

LYN AINSWORTH & LOUISE DIBBS (HWNS)
'The National Disability Insurance Scheme - supporting Australians living with mental health issues'
Mental Health Symposium June 18th 2016

[19:29] LoriVonne Lustre: Hello everyone.

Today's presentation is being transcribed so those without audio or who require text only can participate in real time.

A little explanation about this service.

Voice-to-text transcriptionists provide a translation of the key ideas discussed, NOT a word for word transcription.

Voice-to-text services provide an in-the-moment snapshot of ideas and concepts, so that those who are unable to hear or to understand the audio program are able to participate in real-time.

You will see the transcription in Nearby Chat.

Transcription is provided by Virtual Ability, Inc.

The transcriptionists are:

LoriVonne Lustre

Carolyn Carillon

The following initials in the transcription record will identify the speakers:

LA = Lyn Ainsworth

LD = Louise Dibbs

[19:32] LoriVonne Lustre: << transcription begins >>

[19:32] Orange Planer: Hello and welcome to the Virtual Ability Mental Health Symposium.

The title of this session is "The National Disability Insurance Scheme - supporting Australians living with mental health issues."

My name is Orange Planer. I was born a poor black child. Most of the salient details about me are in my profile. Feel free to read it. The rest of my time is dedicated to saving the IT world at work where I am the network administrator for a 200-person [sic]

It gives me great pleasure to introduce Louise Dibbs and Lyn Ainsworth.

Louise has had a 15 year journey working in the community sector, commencing as a frontline worker, progressing to supervisory roles and finally most recently in senior management.

Louise also has several years experience in the corporate/business sector as a Human Resource professional which has embedded a strong customer experience ethos in her work. She has a Master of Arts in Psychology and is a certified trainer and assessor. In the past 3 years Louise has been working for House with No Steps in one of the key National Disability Insurance Schemes launch sites, in the Hunter region. She has worked with teams to transition approximately 400 participants to the Scheme.

Louise's interests and work passions include Human Rights, organisational change, mentoring/coaching, developing individuals and teams, influencing and leading, and designing systems.

Outside of work, she enjoys anything active or travel related with her husband and three teenage daughters.

Ms. Lyn Ainsworth, Head of Strategy, Excellence & Innovation at House with No Steps, has 18 years executive management experience in the disability sector, including her current role with House with No Steps, one of Australia's largest disability services HWNS has been at the forefront of the introduction of the National Disability Insurance Scheme, Australia's response to the UN Convention on the Rights of People with a Disability, an extraordinary social reform.

Lyn is a lawyer by background and has supported organisational transformation around Human Rights as well as having leadership responsibility for HWNS' international accreditation with the Council on Quality and Leadership (CQL).

Please hold your questions until the talk is over.

Thank you.

[19:38] Carolyn Carillon: LA: Good morning everyone!

Thanks for the opportunity to present

it's exciting if somewhat scary

I promise I haven't been drinking!

It's purely inexperience

We're from Australia

from an organization called House with No Steps

that supports people with disabilities

I'll provide some background & context

and then Louise will share her experiences as a practitioner

and then we'll take questions

First, a bit about House with no Steps

HWNS

We're one of the larger service providers

We have about 2500 staff
I don't know if you're familiar with Australia
but it's a big country
We operate over 1000 square miles of territory
The context for our conversation is to look at a transformational social reform
that's about to see a rollout this July
It was always envisaged that there were some real challenges in including people
we set up pilots
to iron out problems
A little bit of background ...
this is social policy at the grassroots
this is a first
It was designed to move away from the institutionalization of people with disabilities
away from a welfare model
and towards a social model
There was a tension between states and a national policy
In 2011 our government commissioned a report to identify ways we could improve
support systems to those with a disability
the findings were damning
said our system was broken
we had a sector that divided support and allowed people to fall through the cracks
our system focused on a recovery model
that assumed people had mental health issues for a certain time that were curable
it failed to recognize the episodic nature of mental health

I'll give you an idea of what the commission said
the system was broken and inequitable
many were not getting access
it was a prescriptive process
people had no choice
there was a limited bucket determined by each state's budget
it was inefficient
we had expensive waiting lists
it was complex
Australia was identified as the worst country for poverty for those with a disability
we designed a system based on insurance
the proposed system required collaboration between levels of government
unheard of
to give you a context ...
Australia was one of the first signatories to the UN Convention on the Rights of Persons
with a Disability
We had hundreds & thousands across Australia lobbying for the human rights of those
with disabilities
As a result, we got government support
Trial sites were established

We're about to start full implementation

All but one of our sites has signed an agreement with the federal government to ensure the scheme can be implemented over the next 3 years

Some design features ...

It's an insurance scheme

In the context of two things

First, it provides insurance for every Australian who experiences disability throughout the period of need

Everyone has an entitlement to support

It has eligibility criteria

The other type of insurance

A premium is paid

together with a contribution from the federal government

It's funded to a scheme which delivers benefits

It's a highly individualized scheme

Every person can develop a plan for their personal support beyond a medical model

It's reviewed annually

Service providers are true providers

and consumers are true consumers

Providers can't discriminate

This is a transformational social policy improvement

I'll now hand it over to Louise to tell you how it's playing out in practical terms

[20:02] LoriVonne Lustre: LD: thank for your patience everyone, and thanks to Lyn for setting the scene

Key elements of the NDIS?

I will be talking about my perspective as a team leader -- grass roots level

For the person (the participant)

If eligible will receive individual funding for supports.

Can choose how their funds are managed – options are self-managed, NDIA or Plan Manager, or combination

Can choose how, when, where supports are provided and who provides their supports.

What type of supports are funded?

NDIS - Outcomes Framework

Supports should help participants achieve their goal

Reasonable and necessary

What are reasonable & necessary (funded) supports?

These supports will help a person to:

Increase their independence

Increase their social and economic participation; and

Develop a capacity to actively take part in the community.

Reasonable and necessary supports must:

Be related to the persons' disability
Provide value for money
Be effective and helpful to the person, and
Consider supports provided by families, carers, friends and the community.
the circle of support is very important
Outcome domains and categories of support
8 domains are considered
We are seeing changing labels!
There is still some consideration of the diagnosis, but has less importance over time
Client as customer
Trial sites establishment
Working in an environment of uncertainty
For teams working in the trial sites – there was limited clarity on how it would work for our customers living with mental health issues
How would people living with Psychological or Psychiatric diagnoses be viewed within the scheme?
Would the eligibility criteria include or exclude?
Primary and secondary diagnosis
Dual diagnosis
General mental health supports for people with another primary diagnosis?
The interconnectedness of mental health and wellbeing on all other aspects of a person's life have been considered and planned for in the scheme design
Early intervention is a factor
What we able to do is to plan holistically with the individual
The blue arrows here show the flexibility and resilience of the model

Years 1 – 3 of the scheme – A journey of learning
Early days not always smooth sailing
The scheme has evolved well beyond the design of the early days
A co-design framework
The Agency, National Disability Services (NDS- peak body for the sector) and providers have worked in spirit of partnership through engagement forums.
Practicalities of implementation and the impact on participants of the scheme were regularly discussed and debated.
First year - green year
We were a bit shaky... plans were not as holistic as they could be
By year 2 the planners were getting better, and we were much better about helping clients to advocate for themselves
Year 3 saw much more holistic approach

Case study 1 – with permission....
She insisted her picture be used but I have changed her name
I have worked closely with the team who worked with Lara
She was an independent woman, took a down hill spiral in her 20s
There have been periods of homelessness and hospitalization

Her supports often deteriorated
Her social networks eroded
In 2 years she was offered a site at HWNS
She was grateful for this opportunity
In 2013 she entered into the scheme
She downplayed the level of support she needed to be well at first
She had a medication change that was devastating for her mental health
The team leader advocated for an early review to set up extra supports that would more flexibly meet her needs
Much more comprehensive
She returned to health and community
We developed a support map that was 3 times more than those indicated for her first year
She made a good return to health
As the plan is attached to the person, she was able to look at other options for living with residents who were more compatible with her
I met with her on Friday and she is settling in well and very happy
She said her Mom (89) said she can die in peace now
We have collective learnings to take Lara into the future
So happy to live with 'my people'

Next, I want to talk about Mary
She had been living in a boarding house with over 100 people
Initially I heard that residents in boarding homes did not want to move.
When the closure was announced, residents needed to think about their future
The agency worked to develop plans for each resident
Transition from boarding house to 2 bedroom
with 1 other person
We have supported her to learn the skills she needed to be successful living in the community with another person
Initially the supports were very intensive, these dropped back as her skills and health improved
Now she is starting to think about an enhanced life, beyond merely grateful to have a roof over her head

There are great individual outcomes
These successes belong to the individuals
The teams working with them have done a great job
Responsible and flexible
Empowering
But there are challenges
We are still not seeing great supports in employment and intimate relationships
22,960 participants across Australia
Still evolving - learnings from trial sites shaping the NDIS
When full rollout occurs across NSW the number of people supported will go from

78,000 to 142,000

Funding through the in NSW under NDIS will grow from \$3.4b to \$6.8b in 2019

Definitely 'down but not out'

The inclusion of people with Psychosocial Disability has resulted in better personal outcomes in the following domains:

Living and place of residence

Connecting and reconnecting

Learning

Choice and control

Safety

Taking risks

Health

[20:29] LoriVonne Lustre: LD: I am very excited for what the next 3 years will bring

[20:29] Ruby Vandyke: thanks for a great presentation, Louise!

[20:29] KriJon applauds - awesome model!

[20:29] Gentle Heron: Fantastic report

[20:29] LoriVonne Lustre: LD: thank you so much. Questions?

[20:29] Gentle Heron: QUESTION: Please define "boarding house". I am not familiar with that concept in this context.

[20:29] Carolyn Carillon: LD: A boarding house is a private run facility

They emerged to fill a need to find affordable housing for people

up to now, they haven't had the same oversight

they tend to be about being affordable

there are shared rooms

the person pays a portion of their pension for food and shelter

[20:30] LynAinsworth: Licensing quite light touch - again not really recognising the vulnerability of people with mental health issues.

[20:30] Carolyn Carillon: LD: We're seeing them diminish

the vision is to have them not be the option of choice for those with disabilities

they're private

people with disabilities board there

but also the general public

[20:31] Attica Bekkers: with the decline of boarding houses the homeless has gone up of course

[20:31] Gentle Heron: QUESTION: I know Australia has a more respectful relationship with its native residents (aboriginals) than does the US. How does this scheme work for them?

[20:32] Carolyn Carillon: LD: The first statement might be argued!

they're definitely included

we have a high population

we don't support a lot of aboriginal people

but what we try to do

we attempt to build people's connections with their own communities

we try to help them determine how the supports are provided, who supports them

we didn't see a lot of aboriginal people in our old model

[20:33] LynAinsworth: Unfortunately our track record of supporting our First Peoples is not good. WE are working hard to include Aboriginal people in the scheme. There are challenges with helping them understand the opportunity the scheme provides for them We have recognised that we need different approaches and resources, including strong elements of co-design of supports to make it a success for Aboriginal people.

[20:33] Carolyn Carillon: LD: But now that people have a choice about who provides support

people are connecting with their communities

[20:34] LoriVonne Lustre: [20:29] Leslea: QUESTION: How do you choose which clients are able to access the scheme?

[20:34] Carolyn Carillon: LD: We might choose

If a person thinks they might benefit from being part of the scheme

they can contact the NDIS

they'll be guided through questions

to determine eligibility

the NDI website has a lot of information

[20:35] LoriVonne Lustre: LA: Useful resources

For more general information the following are useful websites:

National Disability Insurance Agency

www.ndis.gov.au

NDIA NSW

www.ndis.nsw.gov.au

House with No Steps – NDIS Section

www.hwns.com.au/ndis

Every Australian Counts

www.everyaustraliancounts.com.au

[20:36] LoriVonne Lustre: [20:33] Attica Bekkers: QUESTION: diagnosis is the worst hurdle, entirely depending on social class and high ability to negotiate systems. Won't diagnosis based access lead to much more fatality and much worse outcomes for those who are not privileged or already supported?

I'm south australian

[20:36] Carolyn Carillon: LD: One of the interesting things that happened in the boarding house transition

is that many of those people didn't have good health records

so the agency will sometimes fund assessments

as part of the transition, we organized for each of those people to be rediagnosed

many were misdiagnosed

originally

now people are able to verify the impact of their impairment on their life

and facilitate early intervention

[20:37] Leslea Aldrin: some criteria has changed

[20:38] LynAinsworth: The scheme has reduced reliance on diagnosis and more on the impact of impairment on a person's life. This is particularly important for the early intervention space.

[20:38] Attica Bekkers: lol through the public system, right, does NSW have mental health hospitals and beds? SA doesn't and turns away people wielding knives
There is no access point in SA

[20:38] KriJon: QUESTION: Are Seniors at risk of losing independent living included in this? I have a friend who is a little frustrated that home support personnel vary - some well trained to listen to her needs and others more likely to "assume" her needs. But I believe she is on a 'credit' type system?

[20:39] Carolyn Carillon: LD: From our experience, the NDIS plan does compensate for some of the inadequacies in the public health system
but it's not all roses

I agree with that

Is this an older person?

[20:40] KriJon: an older independent living adult

[20:40] LynAinsworth: Sounds like an ageing in place package. NDIS doesn't support people who develop disability after age 65

[20:40] Carolyn Carillon: LD: is the question around how that would be supported through the NDIS?

[20:40] KriJon: they have earned their credits, so can they qualify for this kind of support, or is it separate?

[20:40] Carolyn Carillon: LD: the scheme is for those up to age 65
if they're eligible before age 65, they can stay until they transition

[20:41] LynAinsworth: Or people currently over 65 already in the former system

[20:41] Carolyn Carillon: LD: there has been a bit of uncertainty about what would happen to those over 65

[20:41] Attica Bekkers: people currently over 65 with lifelong disabilities are losing support yes

[20:41] Carolyn Carillon: LD: there may not have been a lot of progress guaranteeing support for those people
they are continuing to receive support until other decisions are made

[20:42] LoriVonne Lustre: [20:39] Leslea: QUESTION: Does the customer retain their mental health care team? Or does it change according to the provider they choose?

[20:42] Carolyn Carillon: LD: In the first scenario, she has supports through her mental health team

which is attached to a hospital

so if she's hospitalized

her team would step in to help her transition back to home

and to help communicate with those caring for her

the disability supports don't replace what's provided through the health system

it's a web of people
but it's coordinated

[20:43] LynAinsworth: They help to preserve access to MH support and to implement recommendations from the MH team

[20:43] Leslea Aldrin: Excellent :)
thank you :)

[20:44] iSkye Silverweb: QUESTION: is HWNS the only agency implementing NDIS? or one of many?

[20:44] Carolyn Carillon: LD: No we're one of many
there is choice

when we had forums
we may have 100 providers in a room
so there's quite a large number

[20:45] LynAinsworth: There are many new registered providers including sole practitioners - difficult to understand. There are many providers across Australia

[20:45] LoriVonne Lustre: [20:43] blindman75: QUESTION: How does the NDIS affect those of us who are blind and visually impaired? I'm aware that some of us have been involved in round table conferences, but, those that have been involved in these talks don't seem to be all that forthcoming with information. Does the scheme supplement our current pension, or does it replace it?

[20:45] Carolyn Carillon: LD: the scheme isn't a pension scheme
it's not a source of income to the person

the supports are funded
it's a dollar amount

it may be for equipment
the person chooses the provider
and an invoice is sent from the provider to the agency

[20:46] LynAinsworth: It's like a debit card you can draw down on for specified types of supports. People with vision impairment are certainly eligible.

[20:46] Carolyn Carillon: LD: we have a disability support pension that will continue but it's separate

[20:46] LoriVonne Lustre: [20:44] Shyla: What is the ongoing oversight look like now that it is transitioning out of the trial period? To ensure continued positive results.

[20:47] blindman75: further to that, does that then replace the work place modifications initiative?

[20:47] Carolyn Carillon: LD: Sometimes social reforms can be influenced by the government of the day

but we had bipartisan support

[20:47] blindman75: lol bipartisan support? that's got to be a first, hasn't it?

[20:47] Carolyn Carillon: LD: there's a framework now that would be difficult to break down going into the future

this is something that's supported by a lot of Australians
long term, I suppose at the end of the day

[20:48] LynAinsworth: Two things: outcomes based therefore oversight occurs everytime a person has their plan reviewed. Also - people can vote with their wallets if not getting the outcomes they want. Finally we are awaiting the release of the safeguards framework to provide surety to the most vulnerable

[20:48] Carolyn Carillon: LD: if there's value in providing these supports if people have better outcomes if they're out of the health system then it has sustainability long term

[20:49] LoriVonne Lustre: [20:46] Attica Bekkers: My cousin's daughter has catatonia that is only partly treated, in that she will now move when the voices prompt her and is visited 5 times a week and lives alone, will the NDIS allow her to move to more appropriate institutional care?

Mental age 8 living alone

She's young, crying from being alone, unknown if intellectually disabled because of extent of illness

[20:50] Carolyn Carillon: LD: I suppose in the Australian landscape we're moving away from institutional care we have a combination of health care funding and disability supports so a person could live in a community setting & have their needs met there have been pilots

innovative housing models supporting those situations

[20:51] Attica Bekkers: awesome

[20:51] Carolyn Carillon: LD: where people need additional supports some of that is funded through the NDIS

we can match people together who may like to share housing

[20:51] Attica Bekkers: she is in a housing trust which I think precludes her. Her behaviour is inappropriate to live with family :(

[20:51] Attica Bekkers: yes ty

maybe it will help her:)

[20:52] Gentle Heron: QUESTION: You said that the two areas you are having trouble meeting people's needs are employment and intimate relationships. Those seem both very important areas, but also quite different. And both difficult even for people without disabilities. What sort of plans do you have to address these areas?

[20:52] Carolyn Carillon: LD: that's a tough question! they are quite different and challenging

[20:52] LynAinsworth: These are key policy areas we are continuing to lobby around.

[20:53] Carolyn Carillon: LD: it's a bit like the housing scenario if someone has mental health issues, relationships can fall apart

the work that's happening in the early stages has been successful around housing

[20:53] LynAinsworth: In relation to improving relationships, our support framework is

designed to enhance opportunities, confidence.

[20:53] Carolyn Carillon: LD: in terms of intimate relationships in the boarding house example

they've lost a lot in the past

people want to take time before they take the risk

but it'll be interesting to see what happens in the next few years

but it's hard for anyone

employment continues to be challenging

[20:54] LynAinsworth: The whole employment space is opening up in a positive way but still very unclear

[20:54] Carolyn Carillon: LD: the agency does fund supports to find and keep employment

[20:55] blindman75: that's handy to know.

[20:55] Carolyn Carillon: LD: if there are particular skills or certifications, that'll be talked about during the planning process

and they're supported throughout employment

so we may see some better outcomes there

[20:55] Attica Bekkers: QUESTION: is peer work an option for people who qualify for NDIS or is the level of disability required too high?

[20:56] Carolyn Carillon: LD: I'll need to clarify that. What do you mean by peer work? My apologies for not understanding

[20:56] Attica Bekkers: peer work is like the personal helpers and mentor system. I was agoraphobic

a peer worker had a job to come see me every so often for five years, I'm an ex agoraphobe now i guess

[20:56] Carolyn Carillon: LD: I understand now

are you asking can you have someone like a peer supporting you?

[20:57] Attica Bekkers: I'm asking if it's a potential career path for your clients?

[20:57] LynAinsworth: That would be a type of funded support.

[20:57] Carolyn Carillon: LD: yes, from our perspective

[20:57] Carolyn Carillon: we have minimum employment requirements

[20:57] Attica Bekkers: or are your clients too unwell still?

[20:57] Carolyn Carillon: but we take those needs into consideration

[20:58] Gentle Heron: QUESTION: The US has a federal agency that operates at the state level for employment support, but I don't think we have the fortitude to support people seeking intimate relationships. How did your politicians manage to accept that area?

[20:59] Carolyn Carillon: LD: I don't think they have accepted that area!

It continues to be a challenge

[20:59] LynAinsworth: It's hard to challenge when it's a fundamental human right! and they signed the convention!

[20:59] Carolyn Carillon: LD: there aren't a lot of people who are comfortable having those conversations

we have a framework
that allows for that

[20:59] blindman75: goodness me, they thought of everything, didn't they? krikey!

[21:00] LynAinsworth: The framework reflects the UN convention principles

[21:00] Carolyn Carillon: LD: whether it involves personal development or education

[21:00] Gentle Heron: The US has not signed the convention

[21:00] LynAinsworth: Really!!

[21:00] Gentle Heron: It is an ongoing issue for us here

[21:01] Carolyn Carillon: LD: From our experiences

we hope you seek progress in this area

it has some real life impacts on all US citizens with a disability

[21:01] blindman75: QUESTION: Does the NDIS replace or work along side the work
place modifications scheme?

[21:02] Carolyn Carillon: LD: at the moment, I have a real life example
there's a person I work with who needed adaptations for the workplace
they were referred

for workplace modifications

but over time they'll merge those two plans

but in the meantime those adaptations were done and done well

[21:03] blindman75: good. It's one thing to gain employment, but quite another when
most of what you need to do is inaccessible to you for one reason or another.

Some of that inaccessibility is unfortunately due to the software some of the companies
use and accessibility to things like screenreaders has never been thought of or even
implemented.

[21:04] Carolyn Carillon: LD: so thank you for the opportunity to speak

[21:02] Leslea Aldrin: I found this very interesting and would love to encourage you to
continue and fight to maintain your gains!! I am in Canada.

[21:04] Ruby Vandyke: thank you Lyn and Louise for an interesting presentation!

[21:04] Carolyn Carillon: COMMENT FROM THE AUDIENCE: Keep fighting to keep it!

[21:04] LynAinsworth: WE have the campaign alive and well

[21:04] Attica Bekkers: they have taken away the mentor system that helped me

[21:05] blindman75: I don't believe that will happen. They fought long and hard to get
this all in place.

[21:05] Gentle Heron: I want to take a few moments to thank our excellent presenters at
Virtual Ability's 2016 Mental Health Symposium. I also applaud the work of our
transcribers, introducers, greeters, group announcers, social media/inviters, and all the
other efforts by Virtual Ability community members.

Special recognition to iSkye Silverweb for organizing this year's successful conference.

And all this work would be for naught if not for our attentive interactive audience.

If you have not yet done so, please click the brown Virtual Ability poster to the left of the
stage to get notecards and landmarks about our community.

[21:06] LoriVonne Lustre: <<transcription ends >>