

Improving access to services for people with disabilities: development and trial of a community-based rehabilitation course for allied health professionals – a work in progress

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FACILITATOR: Our first speaker today is Robyn Glynn. Robyn is an occupational therapist who has worked in London, Saudi Arabia and Alice Springs. Robyn now lives in Darwin. Welcome Robyn.

ROBYN GLYNN: Thank you. I would like to acknowledge the traditional owners on whose land we sit today. And this presentation is about an elective that's being developed to run out of the Centre for Remote Health Master of Remote Health Practice.

I just want to start with some stories. These are not real names or real people but reflect experiences of people in the remote context; Arthur an Indigenous man, who's had an acquired brain injury, leaves hospital far too early in the view of the allied health professional in terms of optimising his recovery in mobility and self care. But in terms of feeling more comfortable – safe even – he felt he needed to return to his family and culture. However his family are worried about him and his slow recovery. When he returns home there's very little in terms of continuing his rehab.

Then we have Sarah, who's an allied health professional who has tried to do a cognitive assessment on someone she's working with, who also has had an acquired brain injury. She walks away from the session a bit frustrated thinking, "Oh, I don't know what I really got out of that in terms of helping this person". And the family and the person themselves are thinking, "What was that about?"

And there's Martha, a four year old child with cerebral palsy and her grandmother says to the allied health professional who she does get to see occasionally, "Look, you know, you're only coming out here once or twice a once every two months or so, you can't help Martha enough. You know, we need to see you more. And what about the other person we saw in the hospital? She helped with some language, you know, to help Martha say things and understand, why don't we see someone like that?"

So, hopefully what we're talking about today might help address some of those issues for these people in the future. The aims of the paper are to describe community-based rehab and explore the relevance in rural and remote Australia. To describe the process of development of a community-based rehab course and the factors that have influenced the content. And to highlight issues from literature and course development with some strategies to help reduce the impact of those issues. [Slide] Just to touch on the World Health Organization international classifications of function, disability and health of which many of you will be aware.

Previous classifications (impairment, disability and handicap) reflected a medical model whereas the more recently introduced classifications (body functions and structures, and activity, or limitation of activity and participation) reflect both medical and social models. And I think the approach or philosophy of community-based rehab also is reflected in these classifications. [Slide] I will let you read the definition of community-based rehab for those

who aren't familiar. So, perhaps the main shift that has to occur for many of us as allied health professionals, is a move away from individual approach.

This (CBR approach) is more of a community development strategy, working together with people with disabilities, their families. We're often facilitating them to take leadership roles where appropriate.[Slide] And they (WHO) define community development as this.[Slide] community-based rehab, so here, some factors or features of community-based rehab are represented. Community driven, community-based workforce. The World Health Organization CBR approach came about in the late '70s, early '80s. They developed some manuals where community-based workers could refer to basically do rehabilitation – to assist people to participate more and learn ways that the disabilities that they are experiencing will have less impact on their lives. Overseas there are often different levels of workers.

[Slide] Community-based rehab, the kind of functions of the community-based workers could be therapy, interpreting, support, co-ordinator of services, advocating for the rights of people with disabilities. It very much involves people with disabilities and their families.

CBR also consists of screening activities for preventing disabilities, self help and support groups, child to child activities. It provides a voice within communities on issues that relate to people with disabilities.

[Slide] Now, this table helps us study the question why would we in Australia adopt an approach that's been developed in countries with less resources, so-called 'developing countries'?

It's certainly not about the prevalence of disability in 'developing countries'. There's a much higher prevalence, you're talking 100 to 120 million people with disabilities. In Australia we have an estimated prevalence of 20% of people with disabilities. These figures are all very difficult to establish and compare, largely because of the social construct of disability. But they do provide us with a ballpark comparison. What about in terms of resources – the availability and access to trained professionals, money, rehab equipment, and so on? In 'developing countries' resource access is comparatively a lot lower than in Australia but relative poverty has also been talked about in Indigenous communities.

Disability rates by age – in developing countries the prevalence is a lot higher in children and preventable disabilities whereas here disabilities – people experience disabilities a lot older.

The population in developing countries is very dense whereas in Australia it's sparse. However, in Indigenous communities there are pockets where, as people are well aware, the population is dense.

And where barriers to rehab in 'developing countries' are largely cost related, here they are early discharge, cultural safety and geographical barriers. So, the factors in common are high density of living, comparatively poor health status, poor environmental health, limited infrastructure to help in meeting the needs of people with disabilities and different traditions and attitudes, towards responding to the needs of people with disabilities.

Access and equity is fundamentally why we would look at community-based rehabilitation. We know that Indigenous people are likely to have higher rates of disability by extrapolating from the chronic disease and other health statistics. For example, that the prevalence of diabetes is almost four times higher. And from diabetes lots of disabilities can be an outcome. People leave institutional rehab earlier, attend outpatients less and they may only receive occasional visits from allied health professionals.

[Slide] Now, the purpose of this table is just to say that a lot of principles that are within community-based rehab, are not necessarily new. They are already found in primary health care and in fact community-based rehab has been called the 'primary health care for people with disabilities'.

The disability services within Australia have already developed quite a focus on advocacy and the rights movement, which is a cornerstone of community-based rehab. We heard in one of the keynote presentations about the need for Indigenous people to be active agents within their services, this again is a cornerstone of community-based rehab. Community control, another important feature. And this process, the process of community-based rehab, can help attain this. It will take a lot of time but it will help us engage with what are Indigenous terms of reference in terms of disability services. It will take a lot of time, a lot of trust but with this process, that could happen.

[Slide] This chart shows a comparison between the self management approach, which has been used a lot for chronic disease, and the community-based rehab approach. There are differences, but also there's lots of common features.

[Slide] Rehabilitation services are made up of these three components and its community-based rehab is the one that's often left undeveloped.

[Slide] Who participates in community-based rehab? We have community leaders, disabled people's organisations, governments, non-government organisations, professionals, people with disabilities, most importantly, and families. [Slide] And this was just to show there are often two levels of community-based rehab. There's the individual community focus, individual and community focus, but also there's that program focus which sometimes is called 'twin tracks' or 'disability in development', or 'mainstreaming'.

An example of that might be recently there was some IHANDT housing program funding for increased housing in Indigenous communities and we strongly lobbied the policy makers in that area to make sure that all the houses were accessible – and that the access standards were included in that – which they have been. So, it is important to look at different aspects of any program that happens in the communities and make sure that the perspective of people with disabilities are included and encompassed in them. So, you don't necessarily just have a disability program but ensure that all the other programs are aware of disability issues, that people with disabilities have a profile on all the other programs. And that's quite important, I think.

[Slide] Many of you already know this material and I'm sorry this is a bit 'NT-centric', but this is what's happened in community-based rehab in northern Australia to date. Firstly, there was a rehab review in '92 that suggested maybe community-based rehab would be helpful. And so we had a look at that and a project was then instigated in one of the communities in the NT. There were some learning modules developed, and in subsequent years there's been some workshops. In Queensland, there was a rural project. So, this is interesting because it was application community-based rehab in a rural project as opposed to a remote area project. It was very well evaluated and a really good example of how CBR can fit in the rural context.

Rob Curry's work, which has contributed a lot to looking at how people can access our allied health services better in the bush, also featured CBR. And it features in a lot of the new allied health services. And there was a (CBR) forum in Brisbane that SARRAH convened in 2003. Benefits are, more culturally safe appropriate services so, as I said before, we can fit the services into an Indigenous framework rather than the other way round. And there will be an increased access to professional western developed knowledge and skills.

And CBR can be a means for reduction of disability, which is what many of our services are about. Although it does focus on disability, the principles can also be applied to other services. And indeed have already been. You know, there's many – there's mental health workers that we've heard speak at this conference, there's nutrition workers, Indigenous nutrition workers, environmental health workers, it's happening in a lot of areas. And this framework is a really good framework, I believe to, apply to disability services.

Also, there's many disability services within the communities, and particularly Indigenous communities, that are already practising these principles. They don't call it CBR but they are practising these principles. [Slide] And just a note of warning, that there's lots of potential barriers. You know, this is really a developing approach and evaluation is going to be the key to really finding out what works and what doesn't work. Slowness to get going is a big thing in community development but any of the community development literature will say it takes a couple of years to form relationships in communities and for communities to move along on things.

And it's a bit of a worry if funders perceive projects as failures because things haven't happened. Evaluating with community-based researchers is very important. In any project lots of evaluation has to happen ... and is happening.

Okay, so the RHSET project, to develop and trial an elective in CBR. We're funded through RHSET, have a steering committee, which has had a few formal meetings but many individual consults. On the steering committee we have representation of Indigenous organisations and people, allied health, allied health managers, CBR experts and people with disabilities.

[Slide] We ran a questionnaire just to find out what people wanted and there was a lot of fundamental information about community-based rehab wanted, where did it come from, the history, what do we need to know to be able to implement it and to identify needs. And how to sustain and evaluate it. So, we've got most of that in the course. The need for education about CBR actually came up in a research project to identify continuing education needs for allied health professionals here in Central Australia and it was quite prominent. [Slide] So, lots of foundation information is included, people wanted to know strengths and weaknesses of the approach and skills to implement it.

[Slide] Stakeholders thought allied health professionals first of all had to realise that they had to be skilled in their profession and that the final course assessment should be practical. And that collaborative work skills are really important.

[Slide] So, the topic aims to extend students' knowledge in the Australian remote health context, and the experience of people with disabilities here – historical, social and professional developments. So that is, what's already happened in the mainstream. And then there is development in knowledge about community-based rehab and the values and the skills to work within this approach. And the learning outcomes reflect that.

[Slide] There's foundation – just a very brief historical development of rehab and issues with people with disabilities, we have to cover that again because of the cultural construct, or the social construct of disability, and just see what's happened in the western traditions and history before we move in to other cultures. [Slide] And then look at CBR itself, look at key stakeholders, there are a lot of players. [Slide] Looking at working in this cultural and contextual environment. [Slide] And then the skills to initiate, to implement and sustain and evaluate community-based rehab.

The course writers are grassroots workers with some experience or knowledge about community-based rehab but in close consultation with experts. The course delivery will be

semester 2 this year and it will be an elective but it will also be a stand-alone course. So, if organisations wanted to run it then they can do that. The course 140 hours long distance learning with a week's workshop.

In that workshop we're actually hoping to have interdisciplinary sessions with Indigenous community-based workers studying with Batchelor Institute. So, this will be two groups of students who, in the field, will be seeing the same people or client group. The vision is to actually bring these students together for some shared learning because we know, through research in multi-disciplinary education, that that helps things out in the field. [Slide] And just some other things that will be included. [Slide] Just to touch briefly on the issues that have arisen, one size won't fit all. We've talked about the time. And the allied health professionals – and others, actually this is not only for allied health professionals, anyone working in the field of disability basically. But we need to be responsive when communities actually want to do a community development, or respond in a particular way. We need to know how to do that and to have the skills to do that.

[Slide] In the future there needs to be more infrastructure to support this. This is just – it's developing and this is one little aspect of the development. Evidence base is not a lot, that's why we need to evaluate, evaluate, evaluate. Capacity of community-based workers? – There's an increasing demand for community-based workers and that's great. However, there's not necessarily a large group of people waiting to be, you know, CBR workers. So, we're going to have to be smart about how we work or collaborate with other programs. You know, maybe the chronic disease people, or, you know, some community-based workers may work across different programs.

And so we need to find ways to do that. And professionals need to adopt an approach to foster and support CBR to meet the challenges of this field. And by that we mean allowing Aboriginal terms of reference about the services that we're working in and developing. [Slide] This is a quote from some research done by Anne Lowell and Indigenous researchers, one of whom commented 'Balanda' (non-Aboriginal people) need to better understand and implement their role as support rather than control. And I think that's quite a shift that can be quite challenging to make.

[Slide] CBR, the cost, it's not necessarily a cheaper approach. Because as we've heard, people working as community based workers in communities may need lots of support. We've heard this in various sessions.

So, how might this approach make changes, say, for Arthur who we heard about at the beginning of this paper? He'd still discharge himself home early but there might be an appropriate community-based response by and with local people. Which would be timely, effective and supported by well-informed and skilled allied health and/or community personnel. Sarah would be working in a partnership with a co-worker and developing appropriate cognitive assessments and interventions. That means that there's increased meaning and participation for all players, all people in that interaction. And Martha would receive weekly sessions and support but would also be having access to specialist services supplemented by the Outreach team.

So, we're hoping that this approach to be developed in the future will facilitate those changes- and this CBR education program is part of that bigger picture. Thank you.

PRESENTER

Robyn Glynn is an allied health professional, who has worked in Darwin remote aged and disability services for some seven years. She graduated in occupational therapy in 1981 and with a Masters in Public Health in 2001. Robyn has a strong professional interest in improving access of Indigenous people in remote areas with disabilities to support services. Her experience includes supervising an aged care unit in London, working in Saudi Arabia (in more peaceful times) in service development, and as an allied health academic at the Centre for Remote Health here in Alice Springs, where this work was initiated.

