“Artificial intelligence and disability data justice: representing human function and disability in AI systems”
Denis R. Newman-Griffis, University of Sheffield
International Disability Rights Affirmation Conference 2024
November 15

[2024/11/15 06:59] Carolyn Carillon: Hello everyone.
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DN: Denis Newman-Griffis

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[2024/11/15 07:03] Gentle Heron: Good morning, audience. Welcome to Virtual Ability's 2024 International Disability Rights Affirmation Conference (IDRAC).
We hope you will enjoy your time with us today, and that you will learn a LOT about potentials and concerns at the intersection of disability rights and artificial intelligence.
Although this conference has an overall aim to support people with disabilities, we've seen that a great deal of what will be covered today applies to healthcare in general.
After all, 11,200 Americans turn 65 years old every day! Many disabling conditions start as we age.
Artificial intelligence is inherently contradictory.
We no longer consider a prosthesis an “artificial limb,” so exactly how “artificial” is artificial intelligence?
And for that matter, how “intelligent” is this technology, after all?

As a tool, AI certainly has potential to improve the daily lives of persons with disabilities—actually of all of us—in numerous ways.
But it can also perpetuate and even exacerbate existing biases and inequities.
Yes, AI is highly technical. But those of us who are non-techies (and I am certainly one of those) need to learn all we can about AI's basic principles and concerns about its influence and impacts.
We need very diverse groups of people to guide this technology so that it can offer positive outcomes.
Now a housekeeping reminder for this conference.
Many of our presenters are new to Second Life. Please be patient with them.
Hold your thoughts and questions until they are done presenting; they need to concentrate.
Thank you.
Now Roxksie will introduce our first session and our honored guest speaker.

[2024/11/15 07:07] Carolyn Carillon: LW: Hello & welcome to IDRAC
I'll read Roxie's introduction
I'm introducing Denis Newman-Griffis today
Thanks for coming

[2024/11/15 07:08] Gentle Heron: Hello. I am Roxksie Logan, I have Multiple Sclerosis.
I am a Fine Art BA (Hons) Student for Hereford College of Arts under the University of St Davids Trinity of Wales in the UK.
Today I am introducing Denis R. Newman-Griffis from the University of Sheffield.
Our talk today is titled "Artificial intelligence and disability data justice: representing human function and disability in AI systems"

[2024/11/15 07:08] VAIPresenter4 Resident: Hi, I'm very glad to be joining you today.
I'm Denis Newman-Griffis, and I am a Senior Lecturer at the University of Sheffield and lead in AI for Health with Sheffield's Centre for Machine Intelligence.
A lot of my research sits at the intersection of AI, data, and disability.
And what I'd like to talk about with you today is thinking about the role of AI in helping to shape disability justice, and rooting that in ideas of more just disability data.
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I'll talk about this through three lenses, speaking to different parts of data, AI, and disability.
Let's start with the most immediate topic: AI and data technologies.
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Why would we want to use AI in the first place?
AI technologies have a lot of potential to help us enrich our understanding of human functioning and disability through more holistic and person-centred data.
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When we look at disability and healthcare, we can see a variety of different barriers that lead to us losing important information about people and lived experience in the data we use.
Information about the physical and social contexts we live and act in is difficult to measure, so rarely captured.

Self perception, priorities, and personal experience are not emphasised in healthcare so aren't recorded even when they are shared.
And a lot of important information that is recorded gets locked away in written notes and isn't really used much in care.
These and other barriers leave us with information inequities: incomplete pictures of people's experience that contribute to inequitable health outcomes.
URL: https://doi.org/10.1371/journal.pdig.0000135
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With good design, which I'll talk about later, AI technologies can help to close these gaps.
Digital measurement and self-reported data can help capture information about contexts, experiences, and more.
And natural language processing technologies (like large language models) can help to analyse important information that is locked away in written text.
URL: https://doi.org/10.1371/journal.pdig.0000135
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We can see the benefits of this when we look at the richness of information on functioning that is reported in text.
Here's an example description:
Pt injured himself in bicycle accident.
He twisted his left ankle and ROM is severely limited.
He is currently modified independent in ambulation with L side use of crutch.
He has a job interview next week and his goal is to walk independently for that.
And we can see described here many different aspects of human functioning, including:
Body structures involved, An activity being performed, A social act of a job interview, and An assistive device being used.
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We've developed natural language processing pipelines that can help analyse this information in practice by first identifying where in text information on functional activity is described, extracting things like
'Patient is independent in showering and shaving' and then identifying the kind of activity being described, here linking to standardised activity codes
in the World Health Organisation's International Classification of Functioning Disability and Health.
URL 1: https://doi.org/10.3389/fresc.2021.742702
URL 2: https://doi.org/10.3389/fdgth.2021.620828
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To give you a sense of how we got to these technologies:
We were focused on functioning so we worked with rehabilitation experts throughout.
We started by working with those experts to identify where in a set of reference documents functioning was being described, and what kind of functioning.
We then used machine learning to train two separate NLP models to mimic what the rehabilitation experts marked,
first extracting the text, finding the "where", and then linking to the ICF, for the "what".
We evaluated the systems by using a separate set of expert-annotated documents and comparing how well the NLP systems did on identifying what the experts said we should get.

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This is a good start, but has been limited to medical data.
We can think about building on these ideas to bring together multiple sources of information and we know that to get a more holistic picture of a person's situation
we need to bring together self-reported information, medical information, and more.
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This way of thinking about combining and comparing different approaches is an essential way of approaching the design and AI and data systems.
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AI can help with enriching data and understanding.
And we also know that without reflexive practice, without critical perspectives, those AI technologies can and will propagate ableism.
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Fixing this, and ensuring it doesn't happen is not just a matter of plugging in a magical wand for equity.
Getting at the roots of ableism in AI, and knowing how we can take action against it, requires taking a systems view where we think about and act in the interconnected contexts and decisions that affect AI in practice.
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We often think about AI in very instrumental ways:
For example, you give ChatGPT an input prompt and it gives you an output text in response.
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And those processes are part of a wider context:
Trying to accomplish certain goals, working with particular people and organisations, operating in regulatory and cultural environments, and so on.
So when we're working with AI, and when we're building or evaluating it, we are always working in this more complex network of contextual factors.
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We can take this view, then, to start tracing back the histories of data and AI.
And to understand what decisions were made, how we got from idea to data, in a process of datafication,
from data to technology, via AI system design, and from technology to action, where we want to evaluate and understand the impact.
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Let's look back at the natural language processing work from earlier.
The broader context of this was a research collaboration between two organisations in the US federal government: the NIH Clinical Center and the Social Security Administration.
The goal was to develop data-driven ways to improve disability benefits determination processes,
using the NLP technologies to help find information from medical records about functional status.
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With that in mind, let's look at the datafication step first.
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Whenever we have data, whether it's your web browsing data, geolocation, messages, whatever it is, those data come from somewhere and they are the product of a series of decisions.
Each of those decisions is reductive, so what we really have is a data funnel.
Starting with our whole, complex person or situation in the world, we first choose what we're interested in saying about them, and how we conceptualise it.
Then we identify what we can actually observe about that thing.
For example, I can't say much about your mental state – it's not observable to me.
Then of the things we can observe, what do we actually choose to measure, and how?
And finally, how do we actually record those measurements for others to use?
At each of these stages, we're losing some of what we could know, to get to the data we have.
URL: https://doi.org/10.51952/9781529238327.ch001
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In the context of our NLP example, what's important is Social Security's definition of disability.
So here what's important is whole-person activity and medical history.
We can't observe everything about that, but we can learn about personal experiences and medical measurements.
In practice, information about context isn't measured, and we really only get functioning tests and medical diagnoses.
Of those, not everything is always recorded- we often lose functioning information, and only get the medical diagnoses.
So these are the data we have to work with.
And it's important to note that these aren't necessarily choices that we have:
Often these are choices made by others, which we need to be conscious of and work within.
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This process, and analysing it in this way, lets us see the different decisions that are made and why the data we have are not neutral, but represent specific points of view.
We can always choose to use less data than is recorded, but we can't choose to use more- we're always strictly limited by these choices in datafication.
Seeing these as an exercise in power helps us to understand why we want to imagine alternative data and alternative worlds,
and understand why data are not neutral, authoritative, or necessarily true.
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So our key questions to ask about datafication are:
What can the data say? What are they able to tell you?
And whose perspectives do they represent, and who is missing?
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We start to see similar things as well when we look at AI system design.
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The design of data analysis systems, including AI but also wider systems is also an artifact of specific decisions that are made in design.
For whatever data you are working with and goal you want to achieve, there are many different ways to operationalise that in an implemented technology.

Those different choices help to determine who the technology affects and what impact it has in the world.
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Like we did with data, we can break down the design of an AI system into a series of decisions.
We first decide what kinds of information the system will be used to analyse- text descriptions, medical records, information about function or disability identity.
And then what kinds of contexts we want to use it in- in healthcare, in public policy, in community living, etc.
With this scope in mind, we then choose what data we think is relevant for accomplishing that goal
and what purpose we want the AI system to be put to- will it make a decision, help to review information, generate something, etc.
Only after deciding all that do we get to the point of defining how the technology will actually work and how we build the AI model.
URL: https://doi.org/10.5210/fm.v28i1.12903
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In our NLP example, we see that in operational scope, we're only looking at functional activity (because someone else is looking at medical information).
We're working with medical and administrative records And looking only at text notes, no standardised data (because it's not available).
The purpose of the technology is just to help SSA decision makers search information, not make a decision.
So with all that in mind, we implemented as an extraction and classification pipeline.
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If we imagine going through this process with different definitions of disability, though
Looking at a medical definition, or the social model, or a more political and relational model;
We see how those different definitions impose different power structures on the AI and produce different opportunities and harms.
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These different definitions, then, simply different ways of thinking about what we want to analyse, lead to dramatically different AI technologies
which work at cross purposes to one another and produce different harms.
It is by questioning the assumptions we make in design, by surfacing these decision points, that we see that we don't have all the information
and we can identify what alternative models we might want to consider or develop.
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With datafication we were asking about what the data say:
Here we are asking about what our system says
And what it will do in the world.
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The final piece to this is evaluation- knowing how well your system is working with your data.
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Typically in AI systems we measure this in terms of performance measures:

Accuracy, precision, recall, etc. These tell us about how well the AI is performing the specific thing it is built to do.
What they do not tell us about is its impact:
On the process we're using it in, within the broader context, or in real-world application.
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With our NLP example, what we are looking to find in these documents is fairly complex:
Observations like 'Moderate difficulty walking 300 feet in clinic with cane.'
The methodology to do this wasn't clear, and more importantly, it wasn't clear what it meant to get this right.
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Looking at our ability to find the text exactly, to get every word, we see that our AI systems are quite noisy, and miss a lot of information.
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When we change our focus, and think about the application in helping people find the right information for them to then make the decision,
we're not interested in getting all the text, simply being able to point people to the right part of the document.
And here we see we're actually doing pretty well, where we are able to rank order documents in a way that agrees quite strongly with the amount of functional status information we know they contain.
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Even this, though, doesn't tell us much about the impact of the system in context:
How it affects the process of evidence review:
if it makes it more efficient (to save resources), more effective (to reduce harms), or more equitable (to better justice).
So this is where we need to keep asking our questions that are really focused on the wider system that these technologies are operating in.
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It's this systems view, looking at the interconnected decisions and considerations that affect AI systems in practice
that we need to be using to guide our work in design and evaluation of AI and data technologies.
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By looking at the past and the present in data and technology, we're able to chart some of the paths we'd like to take forward into the future.
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What we want to be building towards is a more informed vision of disability data justice.
Where we are combining the ideas of data justice, advocating for fairness in visibility, representation, and treatment in data systems with a wider sense of disability data,
being data collected and used about people with disabilities.
We aim for a more just approach to disability data that is rooted in the intersectionality of disabled experience
and that is disability-led in its design, its implementation, and its evaluation.
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Working with colleagues in disability data and disability justice, when we map our paths forward in achieving disability data justice

It cuts across all these contexts and questions I've been talking about.
Drawing on co-design methods in research and more identity-led, disability-centred data on disability
combining with organisational culture and leadership to drive change
and envisioning more person-centred, more multidimensional records that better represent disability.
URL: https://doi.org/10.31219/osf.io/j52n6
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Most of all, we see that the futures of disability data, and of disability and AI are not fixed.
And we can, through better representation and more informed design, shape disability data and AI together.
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Thank you.

[2024/11/15 07:34] Edith Halderman: *•.¸'*•.¸♥¸.•*´¸.•*
[2024/11/15 07:34] Edith Halderman: .•*♥¨`• APPLAUSE !!! •¨`♥*•.
[2024/11/15 07:34] Edith Halderman: ¸.•*`¸.•*´ ♥ `*•.¸`*•.¸
[2024/11/15 07:34] Carla Heartsong: .-'`'-. APPLAUSE APPLAUSE .-'`'-.
[2024/11/15 07:34] Gemma (Gemma Cleanslate): : ♪ ♥♫ APPLAUSE !! ♪♫♥ ♪♫♪♥
[2024/11/15 07:34] Scarlett Qi: /me applauds!
[2024/11/15 07:34] GoSpeed Rasere (GoSpeed Racer): **claps**
[2024/11/15 07:34] Lizzie Gudkov: /me applauds
[2024/11/15 07:34] Aиgℓ (Sylviaangel Faintree): ***CLAPS***

[2024/11/15 07:34] Gentle Heron: May I remind our audience to click on the giver box by the podium, to get Dr. Newman-Griffis's handout.
QUESTION- What barriers do you expect in getting medical professionals to use AI in ways that are appropriate and efficient, like you are creating?

[2024/11/15 07:34] Elektra Panthar: DN: d.r.newman-griffis@sheffield.ac.uk
@drgriffis
It's always where we should start when we think of change
The biggest barrier is that it takes time, effort and different ways of thinking, so we always get resistance to change
It depends on who you're talking to,s ome are very open, others aren't feeling involved, but all of them are overwhelmed
There also technical barriers to getting info that matters
And to make it available to the providers in ways that matter

[2024/11/15 07:36] Mook Wheeler: QUESTION: I can see how the sheer 'digital reach' of AI regarding written information can be used to improve holistic service. But that same immense reach also generates a bigger danger to privacy -- the nature of that unprecedented reach means it will be one 'fell swoop' in the event of a privacy breakdown. How can this be balanced? Also, is there a worry that such an AI-generated 'info-profile' of the patient can displace a more nuanced conversation? I know people whose personal

explanations have been over-ridden by a medical service because "the system" has something different on file. In the case of AI, will this authority to override be even greater, due to its perceived 'intelligence'?
[2024/11/15 07:38] Elektra Panthar: DN: important question, yes
There's a huge risk of that
I was at an informatic conference and there's a lot of discussion happening
In terms of the second part, increasing use of ambient AI like transcribing the encounter, for many providers it makes it easier for the provider because they can focus on the convo and not the notes
We got datafication with multidimensional data outside of clinical setting as well, and yes it's a great risk for seizure and abuse of those data for reasons outside of our intent
How do we respond to that? Policy advocacies, making sure we co-design methods, we design WITH and not FOR - disabled led
We need to shift the autonomy and agency away from centered in tech producers to community producers
So we need to change models
The ownership needs to change too
A lot of it is community practice and constant collaborative critique of those systems

[2024/11/15 07:42] Gentle Heron: QUESTION- What is a good way to get people with disabilities involved in all this research?
[2024/11/15 07:42] Elektra Panthar: DN: some good models have been developed in disability studies and computer interaction spheres
Participatory models are important
We need to talk more to people, advisory boards
We need to set up a community advisory board from the beginning that will work throughout the project, also disability advocates
It is from the researcher side
Outside of academia, advocating through organizations like VAI

[2024/11/15 07:45] Gentle Heron: QUESTION- A personal question, you don't need to answer if you don't want to… but you don't sound British. How did you get to the University of Sheffield?
[2024/11/15 07:46] Elektra Panthar: DN: I'm American, I've lived in the UK for a few years, my partner and I really liked the UK and felt at home there so we looked for academic jobs that would allow us to do that
I'm glad we did this because through the role in the faculty of social sciences I was able to combine my technical background with humanistic research methods
It was an unexpected benefit that I like very much
[2024/11/15 07:47] Lissena Wisdomseeker (Lissena Resident): WE have a faculty member from Sheffield in SL--Sheila Yoshikawa!

[2024/11/15 07:47] Gentle Heron: You're able to get the US and the UK research communities to work together?
[2024/11/15 07:47] Elektra Panthar: DN: *laughs* kind of
International collaboration is a challenge

Also simpler in other aspects
I get collaboration by showing up and not shutting up
The thing about working across research communities is working with individuals and not community
So getting contacts you can get platforms
[2024/11/15 07:49] Gentle Heron: We have a Greek researcher in the audience today. Maybe you can connect with her? Collaboration is an important part of these professional conferences.
[2024/11/15 07:49] Elektra Panthar: DN: Absolutely, feel free to contact me

[2024/11/15 07:50] Gentle Heron: I feel I am monopolizing. Any other questions?
[2024/11/15 07:50] Edith Halderman: Gentle you are the voice for us - what we are all thinking.

[2024/11/15 07:50] Carla Heartsong: my main worry is still hallucinations
Esp[ecially] in a medical context!!
((its actually "delusional" not hallucinations))
[2024/11/15 07:52] Gentle Heron: /me agrees with Carla
[2024/11/15 07:51] Elektra Panthar: DN: Carla, that's a big worry yes
I was in a presentation about producing flash fiction that did have other problems, too saccharine etc
[Fundamentally the issue is that what you're getting with an LLM is not something that is based in fact, not based in any sort of symbolic or traceable reasoning, it's a probabilistic system that's going to give you a statistical sample of language, so what comes back from a machine learning system including LLMs is always what is likely, not what is true]
Hallucinations of large language models are about not being realistic - these things come from not being fact checked [No system built in to fact check it]. Tech companies are building more fact based 'filters'
We need better understanding of what these tools are best used for
URL: https://osf.io/preprints/osf/7xtz2
In practice, what specific AI tools are good for and what they shouldn't be used for
So when you work with medical providers the LLMs are great for templates, summaries, but not for information
We need to build practices about where technologies can be used for

[2024/11/15 07:54] Carla Heartsong: I teach in the informatics domain. AI is a part. The present LLM we all know invents 55% of references to scientific articles, that is absurd.
[2024/11/15 07:56] Elektra Panthar: DN: Carla, yes. I've seen good work on using controlled methods to check LLM's results
If you want specific info, LLM is a statistical summary so its not good for specific reference
LLMs are not good search engines

[2024/11/15 07:54] Vulcan Viper: I've watched a video where hallucination was prevented by including the wish that the AI stick to facts.
[2024/11/15 07:54] Elektra Panthar: DN: things like that can be useful yes Vulcan

[2024/11/15 08:04] Vulcan Viper: Here's a link to one of the videos, but the same channel has more videos in which something similar is done.
https://www.youtube.com/watch?v=7bsq5THzUoI
I'm sorry, I meant to say the video I shared is an example of one where the AI was told to be unbiased and so on.

[2024/11/15 07:54] Pecos Kidd: An observation, not question, but I'm not sure people (in general) are yet applying enough healthy skepticism such as "garbage in - garbage out" to AI, like they do for computers in general.
[2024/11/15 07:55] Tegan Jestyr: I think it's corporate whitewashing to call them "hallucinations". Call them what they are: confabulations. Falsehoods.
[2024/11/15 07:55] Gentle Heron: /me agrees with Pecos and Tegan
[2024/11/15 07:58] Elektra Panthar: DN: Thank you Pecos, yes, we need healthy skepticism
We are working on the future of AI skills, to cut through all the sensationalism
Understanding AI literacy, which is data literacy
We are pushing this in academia and need to push in places of power

[2024/11/15 07:55] Lissena Wisdomseeker (Lissena Resident): Just a comment--I have more confidence in the good AI can provide because people like you are involved in developing its use in these ways
[2024/11/15 07:59] Elektra Panthar: DN: ty, that's lovely to hear - it's why I want to keep the conversation going
I want to dampen the discourse of unreachability of AI, and stop those who peddle this fear
There's confusion and lack from understanding, but those narratives are being fed by companies who profit from keeping AI unreachable and unregulated
We have to push back on this, so we need to have more conversations like the one we're having

[2024/11/15 07:55] Carolyn Carillon: [07:50] Mook Wheeler: COMMENT: AI seems to generate extreme scenarios. Nothing in the middle! ;)
[2024/11/15 07:55] Elektra Panthar: DN: Mook, I'm curious about examples you were thinking of
[2024/11/15 07:57] Mook Wheeler: AI is a novelty situation, so it has been generating extreme scenario imaginations in people -- very helpful, or very dangerous. How high is the probability that AI is actually a middle-ground tool?
[2024/11/15 08:02] Elektra Panthar: DN: Mook, you are bang on. AI is a TOOL, and yes it can find the middle ground
As a researcher I see that the difference this tools can make - what does this tool do, where can I use it best?
Like this we can prevent runaway agents
It's not a magical thing we can't control, we can shape them and learn how to use them

[2024/11/15 08:04] Denis Newman-Griffis (VAIPresenter4 Resident): d.r.newman-griffis@sheffield.ac.uk

[2024/11/15 08:04] Gentle Heron: Thank you so much for presenting today, Dr. Newman-Griffis. This was fascinating
[2024/11/15 08:04] Elektra Panthar: Thank you, we had some great questions and thank you for this conversation Dr Newman!
Contacts: d.r.newman-griffis@sheffield.ac.uk
@drgriffis

[2024/11/15 08:04] Liberty Fairelander: Thank you!
[2024/11/15 08:04] Mook Wheeler: ♫•:*¨♥¨*:•♫ APPLAUSE ♫•:*¨♥¨*:•♫
[2024/11/15 08:04] Scarlett Qi: Thank you!
[2024/11/15 08:04] Berry Vita (Arbutus Vita): Agreed!
[2024/11/15 08:04] GoSpeed Rasere (GoSpeed Racer): **claps**
[2024/11/15 08:04] Sigmund (Sigur Roeth): Thanks
[2024/11/15 08:05] Pecos Kidd: Great job - thank you!
[2024/11/15 08:05] Buffy Beale: cheers!
[2024/11/15 08:05] Lizzie Gudkov: /me applauds
[2024/11/15 08:05] Brian Aviator: Thank you for such a great presentation
[2024/11/15 08:05] Bobby Brandon Clayton (FutoiOtokonoko Resident): /appl
[2024/11/15 08:05] Carla Heartsong: .-'`'-. APPLAUSE .-'`'-.
[2024/11/15 08:05] Isaiah 'Zay' Jenkins (Isaiah Onyx): APPLAUSE

[2024/11/15 08:05] Elektra Panthar: <<transcription ends>>