbiome and
34 brain health. Your GI tract, the bacteria there affects brain health and brain health begins in the

1 womb. The health of the mother affects brain health of the baby. The crosstalk between your
2 GI tract, your gut microbiome, and the brain. The next point is oxidative stress. Nutritionists
3 have answers for that. Antioxidant nutrients, Vitamin A, Vitamin C, okay, that's it. Eat those!
4 Make sure that you eat your antioxidant food sources. Now, point number three, how to
5 establish good habits, Lucy? Number one, we talk about different modes for prevention, right?
6 That's very difficult for people to do. So, one is choice, make the goal simple, choose a thing
7 that can be encouraged to do, as Phil mentioned, and the power of goal setting. Simple goal
8 setting, and people can do that. But I guess, choose your battles, right? Because you're going to
9 fight all the fronts.

10

11 Mary McCarron

12 Thank you. Excellent. Okay, perfect. We'll break there. I've been asked to break here for lunch.
13 Lovely, great. We'll resume the questioning.

14

15 Nancy Jokinen

16 So, we'll resume topic two after lunch with the discussion. And I want to thank Mary and Phil
17 and the group two members for a very interesting start to the discussion and presentation. I
18 already have a whole bunch of questions for afterwards, too. And I'm sure there will be lots of
19 discussions. So, lunchtime, 12:30-1:30, but if you could come back just a couple of minutes
20 early, we have a little tribute to, to do that's kind of special. So, we're going to start at about 20
21 after 1. Thank you.

22

23 Sandy

24 So, I think if everybody wants to come and take their seat. Mary, I'm going to put this back in
25 your capable hands here to continue to facilitate the great conversation from this morning.

26

27 Mary McCarron

28 Okay, I'm going to pick back up on the questions, and I can't remember who was in order.
29 Karen, I'm not near as good as you. Okay, and that's because of my age probably. I'm going to
30 start my way around, so I'm just going to do it in this order. Okay. So, at the very back, yes,
31 thank you.

32

33 Laura LaChance

1 So of course, we all know the purpose and the title of why we're here. And I greatly appreciated
2 the slide presentation that we went through before lunch. And, you know, one of the wordings
3 that we've used is not so much that you're going to prevent dementia, but we mitigate the
4 development of dementia, you know, like, just living better, you're going to be better. But one
5 of the things I think we all have to remember, and notwithstanding the years of expertise that
6 many academics around this table have, is that kids today, in 10 or 15 years from now, they
7 come with great skills. And you know, perhaps they've had an upbringing where there hasn't
8 been a focus on their deficits, but there's been a focus on their strengths. And particularly
9 children with Down syndrome have embraced technology and apps and all of the above for
10 learning, that they are going to come to this time in their life where we talk about preparing
11 guidelines for now, but I think we also have to think about what the guidelines are going to be
12 like in, and it's not a generation, it's almost half a generation from now, because they'll come
13 with those skills, and they will not need to be introduced to them.

14

15 Mary McCarron

16 I think that's a really important point. And looking at that intergenerational difference that
17 we're seeing already in people who are 40 to 50 years old now and versus the group that we
18 looked at, you know, 15, 20 years ago. And their lives are grossly different. Their opportunities
19 for education, the use of technology, as you have said and all of these things. So, I think the
20 population who are probably aging now are aging at a particular historic point in time and their
21 aging is very much influenced by the history of our past and that was the past that really we
22 didn't give opportunities to people but I do think now that the next generation will look grossly
23 different. So, thank you. I think that's a very important point. Okay, so I'm moving up and this
24 lady. Great, lovely, thank you.

25

26 Flavia Santos

27 Flavia Santos from UCD, University College, Dublin. Just going back to what we were discussing
28 before the break. One word that I haven't heard here yet, but it's very frequent in this
29 population, is the issue of sedentarism. I see a transition from when they are children, parents
30 are stimulating a lot, putting them in several activities. And then when they, let's say turn 18-20
31 years old, they become kind of independent and there is no further guidance or support or
32 encouragement for doing things. So, when we talk about brain health, I think sedentarism is a
33 big problem and we need to change this attitude as well. Last comment, and I don't need to go
34 into it further now, because you probably will have an opportunity in another moment, but
35 Lucy was talking about interventions. We also have a study on memory clinics, so I would like to
36 talk about it in another moment if the opportunity arises. Okay, thank you.

37

1 Mary McCarron

2 Thank you very much. Okay.

3

4 Unidentified

5 Yeah, I just wanted to add to, when we're talking about prevention or mitigation strategies, I
6 like that word. And I've heard the words motivation and goal setting. And I really think the
7 other important piece to think through is how we break down the skills that we're talking about
8 for people, because I think at a high level for anybody to talk about exercise can feel very
9 overwhelming. And so how do we translate that to people, so it's meaningful to them? And
10 sometimes I think we tend to have like an all or nothing, like, "*Yeah, we're going to exercise 60*
11 *minutes every day*", which can be incredibly overwhelming to someone. So, as we recognize all
12 these brain health related areas to be really important, I also think people get very
13 overwhelmed. How do we work with the carers and the people themselves to identify? Goals, I
14 think for them, they have goals their whole life, and I think sometimes they're kind of done with
15 goals, particularly in adulthood. So how do we support them to feel like it's actually an
16 achievable thing, but maybe not so much, I think goals can sometimes come with a lot of
17 loaded history.

18

19 Mary McCarron

20 Lovely, thank you very much. Very important points as well. Yeah. Really helpful. Okay, great.
21 Yes. Thank you.

22

23 Lucy Esralew

24 There are several points that I wanted to pick up on. A lot of stimulating conversation here. One
25 of the things I think about brain health, particularly for individuals that we work with, is that
26 brain health is a lifespan issue anyway, just generally speaking. When I trained to be
27 geropsychologist several decades ago, we talked about how aging begins at birth. So, if you
28 want to take a real lifespan perspective, what we do early on has significance later. And what
29 happens later helps inform what we might be doing differently early on. And I think it's
30 particularly true for people with intellectual disabilities, many of them with a
31 neurodevelopmental disorder, where their brains are different in some ways, or functioning
32 differently than others, and we'll have more to say about that in group three. So, if we're
33 waiting until people decline to talk about brain health, we've waited a bit too long, right? So, if
34 we can move that conversation upward. Another thing in terms of motivation and lifestyle and
35 habit change. In the general population, what we do is we do motivational interviewing in
36 health care, where we look where a person is at. But first of all, we make sure they have

1 information available to them, so that they can make choices about whether they want to do
2 something or not. And I don't think that that strategy is used sufficiently among people with
3 intellectual disabilities and their families. It's not like, okay, you don't want to exercise? Okay.
4 Well, did you realize that they've had studies in which they found out that people who didn't
5 exercise had a bunch of health consequences. And saying it in a way which meets the person
6 where they are, they might still choose not to exercise. However, they've perhaps chosen with
7 a little bit more information. And we can be a little more confident it's an informed choice, and
8 not something that is just because, well, you told me I should and I'm not going to do that. The
9 other thing is that several people who might work with, when they reach a certain age, they are
10 retired. Okay, so from their work program... I know you're supposed to be retired, Nancy, and
11 that you're not really retired. But in any case, people with intellectual disability are told that
12 they no longer are going return or I've had individuals who've told me, "I am no longer working.
13 I do not have to work anymore. I have reached the age, I'm not going to the workshop or the
14 program or whatever it is". However, what else do we do? And it kind of picks up on something
15 that Flavia was saying is, we're not good with those transitions. So, what happens when
16 somebody stops schooling, and what happens to transition into adult services, what happens
17 when somebody stops working or attending day program or whatever they were doing prior to
18 retiring, and are now sitting home? Now, they may not be able to access a cognitive training
19 program. But are there some activities that we can recommend that will be cognitively
20 stimulating, and helpful, and help them feel that they had a meaningful day and not just kind of
21 sitting around? And then the last point, in terms that of what was just mentioned previously
22 about a new generation of individuals who have access to technology, then my response to that
23 is for some, yes, not for all. So you know, I work in California, and for a period of time, I was in
24 the northern most part of California, where they have awful internet service. And a number of
25 families that I worked with, in California, did not have regular access to internet. So, it wasn't
26 even a matter of could they use it, they didn't even have the infrastructure in which to be able
27 to access it. So I mean, again, we talk about equity, that's an important thing, not only will the
28 people that are coming up in a new generation be able to use that because they've been
29 exposed to how to use technology, but will they have access socioeconomically to what's
30 needed in the infrastructure?

31

32 Mary McCarron

33 They're both great and really helpful points. And certainly, in Ireland, it's very clear that COVID,
34 if it did one good thing, is really exposed and opened up the world of technology to people with
35 an intellectual disability. And we've seen almost a 50% increased use of technology. And we
36 were wondering, would it stay post COVID? And we're happy to say it did, so that's really
37 important. And as I get nearer my retirement, people are busy running programs for me and
38 how to prepare for retirement. So, I think for people with intellectual disability, maybe we need

1 to be running programs in terms of preparation. So, I think they're all really important points,
2 okay.

3

4 Kathryn Carroll

5 So, I thought I would dip my toe in the water here, as a non researcher, non doctor, I'll just start
6 just responding to a point, way back at the beginning of this section. And this relates to the
7 overall topic of looking at how we address goal setting and the ways of breaking it down or
8 building it up and making it more achievable for people. And I'm responding to something that
9 Lucy said, your story about the person who identified as a walker, and I'm wondering, and
10 again, I'm a non-researcher, so there could be research out there, but I am wondering what the
11 consequences are of people taking on those identities and saying, "I am a healthy person", "I
12 am a walker", "I am a balanced eater", and what is the impact of adopting those things for
13 myself on my ability to achieve those brain health education goals? So that was just a reaction I
14 had. And then I thought I would try and respond to the one question about are the materials
15 suitable for people with IDD? And in my experience, I would say largely, no. I'm at the
16 Association on Aging in New York. I work with, we call them area agencies on aging. So, aging
17 services providers, and I do see the offer by these providers of the evidence-informed
18 programs, the evidence-based programs, the chronic disease self management, the diabetes
19 self management, the nutrition programs, all of these things that offices for the aging typically
20 do. And I do know, based on my experience that those programs are just broadly not accessible
21 to people with all types of disabilities, and I do strongly believe that they could easily be. It
22 would not take much at the implementation level to make those things accessible. There are
23 best practices for making materials accessible, there are amazing examples of adapting things
24 to people with a variety of disabilities. Even going as far as our state governments, making clear
25 to providers that if this particular curriculum or option doesn't work, we fully support and
26 would make happen, you are connecting the individual with this other option. So, I think it's
27 totally doable. It's frustrating in my work to be working on that. That all being said, though, I do
28 realize, I guess the big caveat is that while making those things as accessible as they could be,
29 which I think is very accessible, and suitable for people with IDD is that that doesn't mean that
30 people will opt into those or choose those or come to those with their attendance with their
31 family members or caregivers. So, I fully realized that, and it doesn't address what I've seen,
32 which is attention, a competition really, for people's time and attention between
33 developmental disabilities providers and aging services providers that I don't really know what
34 to do about that, it needs to be addressed. Someone has to get billed, right? Someone needs to
35 make their numbers. Classes have to be filled. So, ultimately, there's going to be that tension,
36 and I've seen it in my work, suggesting ideas for programs and having to point out that it would
37 be great to offer this program through an Office for the Aging, directed at people with
38 disabilities. But that local DD provider is not going to, they're in competition. And so, I guess I
39 can't blame them, because you need the dollars to fund the program at the end. But yeah, so

1 that's what I was thinking about. I guess, the short version is that no, the materials are not
2 suitable, but they could be. And I guess I'll just say again, Lucy, I do appreciate the point about
3 the pushing back on the presumption that someone should retire at a certain age. I am trying
4 to, in small ways work on that. So, like involvement with the University Center for Excellence on
5 Developmental Disabilities, and I'm involved with getting them to think about their
6 employment pillar more broadly, and not just transition youth but looking at, you know, like
7 when someone does choose to not work, or do they want to keep working? If I have that
8 expectation that older adults shouldn't, we shouldn't be tied to that idea of, you know,
9 retirement at 65. If I have that feeling for the general population, I'd certainly don't have that
10 same expectation for people with IDD. And I'll stop there. Thanks.

11

12 Mary McCarron

13 Thank you very much. And again, some very critical and important points. Because oftentimes
14 when people with IDD leave their workplace or the workshop or whatever they were doing,
15 they often lose everything; the social connectedness, the community and everything else. So, I
16 think that's really important. Okay, I'm going down to the very back, the lady that yes, great,
17 lovely. Thank you.

18

19 Yumi Shirai

20 Hi, I'm Yumi Shirai. So, brain health. I just wanted to advocate the part of the role of arts,
21 creative arts and culture activities, because a lot of those can be expressed, address those brain
22 health issues in combination with the motivation, right? That's motivating instead of just
23 prescribing the one aspect. But then it makes it very complicated for researchers because a lot
24 of confounding factors in it. So, we really need to strengthen the arts-based research, as well as
25 how we can really navigate that messiness, community practitioner, advocates and family
26 members and researchers work together. So that's how we can really solve the issues. And also,
27 arts-based research can be the one that the general dementia and aging research can open up
28 to our population. It may be easily accessible or adaptive. Because of the nature of
29 communication. It's expressed communicative tool, which is not based on written or spoken
30 words, often time, and how can we take better advantage of that, and that can address. And it
31 also, one last point, those things need to happen earlier in the life, right? So, arts only works
32 when you really practice this as your part of life, throughout your life, then when you have
33 issues with dementia or aging issues, that becomes an additional tool for maintaining your self
34 expression and communication, navigating life. So, we need to promote that activity earlier in
35 all of our lives, including persons with disabilities. So that's my point.

36

37 Mary McCarron

1 Yeah, very important point as well. And yes, the role of the arts is really key, and I always feel,
2 for somebody who has been always interested in activity, in sport, leisure competence is a skill,
3 and you need to be learned. For people with intellectual disability, they need to be supported
4 to maintain that skill and to learn that across the lifespan. So, it's a bit too late when they come
5 to 50 or 60, or whatever, when they're at risk of change. So, thank you for that. Yona. And then
6 Dawna? Yeah, I'm not sure who was first there. Yeah.

7

8 Dawna Mughal

9 There are programs... Beth Marks isn't here... but Beth Marks runs the Health Matters program.
10 Yeah, she has this program. I haven't used their website recently. But I know that it runs
11 continual programs - nutrition and physical activity. But Beth isn't here to speak. And then there
12 are other programs, there's a New York based program that does the same thing. And they
13 looked at your shows. Instructors, or dieticians doing physical activity virtually via TV, and the
14 participants engage in it, and they do very well. In other words, there are programs, but my
15 view is that they're kind of fragmented over there, over there, over there, you know,
16 duplication, doing the same thing. And another point I want to make is that there is a website, I
17 think it's NCHPAD [National Center on Health, Physical Activity and Disability]. And it deals only
18 with physical activity for people with disabilities. Other examples of physical activities that can
19 be done by clients or people with disabilities. So, I think it's important for people to know the
20 resources, because there are resources. The other thing is the social determinants of health, I
21 think we talked about this. Even for non-disabled population, we're not doing that. We do not
22 have the time to collect the data, right? And when we have the time, we do not use them. And
23 that is a big issue for healthcare and people without disabilities and is much more so in the
24 population with disabilities. So now, we're dealing with a lot of problems. Which ones can we
25 do? Because we cannot do all of this. I mean, I don't know.

26

27 Mary McCarron

28 Well hopefully, we'll have more light on that by the end of the two days. Exactly, Yona Lunsky
29 and then Lucy Esralew.

30

31 Yona Lunsky

32 So, two quick points. One is around the physical activity, as well as the social, sort of
33 engagement networks. One group we can look to, that sort of targets this but doesn't use the
34 same language, because they're not thinking about aging yet, in the same way, would be the
35 Special Olympics on the international movement, because there's a huge emphasis on health.
36 But they have like strong minds, they don't have brain health, so a lot of the activities kind of

1 need a bit of tweaking, and also, they have issues around how they continue to support people
2 as they age. And also, they have a big inclusive sport program, which brings people in who don't
3 have intellectual disabilities. But again, it's usually more with kids in school, young people. I've
4 been saying for years, if someone came up with something I could do with my sister, which was
5 like a low intensity sport thing, I would love that, I'd be all over it. I think a lot of older people
6 would. So just to look at them and their research combined with their policy, especially in the
7 States because they're very tied to the CDC. Right? And my other comment was just around the
8 issue of, someone said, I think about people's motivation to do some of these things. And I
9 think there's somewhere between like the big system and motivation that we have to keep in
10 mind, so I'll just give a few fast examples. Like, someone going to the gym or even using their
11 iPod or their video thing, you know, when there's some kind of sensory issue, that's not quite
12 right for them. So, that needs an adjustment, right? We don't need to make them more
13 motivated, and we don't need to change the whole system, we have to make it work better.
14 Another example around sleep was someone I'd worked with years ago with Down syndrome,
15 who we were screening for depression, we found that they had sleep apnea, they got fitted,
16 they got a CPAP machine, we followed them over time, and they still really could not be awake
17 and do things during the day, and they were missing work. But no one actually asked them if
18 they're wearing their CPAP machine, right? Which they had stopped doing at a certain point, for
19 a particular reason and needed some new education and modification about it. And I was
20 thinking about the hearing issue as well. And, once you get, for example, a hearing aid, first of
21 all, you can't lose it, you can't break it, they're very expensive. But also, you have to be able to
22 adjust it, so that you can hear just the right amount. So, if you can't do your own self adjusting
23 what happens? Or like, your shoes that you're wearing for mobility, and they're not
24 comfortable. So, there are so many things we can do to help people, but we have to understand
25 why are they not motivated to do X? And then how do we make accommodations or adapt
26 things kind of like the reasonable adjustments, but not at the physician's office, just in their
27 own home or wherever? Just to keep that in mind. And for their carers, so the carer might not
28 have good shoes, or they're not willing to do the activity because of these other little things. So,
29 we have to understand what their barriers are too.

30

31 Dawna Mughal

32 Can I add something? Remember Special Olympics? Special Olympics is doing a good job, right?
33 It has different disciplines. I've been volunteering with Special Olympics in Pennsylvania since
34 2014. I'm a clinical coordinator. So, I see the athletes perform and they show me the medals,
35 they're so proud of them. And then the parents or the staff are there. It's a global public health
36 program, Special Olympics is a global public health program, and it delivers. So yeah, there are
37 programs out there.

38

1 Mary McCarron

2 Yeah, there are, and it is about making the reasonable adjustments, as Yona said to some of
3 those programs. And we ran a great program. And Alyt is here with the group in Rotterdam,
4 running what was called the P-PALs program, which my colleagues at the Trinity Center ran.
5 And that was training people with an intellectual disability to be physical activity leaders within
6 their own community. They were highly motivated to engage in that program and we've rolled
7 that out now, right across different areas. So, there are things we can do and that was making
8 an adjustment to an already existing program but training people and empowering people and
9 giving them the autonomy and motivation to run that program for their peers, rather than us
10 running it. So, there are some interesting things we can do. Great. Is there a further comment?
11 Oh, lovely. Great.

12

13 Seth Keller

14 Yeah, it was wonderful that you brought up Special Olympics; I'm actually part of Special
15 Olympics Aging Task Force. The program that they have is called Healthy Athletes program - eye
16 screening, foot screening, dental screening, they have another, Strong Minds. All these
17 relevancies for healthy screening are not for older people. And then the competition, which is
18 really it's a competitive sport organization, that's really their doctrine is competitive sport, it's
19 all for young people. So, they don't really decide and work for aging populations. So, I had
20 worked with the Special Olympics of Alaska and other States in the country about creating
21 what's called the Aging Task Force, and is trying to really create in Special Olympics, older
22 related issues related to competition, and the Healthy Athletes program. So, they can do
23 screening, essentially a lot of what they do, they screen out. And definitely for early onset
24 Alzheimer's, they're not seeing it; they're not seeing because they're not really noticing it. And
25 then a lot of people in Special Olympics, they drop out. So, the average age is your like, early
26 20s. So, a lot of people age out of Special Olympics for various reasons. So, we wanted to look
27 at the Aging Task Force at how do you bring people back in to be, not only competitive, but
28 really health promotion, because it's a competitive organization. So, we actually had to go back
29 and forth, and we had to find different program that gets support, and a lot of programs are
30 supported by money. So, if you want to actually be able to have an aging related issue, you
31 have to have an organization that can support. So, for Opening Eyes, which is the ocular one, its
32 The Lions Association, or I don't know if I got their name right. So that's an evolving thing right
33 now, but it's really appropriate for Special Olympics, both nationally and internationally to get
34 involved in this kind of dancing backward, but the pandemic kind of put a fork in it. But I'm glad
35 you brought that up.

36

37 Mary McCarron

1 Great. Really interesting and important. Yeah, lovely. Thanks for that.

2

3 Unidentified

4 A lot of what I've put down has already been said, but certainly we need to look at what gets in
5 the way for people with intellectual disabilities in terms of promoting a healthy lifestyle that
6 would promote brain health and education and knowledge of both the individual, but also their
7 caregivers is key. I mean, the people that we support are so reliant on their caregivers, and the
8 support to go and access those services. One of the things that we haven't mentioned, is
9 poverty. And poverty is such a significant issue for people with ID, especially living
10 independently or semi-independently, just in terms of access to healthy food. Even if someone
11 has the knowledge of what to eat, they may not have the resources to purchase that. Same
12 with access to exercise, when we think about, we've talked a lot about walking and others and
13 yes, those are low cost, but maybe not low cost if you don't have the right footwear, or you
14 want to buy a bike, you don't have the money to buy a bike, you certainly can't join a gym. So,
15 there's a lot of financial barriers that get in the way for people with ID in order to accept and
16 adopt a healthy lifestyle that would promote brain health.

17

18 Mary McCarron

19 Very helpful, really important. Yeah. And looking at the whole area of poverty and I think the
20 poverty scales that are out there at the moment to look at poverty, you know, we really need
21 to relook at those because they're not terribly applicable to this population as well. And I think
22 there are a lot of different issues, but we should work with people with IDD to redevelop some
23 of those. Okay, Nancy.

24

25 Nancy Jokinen

26 Just a couple of things to bring us back a little bit. When we talked about cognitive training and
27 something else. I was just wondering, in an older adult population, I often hear the terms
28 lifelong learning, and what happened to lifelong learning as a concept that can be employed
29 with people with intellectual disability versus cognitive training. It would seem that we don't
30 need to change the language to get people engaged in activities that stimulate the mind and
31 have social engagement and those kinds of benefits, without necessarily having a trainer, so to
32 speak. And there are two other points that I want to make. I know I spoke with Janice about
33 this, and the role of support staff in terms of not enforcing choices to be living healthier, but to
34 model it. Because I think staff have an influence that they don't necessarily realize they have, in
35 terms of how they live their lives and how they present themselves. That could be very useful, I
36 think, both for the staff in terms of their own health, as well as for the people that they

1 support. And I guess the final point that I want to make is, I hear a lot about brain health and
2 healthy aging, starting when people are young, we need to start when we're really young, I
3 want us to really remember that it's never too late to start. In other words, you can be 50 years
4 old, you can be 60 years old, and you can make some lifestyle changes, relatively simple ones
5 that can enhance your health. So don't look at the older person and say, "*Oh, wow, see ya later,*
6 *there's not much I can do*". I think we owe it to an older population of people with intellectual
7 disability, to celebrate their age, but to include them in various activities that would enhance
8 their health, too. And I think they will in turn, be an influence on younger people with
9 intellectual disability. So, I think we can do a lot more. I'm worried sometimes when we say, Oh,
10 it's a lifespan thing. Oh, you have to do it when you're early, to get any benefit. I'm afraid we're
11 going to dismiss, or some people will dismiss an older age population.

12

13 Mary McCarron

14 I think that's an important point. You know, it's always better, of course, if we develop these
15 skills and competences and we're younger, but it doesn't mean that it's too late to introduce
16 some of those things to our lives as we get older. Oh, lovely. Another comment. Great.

17

18 Lucy Esralew

19 So, I just wanted to clarify something in terms of lifespan and just kind of point out, what I
20 mean is continuously throughout the life, not either early or late. Because I think for all of us,
21 we are on individual trajectories of aging. And with the people that we support, who have
22 intellectual disabilities, they will have their own individual trajectory and natural history of their
23 aging and may have different challenges along the way to which they have to make
24 accommodations, adjust, adapt, whatever. And so, if we could think about it more flexibly, not
25 just kind of an age specific kind of thing, especially because neurodevelopmental disorders are
26 lifelong conditions, as we would tend to think of them just broadly. Another thought about
27 lifelong learning, and I agree with you, Nancy, the problem is that very often, that is given an
28 academic kind of flavor to it, like taking continuing education courses, or whatever. If we can
29 work with people to think about what activities, whether it's learning a new hobby, or whatever
30 it is, being involved in some way that continues their learning and is cognitively stimulating, but
31 doesn't have the kind of baggage of it being, you know, like, for me, I will be going to school for
32 the rest of my life. That's a choice that I make. But not everybody sees themselves as a lifelong
33 learner in that way, particularly individuals with intellectual disabilities who may have struggled
34 in school. And that was not among their better experiences. So, you know, some way for us to
35 kind of open up what do we mean by lifelong learning and be clear. And then the last kind of a
36 comment, and I'm not even sure where my thinking is with it, other than to kind of note that
37 when I'm working with families, or with professional caregivers, very often there's a push to a
38 more reductionistic, rather than a more complex way of looking at things. So, they want an

1 answer. Is it this or that? And I get that on one level. On another level, I'm like, it's a this and it's
2 a that and it's a this, and it's a that, and it's much more complex than, you know, it can't be
3 bifurcated as okay, it's either this or that or nothing. And so how do we keep people open to,
4 for instance, I'm thinking and back to the comment about, well maybe, the person can't afford
5 to get a good pair of shoes? Well, maybe the person has a pair of shoes, and their feet hurt,
6 they don't fit well. And that's the reason they're not walking, not because they're not interested
7 in walking per se. But that never comes to light. Because all we know is we asked John, do you
8 want to go for a walk? And he goes, "...no, I don't want to go for a walk." We don't ask why?
9 Well, it's his choice. He said, "*No, I don't want to go for a walk.*" So, we miss the fact that the
10 guy needs another pair of shoes that fit better, and then he'd be more willing to engage in
11 some kind of lifestyle activity. So, to me it has to do with, can we open up and think more
12 complexly about people rather than in a reductionistic way?

13

14 Mary McCarron

15 Yeah, yeah. And it's certainly not black and white. And you'll be really glad to hear that as part
16 of wave five in our study, we included an objective measure of foot health. So, I'll send you the
17 findings, and there were really not pretty, in terms of people's foot health. So, that was
18 interesting, really not pretty. Okay, so Matt. Great. I think it's you, Matt, is it?

19

20 Matthew Janicki

21 Just a quick comment, kind of segue to a little bit different thought. How do we design the
22 interventions that enable people, who are our target population to accept some of these
23 notions of healthy living and lifestyle changes, etc.? And I'm thinking in terms of the social
24 environment, where do they live? Who affects them the most, who they're who their role
25 models are? Is it in a family setting where there's adoption of those kinds of healthy eating
26 notions and exercise and discussions and social engagement? Or is it an environment that may
27 be deprived of those things? And, if the individuals who are in that social environment, the
28 people that influence the person's behavior, don't practice those, is probably not going to take
29 very strongly with the person that you're trying to say, oh, you should be doing this. And so, the
30 pickup is something we need to take a look at and see how do we modify those factors in the
31 social environment to enable people who we're targeting for this intervention, to accept and
32 adopt these principles of better health and whatever we're looking for in terms of brain health.

33

34 Mary McCarron

35 Yeah, I think that just came up a few times today and it is just so important that the role that
36 staff carers or family carers or whoever and the social environment in which people are living,

1 and the influence that that has, because whatever interventions we come up with, unless we
2 can really work with their social environment that people are in, they're probably very unlikely
3 to gain much traction.

4

5 Shahin Shooshtari

6 Matthew Janicki said what I wanted to say in terms of social environment, supporting social
7 environment, but also beyond just family and direct support staff. for example, for people to
8 feel safe to take part in physical activity programs in the community in an inclusive way to feel
9 safe to actually go and participate. And also, we talk about the use of technology for promoting
10 healthy lifestyles, to be mindful of the safety. So, safety, supportive social environments, they
11 go back to social determinants of health that was mentioned.

12

13 Mary McCarron

14 Yeah. Great. Thank you.

15

16 Vikram Palanisamy (?)

17 Hearing about all the things that we have spoken today, one thing that comes up quite a
18 number of times is about making choices. And in a very medical model, sometimes we get very
19 much fixated on looking at how to get things better, how do we fix this problem kind of thing.
20 And in that regard, I think we should always think about informed choices that a person might
21 be able to make when it comes to brain health. I may not want to exercise; I am just as happy
22 as I am. But then being able to make that informed choice, I think is really important. And how
23 do we facilitate that in this population. The second thing is about, we heard about how mental
24 health can also influence brain health in the long term, as well as physical health issues. And
25 within that, I think there's a huge role that primary care providers can actually help in
26 promoting brain health. So, I think in this whole discussion, we should also try to look at the
27 role of primary care providers, both family physicians, nurses, other community providers, not
28 only raising awareness, but also trying to look at early detection of physical health issues and
29 treatment.

30

31 Mary McCarron

32 Yeah. All really, really important. I think that word of choice has come up to both sessions
33 today. So, I think that it's really important. Eimear, you wanted to come back in and then Yona.

34

1 Eimear McGlinchey

2 Thanks so much, it's kind of following up on the idea of choice. And I think it's, again, thinking
3 about the messaging around brain health, and that it isn't seen as a list of things that people
4 can do and then this will lead to better brain health. Because I think that can lead to some
5 people might see a list and, Okay, the person I'm caring for, they are already going for walks,
6 they already meet up with people, and I'm ticking off these boxes, whereas the messaging is
7 around, it's around engagement, and it's around how do you either maintain engagement or
8 increase that across all these different activities, and I think choice comes into that in a big way
9 as well. So, if we think about what the mechanism is, by which each of these different activities
10 can support brain health, so when we talk about social connectedness, the way in which that
11 can contribute to brain health is beyond, say, activities, people being involved in activities
12 without the choice of being involved in those activities. So, while that may tick a box of being
13 socially active, or they're doing social activities, the meaning behind what they're doing is going
14 to impact whether that can then influence brain health. So, I think, again, it's just thinking
15 about the messaging and how we're speaking about it, and that it's not, it's not a tick box
16 exercise.

17

18 Mary McCarron

19 It's not a tick box exercise. And I think if it is, Eimear, you're absolutely right, it will not be
20 sustained. And it will probably bring very little benefit and a lot of stress as well to people. So,
21 we do need to be mindful of that. Yona?

22

23 Yona Lunsky

24 Just a quick point, because this population ages prematurely, even if the people working with
25 them, whether it's like, in my case, as a sibling or as staff, they're generally not in those
26 situations yet. So, they don't know what certain things feel like. They don't know why it might
27 be hard to do a certain activity. They don't feel the same motivation for why something is
28 important. They haven't had a particular healthcare experience yet. So just thinking about how
29 we explain or engage either younger staff or same age staff, because it's as though they're
30 younger or younger siblings. Because again, the parents who maybe went through it, maybe
31 aren't even around when we're trying to promote these things, where they can't do those
32 things themselves. So, just thinking about how we help people understand those things who
33 are in that person's life.

34

35 Mary McCarron

1 Yeah, I think that is a huge issue. I was just talking to my niece the other night. She's a nurse,
2 but she works across the disability sector in Ireland, and she was just talking about her
3 experience in working in two houses, a mile apart. And so, the first house she went and worked
4 in was a very health-focused house and the staff are all that way. The people who were living
5 there seemed to be really engaged, there was all of these good choices, and really interesting
6 things to do. And then she moved to another house, literally a half mile down the road. And
7 none of the staff or people were interested in that way of life. And they had a takeaway four
8 nights a week. And she was told, well, that's people's choice. So, there's such a dependence on
9 the education and the support and the staff who are working are supporting people. I think it is
10 a cultural thing. It really is a cultural shift; I think that we need to see happening in
11 organizations as well.

12

13 Seth Keller

14 I just wanted to add one additional comment about the change of resiliency with age. So, when
15 I'm losing my vision, my hearing, my balance, I can compensate, and I can still maintain a level
16 of ability to function. So, I'm still independent. People with intellectual and developmental
17 disabilities, as the age, as we know, they are already functioning at a certain kind of level, but a
18 smaller decline to them may have a larger impact for them to be able to continue to maintain
19 their level of support or at least need for independence. So that's another aspect to appreciate
20 how important it is for wellness and health promotion for them. And to have adaption, I
21 suppose, to enable them to care and be able to have a higher level of independence or such,
22 because if they lose that, they're becoming more and more dependent upon others, whether
23 that's pathologic or not.

24

25 Mary McCarron

26 Yeah, absolutely. So, any small change can have a tipping effect or a major effect. Yeah, so
27 that's true. And I think Leslie and Kathy want to both come in there.

28

29 Leslie Udell

30 I just wanted to expand a bit on Yona's comment. In one of the focus groups that we did with
31 family caregivers, we asked the question, "*What have you found helpful in supporting your*
32 *family member with dementia?*". And one parent, who was in her 80s, said, I found it really
33 helpful to reflect on my own aging process and that has helped me to try and understand
34 what's happening with my daughter, that might be an aging process, as opposed to the early
35 signs of dementia. And what struck me is that we tend, again, to disregard the perspectives of
36 older caregivers, and what a wonderful resource if that mom could sit down and share with the

1 paid staff, her perspectives on growing older. So, that's a whole resource that we don't tap into,
2 because, number one, we tend to disregard parents to start out with, and if you're an older
3 parent, you know, what are they got to contribute? But she saw her aging process as so helpful
4 in her ability to support her daughter.

5

6 Mary McCarron

7 Great, thank you. Absolutely, really important. Thank you, Leslie.

8

9 Kathy Service

10 I wanted to echo that, and I even though I'm a Gerontological Nurse Practitioner, you could
11 read everything in the book, but until you start to experience those normal changes of aging,
12 you have no idea what it means to the quality of your life and the adjustments. We can make
13 rationale and understand, oh, you know, I'm having a hard time getting a bed and you get it oh,
14 it's blah, blah, blah. But for people who have intellectual disabilities to understand that and
15 then when you're working with younger staff, they don't really kind of get some of those
16 nuances, you know, lighting, things like that, you know, going into somebody's house and
17 there's hardly any lighting and I can't see myself and it's like, how do you get the message to
18 people about what's a healthy environment for people in a positive that will enable people to
19 be the best they can and do what they can do? It's a different kind of mindset. And unless you
20 have a sense about what it means to be getting older, in terms of the normal changes of aging,
21 many of the young staff have no idea. So, how can we help them to kind of understand these
22 kinds of things. Even in terms of their running around, you know, people with ID, older people
23 are freezing in their chairs, waiting to go out to day program, and the staff is running around,
24 they're hot. But it's just how did they get understand these kinds of things? And I think we
25 really have to support people in those kinds of understanding of the world when you get older.

26

27 Mary McCarron

28 Yeah, absolutely and thank you for that. Five minutes left, I'm not sure if it's Ivan or Evelyn, at
29 the end.

30

31 Ivan Brown

32 Yeah, when it goes around from person to person, I forget what I was originally going to say.
33 And I want to pick up on some of the other comments. Actually, what I was wanting to kind of
34 add to the conversation is, I think we need to not forget that the kinds of physical activities

1 should do with the learning activities that we promote, in order to promote brain health,
2 change very much over time, they're dynamic. And when I think of my own life, for example,
3 which has changed quite a lot, I used to jog when I was young. I used to ski every weekend. And
4 I used to play tennis. But I lost interest in tennis after about five years. And as I grew older, I
5 had a hip replacement, so I can't ski and I can't jog, but I can go to the gym. And when we're
6 dealing with people with people with intellectual disabilities, we often forget to encourage
7 them, to show us what they continue to like and what they might like to do next. I have another
8 example of a man I have known for 30 years, and he has a mild intellectual disability, and he's
9 blind. And I discovered recently that he loves watching nature shows about wild animals. And
10 I'd say all these years, I never knew he was interested in this. Why? I didn't ask. When I was at
11 his place, I never turned the TV on to those programs. My point is, we have to keep giving
12 people with intellectual disabilities, opportunities to check out if they're interested, if they have
13 difficulty telling us. If they don't have difficulty telling us, we need to listen, because their
14 interests do change. And if we're going to do activities that affect brain health, we need to
15 know what the activities are that are meaningful to them, and that are going to be adopted by
16 them and continued over some time.

17

18 Mary McCarron

19 Yeah, I think it's so important. Yeah, things change. And oftentimes, I think for people with an
20 intellectual disability, their horizons are often limited by what they know and what they have
21 experienced. And we have to open up that menu of life enhancing pursuits, I call them and give
22 people tasters and give them that type of exposure, in order to be able to enjoy.

23

24 Colleen Hatcher

25 Ivan, I appreciate what you said about listening. I think it's also watching, and I know we've said
26 it, right. Like if people, their gait is changing, maybe their shoes are not comfortable. I was
27 doing a tour a local Down syndrome organization where they have a facility, and they do adult
28 programming. And after COVID, sort of subsided a little bit. They were able to get back in the
29 building and they noticed an adult with Down syndrome, who was in her 40s was like really
30 petrified of walking down a specific hallway. And so of course the staff is getting frustrated.
31 Why is she not walking down this hallway? This makes no sense. She's going everywhere else.
32 It's this one hallway. Well, they realized because she wasn't able to communicate why, they
33 realized that her vision had changed. And the pattern in the floor was becoming like an optical
34 illusion for her and it was very scary, and she didn't want to like take that step because it looked
35 like she was going to fall or whatever. But the staff had to realize like okay, she's not able to
36 communicate, what are her actions, what are her behaviors telling us? And I think that's really
37 important, especially so many people with IDD, especially individuals with Down syndrome,

1 maybe not be able to communicate verbally, but they're communicating to their support staff
2 and to the people around them in a different way. It's just not verbally communicated.

3

4 Mary McCarron

5 Yeah, I think that is just so important is to be able to look at the meaning behind some of the
6 responsive behaviors, as we would call them, or that we see in dementia. I think we have run
7 out of time. And I just want Oh, Dawna Mughal has her hand up. Apologies, one more.

8

9 Dawna Mughal

10 I just would like to add comments to Matt's comment regarding social environment. And that is
11 the role of role modeling or modeling good behaviors. The family members model good
12 behaviors for people with IDD or younger people to emulate, that can help with behavioral
13 change. Nutrition is a family affair. So, ask the children to help prepare, or the clients help
14 prepare food in the kitchen, and teach them simple lessons at the same time. And the other
15 point I'll make, and then I'll shut up, the point regarding asking them to tell you what they like,
16 the power of storytelling. Have them tell a story, rather than asking them questions like a
17 questionnaire. I used to supervise students develop their skills in teaching. And instead of
18 asking questions on your questionnaire, have them tell their story. You'll get the information in
19 a different way, but in a more personal level. Storytelling is very powerful and there's literature
20 on it. I'm done.

21

22 Mary McCarron

23 Lovely, thank you very much. Thank you. And thanks to everyone for their participation. I think
24 this has been a really good discussion and lots of useful, I think food for thought really. I want
25 to thank Philip for co-designing and working together with me on this particular workshop and
26 everybody else who has been involved. So, look forward to the next level of this and getting our
27 thoughts together from this really fruitful discussion. So, thank you, everyone.

28

29 Sandy Stemp

30 That was awesome. That was a great topic too. And great leadership there by Mary McCarron
31 and Phil McCallion. So, thank you very much for all of that. Great discussion by everybody.
32 How's everybody doing everybody? Do we want to take five minutes before we dive into
33 number three? Let's do that. So, please help yourself to coffee or run on the spot or maybe, you
34 know, raise your arms and yell or you know, maybe a quick jog around the building.

1

2 Sandy Stemp

3 So, without further ado, I'm going to pass this to Lucy, who's going to take us through for group
4 three.

5

6 Lucy Esralew

7 Yeah, so hi. So, the way Vikram Palanisamy and I are going to do this is I'm going to take you
8 through a certain portion of the presentation, then Vikram is going to pick up and then I'll come
9 back, we're just going to trade back and forth. So, we have the privilege of working with group
10 three. And our task was to understand concurrent, lifelong, neurodiverse conditions and their
11 additive features to raising the risk for dementia. Thank you, Nancy Jokinen, for assigning us to
12 that. We had quite a time kind of understanding what neurodiverse was, we really kind of
13 struggled with that a little bit. But one of the things I want to say, just as a preface is that, it
14 gives us a chance to think about the heterogeneity of the population of individuals with ID and
15 the fact that there are many people who do not have Down syndrome, and we don't really
16 know if they're at a heightened risk for dementia. And we don't know if they were at a
17 heightened risk for dementia, if it is Alzheimer's disease, or some other form of neurocognitive
18 dementia. So, it gave us a chance to at least begin that inquiry among ourselves. So, we had
19 several guiding statements. Among them, what's the connection between select neuroatypical
20 or neurodiverse conditions of intellectual disability and increased risk for dementia? What are
21 the difficulties in assessing population of individuals, adults with intellectual disability who
22 might have concurrent neuroatypical and neurodiverse conditions? And what are the best
23 practices in addressing intervention and support for these individuals. And in your packet, there
24 are two things I wanted to direct you to; one, is we have printed out a reference list, a select
25 reference list on seizures and ID, that I think can be very informative. The other thing is, both
26 Ivan and Matt worked on, kind of an introduction to what will be hopefully our post-summit
27 document. But I think that it is a very good framing, for thinking about what we might mean by
28 neurodiverse, and what we might mean, even by the term intellectual disability, which we've
29 been using pretty freely throughout this. So, I suggest that you take a look. We had a very
30 illustrious group of individuals who are with me, the participants are listed here. And Vikram
31 was my co-lead on this group. So, I want to give a particular shout out to people. Indeed, both
32 Yona and Ariana helped us in terms of language and terminology, particularly with regards to
33 individuals with autism and the variety of ways we might refer. And also, how we may refer to
34 individuals who have intellectual disability, because there are differences among countries, and
35 what language is used to refer or differences among groups, and how self advocates choose to
36 be identified, as well. So, our process - we met twice, once in the beginning to kind of get what
37 our task was and identify what we were going to be doing. And then we met, kind of towards
38 the middle, to just check in with one another, and generate the material that we generated.

1 And I also want to thank again, Ivan Brown and Matt Janicki, because they did a lot of the heavy
2 lifting with regards to synthesizing the background information, and getting it posted on the
3 NTG website. So here we are in terms of how we divided ourselves up as subject matter
4 experts. And there were essentially four sub-topics that we focused on. One was autism, both
5 with ID and without ID. And one was Fragile X syndrome. Another was seizures. And the last
6 was mental illness. I also want to suggest for those of you who might not have had the chance
7 to look at the report that was generated by members of the NTG, having to do with
8 neuroatypical conditions. A lot of our thinking and examining neuroatypical conditions, a lot of
9 our thinking about what might be neurodiversity and increasing risk of dementia was guided by
10 some of the thinking within that document. And that is listed and has been listed among the
11 resources for you to look at. So, in our initial discussion, as I said, we had quite a bit to say to
12 one another about terminology. And one of the things that I think guided us was thinking in
13 what ways might the literature in general and thinking, tell us that brain changes with aging,
14 and certain conditions that might kind of raise our suspicion about the possibility of aging into
15 dementia. And so that's how we kind of arrived at several of the subtopics that I just
16 mentioned. However, I should point out, there were many other areas we could have gone into
17 but did not go into. For instance, a big one was TBI [traumatic brain injury], because the
18 literature for the general population suggests an increased risk with people who have had a
19 history of traumatic brain injury. We did not go into that area, we did not go into the area of
20 cerebral palsy, there has been some suggestion. There has also been suggestion there are other
21 genetic disorders that may raise the risk for individuals who have those disorders. So, I just
22 want to invite you to think about the possibilities of specific conditions, as they may increase
23 risk, and just come along with us for the ride, in terms of what we found out. So, we were
24 interested in dementia occurring in people with intellectual disability. We talked about what
25 about developmental disability that did not involve ID, and we kind of arrived at we can't do
26 everything, we are going to focus more on individuals who have specific conditions associated
27 with ID. And some of the things that we came up with are actually cross cutting. You can have
28 seizures and have a number of other conditions. So, seizures itself, or epilepsy is kind of one of
29 those cross-cutting conditions. You can have intellectual disability, obviously, and have a
30 number of specific conditions. You can be diagnosed with autism, with or without intellectual
31 disability. You can be diagnosed with Down syndrome and autism. And so there are a number
32 of concurrently concurrent neurodevelopmental disorders and we really have virtually no idea
33 how individuals age with those conditions, let alone how they may age into dementia or not,
34 with those conditions. However, this gave us a chance to at least ask the question. And then the
35 other thing that I just have to say is, we didn't really discuss the terminology of dementia. So,
36 you could arguably say dementia is a neurodiverse condition for aging. You know, so it is a brain
37 change, something that one develops into, it's not lifelong. However, one could argue about
38 that and what do you mean by dementia? Do you mean Alzheimer's disease only? Do you mean
39 any of the neurocognitive disorders? What do you mean, dementia is not a diagnosis? It is a
40 descriptor or category, in which we talk about significant change from baseline cognition and
41 adaptive functioning. And so, as I proceed, I'm going to talk about specific conditions with ID

1 and you know, these are the conditions that we focused on in group three in terms of autism,
2 Fragile X, seizures and mental illness.

3

4 Lucy Esralew

5 So, we were looking for this specific condition, whether it increased, what are the factors if, in
6 fact, there was an increased risk of that? And what could we say specifically about assessment
7 or treatment and support, with regards to this? So, the group that was facilitated by Matthew
8 Janicki on autism, did quite a bit of research in terms of what does the literature say about
9 possible connections between autism spectrum disorder and dementia? So, there was a
10 question about the possibility of shared genetics and neurobiological factors. And that came up
11 particularly with Frontotemporal dementia. So, that was an interesting thing for us to think
12 about. We also paid attention to lifestyle factors, including limited physical activity, social
13 isolation and sub optimal diet, as possibly increasing the risk of dementia for this group of
14 individuals. And then, what about preexisting cognitive and adaptive skills in terms of looking at
15 further decline? Did that put people, the fact that they had preexisting deficits, at greater
16 vulnerability for decline as they aged? So, neurobiology, chronic inflammation associated with
17 oxidative stress, what Kathy Service has mentioned before as weathering, with the increase in
18 allostatic load and mitochondrial dysfunction. All of that kind of brought up the possibility of a
19 common pathway, shared by aging with autism within the autism spectrum, and with
20 Alzheimer's disease. So, if you looked at the background material, you've seen literature that
21 supports a higher risk and literature that said there really is no particular higher risk for
22 individuals. So, what about assessment? Well, we thought that we had to have assessments,
23 which we currently do not have, that really take into account the particular sensory issues of
24 individuals with ASD, and the likelihood of heightened anxiety, which is very commonly found
25 among individuals with ASD. And the tools needed to be specifically designed for the
26 population, not necessarily something that we are applying that was developed for another
27 population and standardized data for this group. That would be essential for us to address the
28 challenges effectively. We also have to think, given the heightened likelihood of communication
29 problems or challenges, alternative communication methods that we would use in assessment,
30 such as the use of visual aids, augmentative and alternative communication systems. How do
31 you conduct and incorporate information from behavioral observation? And how do you
32 provide the benefit of a multidisciplinary, whole person, holistic assessment that definitely keys
33 on collateral information provided by family and professional caregivers, who know the
34 individual, and can supplement what is observed and what the individual can tell and
35 demonstrate themselves. In terms of treatment and supports, we thought about person-
36 centered care, coordinated by the multidisciplinary team. And I'm just going to refer to our
37 earlier discussion and saying, in addition to person-centered care, we should be thinking about
38 relationship-centered care, as a focus for how we develop our treatment and supports. We
39 definitely wanted to key in on the Six Pillars of Brain Health, so that this would apply for this

1 population and for all individuals. Communication strategies that increased functional
2 communication. Behavioral interventions - behavioral issues are very commonly a reason that
3 individuals on the spectrum lose their placements in the community. And to the extent that we
4 can support individuals, in terms of safe behaviors, we're more likely to help them age in place,
5 rather than have them lose their placements. And continuous monitoring of functional change
6 that has implication for support and treatment. What is helpful is to establish a baseline early
7 on, you know that as a member of NTG, I'm going to say utilize the NTG-EDSD. But one of the
8 things it helps us do is to establish a baseline from which we can then note departures from
9 baseline. And that is very important for us in terms of continuous monitoring. Legal and
10 financial planning is important, as are respite and support services. I know from the state of
11 California that is very much the most frequent request by families. And very often we do not
12 have the resources to provide. And of course, end of life care and planning.

13

14 Lucy Esralew

15 So now, after having given you this rapid overview, and I do hope that you had a chance to look
16 at the wonderful material that the group on autism and ID and dementia had assembled. I'm
17 going to take you over to Fragile X. I want to make a comment. When I said that I would do this,
18 this is after multiple decades of working with people who have Fragile X, but never really
19 considering how they might have a heightened risk for developing dementia as they age. So, it
20 was very interesting to me as a clinician because clinically, I have not had people present to me
21 with Fragile X as somebody who might be developing dementia. And I was glad to hear from
22 Vikram Palanisamy that he has a case that he's going to be following, that just presented to him
23 in the clinic recently. We have to write up these cases, because the clinical literature does not
24 have these vignettes available to us. But we do know from neuropsychological profiles, that
25 there is a change in IQ over time, among many people who have been serially evaluated with IQ
26 tests, reason to believe that there may be a decrease of IQ, measured IQ, as well as a change in
27 working memory. So that should raise our suspicion about possibilities of cognitive and
28 adaptive decline among people with Fragile X. So, you know, Fragile X syndrome is one part of
29 an array of changes that can happen with a Fragile X gene. And this somewhat confusing slide,
30 what I want you to just get from this is that the development of Fragile X syndrome, comes
31 after multiple generations, successive generations of the Fragile X gene being varied and
32 transmitted. So, somebody's grandparent may be, what they call a "carrier". They have pre
33 mutation of Fragile X, they themselves do not demonstrate Fragile X syndrome. However, they
34 may be at higher risk for FXTAS, which is the Fragile X-associated tremor/ataxia syndrome,
35 which is associated with dementia. However, their grandchild might have Fragile X, because
36 with each successive generation, there are more repeats of the CGG sequence, which is
37 associated with changes in the Fragile X gene. The protein that is produced essentially shuts
38 down, it is not produced, and that protein is very important for brain functioning, brain health.
39 So much for that confusing slide. So, a little bit about the connections between Fragile X and a

1 possible dementia. We know that individuals with Fragile X, according to the literature, may
2 have a process that they undergo that's not dissimilar to individuals with Down syndrome, as
3 far as deposition of APOE. So, the APP, the protein may be deposited in excess and there may
4 be some cellular changes that overlap with what has been seen in Down syndrome. So that's
5 kind of the recent thinking of some researchers. And we know that in terms of assessment, it's
6 very important for us to know about individuals who may be carriers and are in the pre
7 mutation stage and that they're in at risk for having dementia, or FXTAS. And then we know the
8 possibility of successive generations. And of course, there are ethical considerations about
9 whether people want to undergo genetic testing, there is a lot involved with that. But it would
10 help us understand a little bit more about the progression of the variation in the Fragile X gene,
11 if we were able to get that information, particularly among people above the age of 50, who
12 begin manifesting unexplained movement disorder. Because Parkinson's disease is very highly
13 correlated with individuals who are carriers and have that pre mutation of the Fragile X gene.
14 And also, if there's some unexplained personality or neurological changes, it would be helpful.
15 And that, we can attribute to the work of Hagerman in California, in which she helped to
16 identify the connection between grandparents who had the Fragile X tremor, and ataxia
17 syndrome, and then their grandchildren who had Fragile X syndrome. So, treatment and
18 support. I think it looks a lot like what we would talk about in terms of treatment and support
19 for people on the autism spectrum. But we might want to pay particular attention to the value
20 of occupational therapy and speech therapy early on, behavior intervention, because
21 individuals with Fragile X are at higher risk for behavioral challenges, and also in terms of
22 sensory sensitivities. By the way, Fragile X is the leading, inheritable cause of intellectual
23 disability that we know about, and it is highly associated with autism spectrum disorder. So,
24 there are certainly individuals that are diagnosed with autism, as well as fragile X syndrome.
25 Early intervention services can definitely be of value to individuals who have this Fragile X issue.
26 And I'm going to turn this over to Vikram, who's going to talk about seizures and talk about
27 mental illness.

28

29 Vikram Palanisamy

30 Thank you, Lucy. We looked at two conditions, autism and Fragile X syndrome. So, moving on to
31 the third condition, seizures. So, what's the connection? Again, looking at three areas, what's
32 the connection? What are the issues that we need to look at when you're assessing and what
33 sort of treatment and support interventions need to be modified? One, what's the connection?
34 There is a bi-directional relationship, so people with intellectual disability and epilepsy. There is
35 an increased incidence of dementia, up to tenfold. And then we know that people with
36 intellectual disability, when they develop dementia, are more likely to have seizures. The exact
37 mechanism is not well understood, but likely to be related to seizures, underlying costs of
38 seizures, intellectual disability, and other biological factors like genetic predisposition,
39 neurotransmitter dysfunction, abnormal neural circuitry, and neuroinflammation. So, you can

1 see that some of the things are shared across the different groups, as discussed before. So
2 then, what are the assessment aspects that one needs to consider when somebody with
3 intellectual disability, who has lifelong seizures develops cognitive problems? One is certain
4 types of seizures or complex partial seizures, or non convulsive seizures might present with
5 symptoms such as stereotyping moments or confusion or altered consciousness, which might
6 lead to confusion with dementia, like presentation. So, that's something we need to keep in
7 mind. Then, in those situations, we often use EEG and imaging techniques to help us
8 understand what's going on. And people with intellectual disability have some difficulty going
9 through some complex EEG. It might not be just a short period of monitoring, it might be 24
10 hours monitoring, 48 hours monitoring or MRI which is quite phobic. So then, when they
11 develop cognitive problems or dementia, then there's all these difficulties compounded. Then,
12 some of the comorbid conditions. A perfect example is sleep apnea and REM behavior disorder.
13 So, they might present with symptoms that could be quite confusing as to whether these are
14 seizures or whether these are memory problems, particularly people with intellectual disability.
15 Then, most people with lifelong seizures are on polypharmacy, not just for seizures, but for
16 other conditions as well. And then when they develop cognitive difficulties, it's very important
17 to tease out what's the effect of polypharmacy on cognition? What is the effect of seizures and
18 whether this is an additional factor like dementia? Lastly, what are the treatment and support
19 modifications that one needs to consider? The best practice in managing epilepsy and people
20 with intellectual disability applies here as well. So, very important that we track seizure data on
21 an ongoing basis. And then, appreciating what are the ultimate goals? It's the balance between
22 complete cure of epilepsy versus quality of life? And how do we achieve that balance?
23 Important to choose medications, particularly anti seizure medications that are likely to have
24 less impact on cognition, mood, behavioral aspects. And then having a clear action plan and
25 educating caregivers, healthcare professionals, starting from what's the first time? What is the
26 intervention that one needs to deliver in the community? And then when do you call an
27 emergency? So, these principles are applicable in anybody with intellectual disability with
28 chronic seizures, but when they have cognitive difficulties or dementia, then you need to make
29 sure that these are ironed out because you don't want somebody with dementia, to rush out to
30 emergency when you can manage that in the community. Understanding what are the standard
31 policies that are available to treat epilepsy in different areas, both in our country and across the
32 country is quite important. And again, while looking at treatment aspects, the polypharmacy
33 and the side effects the medication becomes very important, particularly when people with
34 intellectual disability and seizures develop additional cognitive difficulties. Now, the last group,
35 mental illness. So, we decided to focus on severe mental illness. The National Institute of
36 Mental Health surveyed people and then came up with some sort of definition of severe mental
37 illness or psychiatric condition that have significant functional impairment. And in practice,
38 usually we consider bipolar affective disorder, schizophrenia, and severe depression, to be
39 fitting into this group. So then, what are the connections? In people without intellectual
40 disability, there is evidence that people with severe mental illness are at a higher risk of
41 developing dementia. So, you would assume that that will be the case in people with

1 intellectual disability as well. But the actual research in this area is quite sparse. Possible
2 mechanisms, biopsychosocial model, biological neurobiological vulnerabilities, genetic factors,
3 medication side effects, and comorbid medical conditions that are over prevalent in people
4 with severe mental illness are likely to be related to the increased risk. Health disparities,
5 lifestyle factors that are associated with serious mental illness and social factors that you would
6 see in somebody with severe schizophrenia, bipolar, other conditions are likely to contribute to
7 the risk of dementia as well. What are the assessment factors that you need to consider for this
8 particular population? Just like in other people with intellectual disability, establishing baseline
9 is very important. So, in addition to establishing baseline, it's very important that you do serial
10 assessments, particularly given the long-term nature of comorbid, serious mental illness. Then,
11 establishing that there is a deterioration. Is this deterioration because of serious mental illness?
12 Or is it on top of the serious mental illness? So, that's a factor that's going to be difficult, but
13 that's important. And then, if there is a deterioration, is this a significant deterioration that will
14 meet the criteria for dementia or not? And what would qualify as significant deterioration?
15 There is not enough evidence that we could find in research, it's still left for clinical judgment. In
16 this population, it's very important to differentiate whether this deterioration is because of
17 associated conditions, and especially serious mental illness. Is this because of relapsing and
18 remitting condition, like bipolar affective disorder? Or is it because of progression of
19 schizophrenia? Or is it because of a new condition, dementia that's developing? So, those sorts
20 of issues need to be teased out when you're doing an assessment, particularly psychiatric
21 assessment. Moving on, what are the treatment and support adaptations that you need to do?
22 One, is principles of managing severe mental illness in people with intellectual disability? Good
23 practice guidelines of managing dementia in people with intellectual disability all apply for this
24 population. So, principles for management of severe mental illness as well as principles of
25 managing dementia applies in this group. The second aspect for us to think about is assessing
26 the impact of specific interventions that are delivered to treat those conditions. So, for
27 example, interventions that are delivered to treat the primary mental illness, interventions that
28 are delivered to treat dementia. How do we assess the effectiveness of those interventions for
29 those conditions and balance it against the risks of those interventions on the other condition?
30 A good example is antipsychotics prescribed for people with schizophrenia. We know that
31 antipsychotics are important for treatment of schizophrenia, but what happens when they
32 develop dementia? We know antipsychotic use in dementia is associated with increased risk of
33 stroke, falls and chest infection. So how do we balance? That's a very difficult situation, and not
34 enough guidance and research, that's very hard to focus on coming up with consensus
35 statement.

36

37 Lucy Esralew

38 So just want to point out something with mental illness and why we thought severe mental
39 illness was worth our attention. One is that, in the general population, we've learned that there

1 are structural brain changes that can be associated with bipolar disorder, schizophrenia, and
2 some have argued also, major depression. The other thing is, we know there's a high
3 coincidence of people with ID and mental health concerns. Now, that's not the case that there
4 necessarily is a high percentage of people with severe mental illness. But we do know that
5 there is a high co-prevalence of mental health concerns for individuals with intellectual
6 disability. We also know that, particularly bipolar disorder, and schizophrenia, are essentially
7 lifelong disorders. They tend to be illnesses that are diagnosed fairly early in life and continue.
8 So, those were among other concerns that we had. So, just some summary for our thinking,
9 what does this say about increased risk for dementia among people with specific conditions?
10 Well, we had mixed results regarding support for increased risk among individuals with autism.
11 As you'll see from the background literature, some research supports that notion, other
12 research does not support that notion. There were mixed results regarding support for
13 increased risk for individuals with Fragile X. There really isn't anything in the literature clinically,
14 that suggests that individuals age into a dementia risk with Fragile X. However, new research
15 suggests that there is a mechanism by which we would suspect that that could very well be the
16 case. There is a known association between late onset myoclonic seizures, Down syndrome and
17 Alzheimer's disease. But it's less clear about increased risk, for instance, for individuals with
18 lifelong epilepsy and ID. So, literature is not necessarily clear with that. We do hear that there
19 may be a common pathway, neuro-biologically, in terms of autism, bipolar disorder,
20 schizophrenia, with some non-AD neurocognitive disorders such as frontotemporal dementia.
21 Changes within the frontal lobe or frontotemporal region may be associated with increased risk
22 for the population, for that form of neurocognitive disorder. Among the things that struck us is,
23 one, we don't know a lot about aging and ID with special conditions. And it's very hard to talk
24 about people departing from some baseline, if we don't know what baseline is for individuals.
25 One area for research, I think, is becoming more conversant with how people age with these
26 specific conditions, the ones that we mentioned, and others. And also, because of the
27 heterogeneity of the population of people with intellectual disability. Most people with
28 intellectual disability have unknown etiology. We just don't know what results in lower IQ, in
29 terms of their measured IQ. However, it can't be necessarily assumed with confidence that the
30 same assessment will be valuable for anybody with an intellectual disability. What do we have
31 to consider particularly about conditions that would lead us to assess and support people in
32 different ways? So, I'm going to leave you with that. We had a bunch of discussion questions,
33 but I think we're going to let people take us where their ideas are, about what they want to
34 learn more about. What I'm going to suggest, Vikram Palanisamy is going to call on people, but
35 perhaps the facilitators for our sub-topic groups would like to respond to any questions that
36 come up, as they do. So, thank you.

37

38 Vikram Palanisamy

39 Okay, thank you, Lucy. Let's start with Seth Keller.

1

2 Seth Keller

3 Thank you very much. It's an honor to be part of this group. I appreciate the overview. One
4 comment I'm just going to make about autism specifically, and I was involved in the seizure-
5 focus one is being very careful and thinking about the trajectory of people with autism. And I
6 appreciate the word heterogeneity, and I think that's hugely essential when you think about
7 autism, or you think about CP, is what are we talking about? So, it's almost like comparing
8 Fragile X as they get older, **to tourists grows as complex?** as they get older, Down syndrome as
9 they get older, but they all can have autism. So, what are you following? And do you feel
10 reliable that their aging is manifested similarly, when it's the underlying neurodevelopmental
11 cause, genetic or others that really might be essential to what their aging trajectory be. So, we
12 have to be very careful, as much as it's important to think about autism when they get older
13 and what to expect, and we all want to understand that. But sometimes it's apples and oranges.
14 So, you have to be really careful and hard to make some predictability unless you have a
15 uniform situation like Down syndrome. We know that Down syndrome, we understand that we
16 can look at it and think about that. I think that I just wanted to make that point. And definitely
17 from the seizure standpoint, I'm looking forward to other conversations on that, because that's
18 what I treat on a regular basis, so I look forward to more talking on that.

19

20 Vikram Palanisamy

21 Thank you, Seth. Lucy, you mentioned intellectual disability being a varied condition. So, autism
22 as well is a varied condition with different...

23

24 Lucy Esralew

25 With or without intellectual disability, which, by the way, is a change in our thinking about
26 autism spectrum. I know when I came up in my training, I was taught, and of course, we then
27 had Asperger's as a separate diagnosis, that everybody pretty much who was on the autism
28 spectrum had some form, albeit it might have been mild, form of intellectual disability. Now,
29 we know that the reverse is true, that most individuals on the autism spectrum have average
30 IQ. So, that has been a little bit of a change with that. And to your point about co-occurring
31 neurodevelopmental disorders. How do you understand somebody who has both Down
32 syndrome and autism? What may be contributing to their aging trajectory? It's very hard to
33 parse out, until we know more, about different conditions and the natural history of various
34 conditions. It's going to be very difficult for us to figure that out.

35

36 Vikram Palanisamy

1 Thank you. So, is that Leslie or Kathy? Yes.

2

3 Kathy Service

4 Hi, thanks. Well, one notion that I really think we need to consider with these syndromes is this
5 notion of secondary conditions. And secondary conditions, I first read about that in a booklet
6 that came out by the Institute of Medicine in 1991 or something. There were firm proceedings
7 on people with cerebral palsy and Spina Bifida. And we do know that many of these syndromes,
8 or other kinds of entities, do have accompanying characteristics. And I think they really have a
9 lot of implications for us in terms of assessment and in terms of supporting and managing. For
10 instance, I'm reading things about the microbiome and the gut issues for people with autism.
11 What does that mean for us in terms of when we're supporting people? And does that make
12 people at a higher risk, in terms of some of the brain health? And then, I forgot about Fragile X
13 has connective tissue disorders. So, I think about, for instance, are these people because of the
14 ligamentous laxity and things? Are they in pain? What about this whole notion of pain when
15 we're working in supporting people, whether with regards to diagnosis and assessment, or with
16 regards to treating people. People with Down syndrome have a lot of secondary conditions, and
17 one that I think about that has implications is orthostatic hypotension. And I've tried to tell
18 people, if you have somebody who has Down syndrome and they have a fall, it's really
19 important to really diagnose the details, not just say, Oh, they fell because of a seizure, they fell
20 because of this. Because the treatment for people with orthostatic hypotension versus seizures
21 are very different. And a lot of people don't know that. So, there are many things that, I think,
22 we need to be aware of. And I've even seen where we've had people with these little odd
23 syndromes that don't age, you know, they haven't aged in place. And people will come to us
24 because of changes in behavior, and they get the diagnosis of dementia. But when you start to
25 look at what are associated secondary conditions with them, they could be very well part of the
26 secondary conditions and not dementia. So, there's a lot of things that a careful assessment and
27 a careful understanding about, if we know about some of these syndromes and some of these
28 entities, how we can assess and then support people throughout their lifespan. Thank you.

29

30 Mary McCarron

31 Thank you and find this fascinating and so timely. Firstly, I think for the longitudinal study that
32 we're running, we found that those who have Down syndrome are about 10 times greater risk
33 of developing dementia than the general ID population. So that's 10 years on. Okay, so that was
34 useful. But the group that we see now coming to the memory clinic, the National ID Memory
35 Clinic in Ireland. I think we know a good bit about the presentation of dementia in the Downs
36 population, but I feel we know very little about the presentation in the non-Downs population,
37 particularly the various subtypes of dementia that we we're particularly looking into. So, these
38 are really complex. And we struggle a lot as well with, you know, these people are coming in

1 with hyper polypharmacy, we don't really understand the brain and people with lifelong history
2 of mental health. We talk a lot about this now in our clinic, because we have an ID psychiatrist
3 there as well. And we do talk a lot to this huge, huge need, for a greater understanding of this.
4 And also, we're using a lot of neuroimaging and what we really don't fully understand is the
5 brain structure is different in many of these people. So, when you're looking at the scans,
6 what's the scans really telling you? Because the baseline for that person's brain is different to
7 start with. So, I'm really glad to see this topic being discussed, because I think there's so much
8 we just don't know.

9

10 Vikram Palanisamy

11 These were exact conversations that we had when we were trying to tease out the issues. Yeah,
12 so we know, to some extent what's happening with Down syndrome. But if you move beyond
13 Down syndrome, very limited, right?

14

15 Yona Lunsky

16 Just to build on Mary's comment, so we know that we don't know these things, but we've
17 gotten really good at measuring many of these things with people with Down syndrome. And
18 for many of the people we've been talking about here, there may be some adaptations we can
19 make. But when we think about assessment, if we want to get more baseline information, we
20 already have ideas about how to do those assessments that probably could apply to many of
21 the people we're talking about. So, it's not that hard to kind of extend that. The other piece is
22 that we also know, with Down syndrome, that we need to start looking at those things early.
23 We know there's early aging, generally, we don't know if there's early dementia, quite as much.
24 We just know that there's higher rates of dementia in people with these other conditions.
25 Right? But could we at least consider doing more early screening, right? And using assessments
26 that already seem to work? Like why aren't we doing that more broadly?

27

28 Mary McCarron

29 I think just coming back on that, we are using the battery of test instruments that has been
30 developed for the Downs population in the memory clinic. So, for people with ID from other
31 etiology. We are using that. And certainly, there's the international recommendations back in
32 2005, I think recommended that we did a baseline screen for people with ID from other
33 etiologies over the age of 55. And that's a long time published, in my head. But a lot of the issue
34 here is a resource issue, in terms of actually being able to follow that cohort. But I just think
35 that there's so much that we don't know about these other syndromes, and particularly the
36 brain, and what has happened. Yeah.

1

2 Yona Lunsky

3 Maybe I should say it differently, then. We have guidance. It's expensive. We don't necessarily
4 do it, but also, we don't publish on it. Right? So, what we've done with Down syndrome is not
5 only do we follow it, we also can read studies, and there's groups of people working together
6 with similar protocols. So, we have protocols we can use, but we haven't read, you know, and
7 that will help us I think, answer these questions.

8

9 Phil McCallion

10 Yeah, you know, we're behind in terms of looking at these groups. But increasingly, over the
11 last year, I've been looking much more at what may be available to us retrospectively, in terms
12 of electronic health records and other kinds of administrative datasets. We've just accumulated
13 a population of people with autism, for example, over age 60. And one of the things that's
14 interesting, going back to a remark that Seth Keller made about sort of what drives health care
15 in the United States, is that there was a period where Alzheimer's diagnosis, you didn't get paid
16 for that, because it wasn't seen as a curable disease. And so, what physicians became very
17 adept at was documenting the other diagnoses. So as a result, even just a preliminary look at
18 this data, we're seeing that there's a lot of information on other diagnoses. I would say the
19 same would be true for a serious mental illness. So, I think that there are things that we can do
20 fairly quickly, to really establish what dementia looks like in these populations. And currently,
21 we're just beginning to look at can we track onset of at least diagnosis. Fortunately, in the data
22 set that we're looking at, often we've got the primary care data as well as the hospital data. So,
23 we know when some of these things are happening. And we're interested in looking at that.
24 And I just think that, rather than starting, you know, I think Matt Janicki, like sort of the first
25 meetings that you organized, were mid- 90s, and here we are now, sort of 30 years later,
26 looking at people, still talking about what we need to discover about people with Down
27 syndrome. We can't spend another 30 years doing this for the groups that you've identified,
28 who are clearly important groups. We should be doing some primary data collection,
29 absolutely. But I think we're in a different era. There is secondary data analysis that's possible.
30 And so, let's exploit that to at least get a preliminary picture.

31

32 Lucy Esralew

33 A couple of things. One is, I'm going to have my clinician hat on for the moment and think about
34 people who come to me and that I might assess. So, the assessment that I might do, would be
35 very different if I'm looking at whether somebody is cognitively declining, as opposed to the
36 type of assessment that has usually been done in the population. For instance, for eligibility,
37 typically, you would have an IQ test and adaptive behavior scale. That's typically what's done to

1 establish whether somebody meets the criteria for a particular benefit under a disability. So, I
2 have people coming to me who are in their 50s, in their 60s, etc., who have not had an IQ test,
3 since they were found eligible. So, we're talking about not being tested for several decades,
4 okay. And that the information that I can extrapolate from that, it gives me at least some sense
5 of where did they start out? Or what caused people to think that they had a developmental
6 disorder of some kind? But it doesn't help me understand the kind of cognitive changes or
7 adaptive changes over time that may have occurred. Most people are not getting tested, unless
8 there is a problem that has been identified. So, for a long period of time, within the State
9 system, they used to do IQ tests and adaptive behavior tests every three years. So, when I
10 worked in a developmental center, every three years, we did a reassessment IQ and adaptive
11 behavior scale. But in the community, unless there's a particular reason for you to come in and
12 be assessed, you're not going to be assessed. So, to a large swathe of individuals, there's no
13 baseline data. Then it becomes hard to say, well, what are we looking at here? Yeah. So, that's
14 basically what I wanted to say about it. And that the kind of testing that we do, people think
15 testing equals IQ test, and adaptive behavior scale. They're not looking at attention, they're not
16 looking at memory, they're not looking at a variety of other skills that we would really want to
17 look at, in terms of understanding if there's been some cognitive decline.

18

19 Vikram Palanisamy

20 Thank you, Lucy.

21

22 Laura LaChance

23 Thank you. This is a question not specifically about conditions other than Down syndrome. But
24 I'm just curious, Phil and Mary, you know, you talk about it being 30 years ago that some of this
25 work was done. Would you know, I'm very aware of sort of this lump of Down syndrome, but
26 there are different phenotypes within Down syndrome, translocation, mosaicism. Does any of
27 the research support any increased prevalence of dementia development within those variants
28 of Down syndrome, other than Trisomy 21?

29

30 Mary McCarron

31 My understanding is that those were Trisomy 21 really carry the risk, but those with mosaicism
32 and some of the other forms, we're not seeing that same expression of Alzheimer's risk.

33

34 Kathy Service

1 And I agree with that, because Brian Chicoine wrote one case study about an 80-something
2 year old woman with Down syndrome, who died with cardiac issues and she had no evidence of
3 dementia, but she was mosaic Down syndrome.

4

5 Seth Keller

6 But there also are those subtypes with trisomy that are more progressive, rapidly progressive
7 and including even myoclonic epilepsy has very poor prognostic sign of more rapid progression,
8 poor outcome. So, there are some subsets that are worse, then worse, then worse. I think, one
9 of the saving graces was the assessment part that we're talking about. So, one of the saving
10 graces, and I'm being rhetorical in my comment here, is the annual wellness visit in the United
11 States. So, this was part of the primary care visit, and we think, they would now have time, and
12 they're actually being paid for a complex health visit, to be able to sit down and talk, as many of
13 office visits go, it's crisis management. You go to see your primary doctor for what's
14 immediately crisis involved, and you take two seconds, you patch them up. But because of
15 dementia, is often very indolent, it's not like an acute, abrupt onset, because that's not
16 dementia. It could be a stroke; it could be a urinary tract infection. It can be whatever it could
17 be, but it's indolent, so it's not really recognized. So, the annual wellness visit theoretically
18 would be set up. But the problem is, we don't have the assessments for this neuroatypical
19 population. So, it does go back to the clear reality of focus following and tracking change over
20 time, and also to avoid diagnostic overshadowing. There's many of these people are not being
21 seen because it's so Oh, they've got this nonspecific IDD scenario. And yes, this is what they do
22 when they change, so it's not really being picked up. I think a lot of people with ID, non-Down
23 syndrome IDD, are really being missed as functional change, when it might be cognitive decline,
24 and not really being seen. And then finally, what's the impact of long-term use of the
25 medication we provide? So, I talked about autism and all the neuroleptics. They're used for
26 their behavior, what's the relative impact upon them and they age and what's going to happen
27 to their every shape and form to them when they get older?

28

29 Sandy Stemp

30 I was just wondering if people want to take a few minutes break because our break was actually
31 at 3:30pm. So, they have put out some sweets and different things like that. How do you feel?
32 Do you want to power through, or do you want to grab your break and come back and keep
33 going? A five-minute break, the boss says. Okay.

34

35 **BREAK**

36

1 Sandy Stemp

2 Okay, if everybody could take their seats. And I'm not sure if it's Vikram or Lucy, who wants to
3 come back up to continue the conversation. And I think what we're going to ask is just at the
4 conclusion today, if the leads from the groups wouldn't mind staying back, just for five minutes
5 or so. And then that way we can talk about the agenda for tomorrow.

6

7 Vikram Palanisamy

8 Okay, so shall we continue the conversation? We can finish early, and we can leave early.

9

10 Lucy Esralew

11 Vikram, I do have a comment that I wanted to make. In the conversation before the break,
12 about mosaicism, mosaic version of Down syndrome. I did want to point out that there is a
13 similar kind of situation with Fragile X, where there are individuals that have a mosaic pattern.
14 And it looks like they also are less affected than those individuals with a full mutation. So again,
15 with that Fragile X gene, there is an array of conditions, going from individuals who are carriers,
16 and what we would consider pre mutation and individuals who have kind of a mosaicism. And
17 then individuals who have the full expression of the change in the Fragile X gene and are most
18 likely to have Fragile X syndrome. So, I just wanted to point out that that occurs as well.

19

20 Matthew Janicki

21 Can I just make a comment on that, if that's okay? Lucy is raising an interesting point, because
22 what we're finding in the States is an issue raised around access to these new Alzheimer's
23 medications that are being approved by our Food and Drug Administration. And there's two
24 medications that are approved and one will probably be approved early next year. And there's
25 exclusionary clauses in some of the prescribing criteria that talk about people with Down
26 syndrome not being eligible. And the point about mosaicism is a very important one, because
27 there is a low probability of folks may have Alzheimer's disease with that condition. If you just
28 simply use Down syndrome as an exclusionary criterion, you're eliminating potential individuals
29 who probably wouldn't benefit from the medication if they don't have the condition, the
30 disease. But it's unfair to just use that particular term without specifying which ones that you're
31 talking about.

32

33 Vikram Palanisamy

34 That's very interesting. Yeah, thank you for that.

1

2 Matthew Janicki

3 I'm just going to go back to the point I was going to make before the break. I wanted to talk
4 about, going back to a broader topic, on neuroatypical conditions and emergent conditions.
5 And that's all the issue of, one of the things that Seth Keller brought up was the annual wellness
6 visit. We have this provision of the Affordable Care Act, which is the driving force that created
7 somewhat equitable health care access in the United States after many, many years of not
8 having it. And one of the requirements is that there's an annual, potentially cognitive
9 impairment wellness kind of check, for individuals who are eligible, and that is for people that
10 are eligible for what we call Medicare, which is anyone over 65. So, they're able to get this
11 annual wellness check without having to pay for it. But the issue is, what screen do you use?
12 And the kinds of instruments that have been recommended for screening by general
13 practitioners or primary care practitioner physicians are the ones that are applicable to the
14 general population. And consequently, there's always a challenge when you're trying to do that
15 with people who don't present the same way that someone from the general population
16 maybe, because it's different presentations. And maybe they're sight impaired or hearing
17 impaired or have a pre-existing cognitive impairment or have an emotional issue that blocks
18 their ability to navigate the discussion around cognitive impairment with a physician. And so,
19 that kind of skews how those individuals are then assessed, either adversely or in favor of
20 recognizing that there's a potential disease bearing cognitive impairment occurring. So that's
21 something that was raised in that NAC report that we did, but it's something that we may want
22 to consider also. So, my question really, is in terms of national practices, are there are there any
23 kind of guidelines that other countries have developed, in terms of the screening or the
24 assessment of individuals who show atypically, in terms of the cognitive presentation? So, just
25 throwing that out.

26

27 Vikram Palanisamy

28 Mary, we were talking about, or you mentioned, brain and body check, instead of baseline
29 screening.

30

31 Mary McCarron

32 Yeah. Oh, yeah. We moved away from calling it a dementia baseline screen. Because we felt
33 that dementia was a loaded term, and that for young families and young people with Down
34 syndrome themselves, it was very stressful. It's harsh. And you're putting this into their head.
35 So, we have moved to calling that a brain and body health check. We got rid of the word
36 dementia in its totality. But for that brain and body health check, and Eimear McGlinchey is
37 very involved in that, we would do, many of the other neuropsychological tests that we're using

1 for the Down population in terms of, we are using their, the DSQIID is one that we use at
2 baseline. We do it, we find it, and the nurses do that to see whether people will be eligible to
3 come to the brain health clinic or whether people will be eligible come to the memory clinic. So,
4 we do that as the first screening instrument. And the nurses do that. And then people are
5 triaged to whichever clinic. But then when they come to the brain health clinic, we use the
6 CAMCOG or the CAMDEX- DS. Eimear, do you want to add anything to that?

7

8 Eimear McGlinchey

9 No, I don't think there's anything else to add, really, I think, as you said, having that as an
10 opportunity to be able to proactively discuss brain health and recording a personal prevention
11 plan with people, I think has been effective.

12

13 Seth Keller

14 Can I just add one comment to that? I think the challenge of doing these early assessments is,
15 who's going to do the assessments? And I think that most assessments that are done are non-
16 specialists, non-IDD specialists. They're done by general practitioners around the country. I
17 think that's really the majority, there's not enough specialists around whether it's a Down
18 syndrome clinic or a neurologist, or a specialized practitioner. So, the problem is the
19 assessment tool has to be a neuroatypical-appropriate, easily performed, that's really what it's
20 got to be. It's got to be this easy, recognized tool that primary care providers could use.
21 Otherwise, you say, oh, we will then refer that person to a specialist. Where's that specialist?
22 Where are they going to see that specialist? And I think that's really where the challenge is,
23 where they're going to go unless you have a tool that is so easily recognizable by a generalist
24 that they can use, but then the result of it then has to be then sent to the next level of care.
25 And that's where the problem is always going to be.

26

27 Vikram Palanisamy

28 So, I don't know, I was having a conversation with somebody this morning. It's very important
29 that the tool that we come up with is easy to use by the primary care practitioner. It's also
30 important that there is an action following the outcome of this tool. Most general practitioners
31 or other primary care physicians may not be comfortable about interpreting, so maybe some
32 steps, depending on what the outcome of the tool, will certainly help having those
33 conversations. But that wouldn't address the limitations of specialists available to go to get this
34 assessment for them.

35

1 Frode Larsen

2 In Norway, we have two national guidelines. That's our normative. One is for dementia, where
3 you should do the assessment for dementia with people with intellectual disability. We didn't
4 have all the instruments before, because now we have these CAMDEX instruments. So, this will
5 be followed up in this one. But there is also another one that's normative, that says that the
6 assessment of people with intellectual disability should be done in the special health care. We
7 have built up special health care in every hospital around in the country, where we have
8 specialists, and they should do this. It is very clear in the national guidelines. Now we use also
9 this CAMDEX, CAMCOG. And we have other tools, the ABDQ, that is more of a screening
10 instrument. And then they also have other instruments, and other health checks.

11

12 Evelyn Reilly

13 Thank you, just to give a little bit more detail on what Mary was talking about at the national
14 memory clinic. So, it's a nurse-led service. They're ID-trained nurses who have a master's in
15 dementia and advanced Nurse Practice under subscribing. And we do a full physical health
16 check, including ECG. We particularly look, as Kathy Service alluded to earlier on, postural
17 hypertension, because there's so many people coming into the clinic with the assumption that
18 somebody has epilepsy. And this is easily managed. And we provide an awful lot of training and
19 education to families and to services who come and visit the clinic. But it is, as I said, it is a
20 nurse led clinic. Once they have had their initial screening, then it's a full assessment, then the
21 report is written up. It's discussed at MDT with the full team. Consensus diagnosis is made
22 thereafter and a plan of care and follow through over the next couple of years is made for that
23 person. So, we keep on track, we keep in contact with them, we will invite them into the clinic,
24 we will make phone calls and see how they're doing. We do find, as the dementia progresses,
25 that myoclonic epilepsy is more difficult to manage. And they can become resistant to the drugs
26 that we are recommending. So, they need more careful monitoring at that point in time. And I
27 just wanted to talk about as well, the mental health issues. Very new to me is we are seeing
28 people now coming into our clinic, who are homeless, people with mild intellectual disability,
29 who have no homes. They're being referred to their GP by social workers, generally speaking.
30 And I was quite nervous with the first lady who came into my clinic because I didn't know how
31 she was going to present. She was absolutely gorgeous. I loved her. But she definitely had a
32 cognitive impairment, though we had no baseline to compare it to. So, she is due to come in
33 now to see the team. And they'll do a full workup on her as well. But I think it's an issue that we
34 haven't really touched on yet. But I think it is going to become a problem in the coming years as
35 well.

36

37 Vikram Palanisamy

1 Thank you for that.

2

3 Phil McCallion

4 So, I want to address a couple of things. This issue about the lack of a baseline assessment. I
5 think there are baseline assessments available. It's a question about whether we can access
6 them or not. I think in most jurisdictions, the school districts are doing those assessments. But
7 they have traditionally not been linked to other data. But those assessments exist. Families can
8 request them, at least in the United States, families can request them. I would assume that
9 that's possible in other jurisdictions as well. And I think that we have to start encouraging a
10 practice of obtaining that information. So that a genuine baseline actually is available. But also
11 want to deal with this issue of screening. I'm very clear and very contrary about this issue. I will
12 admit that screening is a short instrument, it is not something as long as the CAMCOG; it's not
13 going to be done, not during a wellness visit. And, you know, we continue to insist on
14 something much longer and more detailed. But what's the point if it's not going to be done?
15 And you know, Mary just passed me a note saying that GPs don't do screenings anymore, and I
16 think that that's probably for that reason. And so, I think that it's incumbent on us, and I know
17 Matt's sitting here and he's thinking he said this 30 years ago and he hasn't given up. And I
18 haven't, because I'm really concerned that we, who are the research leaders in this area, we're
19 not doing what we need to do, if people are not going to get screened. So, I think, the example
20 that was given of the wellness visit, it's a benefit, people are using it, the rates of utilization are
21 incredibly high for the wellness visit. For the general population, people are getting screened.
22 Screening does not mean you have dementia; it means that you need to be assessed further.
23 Seth Keller raises a really important point about who's going to do that assessment? But if it's
24 under the radar, nobody's going to do it, nobody's going to be asked to do it, nobody's going to
25 be reimbursed to do it. Data have got to drive change. And so, I think that we need to be
26 looking at how do we ensure that screenings are done for people, not just with intellectual
27 disabilities, but people with autism, people with mental health issues? That's how we're going
28 to change what's happening.

29

30 Lucy Esralew

31 Well, you know, as somebody who also has passed the age for wellness visits, I have to say that
32 I have not had more than two wellness checks, in terms of cognitive. I guess, they assume,
33 because I have a doctorate in psychology, that I am not showing any cognitive decline, although
34 I think contrary to that. So, it may be on the books, and people may report it. But I even wonder
35 for the general population, how well implemented it is. I think your point about needing to get
36 a usable screen is extraordinarily important. And it has to be something that can be in the
37 electronic medical record. Because it won't be helpful to the primary care physician, otherwise.
38 So, we're very challenged by that. The other thing we're challenged by is that people who are

1 on Medicare, who have intellectual disability, can't get that wellness check, if they're going to
2 get it, until they're 65. But we already know that people with ID age more quickly. So, I used to
3 work with somebody who used to say whatever the person's age is, add 10 or 15 years, if
4 they're intellectually disabled, and that's probably where they are in terms of their overall
5 health cognitively and physically. So, you know, how do we get a wellness check that's a
6 screen? Also, how do we get it paid for in the States, for somebody who is younger than 65 but
7 we know may, in fact, be at higher risk for cognitive changes?

8

9 Vikram Palanisamy

10 I won't respond to your comment about, the tests are already there, but we are not able to
11 access that. That's very true. So, I work with adults, but people come through child system. In
12 BC, we have a process whereby when people graduate, become adults, the MCFD which deals
13 with their needs, transfers their care to CLBC [Community Living British Columbia], which deals
14 with adults. And at that point, the documents are handed over to CLBC, which is so helpful,
15 because I've had so much difficulty getting that from the school system. But if I don't
16 necessarily access that for dementia purposes, but quite often the person with significant
17 mental health challenges, very atypical. So, I don't know whether this is a new onset or whether
18 this has been the case. So, that's very helpful. Yeah, thank you.

19

20 Matthew Janicki

21 I was just going to suggest something that we think about, as we dig deeper into this particular
22 topic area. The discussion on screening is a useful one, because it enables us to think about
23 what instruments out there are the first instance indications that there's something, perhaps a
24 miss, in someone who's already disadvantaged cognitively. But a bit bigger than that, is this
25 new emerging requirement to have more accurate diagnoses, documentation for access to new
26 Alzheimer's medications. There's something that we hadn't thought about, up until maybe just
27 now, at least in the States. One country that I know where they've approved one of these
28 medications is Japan, some of you must correct me on that. And the requirements are quite
29 interesting because they require, from the general population to have a recognized screening
30 assessment instrument to document the fact that someone is showing either MCI or early-stage
31 Alzheimer's disease. These are for Alzheimer's disease at this point. In the area of intellectual
32 disabilities, most of the State prescribing criteria are silent, specifically on any adaptations. And
33 in some cases, as I mentioned before, they exclude Down syndrome as one of the eligible
34 conditions to be prescribed, which we're working closely with our federal authorities to have
35 that changed. The point being, is that there needs to be, from our field, some recommended
36 instruments that are the equivalencies of those that are used by the general population. In the
37 States, the instrument that's usually listed is the MOCA, which is the Montreal Cognitive
38 Assessment, and the MMSE. And you know, those are not really down deep diagnostic

1 instruments, they are sort of like screening instruments. So, we need to come up with an
2 equivalent for intellectual disabilities, or other conditions, neuroatypical conditions, where
3 there is a cognitive issue, in terms of blending with either disease-based neuropathology, or
4 something that has been evolving in an individual over a lifetime. So, those are the things we
5 have to think about too, when we talk about this whole issue of the neurodivergent conditions,
6 neurotypical conditions. What's coming down the pipe is more specificity in diagnostics and
7 assessment, and potentially screening from our field. So that practitioners that are working
8 with individuals like Seth Keller mentioned, is the GP and the primary care practitioner who's
9 going to see someone, and they're going to be asked to do this assessment of someone. And it
10 potentially may even be the prescriber for Alzheimer's medication, disease modifying
11 treatment drug. So, we have to be precise in what we're looking for. I'm hoping that out of this
12 entity, we have discussion around this topic and may be able to come up with some thoughts
13 and recommendations, or at least cautions, in terms of what this means for the general
14 population and what it means for people with neurodivergent conditions.

15

16 Vikram Palanisamy

17 Seth Keller and then Mary McCarron.

18

19 Seth Keller

20 One, real quick, is that the annual wellness visit, the assessment tools that they use are direct
21 tests on the patient by the office staff. But what would be more essential for our population, is
22 pre-testing, like the informant based, like the EDSD. I don't have any you do, you're off that you
23 go to your doctor and online, you fill out your forms before your visit. Well, if it's the same
24 thing, so, what's so hard about that? You do a digitalized version of the EDSD beforehand, and
25 all the doctor does, he pulls it up and he's actually trying to then interpret it, then that's kind of
26 what it is. And that's all that these assessment tools are done, they're screeners. Whether it's a
27 MOCA, or MMSE, they don't diagnosis anything, they just set the discussion toward, leading
28 toward the differential workup, the next step. And ultimately in this population is a biomarker,
29 so it's really going to decide excluding other reversible causes, etc., comorbidity issues, like
30 behavioral things, sleep apnea, hearing loss, and then you're going to get a biomarker and the
31 biomarker is going to drive it. And the thing that you said Matt that is so essential is that these
32 therapeutics, the anti-amyloid drugs, for now and in the future, they're always going to be for
33 MCI and mild AD. So, if we drag this out, and you're talking about dragging it out for months or
34 however long it takes to get that diagnosis, it's too late. So, you might actually be able to do
35 that diagnosis, be there out of the window of a therapeutic that they might one day be eligible
36 for. So, timing is essential.

37

1 Matthew Janicki

2 What we're talking about in this situation is really about Alzheimer's disease, and that's what
3 the drugs have been designed for at this point, to mitigate the amyloid build up in the brain. So,
4 the theory is that if you've dropped down the amyloid build up, the cognitive decline should
5 basically be mitigated to some effect. But it's not for all the other dementias. So that's
6 something that we have to think about also is the differentials, if we want to get that way. But
7 the prescribing is limited to Alzheimer's disease.

8

9 Mary McCarron

10 Completely agree with the issue for short screen. I mean, from my experience over many years,
11 at this stage, really the only way you can diagnose dementia this population is you're able to
12 understand decline from somebody's previous level of functioning. And I think in this
13 population, because you have so many changes to staff, you have so many different caregivers,
14 people are slipping through the net, and they will not benefit from the disease modifying
15 agents because there will be a nearly mid stage dementia before they're actually diagnosed.
16 And we need to do objective testing of memory as well, of function when they when they come
17 to the clinic. It is useful having the informant-based and we still get the informant-based, but
18 from our experience, you really need to do objective testing with the individual, to really
19 understand where people are at and measure change.

20

21 Matthew Janicki

22 Let me just clarify one other point. The authority to prescribe is based on a complex component
23 and aggregation of different things. One of them which is a biomarker. And the critical
24 biomarker being that there is amyloid in the brain. And it shows up in either the blood or spinal
25 fluid. It's not just the paper and pencil test or the psychology, the neuropsych test, it's actually
26 confirmation from a biomarker and then substantiated with impairment, that's resulting from
27 the amyloid presence. And that's where the testing comes in. So, I just wanted to clarify that for
28 those of you not following this. Right now, it's kind of a U.S. thing, but I'm hoping that we can
29 translate that to other places as well.

30

31 Kathy Service

32 I just wanted to tell people that I'm a part of the group, the Down Syndrome Medical Interest
33 Group, and we're looking at this tool, like a dementia screen. And it's almost like algorithm, it's
34 very graphic and following things in terms of, at least people for Down syndrome. And we're
35 still in the midst, it's taken a long time to get the group together to work on it. But that might
36 be something that we could bring forth to people and see. It's a screen, it's just a screen and it

1 goes into some of the other, the rollout correctables, part of the differential diagnosis. But
2 again, it's for primary care, to kind of follow. Real brief, really easy to read, etc.

3

4 Lucy Esralew

5 Yeah, that wouldn't be valuable to kind of, to hear that. Just a couple of comments. One, is
6 about this idea of observation of change from baseline. So, although you know, Phil, I think
7 your point is well taken there, as long as somebody is in school, they have been tracked. Once
8 they leave school, there is really no consistent tracking of the individual, in terms of how
9 they're functioning or performing. And you know, somebody's coming to me, and they're 50, 60
10 years old, although it's interesting to me how they did up till age 21, it has limited utility for me
11 to understand if change has occurred, is that change likely to be due to a dementing process
12 one or another? As Mary McCarron has indicated, there are a number of things that happen to
13 adults with ID that can cause changes. So that's why, as useful as that is, it's not particularly
14 helpful when you're looking to see if somebody's changes are attributable to a neurocognitive
15 disorder. Because it's not just change per se. It's meaningful change, significant change along
16 the lines we think is consistent with a dementia. The other thing is, I'm hoping that our group
17 will, towards the end of our time together, come forward with this desire to learn more about
18 aging with intellectual disability. And our ability to wrap our minds around, whether it's
19 clinically through vignettes or via research, qualitative and quantitative. What does that look
20 like? And what does that look like when you have specific conditions? I mean, is aging with
21 Fragile X, the same as aging without Fragile X syndrome? So, what does that look like? And also,
22 our interest in other neurocognitive disorders. Now we know by far and away, Alzheimer's
23 disease is the leading cause of neurocognitive disorder among individuals. But that doesn't
24 mean that other forms of neurocognitive disorder do not exist in our population of people with
25 ID. I haven't seen that much, I'm sure there is stuff in the literature, about individuals with
26 Down syndrome and multi-infarct dementia. Given the fact that there is a higher risk for stroke
27 or certain kinds of cardiovascular events among individuals with Down syndrome, you would
28 think that there would be more of a play on to what extent does that influence the aging
29 trajectory of somebody with Down syndrome? So, I think our kind of really intense focus, and
30 I'm not saying it was not good for us to focus in this way. But I'm hoping we can expand out our
31 research agenda and also our clinical curiosity to these other conditions, that at least deserve a
32 nod in terms of our attention.

33

34 Vikram Palanisamy

35 So, there are a couple of people. How are doing for time, Sandy? Okay, sorry, I don't know your
36 name.

37

1 Alyt Oppewal

2 To respond to that. After this meeting in Toronto, I'm visiting a colleague in Las Vegas, and we
3 are actually looking into aging in people with Down syndrome, specifically, within our Healthy
4 Aging study that we have. The group of Down syndrome is big enough to have a specific look at,
5 not only focusing on dementia, also just broadly the aging in that group. So, we are working on
6 it. For other syndromes, it's a bit more difficult, because the groups are usually quite small that
7 we have in our cohort. But I think it's a really interesting topic to address more. Yeah.

8

9 Vikram Palanisamy

10 Ashok, did you have something to say?

11

12 Ashok Krishnamoorthy

13 So again, a couple of things. I want to talk about the screening. But obviously, we have
14 discussed enough about screening. So, I don't have anything to add to that. But I really want to
15 impress on the idea of until somebody gets into a moderate stage of dementia, we don't
16 necessarily establish that diagnosis. So, the challenge of observational change in measurement
17 takes time, while the other parts of dementia care, which I'm involved in as well, including the
18 mild cognitive impairment due to Alzheimer's disease and other things, have progressed
19 significantly in terms of either lumbar puncture based amyloid tests, amyloid imaging, SPECT,
20 FDG-PET, dopamine transporter scan. All these things would help to, not only diagnose earlier
21 Alzheimer's, but also Frontotemporal dementia and other types of dementia including Lewy
22 body dementia. So, there are good standards of practice expected in other dementias in a non-
23 ID population. I don't think it is too much to think about importing those recommendations into
24 helping with early diagnosis, as much as possible, if it is possible to do. In the province I
25 practice, British Columbia, if there is a mild cognitive impairment suspicion, the lumbar
26 puncture amyloid, Ab42 ratio test is covered under public health care. I don't do LP, but you
27 wouldn't believe, even in a rural setting, my anesthesia colleague, our emergency department
28 physician would do it for me and get it done. I have done about five of those in a rural setting,
29 where there are no specialists and I'm the only psychiatrist who's visiting there. So, it's still
30 possible to do and I'm just trying to impress upon whether we can use some of the
31 recommendations which are otherwise available for early diagnosis of dementia, could be
32 transported and utilized in this situation as well. Especially when we are talking about other
33 non-Alzheimer's type of dementias, because the numbers could be small. But at the same time,
34 neuroimaging could have a really good specificity. That is one idea, including amyloid imaging. If
35 we are not able to do LP for taking the amyloid ratio, can we do amyloid imaging, which is not
36 widely available in Canada? I don't know in the U.S., you might be able to do that. This is
37 especially important in Downs population when we are talking about Alzheimer's disease. The

1 second thing is, while there was a really interesting slide deck here put for severe mental
2 illness, that the sufficient number of intellectually disabled population, also staff, started using
3 substances. And then substance use, because I run a program for substance use-related
4 cognitive disorders, without intellectual disability. So, if you add the intellectual disability and
5 substance use and the possibility of severe mental illness, where it does lead to some
6 significant cognitive deterioration, whether you want to call it as a neurodegenerative change
7 or whether it is directly related to severe mental illness and substance use, is going to be
8 another cohort of people we're going to have or see more in future. So, we cannot distance
9 ourselves from that. If you want to think about what we do now, going to be valid for five years,
10 10 years. Or, if you want to be really forward looking, we need to think about comorbid,
11 concomitant cocaine, crystal meth, all those things will have a significant neurotoxicity and
12 impact on cognitive functions.

13

14 Vikram Palanisamy

15 Thank you, Ashok. We're going to have a discussion tomorrow. So maybe we should pick on
16 medical imaging.

17

18 Seth Keller

19 I apologize, I just wanted to pick up on what you're talking about, in terms of thinking about
20 where we're going to be. I really think, and I don't think it's a science fiction really, is that the
21 biomarker availability is going to be there. And I think what's going to really happen, and I do
22 believe this, is that we're going to be able to make a pre-clinical diagnosis of AD and those with
23 Down syndrome. So, you're talking about a 30-year-old with Down syndrome that you're going
24 to, most likely, be able to diagnose that they have the preclinical makings of it. It's not if, it's
25 when, and that's going to change everything, will it not? It'll change everything, in terms of how
26 we think about it, or the treatment of it. And that's going to be very interesting in how we, our
27 care practice and how we think about it.

28

29 Ashok Krishnamoorthy

30 Absolutely. So, in an ideal situation, while we talk about lots of screeners and yearly annual
31 health check, if at some point in time, if you're able to do some kind of a biomarker testing at
32 around third decade, it will give you a very good indication for robust advanced care planning
33 with a lot of intention. And then, even demanding mandatory annual review of things, including
34 physical health, sensory deficits and cognitive functions and communication issues.

35

1 Kathy Service

2 Even right now, there's going to be at home testing. So, what does that mean for us, and
3 healthcare providers, and then the ethics of all that. So, I think that's something that we really
4 need to kind of address and kind of figure out too.

5

6 Vikram Palanisamy

7 I'm aware of the time, so Dawna Mughal and Mary McCarron for the final comments.

8

9 Dawna Mughal

10 This discussion reminds me of the problem in nutrition, we have difficulty defining malnutrition,
11 the measures were different. I can tell you, there may be 11 screening tools for nutrition; some
12 are long, some are short. And the short ones are given to the practitioners because they're
13 easier to do. If the toll is burdensome, they won't do it. They don't have the resources to do it.
14 And then when somebody is identified as being at risk for malnutrition, that client or patient is
15 referred for assessment. That's the next step, which is more in depth. I have experiences in
16 both screening for people with ID and group homes, maybe I had 90 participants way back
17 when, and I use a long form. It's not perfect. And they are all at level three. Level one, level two,
18 level three. Because the form includes diet, observations, functioning status, and I believe lab
19 values. But the facility could not use those, but I use them for research. But I can tell you, from
20 a nutrition standpoint, using that form, they are malnourished, right? Or yeah, they're
21 malnourished, but then you assess the ADLs. Correct? So, we include that in our assessment.
22 Putting all this together, you can identify people who really need attention. But some clinicians
23 say, you do not need a lot of that, you are really over killing it. So, if you have somebody who
24 has poor food intake, poor appetite, has diarrhea, has weight loss, that person needs attention.
25 So, the goal is to create something that people can use, otherwise they do not use it.

26

27 Mary McCarron

28 Yeah, and just a final comment. I mean, we've talked in the field for a long time about both
29 diagnostic overshadowing and under shadowing, and people are excited by the fact that we
30 may have blood biomarkers and that they are very near been here. And I suppose we just need
31 to be careful, like we understand that people with Down syndrome will have the
32 neuropathology of dementia, so they're likely to show positive on these biomarkers without
33 clinical, which may not mean clinical dementia. So, I do think that we need to be very careful in
34 terms of the related demand for this, be the hysteria that it may cause as well, and I just feel we
35 do need to think those things through because there is an ethics the whole thing.

1

2 Sandy Stemp

3 So, we made it! Thank you very, very much. That was very interesting, Lucy and Vikram. Many
4 thanks to you for taking the lead for group three and to your group, but also to everyone here
5 today for participating and providing such rich discussion. That was amazing. So, we made it
6 through the day!

7

8 **END OF DAY 1**

9 **V.12/19/23**

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