

**1 Day 2- Wednesday, October 24, 2023****2 OPENING****3 Sandy Stemp**

4 Welcome back everyone, and welcome to day two. I realized yesterday, I failed to do a land  
5 acknowledgement. So, one of the things that we are trying to do in Canada is really, through  
6 reconciliation is one thing, before events, is to acknowledge the land that we're on. I think you  
7 saw the Federal Minister do that. So, I'd like to take a moment to acknowledge the land that we  
8 live, work and play on. We are on the traditional territories of the Mississaugas of the New  
9 Credit First Nation, as well as the Anishnawbe of the Williams Treaty, First Nations, the Huron  
10 Wendat and the Metis Nation. So, welcome back to the second day! I know that some of you  
11 are catching flights or having to leave a little bit early. And if that's the case, I just want to take  
12 this time now to really acknowledge your contribution and really, thank you so much for your  
13 participation. Obviously, today is not it because I know the planning committee and the leads  
14 will be after you forever. So, you've locked in, you've locked in for life, now. So, stay tuned,  
15 because certainly there's going to be much reach out to you. We've connected to the leads,  
16 basically, I think Phil said, Sandy, we've rearranged it, it's done. It's done, don't worry about it.  
17 So, that's great. What I will do is, instead of being in the big group, there's going to be some  
18 more small group. And I'm going to have Matt and Karen, maybe come up here in a moment to  
19 give a little bit of guidance about this next section, about what it looks like. But we did have two  
20 breakout rooms, downstairs on the second floor. We didn't know whether we were going to  
21 use them or not for this event. But now that we're kind of reconfiguring, we thought, oh, this is  
22 great. And that way too, it just gives people a little bit more time in your groups and in a  
23 separate space to do that work. So, did you guys want to come up, Matt and Karen to give us a  
24 little bit of direction for the groups?

25

**26 Karen Watchman**

27 Ok, hi! What are we going to say? So, I think in terms of recap, and going forward, I think let's  
28 think first of all, let's think going forward for what we're going to do today. And then perhaps  
29 we'll take a step back. I think what we need to do from the groups, is to talk through, not  
30 repeat the discussions from yesterday, that's what we don't want to do. But to come up with  
31 the consensus around what the key topics are that we want to take forward from today.  
32 Because what we'd like to do is to go away, eventually from today, with an idea of the  
33 deliverables, the outputs, and starting to think, not in the groups this morning, necessarily, but  
34 starting to think who might like to be involved in that. Because we're very aware that many of  
35 you will be in a particular group, but actually, you might want to contribute to the work of  
36 another group as well. And we don't want to lose that opportunity. We don't want to let that  
37 go. So that's really important. And when we come back this afternoon, we can start to hear the  
38 ideas from the groups about what you might like your outputs to be. And that's when you can

1 start and think actually, I can contribute to that, and the group leads can take note of that. So  
2 that we go away, and we've got, not a finite, but a clearer idea of what the outputs will be, and  
3 what we want the deliverables to be and a timeframe, as well. Now, we're aware that some of  
4 the outputs will be academic, but we don't want that to be all of them. And so, it's really  
5 important that we have that variety in that mixture. But just to be aware, and the group leads  
6 knew from yesterday as well, that we do have the option for the special issue of JPPID, which is  
7 the Journal of Policy and Practices of Intellectual Disabilities, for early 2025. So, if we can get  
8 ourselves in gear and get about nine articles ready, by this time next year, we're good to go!  
9 But of course, I'll say again, it's not just about the academic outputs, but that's an option for us.  
10 So, keep that in mind, as you're thinking about what the outputs might be from our individual  
11 groups this morning. And then, we'll come back later in the day and talk more about that. Matt,  
12 do you want to say anything?

13

14 Matthew Janicki

15 Thank you, Karen. Just want to give you a quick history, Karen and I were instrumental in pulling  
16 together that meeting in 2016, a few years before the pandemic, when everything closed down.  
17 And the notion of that meeting, obviously, it was a much more broadly topic meeting. I think  
18 we had like, what 15 or 16 things that we were talking about in sequence. The idea was that we  
19 would try to get a consensus, in a way of the scientific thinking and the clinical thinking and the  
20 academic thinking on various topics and see what that would generate. While we're lucky and  
21 unfortunate enough to have a really good group there, some of you were there. And it  
22 produced literally 17 manuscripts that were published in highly regarded professional journals  
23 around the world. And so, we're very pleased that that's the output of that. If we had thought  
24 that we would maybe have another meeting at some point, but the pandemic shut everything  
25 down. So, we were fortunate enough when Reena approached us about potentially doing  
26 something here, and we said, hey, how about another Summit. And on that note, I just want to  
27 announce that last night, a secretariat was formed to look at these Summits and kind of  
28 administer them over the years and follow up from this one. You'll be getting some information  
29 about that from us shortly. So, we now have a formal, not an Incorporated, but at least informal  
30 Summit Secretariat, and the National Task Group in the States is going to host that webpage for  
31 it. So, we'll give you information on that. What we're looking for, hopefully, from this is the best  
32 thinking that you have in terms of what would be good outputs, to kind of synthesize the  
33 information that has come up from each of the topic areas. Now, there may be multiple things  
34 that come out, like in Glasgow, we had several papers on advanced dementia, we had several  
35 papers on other topics and things like that came from different perspectives, and went into  
36 different constituent reading journals. And this could be the case too. The other thing to think  
37 about, and I think Karen brought that up very nicely is the outputs. Do we want to also think  
38 about, producing some materials which are easy read, for a constituency, like the brain health  
39 information, other information that would come inform people that have some of the

1 conditions that we've been talking about or that we want to affect in some way and produce  
2 materials or look at how we can commission some materials that would be useful for  
3 organizations and agencies and websites to use, besides the academic capacities. So, what  
4 we're looking for this afternoon is, hopefully some of you will volunteer to be topic leaders, and  
5 only topic leaders in that we already have leaders for today, in terms of the organization of this  
6 morning's discussions. But those that may want to take the lead on creating some of the  
7 outputs. And also, people would sign on as team members for those outputs. And again, as  
8 Karen very nicely said, you don't have to restrict yourself to the topic that you were put in, in  
9 this particular Summit. You can go across topics, you can contribute to multiple documents, like  
10 we did in Glasgow. And we had a very nice number of people who cross-participated in various  
11 publications there. So, that's sort of the themes. So today, we'll be talking within the small  
12 groups, to kind of narrow down what are some main things that we want to say as our  
13 consensus issues. And note those down, hopefully, we'll have it recorded, if somebody can  
14 write those down. And hopefully our recording from this Summit will get a transcript out of it,  
15 so we'll have that to share as well. And then the next step would be, in the afternoon, to look  
16 and see who wants to take the lead, because we'll need someone who's going to be the senior  
17 person to kind of coordinate things, in conjunction with the Secretariat officials, who will help  
18 coordinate some things too. Like Karen nicely said that she has already got a good offer from  
19 JPPID to publish some of the papers. They have to go through review, obviously. And then we  
20 may look for some other venues as well, depending on the constituency, because sometimes  
21 we gear it toward other groups. In Glasgow, for example, we went out after the general  
22 Dementia Care constituency in some of the publications and other groups in the aging  
23 constituencies. Sometimes it's a disability constituency, sometimes in a disability-specific  
24 constituency. So, some things to think about. As we move through the morning, if you think  
25 about that, and then the afternoon, we'll try to synthesize that, come up with some people who  
26 are taking on the responsibility for managing some output documents, and then people signing  
27 on to that. And we'll be following up with you afterwards as well and say, look, these are the  
28 ones that were created, do you want to be co authors on these, and do you have something to  
29 contribute? So, we'll be doing that. And a timeline is the publication for JPPID is early, like  
30 January issue of 2025. It's hard to imagine 2025. I didn't when I was doing workshops, back in  
31 the old days, when I worked for the State, we used to talk about the next millennium, we'll be  
32 doing this and now we're in the next millennium and 20, almost 25 years have gone by. It's  
33 amazing. Anyway, that's a quick nutshell of what we're looking for. So, it kind of gives you a  
34 flavor of the framework. And I know, I see some faces here who contributed to those  
35 documents in 2016, and did a bang-up job, really great stuff that came out of it. And we didn't  
36 have any rejected, which was very nice. Anyway, that's what we have, right? Anything else you  
37 want to add Karen or Sandy?

38

39

1

2 Sandy Stemp

3 So, just as a matter of what's our timing going to look like this morning. What we thought is  
4 that people would go in your group, like I said, we have group one and group two. Group one is  
5 in the St. Laurent room, and that's on the second floor, both are on the second floor, they're  
6 just across from each other. And the other one is the King room. And then topic three will stay  
7 here. And you can have the entire room, just keep running around. So approximately, an hour  
8 or take you to about 10:30. And then, we'll set up the breakup here. So, if you're downstairs,  
9 stretch your legs, get a little bit of movement, come on up here, grab a coffee, grab a snack,  
10 and then continue on for about another half an hour. And then just before lunch, today, each  
11 group will give a small recap. So again, if you can elect or volunteer someone from your group,  
12 so when you come back into the room, there can be a little bit of a recap on what you've come  
13 up, as far as some of the, as Matt was saying, looking at some consensus within your group,  
14 about what are some of the things that you develop, that you heard about yesterday, try to  
15 bring it together in a way of Okay, this is what this is all about. This is sort of where we're going,  
16 and then getting ready to contemplate what are the next steps. Another thing, I think that we  
17 were floating around, who was it? I think, oh, Seth! We were talking about even products, like  
18 you said, in addition to the academic work is, maybe something a bit broader. And I know that  
19 when we were talking to some of our sponsors, like the Azrieli Foundation, they're really  
20 interested in what things come out of the Summit, and whether we'd be willing to do  
21 something like a broader webinar, just to kind of be open to all kind of thing and just to help  
22 people understand and whether people are interested in doing that and how we could help  
23 create those things. So, if I think Ziv, you've got the magic keys for the room, it's sort of like the  
24 key fob for your room. And then that's just on the second floor. So, if everybody wants to grab a  
25 coffee, grab a few of your papers and then head to your breakout rooms.

26

27 Sandy Stemp

28 Okay, we'll get started. So, I think we're all here. And because last time we went 1,2,3, we're  
29 going to go 3, 2, 1 for something different and mix it up! Lucy, you can either come up here, or  
30 you can just stay where you are and grab a microphone to give a quick recap.

31

32 Lucy Esralew

33 Yeah. Hi. So, we actually had quite an active conversation, resulting in at least eight potential  
34 areas of output. So, the members of the group will help me correct, if I misspeak at any point.  
35 But one of the ideas was, having a paper which is on the concept of screening, just as the broad  
36 issue. And what this is looking at is the fact that many adults really don't have any baseline  
37 information about them during their adulthood, prior to presenting for what is thought to be

1 changes in their functioning. So, how do we begin to encourage this idea of the kind of process  
2 in which one could undertake, in terms of screening, assessment, prior information in one's  
3 record, so to speak, about functioning? What might that look like? Could we create a checklist  
4 in which a PCP, who's first looking at somebody, might be able to gain from certain psychosocial  
5 data about their previous functioning, such as educational level, occupation, relationships, etc.?  
6 So, it's a paper devoted to that process. How do we move that person to the process of  
7 screening, assessment and follow up referral? So, that was one concept paper. Another concept  
8 paper was general guidelines for dementia assessment for individuals in the general population.  
9 As might be posted by different countries, distilling from that, Matt generously offered to be  
10 the distiller and synthesizer of this, and then creating a crosswalk to some IDD-specific  
11 guidelines, as they may exist. So, that idea of how do we help people? - and by people, I mean,  
12 PCP people, and advocates and families - move from an understanding of what is generally  
13 guidelines for dementia assessment and care to IDD-specific guidelines. Helping them be better  
14 advocates and better supporters of individuals with ID and suspected dementia. So that's two.  
15 Three is building upon the lessons learned from our knowledge base and research and clinical  
16 practice on Down Syndrome and dementia, and what we might also know about autism. Okay,  
17 to what extent do practices regarding dementia screening, assessment, treatment and supports  
18 that we've learned in our work so far, apply to other specific neuroatypical conditions? So, it's  
19 kind of lessons learned and how do we build on what we know and extend that knowledge base  
20 to those other conditions that we may not know as much about. And we're kind of talking  
21 about it as a series of papers, not just one paper, but a series of papers. Alright, so as you can  
22 say, several people have their lives work set out for them at this point in time. Then, we talked  
23 about having a separate paper on aging, and aging into a potential dementia with Fragile X.  
24 That's something that I have become very interested in, in terms of my preparation for the  
25 Summit and invite any and all to join me on that. We have this separate idea of looking at  
26 reasonable accommodations or adjustments, adaptations. So, what can the primary care  
27 physician or GP, who's seeing an individual with memory problems and ID, maybe other  
28 complicating conditions, such as mental health, etc.? What would be some reasonable  
29 accommodations and adjustments, and we thought maybe focusing in on particularly the areas  
30 of sleep apnea or sleep disorders, and hearing or sensory problems, might be very productive.  
31 And that we would envision this as a multidisciplinary approach. Practically speaking, what can  
32 one do? What can one recommend? And a place to start would be looking at what is currently  
33 being done in the area of making those reasonable adjustments or accommodations? We have  
34 an interest in doing a meta-analysis of the literature on aging with autism and looking at  
35 specific risk factors for dementia. And we have two more issues. Okay. One is kind of a related  
36 issue to the one in terms of ageing with autism. It's issues facing somebody who is on the  
37 spectrum and interacting with the medical system. What is their actual experience in terms of  
38 being able to get treatment, in terms of assessment and treatment? And then Arianna had  
39 suggested we may want to pull in the Autism Speaks National Learning Health Network, in  
40 terms of getting some voices of individuals on the spectrum, in terms of lived experience. And  
41 then another output in terms of a paper was how do we approach obtaining informed consent,

1 for therapeutics, for research and so on, for individuals with ID and suspected dementia? So,  
2 this has a lot of implications for the upcoming new therapeutics, the antiamyloid therapeutics,  
3 that we're hoping at least our individuals with ID will have access to, and it certainly has  
4 implications for other treatments and research. For instance, what can we do to help get  
5 informed consent regarding the use of some of the anticholinergic medications that are being  
6 prescribed, and what do we know about that? Now, we did some talking about, it's not just  
7 papers that we're interested in, we're interested in the broader dissemination through training,  
8 webinars and other formats. Was that enough, Phil?

9

10 Phil McCallion

11 It was pretty good.

12

13 Lucy Esralew

14 Just checking. So that's kind of it in terms of where we are, and we could have still continued.

15

16 Sandy Stemp

17 I was going to say, do you have full time staff?

18

19 Lucy Esralew

20 Well, I was going to ask you, Sandy.

21

22 Sandy Stemp

23 Well, I'm not doing enough. So, I can certainly... Amazing, that's great. Anybody have any  
24 questions? Other than oh, my goodness. But other than that?

25

26 Lucy Esralew

27 Oh, my goodness and a general invitation. It is not like we don't want to extend this to others  
28 who might be interested in joining us.

29

30 Nancy Jokinen

1 I have two, just shortly. The one where we talk about people with autism and their experiences,  
2 and including some people with autism, the autism voice, we might want to include one or two  
3 others from other countries. For instance, in Canada there are a couple of groups that we might  
4 be able to draw on, and Sandy Stemp and I are going next week to one that we could solicit  
5 interest. And the group, whoever is doing that paper, might want to include somebody from  
6 overseas.

7

8 Lucy Esralew

9 You know, if they're interested in that, we do want a global perspective on all of these topics.  
10 So, whomever you think, you and Sandy will provide.

11

12 Nancy Jokinen

13 My second comment is that we also looked at reasonable accommodations. So maybe I'll let  
14 Karen speak to that. But I think you need to clone yourself, Lucy.

15

16 Matthew Janicki

17 Can I just offer a comment too, if I may? I think it's important to point out, as we give these  
18 presentations, that these are not exclusive to the group that was assigned to the topic, it's open  
19 to anyone around the table or any colleagues that weren't able to be here over on our  
20 invitation list, or others who may be experts, content specialists to help frame these arguments  
21 and be co-authors. Lucy Esralew has committed to one. But the shared responsibility is going to  
22 be among the rest of us.

23

24 Mary McCarron

25 Make a comment and well done and fantastic! Okay. I'm very interested in the group who have  
26 got long term mental health illness. And are you looking at are we going to learn anything about  
27 that group? Are we going to try to know anything about that group? Because that's the group  
28 that's coming in now, that we're seeing, who have a long-term history of depression, anxiety,  
29 schizophrenia, whatever. They're coming into the clinics on massive mounds of medications.  
30 Trying to understand even the brain or the difference in brain structure or whatever else.

31

32 Lucy Esralew



1 I'm so glad Mary brought that up, because it didn't come up in our discussion, when I am glad  
2 you did, because I would very much like to work on that. So, Mary, are you volunteering?

3

4 Mary McCarron

5 I know there's lots of better experts than me around this table. But I do think that it is certainly  
6 something I'm happy to contribute. But I think there are probably much better experts. And we  
7 have lots of psychiatrists here who probably, you know, a newer psychologist, but I'm happy to  
8 contribute, because it is a really big issue. These people are coming to our clinic, we don't even  
9 know where to start. Even when you look at scanning, we don't even know what's baseline in  
10 terms of brain function or what the brain looks like for some of this group.

11

12 Sandy Stemp

13 I see that Laura had her hand up.

14

15 Laura LaChance

16 Thank you. Wow. That's quite a list. Did we get to eight? I think you got to eight. And yes, to  
17 Mary's comment about there being experts around the table, but somewhere in there, and I  
18 don't know where, I would like to see the voice of individuals with Down Syndrome reflected in  
19 the discussion. Certainly, in terms of, as I've spoken with Arianna, the dual diagnosis,  
20 particularly with autism, where their evidence is showing, 16,18,20,30, depends which study,  
21 you look at. You know, 20% co-morbidity that I think, that small group as we are, not perhaps  
22 the numbers of the autism community that I would like to see that work reflected or  
23 somewhere in that massive list.

24

25 Sandy Stemp

26 Okay, Dawna, you have the last word. One word. I'm just joking.

27

28 Dawna Mughal

29 My comment is about the fact that there may be an overlapping group. Meaning, after hearing  
30 all of this, we have a way of condensing them. You know? Because there may be topics that  
31 came up with my group, brain health, my brain is still functioning thank God. And then the  
32 other groups, in other words, after all of this, we can see some overlapping themes. Thank you.



1

2 Sandy Stemp

3 And, so I'm going to go to group two. Phil?

4

5 Phil McCallion

6 Yes. Sitting here next to Lucy, you know, like she has this very organized, typed list, things  
7 highlighted, everything else. So, I'll just share, this is what I'm working from. But on the other  
8 hand, I think we were the fun group, right? We had a very extensive discussion and came up  
9 with a number of products. And I think that there's a challenge, both in terms of how you're  
10 going to structure the work that we're going to do and then also, what are the pieces that we're  
11 going to pick, because we can't do everything? Well, maybe we could, but not if Matt organizes  
12 another conference in two years, it won't all be done by then. So, we were really sort of  
13 thinking very strategically about where we needed to start from and where we want it to go to.  
14 We felt that in terms of brain health and risk reduction, that so much of what we rely upon, is  
15 what's out there for the general population. And some of the assumptions that are made for  
16 the general population, aren't necessarily going to be true for people with intellectual  
17 disabilities. We had a discussion about whether we wanted to focus exclusively on people with  
18 Down Syndrome, or whether we wanted to look at people with intellectual disabilities. We  
19 decided to focus on people with intellectual disabilities, because jurisdictions are different. In  
20 some jurisdictions, there are programs specifically for people with Down Syndrome, but there  
21 are others where that's not as true. But we talked about ensuring that people with Down  
22 Syndrome were always thought about in what we were doing, given the challenges that they  
23 experience, in terms of dementia. So, we started out by thinking that we wanted to develop,  
24 specifically from the perspective of people with intellectual disabilities and their family  
25 caregivers, and staff caregivers, too. We wanted to develop a paper that laid out a social-  
26 ecological model, but which also laid out ideas on macro, mezzo and micro level interventions.  
27 When you think about modifiable risk factors, there are things that my individual behavior  
28 change can address. There are things that are modifiable, that will require at least the  
29 involvement at people at the mezzo and the macro level. So, we wanted to be thinking about  
30 this that if we targeted a specific area, it was about what does this contribute to this larger  
31 picture that we're interested in? We talked about several things. We talked about the theories  
32 of change, not just behavior change, but also system and structural change. We wanted to  
33 develop a paper that talked about if we're going to be effective in improving brain health and  
34 reducing risk, what are the change processes that potentially will address this and that we  
35 should be targeting? And again, in terms of what we might do next, we will be thinking about  
36 what are the pieces of this that we would want to address? But we felt that for the brain health  
37 and risk reduction agenda for people with intellectual disabilities and for caregivers, that we  
38 wanted to sort of set those theories out. And as something that was really what we were

1 seeking to do. We talked about, let's look at the opportunities that are already out there. And  
2 so, we have work that's going on in several countries, that are already addressing some of these  
3 issues. There are some systematic reviews that are ongoing and actually, either under  
4 publication or about to be under publication. And because we have access to the researchers,  
5 both who are present here, but also who were not able to be here, for example, the Health  
6 Matters group, that we would look to integrate with them and incorporate their work in what  
7 we developed, rather than writing one more systematic review, when that work is going on and  
8 it's very current. We talked about the voice of people with intellectual disabilities, and the voice  
9 of people who are caregivers. And we decided that this was an area where we could actually do  
10 some data collection ourselves. And there was a commitment around the table, but we'll be  
11 reaching out to other people, trying to hopefully encourage, develop our involvement as well.  
12 We felt that we wanted to do some focus groups and interviews that we collect data about the  
13 not just the experience, but the sort of the interests and the desires of people with intellectual  
14 disabilities and of their caregivers around this issue. There was a great discussion about often,  
15 when you do these kinds of focus groups, they end up being a therapeutic intervention in and  
16 of themselves, so that there was great value in that. But we wanted to introduce diversity,  
17 diversity of countries, certainly. We talked about diversity in terms of the groups that would be  
18 represented, we didn't want to stretch ourselves too far, because basically, this is not  
19 something that probably will be funded by anyone immediately. But we wanted to put it on the  
20 table that we were interested in looking, you know, we were very struck, Sandy, by your  
21 discussion of the land that we are on, and that we should be looking at indigenous peoples, we  
22 should be looking at migrants and looking at people across countries, to sort of really that too  
23 often, either we don't include the voice of these groups at all, or we think that sort of, Oh, we  
24 talked to 15 people, we know what everybody wants. We wanted to do something, because we  
25 felt that our responsibility as a group was to really set an agenda and not just to put out some  
26 papers, but we are going to put out papers. So, we spoke about that. The other piece that we  
27 talked about was that we have some existing longitudinal studies that are represented here in  
28 this room. And that there was an opportunity to do some mapping, particularly of the Lancet  
29 listing. And we know that Health Matters also did some work mapping the modifiable factors.  
30 But really, to look at what data is potentially available, that helps us to really understand what  
31 the experience of people is, in terms of these modifiable risk factors. But then the other thing  
32 that we talked about, which again, is about really utilizing some of the resources that are  
33 available to several people who are part of the group, is that we would look at doing some  
34 machine learning approaches to see if we could predict onset of dementia, precisely because  
35 we have longitudinal data. So, I think that that will be a really important part of how we begin  
36 to develop this literature. And it potentially helps us to make decisions about what are the  
37 areas that we want to target? We can't necessarily do everything all at once. Thinking again,  
38 about people with intellectual disabilities themselves. We talked about some of the models that  
39 are out there, particularly the P-PALs model, which have been utilized to enable people with  
40 intellectual disabilities themselves to be leaders in terms of improving their own health. And  
41 that led into a discussion about what are the theories of learning that underpin interventions?

1 The majority of the theories are about individual behavior change, and again, we respect  
2 individual behavior change, but we're also looking at theories of learnings that look at other  
3 types of issues. And then, we also had a piece where we talked about, at the end of the day,  
4 how is programming likely to be delivered? We see that being delivered, not in a systematic  
5 way, because it's often specific to a particular discipline and the emphasis that they have and its  
6 particular practitioners, as opposed to discipline wide. We talked about the potential to  
7 influence curricula. And we recognize that that's really hard, perhaps that we have a role to  
8 play in influencing continuing education so that these ideas become more embedded. But we  
9 were concerned that too often, what happens is its one-off events, it's reaching very limited  
10 people. We decided upon the idea of targeting Brain Health Week, which is held in many  
11 countries. I realize that in and of itself, it does not get a lot of publicity, or not publicity, but it  
12 usually occurs in the middle of February. And so that gave us of a little bit of time. And so, we  
13 are interested in developing a Brain Health Week series of activities that can be spread. For  
14 example, in Ireland, there's a program that has been previously developed and delivered. we're  
15 interested to hear from, certainly other members of the committee, but from others. And we're  
16 going to be reaching out, asking people to commit to participating in some way, in their local  
17 areas. And so, you know, I think that a gathering like this, which gathers both researchers and  
18 practitioners and providers, gives us a real opportunity to develop this in a way in which there  
19 are multiple sites where something like this happens. We didn't get to discussing whether we  
20 wanted to collect any data about it. But you know, if nothing else, to be able to publicize that  
21 this is an issue for people with intellectual disabilities and their caregivers, that this is an  
22 international concern, and that there are international efforts focused on doing this. We felt  
23 that this was an important contribution to make in terms of awareness raising and would be  
24 another dissemination product that we would utilize. We talked about best practices. You  
25 know, and it is an unfortunate reality, that there are good things going on in localized deliveries  
26 that are not always publicized, and don't always then translate to being more widely  
27 disseminated and more widely utilized. And so, we committed to gathering some of those best  
28 practices. I think that that will be an activity that the group will continue with over an extended  
29 period, reaching out and trying to find information on practices that are being implemented.  
30 And hopefully, that helps us then to think, you know, I always think about, it's not enough to  
31 say that something's really good and it'll work. You also have to think about, something's really  
32 good and it works and people are actually doing it and want to do it. And so that in our  
33 gathering of that information, we get to gather some information about what's really  
34 happening. We have a number of organizations that are present, representing different groups  
35 here. And so, we would also be reaching out to them to help us with reaching out to their  
36 membership, helping us to gather some of that information. I think there's a great opportunity  
37 through a group like this, to build that compendium of best practices. Trying to think if I got  
38 everything. Oh, and then the other piece we had a lot of discussion about, the discussion  
39 started with easy read materials. But then as the discussion went on, people were talking about  
40 that even those easy read materials, or those materials that are directed at families or at staff  
41 that you often hear when you talk then about the topic that people said, no, I never got any

1 information. Because none of us read everything that comes in and across our desks. And so  
2 why should we be surprised that the materials that we have. It's not that we are against those  
3 materials, but we started talking about what are some other ways in which we can get  
4 important messages across in terms of brain health. We talked about at a later date, and  
5 perhaps when we got some funding, that we would develop a series of animated videos, short  
6 animated videos that talk about critical issues for brain health, as hopefully a more effective  
7 way of getting that information out to people and getting people interested in and even excited  
8 a little bit about some of the things that are being proposed. What did I miss?

9

10 Mary

11 No, I think that's a good summary of everything. Yeah. So, we're quite excited. There are some  
12 practical things there which we felt were important and we heard what people were saying as  
13 well, that we want to a variety of outputs. And I think the group, we were very mindful of that.  
14 And imagine, if the Summit was really involved in, I'm very excited by National Brain Health  
15 Week, and we run that in Ireland very successfully. And you know, someone should take a role  
16 in advertising that and getting that, because this is a world Alzheimer's Week and Brain Health  
17 Week, but I don't know how many countries or services or organizations even know about it.  
18 We certainly are very active in it in Ireland. So, we're happy to share with you the programs.  
19 Obviously, people will modify them for your own countries and your own areas, but we can give  
20 you a starting point.

21

22 Phil McCallion

23 Thank you. And any questions? Lucy.

24

25 Lucy Esralew

26 You just kind of retracted a little bit in this seat. So, two observations or comments. One is that I  
27 think, some great ideas. And just want to point out that in the States, there is a Brain Health  
28 Awareness Month, which is kind of celebrated around or with the idea of Alzheimer's  
29 Awareness Day, the longest day, June 21. Some agencies have used that, but it's not a standard  
30 in any way. And I really love the idea of the Brain Health Awareness Week. I mean, that's  
31 something I could get behind in terms of the department in California and using that. The other,  
32 I think, big thing is there are good materials out there. But the issue is more dissemination; how  
33 do we make sure that people who would benefit from seeing this actually get it? And it's  
34 something that if you do anything as well, it's an issue that you're going to be confronting.  
35 What are the channels of distribution? Are there agencies, are there clinics, are there primary  
36 care physicians? You know, how does one get that information? And I think that is where it was,

1 and I'll talk about the California experience, I think that's been a barrier, where there's not been  
2 as much thought about the channels of distribution of the information as there could be.

3

4

5 Phil McCallion

6 Yeah, that that was part of the discussion. And, as you think about brain health, and as you  
7 think about the risk factors, clearly, there's a need for interventions at a much earlier age. As  
8 someone else pointed out across the couple of days, not that interventions at age 60, for  
9 example, are not valuable as well. But if we can introduce some of these things much earlier,  
10 we have the opportunity to reach more people, and potentially to have greater effects. We did  
11 not spend a lot of time on this, but we did talk about the need for greater collaboration and  
12 school systems was one of the things that we talked about. What we thought about was that, in  
13 some ways we have the materials, and what are the messages that are likely to work for people  
14 with intellectual disabilities and their families? We'll have to think about what are the messages  
15 that will work for some of the systems as well. But it is about where do we start with this? And  
16 the Brain Health Week concept, we thought about it in terms of this is a great way to raise  
17 awareness. And if we're serious about it in a number of countries, that will help us to get the  
18 attention of some of these other groups. And if we have materials that are developed for  
19 something like that, it's a way in which they can become engaged as well. But we're a valiant,  
20 small group and we believe in that, how you eat an elephant is one bite at a time. And, so we're  
21 trying to understand our resources as well.

22

23 Sandy Stemp

24 Okay, now it's lunchtime.

25

26 Phil McCallion

27 How would you like to collaborate with Special Olympics?

28

29 Phil McCallion

30 That came up in the discussion and yes, we would. Among the group, there are relationships  
31 with. I think that Special Olympics can be approached in multiple ways. I know the really strong  
32 relationship you have with them. And we would absolutely want you to be involved in sort of  
33 making that.

1

2 Seth Keller

3 I already texted a friend of mine about it, who's in charge of Special Olympics Europe. I don't  
4 know what he'll say, but I really got a head start on that.

5

6 Phil McCallion

7 Oh, he'll say yes, because you asked him, Seth.

8

9 Mary McCarron

10 And just to say, as well, that there's lots of expertise around the table here to fit into any of  
11 those, that we would encourage other people to join us in some of those efforts with some of  
12 those papers and initiatives. Thank you.

13

14 Sandy Stemp

15 That's great. I was just joking that it was lunchtime, it was the eating of the elephant. We still  
16 have one group left to go here. Any other questions, before we move on? Laura?

17

18 Laura LaChance

19 Thank you. You know, it's very interesting when you take a look at communication and how  
20 communication has changed. And Dawna talked about it about it yesterday. And one of the  
21 things that we've never really had to do, or that academics have had to do is to market, you  
22 know, the PR of their work, the digital communication, the ability to story tell, the ability to  
23 bring things to the front line in a very different way. And, I would encourage that, perhaps, with  
24 the guidance of the expertise around the table, that that's an area that this particular group  
25 looks towards, dare I say, branding, storytelling, how this will be meaningful to the generations  
26 that are up and coming.

27

28 Phil McCallion

29 Thank you. Yeah, we did have some discussion of that. I think that we're all realizing, certainly  
30 those of us who are teaching, we know that students are uninterested in getting that those 12  
31 articles that we are so sure that they should want to read and enjoy and synthesize. And I think  
32 we're all looking at, you use the word storytelling and certainly, in social media, that's the

1 mantra at the moment. That's sort of the most effective way. And I'm struck by, and we talked  
2 about this in the group, I'm struck by the number of people who say that, well, no, I've never  
3 seen any information on this, and providers turn to me and say, we've sent all this stuff out,  
4 they got this much. And it's like, yeah, and that's why they haven't read it, because they got this  
5 much. And we do have to do a better job. I think, as researchers in general, we have to do a  
6 better job. But I think it applies at all levels, if we're going to have the influence that we would  
7 hope to have around brain health and reduction of risk factors, we have to find new ways of  
8 communicating. We have to find, you know, the animated video discussion was about can we  
9 come up with short storytelling messages that people will want to listen to, even if they're not  
10 going to read the materials. But actually, what tends to happen in some of the studies that I've  
11 seen is, that when you get people's attention with the story, they ask you for the written  
12 materials. And so, we are thinking about that, but we know we're only at the beginning of those  
13 ideas. But thank you for raising that because it just really reinforced the discussion that we had.

14

15 Dawna Mughal

16 I took courses in health communications and one of them is social media. Going back to the  
17 comment about a health campaign, in a campaign you have to set your goals, your target  
18 audience, your method of communication, and then down the line, the distribution channel,  
19 and then the feedback on that. So, I know I read the information and Brain Health Initiative,  
20 whatever, the campaign is there. I'm a registered dietitian, and I know about it, but I just say  
21 Oh, okay. And then translating that message to my individual action, that's a different matter.  
22 So, I don't know if you can narrow the distribution of the information, rather than just going out  
23 there. But really identifying your target audience, rather than just making a broad  
24 announcement. Because people read it, oh, that sounds good and then go. But if you target  
25 your audience, I mean, if you reach only a small group, that is an effective way, I think it's good  
26 to raise the consciousness of that audience to something that is relevant to themselves. I know  
27 health campaign covers the public, but maybe touching a smaller group of people that can  
28 make a difference, and the ripple effect of that group, you know, here I am successful. And that  
29 sends a message the other group, that they can do it, too. So, I don't know, just narrowing  
30 something, maybe, in a small way, in the beginning, when we're doing this project, do some  
31 kind of pilot study, instead of going all out and spending our time and resources. It's just a  
32 comment.

33

34 Sandy Stemp

35 That's great. Thanks, Dawna. I actually remember something; I think it was Dr. Heller published  
36 something about exercise in people with Down Syndrome who are older. And one of the  
37 interesting things that I picked up and keep trying to reiterate to people, that one of the biggest  
38 things about people exercising was watching themselves. So, if somebody took a video of



1 themselves exercise, they were more likely to sustain that over time. If you put it on and they  
2 watch themselves, do it, then they would mimic that versus me doing it or somebody else doing  
3 it at the front of the room. So, it was very interesting. But yes, there's a whole science behind  
4 that. Ok, go ahead Karen.

5

6 Karen Watchman

7 Thank you. So, we were sort of Team Phil end of the spectrum with our bits of paper. We went  
8 for a yes, no, maybe, based on reviewing the conversations and the directions we went down.  
9 And we did have a few yesterday that probably took us off topic. So, that was our No page. I'll  
10 come back to the Maybes. But in terms of Yeses, for things that we thought were achievable for  
11 from our group. The first is an article on human rights and equality, that we would like to co-  
12 write with people with ID bringing in different perspectives, situations and experiences from  
13 around the world. So, we had some ideas around that and we'd be looking to collaborate with  
14 others as well. And we did talk about an easy read version of that article, that we would also  
15 disseminate through different routes, and through different medias. The second paper was  
16 more of a focus on equity. And this is where we also talked about reasonable adjustments,  
17 reasonable accommodation, but from an equity perspective, we had quite a clear focus there.  
18 And a number of the issues that we talked about as a group yesterday, as we were going over  
19 them again, they come under this category. So, we were able to draw in a lot of the things that  
20 we spoke about yesterday, as potential things to actually contribute to the outcome. What we  
21 would like this paper to do is to lead to a set of principles around equity in relation to ID and  
22 dementia, global principles, not the kind of micro, but developed from the article that would  
23 form part of the article but would also stand alone. And we saw this as the potential for  
24 infographic, that we could share on social media. And we also talked about the possibility of a  
25 video around the principles related to equity, around ID and dementia. So that was our 'two',  
26 but with extra things in there in there as well. That was the main, the main things that we spoke  
27 about. I'll tell you what our Maybes were, because I think they could perhaps be picked up  
28 elsewhere. Or it could be that they're already been thought about, or other groups might want  
29 to think about and say, Actually, I think we could probably run with that. So, we had two in our  
30 Maybes. And the first was we had a discussion around following up on the ethical communities'  
31 concept that we talked about yesterday. And the article that we refer to in the background  
32 document as well. And so, communities around involving people, supporting self advocacy, but  
33 keeping that focus on dementia. If you haven't had a look at the article, you might want to have  
34 a look at it, it's linked in our paper and just have a think about how we might want to do  
35 something with that or use that perhaps somewhere else. The second was dementia as a  
36 disability that we talked about, that maybe there was more of an issue of having an accurate  
37 diagnosis in itself, rather than an additional disability level. But actually, we might want to  
38 consider a response to this. Or it might actually link to one of the articles that group three, the  
39 first group we heard about, what we're talking about in terms of looking across from generic

1 dementia to ID and dementia. So, perhaps it might actually come under there. And we ruled out  
2 some of the other things that we had talked about yesterday as being less specific to the topic  
3 in question that we have, and some of them have been mentioned already as picked up by  
4 other groups. Anyway, does that summarize? I'm looking at others in my group. Or any  
5 questions? Are we all hungry?

6

7 Sandy Stemp

8 Okay, that's great. So, definitely our lunch is ready and waiting for us. So, please help  
9 yourselves and then we'll come on back.

10

11 **BREAK**

12

13 Sandy Stemp

14 Okay, so we're going to get started in just about two minutes, if everyone wants to take their  
15 seat. And while you're getting to your seat, we're going to do a bit of around the room, we're  
16 going to start with Mira Puri down there, because why start an end when you can start in the  
17 middle, right? We've exceeded our own expectations, so we're probably not going to be going  
18 too much longer. But one of the things that we thought would be really nice is that we do a bit  
19 of around the room and share with us any comments, any insights, any additional information  
20 or connections. And as I said, we're not going to let you go so quickly. So, you might leave the  
21 room, but you're not going to leave us as far as some of the follow up and tasks. And one of the  
22 things that we had thought from the three groups, I know that Lucy has a very organized list,  
23 whereas Phil, you know, it's there, it's all there. And Karen is a fan of the little papers there  
24 from the hotel. If you could just type that up, just so that we know we've got it right, as far as  
25 the outcomes. That way, we can put that all together and send that out to everyone. That also  
26 is a way, if you're thinking about Oh, you know what, yes, I sat in on this group, but I'd really  
27 love to work on this project, then we can also make sure that we're sharing those details. So,  
28 people can put their hand up for various projects that they might be interested in. And  
29 everybody again, post-conference, I think Ziv has emailed most of you, you probably have  
30 Nancy Jokinen's email as well. So, those would be ways to try to get in touch with us. I'm not  
31 sure if you've got my email, but we'll include it in the in the cc so you've got it as well, just so  
32 that we can try to coordinate people after the event. The website as well is a great place to go,  
33 because we'll try to put information there. So, I thought we'd just start with a bit of around the  
34 room and sharing some information. And Mira and I were just talking before, and she had some  
35 pretty interesting things that the Azrieli Foundation has supported, so maybe you could start us  
36 off.

1

2 Mira Puri

3 Sure. Hi, everyone. Thank you so much for the opportunity to be here and listen and learn. I've  
4 been a sponge this whole time. And I just want to congratulate you on I think one of the best  
5 meetings I've ever attended in this area. I attend a lot of meetings and it's very rare to  
6 experience a fairly seamless presentation and coordination of ideas that span biomedical  
7 research and thoughtful research work with practice and the future and thinking about needs  
8 for the future. As well as the diversity of jurisdictions that are represented here. All in a very  
9 friendly group that seem to really work well together. So, congratulations, this has been an  
10 amazing experience. As Sandy mentioned, at the Azrieli Foundation, we support a very broad  
11 spectrum of activities and projects that address the quality of life of people with  
12 neurodevelopmental conditions and neurodiversity in general. And besides doing that, with a  
13 very, very small team, we are a bit of a systems convener in many ways. And I would just like to  
14 offer that we would like to stay in touch with this group. I think we have some interesting  
15 connections to make. And I think the one that Sandy and I were speaking about was an  
16 initiative at a social enterprise associated with the University of Ottawa. It's called 'Open,'  
17 where people with intellectual disabilities are employed to create communications products for  
18 their community. And this enterprise is addressing accessibility legislation in Canada. Their  
19 contracts are with government, with private companies who are providing accessible materials  
20 to their stakeholders. And I think a group like that, I think just bouncing off of the remarks  
21 around communication and knowledge translation of what comes out of meetings like this. You  
22 know that is, I think, one example of maybe how we could make connections. Also, for any of  
23 the research work that was identified; papers, meta reviews, we have a number of grantees  
24 who, I think, could contribute, and I encourage you to reach out to us for suggestions, or even  
25 me to do a little back-end work on finding those contributors for you. So, with that, thank you  
26 so much. I'm sure I will have some follow ups with individuals as well. And just like to thank you  
27 again for the opportunity to learn so much.

28

29 Sandy Stemp

30 That's great, thanks so much. We're going around the table, I think, right?

31

32 Yumi Shirai

33 It was well said. So, reflection of the meeting, I'll just echo what Mira said, it's just fantastic to  
34 get to know. And just the missing part is time and more opportunity to get to know each  
35 individual participant, because everybody has something to offer and trigger my interest and  
36 connections. So, that's the time that I wanted more of from you. So, I'm very excited to  
37 continue the relationship in the future. So, I can collaborate and learn more and work together.

1

2 Matthew Janicki

3 Can I jump in in terms of what we're trying to do here. One of the things we wanted to get from  
4 you also is some reflections on ideas for other topics that might come up in future  
5 aggregations, webinars, meetings, things like that. So, if you have some thoughts that although  
6 we didn't cover here, obviously, we limited it to three things, because of the time and generally  
7 to kind of focus the energy. But there are other things that came up in the discussions and  
8 things that we haven't had time to hear from you. So, if you have other thoughts, I know you're  
9 interested in the arts, that might be an area that...

10

11 Yumi Shirai

12 The arts would be one of the areas and I had a discussion with multiple people. One of the  
13 things that arts has been kind of a secondly result to come down to but then I want to bring  
14 that up to more forward, in terms of how we navigate our lifelong transition, challenge,  
15 connections and everything. My colleagues at the AAIDD, American Association on Intellectual  
16 and Developmental Disabilities, creative arts group are working on together. So that's  
17 upcoming and also, I think it can be a great collection for maybe next round of topics. And  
18 another part that I'm interested in, that we didn't talk about, some talked about research  
19 methodology, how we study, we talked a bit, but then it's not to the fruition in terms of how we  
20 address that issue that where are we going to move forward with that. So, that's another topic  
21 that I would be very interested in. Thank you.

22

23 Arianna Esposito

24 This has been such a great event, and thankful to be a part of it. And sitting in these  
25 conversations as representing Autism Speaks in the US and being a neurodiverse person myself,  
26 I think the inclusion of neurodiversity and co-occurring conditions is something that I was really  
27 excited that was included. When I think of opportunities for the future, looking at trainings, and  
28 not just, I know we have to advance the knowledge base before we can start focusing on  
29 training, but training for physicians and clinicians and even community service providers. And  
30 the other topic too I'd be really interested in exploring is, as we start to make progress on aging  
31 in particular, how can we be proactive by engaging other youth service systems, education  
32 systems, to disseminate this information to help create a more inclusive, brain healthy world?

33

34 Ashok Krishnamoorthy

1 It was quite a breath of fresh air, coming out of the busy clinical world and having had some  
2 time to reflect on many of the topics in broad, especially the brain health related topics. There  
3 are a few things I learned a lot and a few things I just wanted to put it on the table as well. As to  
4 the collective wisdom of a group, the value of that is usually shown in the outcome of the  
5 documents and contributions, what we create. To that end, we did discuss in detail in our  
6 smaller topic-based group, I think some form of going one step forward, doing some clear  
7 recommendations or advice to either professional organizations or commissioners or health  
8 and social care organizations, will be beneficial because we are all fighting the society, which  
9 we talked about ableism in this society, and often quite a lot of challenges. So, both in terms of  
10 health and social care organizations, where you had international experience in multiple sites,  
11 and even identifying some good practice points or good services that exist in other parts of the  
12 world, which can be taken into account and showing us an example in the appendix or  
13 addendum would be beneficial. I do see that it carries a lot of weight, where local advocates  
14 can take this forward. Also, I was very interested in whether there is a possibility of webinars  
15 and educating professionals early in their career. So, we try to educate professionals when they  
16 are in their family practice training and psychiatry training and other non-medical professionals  
17 as well. I think even to an extent of targeting people in early years of their training, even to an  
18 extent, I would say grade 11-12 onwards, if we start having some form of education, even if it is  
19 not a webinar, or even if it is going to be a video recorded session that can be shared, that can  
20 be very helpful. So, that is one thing which I really wanted to put it on the table. The third thing  
21 is more of a is it possible as an outcome in our different topics of interest, what's been  
22 discussed, and a lot of expertise on the table, whether to create a standard of care  
23 documentation based on what would be the expected standard of care for somebody who is at  
24 risk of significant dementia, identifying if somebody is identified as a mild cognitive impairment,  
25 or even going one step forward, the nuts and bolts of annual physical health and mental health  
26 reviews for this population. I know that quite a sufficient body of evidence exists in terms of the  
27 annual reviews, but it's still not practiced. And the reason for that is mainly found in different  
28 countries, because countries set up their healthcare system based on their needs, and political  
29 will. So, it varies. What else can we give to advocates to take it as well into their local region?  
30 So, those are my thoughts. I have learned quite a bit. So, I will take it and advocate for that,  
31 from my end. But having said that, having something published or printed and put it in a  
32 website kind of a standards, will be extremely beneficial when experts come together and  
33 recommend that. Thank you.

34

35 Alyt Oppewal

36 Yes, I really enjoyed these two days. What I like is that there are people with different  
37 backgrounds, which makes the discussions really interesting. And I learned a lot from it, I got  
38 really inspired also with new research ideas, so that's always very nice to take home and think  
39 about what we're doing and what we could do more in the research part. And what I think

1 would be maybe nice as a topic for next time is to focus also more on what interventions are  
2 there if someone has a diagnosis of MCI or dementia? What could we do? And also, I know, my  
3 background is physical activity and sports, there are a lot of interventions, but what does really  
4 work? What kind of effects do we see on brain health etc. And we could do that for sleep,  
5 nutrition. So, I would be really interested in that. And I think, well, the list with all the ideas and  
6 all the publications and outputs that we came up with. If we are really able to do that this  
7 would be great. It would be a really fruitful two days. Yeah. That's it.

8

9 Janice Barr

10 I suspect I'm going to be echoing what everyone else has said. Just very grateful to be invited.  
11 And as a service provider, running a large organization, I am day to day immersed in the  
12 challenges of the work at the very ground level. And so, this has been a wonderful opportunity  
13 just to step outside of that and look a little bit broader and a little bit bigger. The organization I  
14 run has embarked in the last couple years on some significant work around aging and  
15 supporting people while they age. And especially, being a part of the brain health group, it's  
16 really helped me take a look at it from a different perspective. And not only how do we support  
17 people as they age in their decline, whether it be dementia, whether it be other illnesses, but  
18 how do we help people age well? And how do we promote healthy practices, that in a very  
19 practical way, will lead to healthy aging. I got some wonderful ideas, I'm leaving with a bag of  
20 ideas, which is great. And I didn't get a chance to connect, Yumi you were saying about the arts,  
21 and we have two art studios in our organization. And so, I'd love to connect. Thanks.

22

23 Dawna Mughal

24 I have three points. Number one is the culture affect; our habits, our worldviews are culture-  
25 bound. So, our cultural literacy is very important in communicating with clients and other  
26 stakeholders. I cannot emphasize enough the importance of culture and respect for cultures  
27 different from ours, because they have different worldviews, and a different perception of  
28 health. I came from the Philippines and my worldview of health may be different from yours.  
29 Right? And how I prioritize my health goals may be different. My context may be different. I  
30 have been Americanized, unfortunately. And so, I joke a lot. I mean, it's my stress reliever, so  
31 when I'm stressed, I joke. But anyways, seriously, going back to the serious strap of my mind,  
32 the culture effect is so important. I mean, we should not think like that. The cultural  
33 competency of the caregivers, the educators, the providers is very important. And Asians, it's  
34 not one group, we know that, right? There are so many countries and cultures under the so  
35 called 'Asian' cultures. So, we are all different. And so, we should be mindful in how we  
36 communicate, how we create programs, but communication is really the heart of the  
37 connection with other people, our ability to communicate. And that brings me to the topic of  
38 plain language. How we write a document to make it understandable for clients and consumers

1 we serve, is very important. So, when you go home, examine your documents, how simple they  
2 are without being condescending. Very important, I think, because I don't care where you are,  
3 good communication skills, communication problems really are the root of many, many  
4 problems. And the next point is taking care of the caregivers. We have a shortage of them. And  
5 so, how do you take care of your caregiver? How do you take care of yourself, as a caregiver?  
6 We talk about other people, 'they' and 'us' here, it's not like that. So, take care of yourself, it's a  
7 personal and professional responsibility. If you don't do that, we cannot take care of other  
8 people. So, self care is very important. And the last one, is ethics. I cannot emphasize enough  
9 the importance of ethics. I chair a section on ASPEN, which is the American Society for  
10 Parenteral and Enteral Nutrition. I chaired the clinical section on ethics. And we talk about  
11 ethics when people are on nutrition support, like if you have clients on nutritional support,  
12 because they are unable to eat by mouth, the ethical principles involved in that, the decision  
13 making, who is involved with that. So, anyway, that's the last item on my list that I think is very  
14 important. We talked about ethics before, but we cannot overemphasize the importance of  
15 ethics, really. So, revisit the topic and see how that can be framed in another way. I mean, how  
16 you can address that. But in summary, cultural competency, because it affects my worldview, it  
17 affects my habits, my values and philosophy. And number two, taking care of yourself and  
18 taking care of the caregivers, support, and then ethics. These are the three main things. Thank  
19 you.

20

21 Yona Yunsky

22 Thanks, everyone, I had to miss the most important part of the event when everyone shared all  
23 the things they came up with. But I will catch up. I really appreciated being able to meet  
24 everyone. I'm excited by many of the things that I learned. And also, by putting faces to names  
25 and just having nice, informal conversations with people, I think it sort of helps sometimes just  
26 in terms of when you have a question, you can reach out in a different way, I think, than when  
27 you just read about people. So yeah, open to lots of things. I think, here in Canada, I'm quite  
28 interested in making sure as Canadians, we're in touch with and working together on different  
29 things that we're doing, but also learning from our peers in other countries, who are doing  
30 things that are related, and who are a few steps ahead of us. We don't have to invent  
31 everything that's our own, when these things have been done, we just have to find ways to  
32 collaborate. So, excited about that and excited about, I do a lot of work in sort of  
33 implementation science, what does it take to actually take something and then make people  
34 actually do it? So, I liked some of the challenges that were posed in the last two days, you  
35 know, do we want screening that's just as long as the assessments we're already doing that are  
36 specialized? Is it so special, that we can't actually get other people to do it? Things we keep  
37 trying that don't work. So, I like thinking about those things and how we bring people in from  
38 outside who aren't here. So, either primary care providers who don't specialize with this  
39 population, family caregivers, people with an intellectual disability, who have to figure out kind



1 of what this is going to mean for them. So, I'm happy to help from our side, in terms of some of  
2 the work that we do, and looking forward to working with other people who do some of the  
3 same stuff.

4

5 Tiziano Gomiero

6 Very briefly, a trick that I learned from Dawna. Thanks, thanks, thanks! I learned a lot from you.  
7 And I thank you for sharing your competence. And for me, it's been a great opportunity to open  
8 my mind. And I need to elaborate the information of this today. Understanding the new  
9 technology, the impact of new technology, in persons with intellectual disability, the challenge  
10 to the quality of life for caregivers and also for the people in intellectual disability. Thank you  
11 again.

12

13 Vikram Palanisamy

14 I want to start by thanking Nancy for inviting me to this conference. So, thank you. For me, I've  
15 seen some of the leaders in this group, I've read about them, so it's good to see them in person,  
16 mix with them. I made some personal connections with people here. I've connected with  
17 clinicians here, so I'm hoping that I could continue this link, so that I can learn from them and  
18 share good practices. Lastly, Lucy, I want to say a special thanks to you. Just seeing your work  
19 for the last four weeks or so has been inspiring to me, I learned a lot. So, just thanks for giving  
20 me an opportunity to be part of this conference.

21

22 Lucy Esralew

23 Thank you, that was very sweet. I want to express my admiration and respect for people here,  
24 my colleagues, and the opportunity to see you in person. This is probably the first in-person  
25 conference that I've attended since before COVID. And now I remember why I used to go to  
26 conferences. I so appreciate the collegiality over the past several days. So, a couple of  
27 takeaways for me. One is, how do I take what I know, and build upon it in a way that will help  
28 practice and in general? So, one that I've become very interested in, actually because of my  
29 work on the Summit, is Fragile X. So, I intend to continue on with that. And just really  
30 understanding aging with people, and going back to something that Dawna said, people with ID  
31 are not all the same. So, how do we begin to increase our understanding of people with  
32 different conditions, and kind of nuance our understanding of their aging process. So, that's one  
33 direction. The other thing is, I am a clinician, and I really know very little about research. And I  
34 would really appreciate, for instance, there was the offer about helping us do a meta-analysis of  
35 the research. I would love to learn how to do a meta-analysis. I would love to understand how,  
36 as a clinician, I could become more involved in research and advanced clinical understanding, in

1 that way, and would love to see that as a topic for clinicians. I don't think I'm the only clinician  
2 who suffers from that deficit in skill around research. And the same point that those of us who  
3 are clinicians have a lot to offer people who do research, because we hear the day-to-day  
4 problems that come in, when people see us in our practices and clinics, etc. So, I really like that  
5 possibility of us interacting and learning from one another. And I just want to thank you all.  
6 Thank you, Vikram, you were wonderful to work with. And I look forward to continuing to work  
7 with you and everyone here. And Nancy, thank you, really, really, and Sandy and the Reena  
8 Foundation.

9

10 Phil McCallion

11 Thank you. So, I was thinking about this. I called my office this morning and I was talking to the  
12 team that I work with at Temple University, and they said to me, so how's it going? And I said,  
13 oh, it's been great! And there was like a collective groan in the room, because they were like,  
14 oh, what has he committed to now? But, you know, to me, this is what a meeting like this is  
15 about. We're all really busy people. It's really nice to see people. We've had great food; the  
16 logistics have all been excellent. But if all we do is come and we talk, and then we leave again,  
17 and nothing else happens from it, as much as I like to see you all, no, it's not enough. Lucy and I  
18 were talking right at lunch break and what we both agreed was that a big part of this meeting is  
19 having that sense that we are moving agendas forward. And sort of thinking about, while what  
20 was presented was kind of ambitious. On the other hand, you're sort of thinking about, okay,  
21 what are we going to do over the next couple of years? And how things are moving forward.  
22 I've been very fortunate to be associated with Matt, as long as I have. This has been part of my  
23 professional research life, that we have meetings, I over commit to doing work, we do the work,  
24 I learned so much from other people, and we have moved this field forward. And so, I'm really  
25 pleased, and I think that idea that I kind of missed not doing meetings like this during the COVID  
26 period, and it's nice to feel like we're back in here. If I had suggestions for what comes next, not  
27 surprisingly, I continue to be interested in seeing us focus on people with intellectual disabilities  
28 and dementia living at home with their families or living independently. In the general  
29 population, one of the populations that has the biggest growth is people with dementia living  
30 alone. And I'm concerned that there are people living alone with intellectual disability and  
31 dementia. And that because of the way in which our field has developed, we have been very  
32 focused upon out of home placements, and those populations, because those are who we  
33 know the best. And that if we're not purposeful about reaching out to families, and sort of  
34 thinking about what still applies, but what is different. So, I do think that that potentially, is  
35 something to think about. And then also, because it did come up several times during the  
36 meetings, to be thinking about what does this mean for people with intellectual disabilities, and  
37 dementia who are from indigenous communities, who are from socio economic minorities, who  
38 are the challenges of inner cities, the challenges of rural areas, that I would hope that we would  
39 begin to look at how we ensure real equity and access. So, appreciate being here and seeing

1 everyone and all that I think we've done, I'm really looking forward to what we're going to  
2 achieve.

3

4 Kathryn Carroll

5 I've enjoyed this event immensely. And I'm just so thankful to be able to sit in this room with  
6 you all and think about these really important topics. One of the first people said it, but I also  
7 attend a lot of meetings, but 99% of them don't spend the requisite amount of time talking  
8 about what the next steps are and the action items. And so, I just love that we're doing that  
9 here. In terms of contributions, I'm thinking about where I can personally plug in to not just  
10 group one's work, but the other two groups, maybe in as simple ways as just connecting in the  
11 work to lift up the voices of people with intellectual disability, and making those connections,  
12 so people in my network that can maybe provide those voices where possible. Internally at the  
13 Association on Aging in New York, we've talked about ramping up our ability to fund research,  
14 especially in relation to the cost effectiveness of aging services. And of course, aging services  
15 that are inclusive of people with a wide variety of disabilities. And my side of the table here has  
16 put out some really good thoughts for topics to think about in the future, definitely plus one on  
17 the technology point, I think about that all the time. Seeing aging services, kind of deploy these  
18 technological solutions to address things like social isolation, and in home monitoring, and  
19 things like that. So definitely plus one. Plus, one to Dawna's point, about caring for our  
20 caregivers, anything related to addressing the needs of attendant workers and family is  
21 incredibly important. And I'm also thinking about looking at current and future opportunities  
22 for people with intellectual and developmental disabilities to participate in, I guess what we  
23 would consider like traditional, like older adult center services and social adult day, whether  
24 those are inter-abled spaces or across disability spaces or even disability-specific spaces. So,  
25 that's something that I'm thinking about. And that might be especially important for the  
26 population of people with intellectual disability, who are choosing to retire or not choosing to  
27 work at this point and what are those things that are available to them? And just again, thank  
28 you so much for all of the amazing work that went into making this happen.

29

30 Nancy Jokinen

31 I think perhaps that I'm a bit biased. So, being the planning committee chair, maybe I'll pass.

32

33 Sandy Stemp

34 I don't think you're allowed to.

35

1 Nancy Jokinen

2 You know, Sandy is a tough woman to work for. I am so honored and so pleased to be a part of  
3 this group. It has been very busy work, as you all well know, if you're planning something like  
4 this, but working with Sandy and the planning committee itself, we did great work in it, I think  
5 it's evident. Apparently, I'm not going to retire soon. And I likely am going to be involved in a  
6 number of projects following this event. Hopefully, not for the next month though, okay? Thank  
7 you for all coming. It's been great to meet you and great to see you again, for those that I  
8 haven't seen for a few years.

9

10 Sandy Stemp

11 Thanks so much, Nancy. One of the things that I was reflecting upon was, like you said, I've  
12 done many events, and some of them, try to put them together... I do a lot of cross-sectional  
13 work, where I try to bring together two sectors. So, as you know, we're a service provider, but  
14 we dip our toe into lots of weird and wonderful things, as Yona knows, getting ourselves into  
15 trouble usually. But as a service provider, sometimes we're out of our depth in some areas. But  
16 one of the things I really appreciated about this event was really how it's structured. I agree  
17 that many things that we go to just don't have the level of meaningful conversation and the  
18 ability to produce outcomes. So, thanks very much to Karen, for that, because all I did was  
19 duplicate what she did. And I think it was brilliant. So, I do want to give credit to the very first  
20 Summit, because without the first Summit, we would not have had a second Summit, and so  
21 on, and so on. So, it's credit to you, Karen, and just wanted to be very grateful for your work  
22 and your insight and your innovation in how to bring people together, which was amazing. One  
23 of the things I'm taking away as, you know, one of my past CEOs was amazing mentor to myself,  
24 Sandy Keshen and I always found it really interesting, when she went to events, she was able to  
25 pick up all these tidbits. And I just thought, these golden nuggets, these little things that people  
26 said, and then it just came up all the time afterwards. And I thought, what a wonderful way to  
27 kind of weave in your learning. One thing that I'm going to take away, and I hope that other  
28 people do as well, is please talk about the event that you've been to, and what it meant to you  
29 and what was important to because I think the more we share it with others, it's a small  
30 amount of people in this group, it's a big and huge issue. I think if we talk about it, then we  
31 show people that it was important to us, and it should be important to them. I think that's  
32 going to be one of my takeaways. The other piece is the webinar idea is something that we  
33 would love to help organize. So, if we do have people that are interested in that, please be in  
34 touch. Because one of the things, as we said, is that people are really interested in what we're  
35 doing. We had a lot of interest in this event, and we purposely kept it with the folks that are in  
36 the room. But we did really want to tell people what it was about what we talked about. And  
37 so, if you're passionate about what happened over the last couple of two days, I would love  
38 that to come across to reach a broader audience. Thank you and thank you everybody for  
39 coming and being wonderful.

1

2 Karen Watchman

3 Thank you, you've probably heard enough of me over the past couple of days. I'll keep it short.  
4 But this was this was always the vision from Glasgow, that it would happen again, and it would  
5 be repeated. So, it really is fantastic to see, and even better than I didn't have to organize it! It's  
6 a win-win. I think in terms of next time around or future work, we're starting to hear consistent  
7 things, which is really good. I would certainly echo as to where people live; that's definitely  
8 something that that I have an interest in, in finding out more about and looking at as well. And  
9 add to that the technology as well. But other than that, just echo my thanks to everyone for  
10 coming. It's great to see some, I was going to say not 'old' faces, familiar faces and some new  
11 faces as well. So, brilliant. Thanks, everybody.

12

13 Frode Larsen

14 Yes, thank you for inviting me to this second Summit and I was also happy to be in the first one,  
15 and I was really waiting for this second one. And I think it's a lot of topics for the coming  
16 Summits, so that's something I'm really looking forward to. If I add something to the table, I  
17 think about intervention, maybe alternative treatments, like Yumi mentioned art, I think about  
18 music, as an intervention, it's very important to bring on. I'm also thinking about models for  
19 best practice, especially this person-centered care. And now in Norway, we have different  
20 models that we're trying to implement in the care. And I think that this gives us something to  
21 work around, focus on to gain and give better services. So, more about models for best  
22 practice, experiences from this. And the last one is maybe more about prevention. How we can  
23 cooperate with other sectors in the community, thinking especially about the school system,  
24 because we need to start very early. How can we manage to get this topic also from the school  
25 system, then we have also several parts to work for the same goal as us? So, that's also very  
26 important. And all the other things, areas that came up. Yes, very important topics, so looking  
27 forward to the next one. And thank you for meeting you all. Very happy.

28

29 Matthew Janicki

30 Okay, I'm just reflecting back when people were talking to the meeting that we held in Boston  
31 in 1990, which was one of the original gatherings of people who are interested in research and  
32 services in ageing and intellectual and developmental disabilities. It was sort of the foundation  
33 for subsequent times when we got together. And particularly when we got together in  
34 Minneapolis, the better part of 1990s, which is now the AAIC conference series. And we had  
35 gotten a grant from the National Institute of Health in the US and brought together again, a  
36 bunch of scientists and practitioners to talk about a number of topics, epidemiology, ethics,  
37 services and I think assessment was the other one. And it was a seminal event; the documents

1 that came out of that were basically three major papers, which are still being quoted in the  
2 field. And what struck me is that we kind of dealt with some of those fundamental issues in  
3 those days, that were just people just alerting themselves and awakening to the issue that  
4 people with intellectual disabilities and other conditions due to age. And there wasn't really  
5 much available in those days to resource out and figure out what's going on. Now, I know we  
6 can enter these nuanced issues, down into the deep dives of various topics and the  
7 construction of a whole bunch of different things that emanated from those days. Which is nice  
8 to see, because there's a whole body of science that's emerging, related to intellectual  
9 disabilities and aging, and now we're focusing on neuropathologies and the related conditions.  
10 So, it's an interesting evolution, and that what, about 30 years? Looking back, it's a long time  
11 ago, last millennium, as it were. But I wanted to kind of segue a little bit to what we're going to  
12 do. We formed a secretariat to help frame what we did here, we had a very successful run,  
13 Karen. And I kind of monitored what went on in Glasgow and encouraged people to do papers  
14 and things. And I think this way, we're going to be able to share some of that work with other  
15 people, who are going to be part of the Secretariat, some of you are here. And what our goal is  
16 basically to produce things that come out of it, you know, the outputs that enable others in the  
17 field to benefit from the think tank this group has become today. So, you'll be seeing that. You'll  
18 be seeing some things coming out from us, guiding things and communicating and keeping this  
19 network alive, and then conceivably also setting the stage for any subsequent meetings. I  
20 mean, we didn't anticipate that Glasgow would be, it's been seven years. Of course, there was a  
21 pandemic, which shut the world down for about two or three years. So, we're back on track. I  
22 think we'll see what happens in the next two or three years. Anyway, I wanted to bring that up,  
23 because I think it's important to know that there's a formative group that's going to be carrying  
24 on the load for this. And I also wanted to thank, on behalf of the National Task Group, which  
25 we've become sort of involved in a lot of these international and national things, from the  
26 State's perspective. And our thanks to NTG Canada and Nancy and the team of folks, Leslie and  
27 others. And Sandy, obviously, with the kind offer to bring us together here in Toronto, under  
28 the aegis of Reena, where we are able to help celebrate the 50<sup>th</sup> anniversary of a great  
29 organization that has produced so many good things for the Metropolitan Toronto area, and it's  
30 expanding its reaches into other areas. And they're expanding also went into looking at how  
31 they're going to try to produce more awareness in this topic across the provinces of Canada  
32 from coast to coast. I understand now, they're going to be up in Newfoundland pretty soon.  
33 Nancy has been looking for an excuse to get out there, I know. Anyway, that's where we are.  
34 And then in terms of the future things, there's a whole foundation of work that's being done  
35 now, and biomarkers and physiological measures that are going to augment a lot of the things  
36 that we're doing on instrumentation care, and it'll give us more information, in terms of how  
37 we might prevent some conditions from occurring. And also, to enable people to live better  
38 lives, if the research and the science is there to help them along. I know Seth is going to ask and  
39 mention a few more things, from his perspective. We are the co-chairs of the National Task  
40 Group and we're very pleased and honored to be part of this process here. So, I'll pass this  
41 along.

1

2 Brianne Samson

3 That's hard to follow. Yeah, just thank you, again, to Nancy, especially for inviting me, it's truly  
4 an honor to learn from all of you. And thank you for all the research you've done and continue  
5 to do, because it really does change people's lives. I'm an occupational therapist by training, but  
6 I'm working right now, kind of between sectors, similar to other people here. So, just knowing  
7 the way it impacts people's lives, it's really important. I don't have anything new to add, but I  
8 would echo something around practice standards, would be really valuable. We still have  
9 conversations in BC, with different clinicians around dementia is because of a developmental  
10 disability. I think, anytime we can have something that we can offer to some of the healthcare  
11 professionals we work with goes a long way. The other thing, just echoing some of what other  
12 people have said, Katie and others around alternative, like meaningful engagement and what  
13 that can look like, and how people might get that, I think would be also an interesting  
14 exploration. Arts and music and what day space is like, I think there's a lot of things that we  
15 don't know around what that could look like. So, I would add that, but thank you, I'm very  
16 appreciative of all of your knowledge.

17

18 Seth Keller

19 Thank you all so very much. I'm going to echo a lot of what Matt was saying about deep  
20 appreciation for the work that our colleagues have done to put this together, and the prior  
21 Scotland event. And it's just really all inspiring. And I think one thing I really wanted to mention,  
22 as I'm looking around the room of my esteemed colleagues and friends, is the importance of  
23 leadership and how each of us into ourselves whether it's locally, regionally, nationally,  
24 internationally, is what we do. I mean, what we do together. But when we work together,  
25 which I think is so essential for us right here, is we're better. I feel very strong and better, when  
26 we're all working together as a team, you heard the team concept. So, I think that's really true.  
27 It's hard to often, as we can appreciate when you do work by yourself, it's hard. But when you  
28 see that we work together, it's inspiring. I think it's very inspiring. And always remind us of this,  
29 and I don't need to tell everyone this, is what's the cause, is always to remind us of why are we  
30 doing what we doing? You know, what's the cause? What's the underlying reason? And it's  
31 from the heart. I mean, I think what's really blessed in what we do is the righteous cause. I hate  
32 to be philosophical about it is remind us about the advocacy work, the cause we're doing, and  
33 why are we doing it and almost like what's at stake in a way. If not us, then who? And what are  
34 we against? I think all of us, in our years of work that we do, fighting this system and fighting  
35 the barriers and the roadblocks that we continue to fight. But again, I think the fact that we  
36 keep pushing, pushing, and as you're describing Matt, in the years, and where we're at now. I  
37 mean, it's really incredible, but we have more work to do. I think at the end, it's important to  
38 appreciate that. And to that end is really the way, how we can continue to collaborate. And I



1 think that's like, Oh my God. I mean, I think it's just amazing. We have all these amazing people  
2 here, and other people in other parts of the world, who don't know what they don't know. And  
3 I think it's something that will be all better, if we continue to work together and use each  
4 other's expertise and knowledge and learn from that way. I feel that way very, very strongly. So,  
5 definitely, I think it really matters. And just think, all that advocacy and advocacy just pushes  
6 everything from hundreds of years ago to now. I mean, God bless our governments, but  
7 without the advocates making and pushing our governments to do what they do, forget it. So, I  
8 think we always got to ensure about the importance of advocacy in all we do. And I'm going to  
9 segue that to the issue about next steps. As a physician, and admittedly so, I'm probably very  
10 cynical in my own view internally, about myself, but also other health care providers, whether  
11 that's the United States or across the world, that they don't know what they don't know,  
12 ignorance is bliss, I guess, or not really. I advocate, and I do a lot of education training, both for  
13 the NTG and the ADMD and my own neurology organization, it's always going to be hard to get  
14 so many healthcare providers and experts in this population advocacy. So, I really think one of  
15 the goals, a lot of people have mentioned this already, is how to pigeonhole or leverage really  
16 our advocates, to get the people to become a better doctor, a better nurse practitioner and  
17 hand them information and get them to be better. And I think creating that kind of relationship  
18 between the healthcare provider and the doctors themselves and the advocates is so important  
19 to do, and I think is a focus point about creating materials that relate to that whether that's  
20 screening or awareness, or medication or testing. And definitely with this, the nuances that are  
21 going to be coming crossing the biomarkers in therapeutics. In the next several years, we're not  
22 talking about decades from now, I think it's really going to make a major switch in how we think  
23 about. All these years, we didn't do much, we didn't know what we could really do. You make  
24 the diagnosis and sadly, they're going to die. And we certainly provide them help and support,  
25 which is not small. But this will change a lot. So, I really think we need to be thinking about  
26 sooner than later what will these nuances of biomarkers and therapeutics, how will that change  
27 everything that all of us talk about? And I think we have to really think through what that's  
28 going to be, because I think it's going to happen to all of us. And then really just a few other  
29 quick things, I apologize, it's been mentioned, webinars, and I'm hugely involved in education  
30 and training and webinars, both NTG and ADMD. We do in ADMD virtual Grand Rounds. So, if  
31 you want to do are interested in doing educational materials, call me up. And then also the  
32 global perspective, definitely listening to each other. I'm actually now on the ADMD part of the  
33 global health committee. So, I'm actually now involved in wanting to reach out and work  
34 together. And then also we're looking to connect with both United States and other countries,  
35 with medical students and dental students and universities. We're creating chapters, we're  
36 actually creating chapters around the world to unite and learn and work together. And finally,  
37 artificial intelligence. I think also, we should be thinking about how leveraging this new  
38 technology and AI is really going to have an impact on everything that we talked about and  
39 such. And then one last thing, is the digital records. I think, as a physician, having the  
40 importance of a digital record of a tool, a screening tool, a quick and easy way. I mean, that's  
41 really going to be where it is in the future for electronic screening information that healthcare

1 provider can look at quickly, be able to ascertain information, and then use that and store  
2 information and surely follow things. So, great. Thank you all so much.

3

4 Flavia Santos

5 Thank you. I would like to start saying thank you for the sponsors, especially for the planning  
6 committee. So, of course, Nancy and Sandy and Ziv. So, thank you so much for taking care of  
7 everything for us. I also would like to say thank you to Matt, we have a long story, but I  
8 definitely wouldn't be here today without your support, the long trajectory, so not just today.  
9 So, thank you so much. It was really, really enlightening to hear all your comments and your  
10 perspectives. I really appreciated the opportunity. And I have three comments. Well, three  
11 points. One, is about representativeness. The second, is about practical aspects. And the third  
12 one is about research. For representativeness, I would like to echo Dawna when she was talking  
13 about Asia, I think we need to have global self included in future and diverse, I definitely think  
14 it's very important. It's absolutely a different reality. So, we need to become aware of it. But  
15 also, they have other solutions that we don't have here. So, I think it's interesting to combine.  
16 The second point is, we are here to discuss healthy aging and support health aging processes,  
17 but it is lifelong. You age well if you live well. I think we need to find the strategies for young  
18 adults, and let's say middle-aged adults, before dementia or any kind of degenerative condition  
19 comes. So, I think this is one aspect that we need to work on a little bit more. And the third one  
20 is equal, in many other colleagues about technology, but I would like to expand a little bit. Right  
21 now, I'm funded by the National Research Council, and also by the European Commission for  
22 some projects related to technology in learning processes. And although they are in a different  
23 area, I believe it gives me some insights of points that we should be looking at here. Because we  
24 can use technology for entertainment, first of all, but we can use it for enhancing cognitive skills  
25 or for rehabilitation, to be clear. And then, we can also use those technologies, especially digital  
26 technologies, for assessment, so that it would be a new challenge, a new area that we could be  
27 looking at. And I think that's very important, as a topic in this future Summit, possibly. Thank  
28 you.

29

30 Shahin Shooshtari

31 Yes, it's been great attending this event. My sincere thanks to the organizers and the sponsors  
32 of the event. It's been great to see some of the friends from a few years back, when, for  
33 example, I presented in Rome in Italy, at one of the ISS events, Matt came to me, he was  
34 chatting, and that was when I first met him in 2010. And since then, we have had some  
35 occasional collaborations, not consistent. So, I'm hoping that my collaboration with the group  
36 will be more consistent. And it's very exciting. Because as a researcher, you work and you do  
37 what you think needs to be done, based on what you can do and resources that you have  
38 locally. But this is an opportunity for us to share resources. And what I heard over these two

1 days, basically, it's confirming that we do have common concerns, we do have common gaps, in  
2 terms of what we don't know. And it's just beautiful that we are going to work together and  
3 produce some outputs, some products that would help to address those gaps. And in terms of  
4 what I'm expecting, I'm very much looking forward to producing what we talked about, what  
5 we discussed, but also to initiate some collaborative research, especially in the area of baseline  
6 assessment, when it comes to cognitive functioning and function in the context of people with  
7 intellectual disability. But also, implementation of dementia screening tools, because we've  
8 been advocating for health checks, we've been advocating for dementia screening, but as you  
9 all know, it's not that easy. Some of the successful models that have been implemented in some  
10 other jurisdictions, just by sharing those and coming up with some guidelines, maybe. That's  
11 something that I'm looking for to. So, it's very nice meeting and making new friends. We even  
12 added each other to our social media. So, thank you so much.

13

14 Kathy Service

15 Thanks, everybody. I echo everything all of you are saying. Of course, you know, having been  
16 involved in the planning committee, I know how much work Nancy and Reena and the support  
17 was, so I wanted to kind of honor and thank you all for all this incredible work. And look at look  
18 what happened! Look at the fruits of your effort. So, the other thing that I really wanted to say,  
19 about our passion, and our willingness to work together, without all these big egos. Lots of  
20 times when you go into a conference or something like that, there's a lot of people who will  
21 have a lot of intelligence, and they have a lot of important things to share. But their egos get in  
22 the way, and you feel demeaned yourself. So, to be able to feel nourished by all of this and to  
23 feel included, is really essential to work together. And our passion together is contagious.  
24 Somebody had mentioned about going out to other places. People can feel that and hopefully  
25 that's going to be communicated as we support people going through. The other thing, in terms  
26 of looking at the areas that continue the discussion around different neurodiverse groups. And  
27 that's one thing that I'm interested in, especially practically. Some of us are clinicians, so what  
28 does that mean for a person, for their well being, for their lifestyle, for the people who support  
29 them? And how can we support people? And also, thinking outside of the box, in terms of  
30 providing support for people, using the arts as failure-free activities, etc. And even practical  
31 things, like how do you write goals? Because a lot of our funding, at least in the States is based  
32 upon goal setting. So, what are reasonable goals or what are mutual goals with people who we  
33 support and their caregivers and care providers and ourselves? How do we work on being  
34 together in partnership? I always talk about partnership in my world. But then the other thing,  
35 is looking at different kinds of relationships. You know, well being. For wellbeing across the  
36 lifespan, wellbeing of people who are living with dementia, things like relationships, what's the  
37 value in how we support relationships? We talked about, you know, taking care of the  
38 caregivers. Also around ecological, what does all of this mean for people and the  
39 intersectionality, and cultural humility? I think about those. And lastly, we're all citizens in our

1 own community, what does this mean? I've been involved with age-friendly and dementia-  
2 friendly communities where I live. So, making sure people with intellectual disabilities are  
3 involved with that, and are welcomed into these communities. So, I think that, in our own way,  
4 we can be an example to people. And I just want to thank everybody for being here. Plus, it  
5 was, you know, passion, and it was fun!

6

7 Leslie Udell

8 I just want to continue a bit on the theme, of Kathy. I have told many people over the years that  
9 I have been astounded as to how someone, who's really kind of a frontline care provider, which  
10 is me, with no initials behind my name that I have been embraced since the 1990s as somebody  
11 who had a place at the table. And that continues, and I'm so appreciative of that. And it has  
12 kept me going and fired up, when it felt like I was the only one. And it was, it was me and then  
13 it was Matt, and then it was Kathy, and then it was Nancy and Sandy. And these few days, I feel  
14 like finally in Canada, we have a potential for a bigger, stronger voice. It's been Sandy, Nancy,  
15 Shahin and me for what feels like forever. And I think we have other people now who can help  
16 us move this forward. So, I'm just so excited and appreciative. And moving forward, certainly  
17 the focus, the increased focus on diversity, neurodiversity. When we do training, so often the  
18 feedback is, but we want to hear about people outside of people who have Down Syndrome.  
19 You know, all you guys do is talk about people with Down Syndrome, and we support all kinds  
20 of people. We want more information about that. Certainly, I'm very interested in the aspect of  
21 people with IDD as caregivers. And we really started to hear those themes in our focus groups,  
22 you know, taking care of parents. And that's a whole group. I know, Karen's interested, she's  
23 raised it before. But that's a whole group, other than all the other people there, that we haven't  
24 really thought about or recognized. Indigenous peoples and so, in our federal project, there was  
25 a requirement to include information on indigenous populations. And we all felt overwhelmed,  
26 like who are we to speak to that? It's a whole aspect that we haven't even considered. So, we  
27 need to do so much work in that area, and rural, isolated communities. I come from a province  
28 that has a lot of really rural, isolated communities, who have little or no resources. And while  
29 Nancy is going to Newfoundland, I'm going to the Northwest Territories, which is in northern  
30 Canada, and I am so interested to hear what's going on there? Is anything going on there? I  
31 think there's going to be a really huge need for information and support and resources to a  
32 territory that has people spread out in small groups all over the place. So, those are just some  
33 of my keen areas of interest. Thank you. Oh, and thank you, for all your work Nancy and Sandy.  
34 And I'm so glad I'm going to get Nancy back for a little bit.

35

36 Colleen Hatcher

37 So again, echoing a thank you to everyone. I've worked at the National Down Syndrome Society  
38 for over seven years now. And around that time was when our organization really started to

1 invest time and energy and resources and team members into this population, the aging side of  
2 our community, within the Down Syndrome population. And so, I think it's very humbling to sit  
3 here and have you guys talk about what was happening in the 90s. This work has been  
4 happening for decades. And this is something that not only my team, but certainly my  
5 generation gets to take advantage of. Because leaders sat at this table, the world is a better  
6 place for people with Down Syndrome now. But I'm thinking about, you know, 30 years from  
7 now, hopefully I will be at this table or my organization, at least will be at this table. What does  
8 it look like in 30 years from now? How will the conversations change when we're looking back  
9 on 60 years, not just 30? So, very humbling to be able to say that. Thank you all for all your  
10 work. Obviously, what I do, and I am not an expert in this area, our health team really does  
11 more of the focus on aging. And none of them were able to attend, so you guys got stuck with  
12 me. But I think this is always so interesting for me to talk about, having a best friend with Down  
13 Syndrome who's entering 30, what does this look like for her? What does this look like for so  
14 many other families who have loved ones who are 60? Right? How do we support our  
15 individuals with Down Syndrome? I know I'm very specific to Down Syndrome, but I think in  
16 general, the IDD community. I think one thing that I would like to see moving forward is, again,  
17 Down Syndrome specific, but having someone with Down Syndrome here at the table, in the  
18 next Summit, having conversations. I have some amazing colleagues who understand this more  
19 acutely, because we do talk about it as an organization. And I would love to see my colleagues,  
20 Charlotte or Kayla, or whoever sit next to me and have these conversations. I often leave  
21 conferences kicking myself for being like, why did I not have someone with Down Syndrome sit  
22 next to me or be the representative for our team? So, I'd love to see that and how I can support  
23 that. I think the other thing is how taking away from this, as you all are doing the research and  
24 the clinicians and all that work on the frontlines. How can disability organizations, such as me or  
25 Autism Speaks or other disability groups across the world take all of the information and  
26 resources that you are all creating? And how do we share that with families in a practical way?  
27 Research is great, and we all need it. But how do we share that with families in a way that's  
28 impactful for those who are who are dealing with dementia? One other last thing, and we  
29 didn't really talk about it, and I know all of our organizations are in different countries, and we  
30 face different political spectrums. But how do we take this into policy work as well? The  
31 National Down Syndrome Society has a huge focus on policy work in the United States. We do a  
32 lot federally, but also at the State and local levels. So, how do we take what we've learned  
33 here? How do we get States and how do we get our country as a whole to be better in terms of  
34 policy work? That's something I think I can take back but continue to share information with me  
35 on what you all see in your local communities, so that our organization can activate us, as Seth  
36 said, our grassroots network and our people in local communities.

37

38 Anupam Thakur

1 I'm deeply grateful for the opportunity to be part of the important conversations we have had  
2 over the last two days. And special thanks to Sandy and Nancy for the invitation. I think there  
3 have been lots of takeaways for me personally, reflecting on what I've learned from the group. I  
4 think there are a few things that I can maybe look at from a clinical perspective. There are  
5 certain things that I can disseminate and share with my colleagues to take things forward. And  
6 then, many of the things that have already been shared around how should we look at future  
7 endeavors? How can we shape things for the future? A few of the things that I thought are  
8 really important are the whole area about integration, integration of practice, something that is  
9 already happening in other populations. How can we look at that to integrate within our  
10 practice? How can we integrate physical health and mental health together, when we look at  
11 healthy aging? How can we do more in that regard? How can we integrate research into  
12 practice? Yona mentioned about implementation aspect there. It's so important. And in that  
13 regard, I think there is a lot that we can do in building capacity, within people who are in  
14 practice, professionals who are in practice, building capacity in their learning communities that  
15 was mentioned about the students and how we can reach further beyond countries to talk  
16 about what we have learned and what we are learning, build champions in the community to  
17 disseminate learning. And the other thing that I was thinking about, as we were discussing in  
18 our group was, in the last few years, it has been decades, but especially in the last few years,  
19 we have got so many tools and techniques these days, especially around learning from big data.  
20 Especially when we talk about artificial intelligence, using analytics, how can we learn from that  
21 to really inform our practice in future. So, apart from biomarkers, I think, looking at big data,  
22 and AI also is something that we should be looking at for the future. And the very final point  
23 about dissemination, we discussed about webinars and how we can reach out to others to  
24 disseminate knowledge. I think looking at knowledge sharing on a more global basis is also  
25 might be something that we can maybe think about, and webinars is a great idea for that.

26

27 Laura LaChance

28 First, let me start by thanking the sponsors, the committee and Nancy, for the invitation to join  
29 you for this for this event. Confession here, I am a parent of an individual with Down Syndrome,  
30 our son will be 31. Part of my learning journey, although not involved with the Canadian Down  
31 Syndrome Society, began a generation ago when he when he was born. In that generation, the  
32 life expectancy for an individual with Down Syndrome has more than doubled. And these are  
33 things about the aging community, individuals with Down Syndrome who age, where there's  
34 still a lot of myth busting to happen, a lot of assumption crashing that we need to do. The  
35 mission of the Canadian Down Syndrome Society, as you know, while providing reliable  
36 information and connections to people with Down Syndrome and those that support them. It's  
37 also to shape the social and policy context in which they live. And for that, I am grateful of the  
38 experience that I have heard and learned from those of you, who have been involved longer  
39 than me, in a different way than me. And we look forward to the knowledge transfer from



1 academics to practical practice guidelines to tips for parents. How do we answer the call of our  
2 community, when they call us with crises and challenge, that we all know is life? But how can  
3 we word that and how can we share that? So, I'm very grateful for all of the work that you have  
4 done, you will do. I'm grateful for the invitation to participate as best that the Canadian Down  
5 Syndrome Society can. I'm proud to be a second, new Canadian. I've been here a long time. But  
6 I think in terms of the development of the Canadian voice in this sector, we have great  
7 opportunity to continue our connections both from a research perspective and from a  
8 friendship and collaboration basis. And I wish you all a safe journey home. Thanks.

9

10 Ziv Har-Gil

11 Yes, I will say a few words as well. Just wanted to thank everyone for coming. It was a pleasure  
12 to meet all of you and kind of, you know, have small discussions on the side and just get to  
13 know everyone. I have a lot to learn from all of you and this was very enlightening for me, since  
14 I'm not an expert in this field and in these topics. And yeah, I have a lot to learn. I'm looking  
15 forward to kind of seeing what comes out of the Summit and I think you all did amazing work.  
16 And the reason it was so successful is also due to all the preliminary workgroups that you were  
17 all a part of. You've been working hard for a while, even before the Summit and looks like you  
18 still have your work cut out for you after, but I'm sure it will be great. I'm looking forward to  
19 seeing what comes out of it and to help in whatever way I can. And I guess Yeah, we should  
20 maybe vote on who's going to host the third international Summit. We can take a vote on that.  
21 But yeah, it was great to meet you all and thank you.

22

23 Sandy Stemp

24 What Ziv is not saying is that she literally started with Reena, how long ago Ziv? Three months.  
25 Okay. So, in her interview, she said, oh, you know, I did this health promotion and prevention. I  
26 had to run this huge event, and I went, great, that is amazing. You're hired! So, I think she  
27 deserves a great round of applause because she did amazing. Talk about being thrown in, like  
28 just thrown in there, and she swam, which was awesome. So yeah, so Ziv is right, one of our  
29 questions that we need to ask people is, or maybe to have you think about is where the next  
30 Summit will be held. So, planning is always great. I want to again, really thank our sponsors,  
31 Mira, please take back our gratitude and thanks to the Azrieli Foundation. Azrieli has supported  
32 amazing work, and we look forward to many more partnerships and many more conversations.  
33 And Anupam, please take back our thanks to Surrey Place. Anytime I've gone to Surrey Place  
34 with some crazy idea, they're like, I'm in! I'm like, Okay, let's go. So, please take back my thanks.  
35 And Phil McCallion to Temple University and the Butz Family Fund. Again, we really appreciate  
36 everybody and all of our supporters as well. And my co-chair here, Nancy, she's not getting up.  
37 Come on, you have to say goodbye. But again, just from the bottom of my heart, thank you to  
38 all of you for, like I said, if somebody said, Sandy, what did you think? And I said, one of the



1 things is you can set the table, but you don't know what will happen. So, it's to all of your credit  
2 that you made this what it was, all we did was set the table. And so, thank you very much.

3

4 Nancy Jokinen

5 What Sandy didn't tell you about Ziv was she hired Ziv and then went away to a cabin in the  
6 bush for a month. Right, Ziv? She left us to the wolves.

7

8 Ziv Har-Gil

9 Yes, exactly. A good learning experience.

10

11 Nancy Jokinen

12 It was horrendous. Anyway, I won't keep us long. I'm going to be really quick. It's been a  
13 pleasure. I loved meeting everyone and seeing all of you again. And I don't know that we get to  
14 vote on where the next Summit is being held today. But I'm sure that someone will figure it out  
15 in the near future, as I look at the lady in red. Thank you, everyone. Go ahead, Dawna.

16

17 Dawna Mughal

18 I just would like to share my experience in attending a Summit, a national Summit with 300  
19 participants, and the goal is looking at changes in dietetics education. So, we had homework  
20 before the Summit, and we had work groups, and we had facilitators at each table. And then  
21 we had speakers from remote places, or in person, but each person walked away from that  
22 Summit with a plan for change. When they went back to the workplace, they had that plan, the  
23 goals, the strategies, the barriers, the promoters, and then there was a follow up with each  
24 group about the progress and then my report is, I failed. Because there were barriers in my  
25 workplace, so the change that I wanted to do with dietetics education that I directed, and my  
26 point is that when we ask people to do something different, I think it's very important for them  
27 to assess the capabilities.

28

29 Nancy Jokinen

30 So, my job as the co-chair on the Planning Committee is to follow up with 34 people in about a  
31 month and say...

32

1 Dawna Mughal

2 It was pre-planned, you're not on the spot. Meaning, it is a big organization the Academy of  
3 Nutrition Dietetics with 70,000 members, so the staff people, there was a sign to follow up with  
4 me and with other members of the group, you know?

5

6 Nancy Jokinen

7 There are only 34 of you. I can send an email out.

8

9 Dawna Mughal

10 There was a certain plan that I walked away from the Summit with, something I had to do when  
11 I went home, before the excitement fizzles out. See, I'm excited when I go home, what do I do,  
12 right?

13

14 Nancy Jokinen

15 So, I have to then think of an email that'll rekindle the fizzle. Anyway, thanks everyone. And  
16 safe travels home. And please feel free to contact Karen or Sandy in the future. Leslie's away for  
17 a month. Oh, and Phil is good too! And Lucy and Vikram, you're on! They'll all follow up. I'll just  
18 be on the CC, blind CC.

19

20 Sandy Stemp

21 Please help yourself to a snack on your way out. So, we have our final break food, just in case  
22 you haven't gotten enough food, for your way home. Thank you, everyone!

23

24 Matthew Janicki

25 And a big thank you to Nancy Jokinen for everything she's done.

26

27 **CLOSING**

28 v.12/19/23

29 -30-