

Thank you.

It is with the combined feelings of pride and privilege that I join you today on the 20th anniversary of the incorporation of **secca**. The agency made the decision to have as the theme for this morning “Past, Present and Future” of **secca** service provision. This idea arose following a conversation I was having with **secca’s** Co-Manager, Amanda Negus when we were discussing how the anniversary should be celebrated. I was reflecting on how quickly (in some respects) 20 years has gone and the changes that have occurred in that time. I was talking predominantly about the technological changes. When we started there were no mobile phones, no internet, and no emails. We were very excited to have in our office a photocopier, a fax machine and a computer. We felt very techno savvy because we knew what a ‘mouse’ was. We used overhead projectors not power point when we ran our training programmes.

Our conversation then expanded to include the genesis of **secca** and the changes that have occurred in how we present our services. Many of these changes are a result of the political agitation that has occurred within the disability sector advocating the rights of people who have a disability. It is with these changes in mind that I speak with you today.

History

To better understand what prompted and motivated me and the small group of professionals who were involved in the development of **secca** it is worth reflecting on what was happening in the area of sexuality and disability in the late 1980’s and early 1990’s.



Social Role Valorisation identified by Wolf Wolfensberger during the 1970s had been accepted by most Western Developed countries as the corner stone for the models of policies and services for the disability sector.

As a consequence, inclusion of people who had a disability in areas previously unavailable to them was taking place; major areas such as education, employment, housing, and recreation clubs. The ramifications for people with disability and service providers were enormous. No longer would the little orange buses moving throughout the metropolitan areas taking their occupants to 'special' schools and 'sheltered' employment segregating them from the community be tolerated. Instead, people with disabilities would be educated with their non-disabled peers and employed in factories, offices, or community settings - depending on their ability - together with other members of their society.

The large institutions housing people with disabilities in an ad hoc manner while ignoring their individual needs and capabilities and which, because of their size, were staffed by people, who could never become familiar with the patients, were being replaced with group homes or, when possible, supported independent living.

What these changes provided was the opportunity for people with a disability to interact socially in a manner that had never occurred previously. Consequently, the need for education and guidance on how to relate in a socially and sexually appropriately manner became apparent. The identification of people with a disability being highly vulnerable to sexual exploitation and sexual ill health without education also became apparent.



But there needed to be a seismic shift in society's attitude to sexuality education generally and in particular sexuality education and people who have a disability before this type of education could be put in place.

I am reminded of a newspaper article at the time (and I wish I had kept it) that had the headlines "No Sex Please, We are British". It reported that a couple on a train in Britain had, in a full carriage and in the middle of the day, engaged in explicit sexual activity. No one said a word.... until they lit up a post coital cigarette. At this point a number of passengers jumped up, pulled on the alarm to call the guard because the carriage was a non-smoking one.

It is curious that culturally we are not encouraged to discuss topics of human relationships and sexuality UNLESS it is being used in advertising. Then, it seems, sex can be used to sell almost anything.

As I said, sexuality and sexual health and wellbeing have not historically been a topic for open discussion particularly for people with disabilities. The following specific 'myths' have significantly shaped the education of people who have a disability in regard to human relationships and sexuality

- being regarded by parents and carers as asexual 'eternal children' who need to be protected from the world of sex and sexuality
- having a well-documented vulnerability to abuse and violence which often result in those around them feeling protective and preventing human relationships and sexuality education
- if human relationships and sexuality education was to take place the concerns were with encouraging 'inappropriate' sexual behaviour



- having a greater dependence on parent and carers. This means access to information can be limited. Also, some young people want to protect their families from their own developing sexuality.
- being confused about conventions and expectations about sex, and about interpreting media representations of sex and sexuality
- having patterns of cognition which mean that facts and information are not necessarily easily absorbed at first hearing

However, changes were beginning to occur.

In the late 1980's, in response to the increasingly emerging challenges facing people who have a disability, their families and workers in the disability sector the Disability Services Commission developed their Policy on Sexuality and Human Relationships. This was enacted and became legislation in 1990. Western Australia was the first State in Australia to have such a policy.

The Guardianship and Administration Act of 1990 was introduced. This legislation acknowledged and upheld the rights of adults with a decision making disability. In particular, it prevented any medical procedures from taking place without the informed consent of the individual or, if the individual was deemed by the former Guardianship Board (now the State Administrative Tribunal) not to be able to give their consent, their legally appointed guardian. This had huge implications for people with disabilities regarding their sexual relationships, fertility regulation (contraception and sterilization). The legislation demands that any proposed sterilization procedure on the life of an adult who had a decision making disability must be approved by the Tribunal. Such a procedure for a minor must be authorized by the Family Court.



In the past there were recorded cases of not just adults but also children having hysterectomies. One of the youngest that was recorded in the literature was a female from Queensland who, at the age of seven, was given a hysterectomy. The reasons; it was assumed she would never be able to manage her menstruation.

The Guardianship and Administration Act also made it possible for people who had a cognitive disability their right to have sexual relationships. Previously, the Criminal Code stated that it was illegal for anyone who was “an idiot, imbecile or epileptic” to have sexual relationships.

In 1992 The Australian Human Rights Commissioner implemented The Disability Discrimination Act 1992. This made it illegal to discriminate on the grounds of disability. The Commission has major responsibilities under the International Convention on Rights of the Disabled.

In the area of sexual health, the HIV and AIDS epidemic had emerged and international and national attention was being given to the dissemination of accurate information regarding transmission, and safer sex practices. In 1985 the WA AIDS Council was incorporated. Sex had been placed on the agenda. Clearly, the disabled community as well as their non disabled peers required access to this information. The Disability Services Commission acquired a small amount of funding for the purpose of providing some education in this area to their clients.



A small group of professionals working in the area disability and/or sexuality communicated to each other their shared disappointment about the lack of services for people who were not registered with the Disability Services Commission and who were displaying behavior that demonstrated the need for them to have counseling, and education regarding human relationships and sexuality education.

In 1990 I was working as a Counsellor/Educator with FPWA and was developing their policy for services for people who had a disability. Gareth Merriman was working as the Consultant for Sexuality issues at the Disability Services Commission. Together we contacted representatives from the Centre for Cerebral Palsy, ACTIV Foundation, and the WA AIDS Council. We all agreed that a specialist agency was required that could not only provide individual counseling and education but work as consultants to disability organizations assisting them to develop their own policies and services as well as provide training for their staff. The services provided needed to be affordable and comprehensive and available to a wide range of disabilities. We were also aware that families required support not only with assistance to help their family member understand appropriate sexual behavior but also to deal with their own grief of having a child with a disability. We were mindful of the 'chronic sorrow' that had been identified in the literature. That is, there are predictable periods during the life of an individual with a disability that are likely to initiate with their family, the feelings of sadness, grief, and apprehension about the future that may have been experienced with the first diagnosis of the person's disability.

Emerging sexuality is one of those times. Other periods have been when non-disabled peers are entering the workforce, getting married, retiring. We knew it was also important to involve parents and significant others from the start of the individual's human relationships and sexuality education.



With all of this in mind, together with a determination and zeal that would stun a charging ox we established secca in 1991. I might add at this point that there was some deliberation about what we could call this agency – **secca** was chosen from the acronym and we also liked the play on words about seeking...information, truth.

Later that year **secca**, in a joint submission with FPWA was successful in a proposal for funding that Lotterywest made available for projects that were “supporting families who had a member with an intellectual disability”. The funding would be for two years. Premises were rented in Townshend Road, Subiaco. It was an old building and we spent the weekends painting the rooms, making it disability accessible (thanks to ex-carpenter Gareth). Sadly it was broken into twice – once taking off with our only computer. We salvaged furniture from State Supply.

So, with a staff of one fulltime Co-coordinator, one part time educator/counselor one part time educator, and a part-time administration officer, we set about the business of providing education, counseling and consultancy to people who have a disability, their families and significant carers.

Our services at that time consisted of providing education to groups of people who had a disability. These were individuals who had been referred by various disability organizations. Also, a large number of individuals and some couples were referred for individual counseling. Community and Professional education took-place under the auspices of the grant secured from the Department of Health for HIV/AIDS education. Some were funded by individual organizations that contracted **secca** to provide staff training.



The emphasis of community and professional training was on providing an opportunity for participants (who worked either in the community sector or disability sector) to examine their own values and attitudes relating to sexuality and people who have a disability. We knew that the training would be more effective if it incorporated these aspects as well as information regarding sexual health – in particular, HIV/AIDS transmission.

In retrospect, the emphasis of our referrals for services was largely on providing information about life development changes (puberty, adolescence) a little relating to menstrual management, and “inappropriate behavior” being the oft used catch all phrase for reason for referral. There were slightly more males than females being referred, and the predominant age group was 14-22 year old. Our resources consisted of a kit of “Circles” (a resource that enables to make concrete the abstract concepts of social relating and appropriate touch, talk and trust) and a three shelf bookcase library. We relied significantly on the library of our partners in the project, FPWA.

Feedback about our work was highly positive. The capacity to provide services exceeded the demand. We also identified a number of areas we would have liked to have attended to, but had neither the financial or human resources to do so – for example, we were aware of the need for parenting classes for people who had a disability, that teachers were ‘crying out’ for resources to teach their students who had a disability. We knew that menstrual management was still a taboo area and the preferred way of dealing with this issue was medically (either chemical or attempts to have permission for sterilization or chemically by use of the oral contraceptive pill or Depo Provera). We were also made keenly aware of the ‘casualties’ of historical policies. Such as those individuals who had been raised in large institutions from a very early age and whose capacity to relate appropriately either sexually or otherwise was severely compromised.



Or, the woman who was traumatized as a result of her forced sterilization by her family. Or the couple who partnered and married without any sexuality education whatsoever. Or the young women who, after making complaints to staff to no avail finally disclosed to a close relative about the behaviour of a male co-resident. She was found to have extensive injuries as a result of ongoing sexual abuse. These experiences consolidated our resolve to ensure adequate service provision for our client group.

The intention when **secca** started out was to be contracted to train organizations who provided services to people who had a disability to develop skills so that they could provide sexuality and human relationships education to their clients. In other words **secca** would be brought in by an organization to teach the staff how to support and educate their clients. We would then step back as primary services providers, yet always be available if future consultation was required.

We envisaged we could, eventually, make ourselves redundant.

With this philosophy in mind, when the two year funding provided by Lotterywest ceased, the Board of Management of **secca** considered they had introduced to FPWA human relationship and sexuality education for people who had a disability to the extent that **secca** could step back and FPWA would continue to provide services. This occurred and FPWA named this arm of their services People First Project. It continues to this day.

Very quickly it became apparent from the constant requests for training and the referrals for counselling that what the community required was the continuation of a specialist agency that could provide one-one counselling, professional and community training as well as a consultancy service.



It also became clear to us that the most effective way to address effective psycho/social education and therapy given the differences in cognitive abilities of our clients was to provide one to one psychotherapy and education that was tailored for them and their specific issues. Working in groups for people who have a disability has been demonstrated to have minimal ongoing success for behaviour change and retention of information. People become uncomfortable discussing sexuality and their embarrassment can prevent them from learning. Or, they may have had a history of sexual abuse and never realized they could disclose it until the subject was raised. Disclosures in a group situation are unhelpful and distressing. In a one to one situation these issues can be dealt with immediately.

The decision was made that rather than expect to 'skill up' agencies, we would more effectively serve our clients and the community by providing quality counselling and education and be available for professional development and training.

We were also mindful that there was a dearth of appropriate resources for us to work with. Most of the resources available to us came from the USA. Some from the UK. Very little from Australia. So, we commenced developing resources that were Australian and Western Australian appropriate. Over the years we have produced:

- "Prickly Issues" – a guide for organizations developing policies on human relationships and sexuality.
- "Sexuality and your Rights". A book about Sex and the Law (written for low literacy groups)



- “Sexual Health and HIV/AIDS” – graphics and text for low literacy groups
- “Safer Sex and Condoms” – graphics and text for low literacy groups
- “What About Pap Smears” – graphics and text for low literacy groups
- “Sexuality Concept Board and Handbook”. A visual tool to assist teachers to teach the components of sexuality education.

We consulted with WA Cervical Cancer Prevention Programme and Disability Services Commission to develop:-

- “Women with Intellectual Disabilities need Pap Smears too”
- We are in the process of developing a DVD relating to Values and Attitudes regarding Sexuality and Disability. This will, we hope, reflect the diversity of attitudes held in the wider community in Western Australia and, by exploring the relationship between the individual and society, demonstrate how one’s values and attitudes impact on service delivery. It will be used to assist in training staff employed in the disability sector.

Current

Psychotherapy stream

Fast forward to 2011. **secca** is now recognized as a unique and specialist agency providing services to people with a disability, their families and significant carers. We provided one to one counseling sessions to over 145 individuals in the last financial year. This equates to 510 counseling sessions. The number of male clients is still greater than female clients. The age group 15 – 24 remains the most referred for services.



These figures generally reflect what we know about pre-adolescents and adolescents in the wider community. It is at these ages that life development changes are occurring rapidly, peer influence is greater than family, risk taking occurs. In our client population they are not as sophisticated as their non-disabled peers in hiding their behaviour so are more likely to be noticed. They usually have greater supervision than their non-disabled peers. We find that people who have an intellectual disability present more frequently than other disabilities. It has been our experience (and the literature would support this) that teachers, parents, support workers do not feel as comfortable talking with someone with a cognitive impairment about human relationships and sexuality as they do with someone whose doesn't. This is often because information must be broken down and communicated in 'plain language' in a manner that is not only easily understood but also best retained. Some may find it difficult to teach in this manner and not be able to 'hide' behind a more clinical way of presenting information. I refer to my earlier comments that discussions about human relationships and sexuality are not encouraged in our culture.

The issues addressed during counseling sessions since **secca's** inception have change dramatically and are now more complex and challenging. In the past requests for counseling/psychotherapy were largely related to life development changes, boundary setting and appropriate touching, talking related to sexuality (this incorporated protective behaviours). There has been a marked increase in the number of people who have been diagnosed with autism/Aspergers and also who have a psychiatric disability as well as an intellectual or physical disability.



Sexual Assault

We notice now that even if the referral to the agency initially is for 'human relationships and sexuality education' the incidence of sexual abuse is extremely high. We believe that this increase co-relates to the introduction of Disability Service Standards 9 "Protection from Abuse, Exploitation". The introduction of this Standard has raised the awareness of workers in the disability sector that people with a disability are vulnerable to sexual exploitation. That they must be taken seriously when they disclose behaviour to them that has hurt them. (a longstanding myth about people with a disability was that they could not be believed) Our clients are now being informed that they can report experiences of sexual behaviour that they consider they have not consented to and they have a right to their allegations being investigated. Services at **secca** are provided based on the premise that people with a disability have the same rights as all people to have safe and fulfilling sexual lives. At the same time, they must be given the skills and confidence to recognize potentially abusive or harmful situations. This contrasts with earlier approaches, which viewed people with disabilities as asexual 'eternal children', dangerously sexual or predominantly in need of protection from others. We need to remember that people with learning disabilities often like to please others in their responses. In involving and consulting them therefore, it is crucial to probe sensitively beyond their immediate statements. The other side of this issue is that people who have perpetrated may, due to lack of education and counseling, have done so unknowingly. Sadly, too often these individuals have themselves been sexually abused in the past so their perception on appropriate and inappropriate sexual behavior is affected. We recognize that they may need long term psychotherapy to work through their own grief before they can learn new behaviours.



Dual diagnosis

There has been an increase in the number of clients who are presenting at the agency and who have a 'dual diagnosis'. That is, they have an intellectual disability or Autism or Aspergers or Cerebral Palsy and a Psychiatric Disability. Depending on the issue and the diagnosis, **secca** psychotherapists will either be the primary worker or work with another health professional in a consultative capacity. What do we consider has been the reasons we are seeing more of these individuals? Possibly the capacity to distinguish behaviours as psychiatric or other and not just assume all behaviours are as a result of another disability. Possibly the increase in community psychiatry and the deinstitutionalization of people who have a psychiatric disability. Again, this presents the opportunity to more effectively identify behaviours and their likely causes.

Paraphellic Behaviour

Previously referred to as 'sexual deviance'. Those presenting with paraphelias has increased. Why? Possibly inclusion in the community makes it more difficult to hide behaviours. At the same time, more freedom increases the capacity to act out behaviours. These behaviours require expert knowledge and sensitive treatment. We are fortunate at **secca** to have two psychotherapists who have training in Sexology..



Internet

What a bonus this has been for our clients! They can now access information on the internet, go on face book, join chat rooms, play computer games. **secca** has recently purchased two I Pads that our psychotherapists use with clients in sessions. The applications available are highly beneficial for engaging our clients in learning about life development changes, appropriate behaviours. The flip side (isn't there always one) to the revolution in technological advances is the increase in referrals of clients who have accessed R or X rated games, R or X rated sites, become involved in chat rooms with no awareness of the danger in which they may place themselves, and cyber bullying.

Mobile Phones

Another great technology for our clients. But..... education and awareness about how to use this appropriately is essential. The capacity to download sexually explicit information, to photograph or be photographed, run up huge telephone accounts, become 'nuisance' callers is, as with the wider community, always present but with our clients, the over-riding desire to be accepted and liked frequently leads them to at risk behaviours.

Education stream

secca is now well established within the disability sector as a provider of high quality, comprehensive education workshops and seminars. In the last twelve months 22 workshops were conducted. We have a Community and Professional development workshop calendar that is generated every six months. The workshops cover the topics of "Sexuality and Disability", "Protective Behaviours and Boundary Setting", and "Menstrual Management, Personal Hygiene & Sexual Health". We also conduct workshops and seminars in response to request for specific topics. These request come from community, non-government and government agencies working with disability.



Our educators travel within the metropolitan area, as well as regional and remote areas to conduct these workshops. Currently we are training teachers from those schools that purchased one of **secca's** Sexuality Concept Boards. Just like our counseling service, the requests for education and training exceed our capacity to meet them. We perceive the workshops as providing a valuable alternative to support workers who are waiting on **secca's** psychotherapy services for their clients. Information and strategies for dealing with a number of issues related to sexuality, sexual health and disability can 'contain' what could otherwise become a volatile situation while a referral is being processed. Currently **secca's** wait list for psychotherapy services is six weeks. At times the demand has been so great that the wait list has been to a 4-6 months.

Web-page

secca's web page is a valuable aid not only for people who live in the remote and regional areas of Western Australia but also for people in the metropolitan area who are unable to come into our premises. The site gives people the opportunity to the most current information about **secca**, the education programmes, our library resources, and our newsletter. Referral for Services forms can be also be accessed through our web site.

Resource Library Service

From a small three shelf bookshelf with limited resources **secca's** library has grown to become a comprehensive and current resource library. We have a delineated large(ish) area in our office which is wheelchair accessible for members to browse. It is electronically catalogued and a lap top is provided for members to do resource searches. It is also available to members on-line. This has been a great advantage for those people who live in regional and remote areas.



Funding for secca's resources comes from the small amount of income generated from our workshops and seminars. Needless to say we are extremely proud of what we have achieved and what we can offer.

Future

So, back to the future.

- **secca** perceives as both a challenge and a priority that we continue to meet the needs of our clients and their carers by providing high quality psychotherapy and education to people who have a disability, their families and significant carers. We know that issues will continue to emerge as people with a disability identify their need and their right to learn more about relationships and sexual health.
- We need to assess the needs of people with a disability for human relationships and sexuality education. Little work has been carried out in Australia on the sexual health needs of this client group.
- We will increasingly be using technology to reach our clients, families and their support workers. I envisage the use of video counseling and video education/consultancy to increase as we make services more available to those in the regional and remote areas.
- The needs of parents and carers are a key issue. Future action could include developing more resources to help parents and carers talk to young people with a disability about sexuality and sexual health and wellbeing. This should make explicit the risks of abuse that people are exposed to if they are not supported by those around them to explore and develop confidence around issues of sexual health and relationships.



- Identifying resources to be developed to use with clients that will enhance the sexual health and the human relationships and sexuality education of people with a disability.
- Continuing to develop ways to support professionals. We know little about how equipped health professionals are to promote the sexual health and wellbeing of people with a disability. Being available to increase awareness of these issues by providing training at an undergraduate level would, we consider, be highly beneficial.
- Advocacy for people who have a disability to be recognized as a vulnerable group when policies, health initiatives are being developed is an integral role of the agency. By being involved in a consultative capacity, **secca** could assist in highlighting ways of making information accessible for this group.
- Cyber issues – internet dating, cyber bullying and predators. How do we prepare people with a disability for these? We must acknowledge that social networking is the preferred method of communicating among young people and fast becoming so for the wider community. We see we have a role in enhancing the skills of people who have a disability so they can make informed decisions when using this form of communication.
- Sexual Surrogacy is an issue that has had some attention in Victoria and New South Wales. Again, as people who have a disability identify they have a right to express their sexuality and that to exercise this right may require some innovative approaches, and because of the information available to them through the internet about what services are currently



available nationally and internationally for people who have compromised mobility, I can see that this will be a topic that will need to be addressed.

- Parenting classes for people who have a disability I would hope will become available in school and community education settings. Currently there seems to be some reluctance to address parenting by a person or couples who has a disability. This means that often the only education available to them is whatever the latest theme in the soaps is. As one of my colleagues said during a particular season when both *Neighbors* and *Home and Away* had young couples becoming pregnant “those soaps have a lot to answer for”. Why is it that we consider that people with disabilities might have education regarding sexuality and human relationships but education regarding parenting is taboo? What of the research conducted by people such as Dr Gwyneth Llewellyn at the University of Sydney about parenting for people who have a disability? Many years ago she and her colleagues had developed a board game for people with a disability entitled “Safe Parenting”. Sadly, lack of funding meant it could not be produced. What prevents us from addressing this highly contentious and very real issue?
- Realizing that our services continue to grow and expand and that the need for our capacity to provide them is essential. I think that as a 20 year old we need to have ‘our own room’ so to speak. This may mean developing a ‘satellite office’ of secca in a geographical area so the stress many families experience as a result of travelling long distances to have their son or daughter attend sessions in West Perth will be ameliorated. This will be a challenge for both us and our funders.



- The ‘Baby Boomers’ have social analysts reeling as they contemplate the demand for services for this ageing group. People who have a disability will be highly represented in this group. This will, in turn, challenge all of us who are working in the disability sector. **secca** will not be an exception. We are already investigating how we can best resource counseling and education tools for issues such as menopause and men’s health.
- Finally, **secca** has 20 years of accumulated knowledge and an understanding of the needs for people with a disability. This must be harnessed and capitalized on.

Before I finish, there are people to whom I would like to give my thanks.

Firstly, **secca** is managed by a voluntary Board. The interest, support and enthusiasm of a Board of Management provide the mainstay to an organization. My gratitude to the many people who over the years have agreed to contribute their time in this capacity. Some have stayed for one or two terms others have been with the agency for many years. All have been resolute in their task of supporting the agency. I thank them for their wise counsel and direction.

Secondly, an agency such as **secca** could not function and survive without quality staff. We have reached a point where we can claim to have staff whose professionalism, ethics, integrity and commitment to the disability sector has contributed to **secca’s** success. To the team, thank you, we couldn’t have done it without you.



Thirdly, my thanks to our funders; the Disability Services Commission and the Department of Health. Through twenty years continued funding they have demonstrated their confidence in us and the services we provide.

And last but by no means least; I would like to thank our clients. They consistently remind us of why we are here and what we want to achieve.

Thank you.

