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Introduction: Hello readers! Welcome to our newsletter. Hold onto your hats! This newsletter will talk about a very sensitive subject for some – sexuality and disability! Any discussion about sexuality seems to be uncomfortable for most and it's particularly uncomfortable for the unaware to combine disability in the same breath. So the purpose is not to promote any particular programs or services as such but just to put it on the table as a topic of debate and awareness raising. If you are aware of any initiatives or services around, I'd be interested to hear about them.

As a response to a request, I have also included some information about 'domiciliary oxygen' – a little known issue for most and have attached an article about the state of play of people who have to use oxygen in the home and the inequities of funding that exist in some parts of Australia.

DWE latest initiatives: We have been doing so much travelling lately, so it's lovely to be able to get on with some office based work in the last week or so and keep out of the cold. As you may remember some months ago, I mentioned that we were producing different versions of a 'tradie's guide' for various clients - booklets that provide simplified information about access and mobility provisions for use by tradespeople, builders or designers. I have recently started to prepare my own collection of flyers and related diagrams that will be even more user friendly and will discuss not just what people **need** to do to comply with the updated standards but also **why** they need to do it from a very practical perspective. We believe that if builders knew the 'why', by using practical examples and providing information in Simple English, then there would be fewer issues around noncompliance or apathy.

These templates are very flexible, inexpensive to produce (photocopying) and can be tailored to suit your needs. They can be held with the building department (and access workers) and handed to relevant developers as standalone topic options or collated as a larger 'pack' of information. I am designing them based on a 'fact sheet' format - a one page, double sided A4 document per topic with my own diagrams which are also user friendly.

It will include information about doors, toilets, bathrooms, 'tactiles', ramps, stairs, retail outlets and so on. I am starting another 'pack' based on AS 4299 – adaptable housing provisions. With an ageing population, I'm sure it will be useful for people wanting to build from scratch (to add value to their homes) or renovate for old age (so they can stay in their homes until they're 100) or adaptable for accessibility pending potential frailty or disability. Please let us know if this is of interest to you.

Soapbox: Some years ago in my role as the RuralAccess Coordinator at the City of Ballarat, I heard a number of stories about paid carers who flatly refused to take their clients to a brothel or any other 'adult' services as it challenged their 'moral beliefs'. Although it was that person's personal view, everyone has the right to choose what services to access or how they want to spend their money without judgment or interference. It wasn't as if the client was asking them to do more than just dropping them off and picking them up again later.

The stories I was hearing prompted me to organise a sexuality forum with the backdrop of a sensation touring exhibition called 'Intimate Encounters'. This exhibition was a collection of tasteful photos of people with a disability in various states of undress and or intimacy. What a great awareness raiser. The target audience was carers, parents or supports of people with a disability and the objectives were to remove the attitudinal barriers and the taboo associated

with disability and sexuality. There were 4 panelists who each gave their perspectives on the subject:

- Dr George Taleporos - who is an expert on the subject of sexuality and disability and talked about adults rights to engage (or not) in sexual activity and the community's perceptions of sexuality and disability. (*Google George if you need some expert advice*)
- A professional sex worker – a sensational presentation about her specialist caring service provision for clients with a disability
- A person with a disability who is married with children and discussed their 'normal' life
- A manufacturer of safe sex toys that have been specifically designed for people with a disability – fascinating collection.

The audience was made up of people with a disability, disability service providers and family members who took away some key messages about the right that every adult has when it comes to this sensitive subject. What do you think?

On the same subject:

Article in the Daily Telegraph –

Disabled patients in NSW hospitals have been visiting brothels as part of their government-approved therapy.

Carers escorted at least six patients on trips to sex workers last year, with one of them making the visit once a month, *The Daily Telegraph* reports.

The NSW Government paid for staff to accompany the patients to and from the brothels but the patients paid for the sex sessions themselves.

The visits are permitted under a Department of Ageing, Disability and Home Care policy that says patients have a "right to use a sex worker and sex aids", the Telegraph reports.

"Sex workers are to be considered as only one of a range of options in meeting the sexual needs of a client," the policy said, but the department would not provide more details about the brothel visits, citing confidentiality.

Sex education would provide greater protection from abuse by Kelly Vincent (*I have shortened her article a little so if you would like to read the entire article go to www.abc.net.au/rampup/articles*)

.....Families of people with disabilities, especially intellectual disability, can often be very protective of their loved one when it comes to sex, and to some extent, I can understand why. I mean, if you've watched them struggle to 'fit in' in society, and to form 'normal' relationships, why wouldn't you be a little anxious and hesitant about their capacity to engage in relationships of a sexual nature?

The real problem here, I believe, starts when these anxieties mutate into assumptions. An oft heard one in my office is the assumption that the person with disability simply does not want to, or is not able to, engage in sexual activity, and therefore does not need to know about it. I have held a keen interest in this phenomenon since high school, when I saw many of my peers with disabilities become the victims of this assumption.

This lack of knowledge is of course not something that only people with intellectual disability can experience - or even people with physical disabilities, for that matter. Of course there are many

reasons that a person may not receive what I would call age appropriate education about sex and biology. Cultural or religious beliefs, for instance, may prevent such conversations from taking place.

But I would argue that people with disabilities are especially deprived in this regard, given the stories that I have heard through my work, and the frequency with which I have seen this occur to my peers with disabilities. A girl of eighteen, for example, who didn't know what a condom was. A fifteen-year-old girl who came running out of class crying hysterically because she had just got her first period and she thought she was haemorrhaging. And, perhaps the worst: a young wheelchair user who was told that she simply 'wouldn't need' the Gardasil vaccination against cervical cancer.

Need a breath of fresh air now?.....As another lesser known issue in the disability sector, there are inequities in Australia for the provision of oxygen in a domestic setting. I was alerted by an audience member of one of my disability awareness sessions (thanks Helen), about the issues faced by people who need to use oxygen at home – I had no idea, so I thought some of you may be interested too. Her sister is the author of the attached article which hopefully you will find interesting. Here are some stats and information from her to get you started.

Updated estimate of Australians on domiciliary oxygen by *Anne Cahill Lambert, AM*

At the hearing of the Productivity Commission's Inquiry into Disability Care and Support on Friday, 8 April 2011, I tabled a document entitled *Domiciliary Oxygen in Australia - A Breath of Fresh Air* which I drafted in 2007. I had made a rough estimate of the number of Australians on domiciliary oxygen and the likely costs of a government scheme.

I have refined those estimates and costs using the following principles and resources:

- Population is based on Australian Bureau of Statistics data: *3101.0 Australian Demographic Statistics, September 2010* released on 29 March 2011 and available at www.abs.gov.au
- Unfortunately there is no central, or indeed jurisdictional, register of patients on domiciliary oxygen, except in the Australian Capital Territory. At 31 December 2010, there were approximately 345 patients on domiciliary oxygen and this has been converted to a rate per thousand and applied to other jurisdictions. Thus, the prevalence of ACT residents on domiciliary oxygen has been used to calculate the prevalence of Australians on domiciliary oxygen.
- In estimating the cost of *portable oxygen*, calculations have been made so that half the patients will be supplied. This is on the basis that some are just too sick to need this technology and some will die. It also accommodates a two year purchasing program. Individual units have been costed at \$2,000 - economies of scale, government discounts and a strengthening Australian dollar suggest that this amount is reasonable.
- The cost of *fixed oxygen* has been estimated at \$1,000 per unit but each patient would be supplied eventually with such a machine. Governments that supply these machines tend to rent them rather than purchase them. The assumptions of economies of scale, government discounts and the strong Australian dollar have again been made.
- The personal cost to patients of fixed and portable oxygen is calculated at \$22,512 pa per patient, as explained on page 10 of the original paper.
- The cost of a fixed concentrator alone, with no consumables, is estimated at \$135 per month per patient.

These last two calculations have been included so as to give an estimate of the personal cost that individual Australians bear when they are required to pay for their own oxygen.

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