Rural-proofing disability policy: Engaging policy makers and service providers in bridging the research - policy gap

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Wobbly Hub and Double Spokes project

PROJECT AIM:

To develop, implement and evaluate evidence-based policies to promote timely and effective therapy service delivery to individuals with disability living in rural and remote communities.



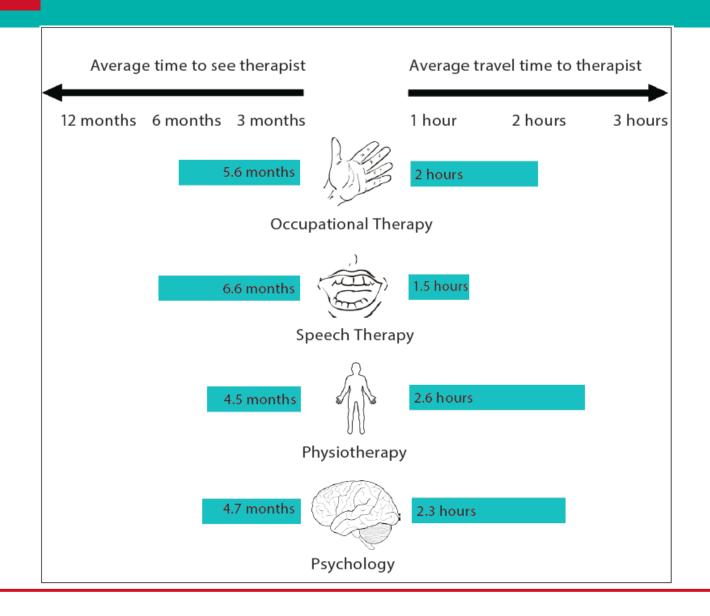


Western New South Wales



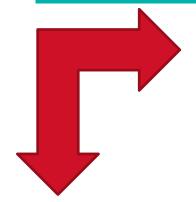


Context – waiting and travel time

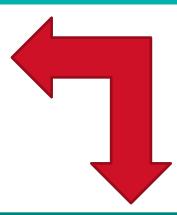




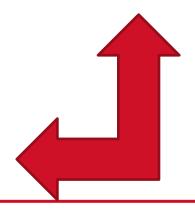
Mixed Methods Study



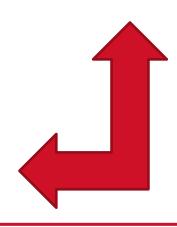
Analysing Policy Documents Reviewing Literature



Therapists' Survey (n = 199)Carers' Survey (n = 165) Talking to Bureaucrats and Service Providers (n = 147)

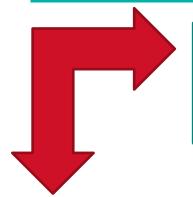


Talking to Carers and Adults with a Disability in Western NSW (n = 88)

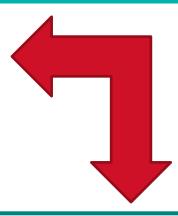




The first 3 years.....



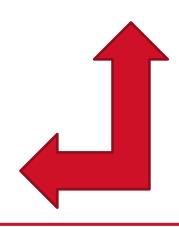
Analysing Policy Documents Reviewing Literature



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Bridging the Research – Policy Gap

Aims:

- > Better understand place of research in disability policy-making process;
- Raise awareness of rural issues 'rural proofing' policy;
- Jointly develop strategies for increasing access and application of research in policy making.

Policies are driven by a number of things, not just evidence. (Forum participant)





"Rural Proofing"

Swindlehurst, H. (2005); Atterton, J (2008)

Impact on rural communities

Raising rural awareness

Ruralproofing

Effective and efficient policy implementation

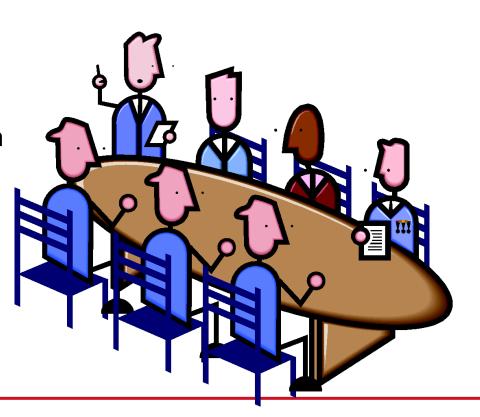
Improving equity of rural access



What did we do?

Deliberative Dialogue (Lavis, Boyko, Oxman et al. 2009)

- Forums x 2
 - Government = 6 participants; Non-government = 9 participants
- > External, independent facilitator
- > Pre and Post Forum Surveys
- Observational notes
- > Analysis via constant comparison





What did we learn?

Time is a major barrier to policy makers using

Time is ALWAYS an issue

But there's no drawing of that knowledge base together...no linking of any key findings back to the literature



You're competing with multiple time agendas

There's lots of work pressures, productivity gains to be made...I just don't see that changing



What did we learn?

Access to journals is a barrier for policy makers or serving the serving servi

It costs my organisation \$7,500 a year to have access to journals

My organisation has an affiliation with a university and that makes a huge difference in terms of access.

Google becoming the main thing for information and that isn't always evidence-based

I am still enrolled as a PhD student [so] this is how I access journals for work



Strategies to maximise time & access

Summaries of key research findings

Visual & Creative KT strategies

Lack of Time & Access

Meetings with researchers

Review articles



Quarterly Newsletter

FACULTY OF HEALTH SCIENCES



Wobbly Hub News



ISSUE 12 APRIL 2014

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PARTICIPATEINRESEARCH: DISABILITY AND STUTTERING

Does your child have an intellectual disability and has been diagnosed with a stutter, and is aged between 12 - 18?

Edward Johnson, a masters student at the Faculty of Health Sciences is researching the characteristics of stuttering in children with intellectual disability and their attitudes toward stuttering and is looking for participants. At present, there is little research about treatment options for this group.

To participate, you and your child will need to be available to complete short questionnaires and be filmed to record samples of your child's speech. If you're interested, please email Edward at ejoh6117@uni.sydney.edu.au or call 0.424 530.258.

FOCUS ON TELETHERAPY

Throughout the Wobbly Hub project we have heard about the issues people with a disability and their carers face accessing allied health therapy services in rural areas. Similarly, therapists often grapple with the costs, both financial and personal, to meeting the needs of the communities they work in.

In this issue, we showcase the potential that teletherapy – therapy provided via computers, tablets and other devices – has for people with a disability, their carers and therapists in rural and remote communities.



TELETHERAPY MYTHBUSTERS

What have we learned from our teletherapy research? We present three common concerns about teletherapy, and how our research is helping to bust teletherapy myths!

MYTH: It's hard to develop rapport with clients via teletherapy

FACT: Clinicians have told us that they are able to develop strong relationships with children online by adapting clinical skills that work in face-to-face settings.

It feels like it is just like normal therapy.

The children were extremely engaged in technology and they were very interested

Parents and school teachers told us that technology might infact promote children's engagement in therapy.

Children are so used to screens, maybe the teachers aren't so much, but these children have grown up in the world of screens.

MYTH: Parents don't want teletherapy

FACT: Clinicians may underestimate families' readiness to use teletherapy. Wobbly Hub honours student, Kate Gardner found that carers were willing to use teletherapy to increase access to occupational therapy (see page 2 for more information).

Messages do need to be short and sharp with links to the details

1



Research Summaries

THE WOBBLY HUB & DOUBLE SPOKES PROJECT:

PEOPLE WITH A DISABILITY IN RURAL AREAS

These two pagers they look nice and you can actually just glance at the headings and go 'oh yeah, I get that'. So I found them fantastic



"Based on our research work in western NSW and the experience of the team, we have developed four streams of enquiry related to people with a disability in rural areas: Insights into Rural Contexts; Access to supports; Alternative Service Models and Workforce Development."

Dr Angela Dew, Project Manager

The team: (back row L-R) Craig Veitch, Rachel Mayes, Bec Barton, Angela Dew, Gisselle Gallego, Rebecca Chedid. (Front row L-R) Michelle Lincoln, Anita Bundy, Jennie Brentnall, Jo Ragen, Kim Bulkeley & Alexandra Iljadica (not pictured)





Visual & Creative - Cartoon

Dan and Sam

Sam is an OT with 10 ye referral for prescript condition. The client,

Dan told Sam that he was living with his cousin.

When Sam arrived, she spent time talking with the Elders, Dan and his cousins until everyone felt comfortable.

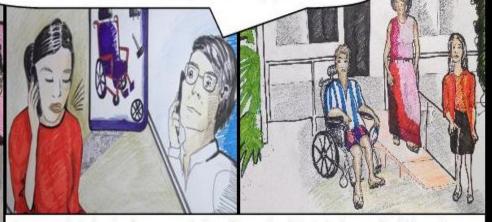
I can get my cousin to build a ramp.

When you use other mediums you HAVE to make things simpler

Some [staff] will look at a cartoon script ...they can just look at a 20 second clip

a small town in far western NSW. Sam received a not for a client with a rare, degenerative neurological mmunity located 200 kilometres from Sam's town.

area in about 8 weeks time. I can bring the early you to trial then. Once the funding is approved it will take about 3 months to get the new equipment.



Sam completed a funding request form for a wheelchair to be supplied through a government funding scheme. They waited nine months for the funding to be approved. Fifteen months after the initial referral Dan received his new wheelchair.

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Visual & Creative - Wordle

Visual representation is far easier than reading a journal.

> **Timeliness Barriers**

UnderFunded

TooManyRules

CreativeSolutions

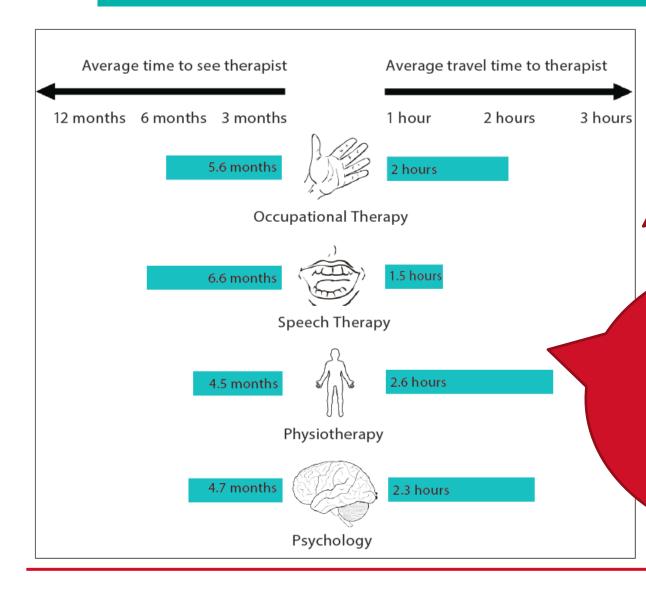
Partnership

Welcome IncreasedCosts

Co-payment **Opportunities** CostsOfTravel NoExtraService GoodOutcomes Innovation Overwhelming NotEnough SectorDevelopment NoChoice AgeLimits Informal Supports dvice Travel Local Workforce Development **PoolingFunds** CostShifting Flexibility VulnerableFamilies HitAndMiss Collaboration **TechnologyOpportunities** FlyInServices ServiceGrowth NotFlexibleEnough



Visual & Creative - Infographics



Infographics synthesise the information in clear visuals

We're looking at using infographics a lot more in publications, again trying to synthesise the information...rather than people trying to interpret statistical masses



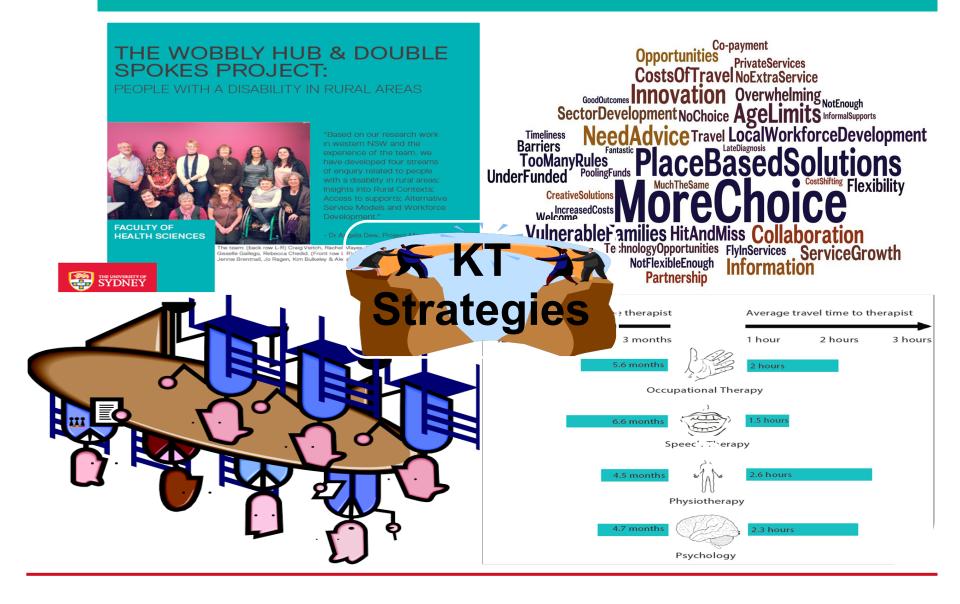
Lessons from the Forums.....

- Need to understand policy maker imperatives
- Use multiple and various KT strategies
- > Engage personally with policy makers
- Have a catchy research title!

KT Strategies **can** Bridge the Research – Policy Gap



Applying KT strategies in your context





References

- Atterton, J. (2008). Rural Proofing in England: A formal commitment in need of review. Newcastle Upon Tyne: Centre for Rural Economy, University of Newcastle Upon Tyne http://www.ncl.ac.uk/cre/publish/discussionpapers/pdfs/dp20.pdf.
- Lavis, J.N., Boyko, J.A., Oxman, A.D., Lewin, S and Fretheim, A. (2009). SUPPORT Tools for evidence-informed health Policymaking (STP) 14: Organising and using policy dialogues to support evidence-informed policymaking. *Health Research Policy and Systems*. 7 (Suppl I):S14.
- Swindlehurst, H. (2005). Rural proofing for health: A toolkit for primary care organisations. UK: Institute of Rural Health.





Australian Government

National Health and

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NHMRC



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Honours Student: Akshay Rai, Bachelor of Health Sciences