



Speech 4 April, 2014

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**National Clinicians Network WA Forum 2014**

Thank you and good morning everyone.

Before I start, I would like to pay my respects to and acknowledge the traditional owners and elders of this land on which we meet.

I would also like to thank the National Lead Clinicians Group for inviting me to speak at this event.

Today's forum provides a valuable opportunity to share ideas about how we can improve health outcomes for young people – both those transitioning to adult care and young people more generally.

I hope today's conversations will add to the momentum for a stronger focus on young people's needs in our health system.

Young people's health is an important topic to me as Commissioner for Children and Young People.

As an independent Commissioner I report directly to Parliament and my role is broadly to monitor and promote the wellbeing of children and young people, and to advocate for policies and services that strengthen their wellbeing.

Another important function of this role is to promote the voices of children and young people, as well as their participation in the making of decisions that affect their lives.

The Commissioner must have special regard for children and young people who are vulnerable or disadvantaged for any reason, including chronic illness, disability or complex health care needs.

Underpinning all of the Commissioner's work is seeking and listening to the views of children and young people and drawing on the best available research and evidence.

These two strategies have been the basis of previous work by the office, such as research and reports on children and young people's wellbeing, an inquiry into mental health, and consultations with children and young people with disability.

Most recently, youth health has been a priority area of focus for the office and today I would like to share with you some of the outcomes and findings from this work.

I will begin by discussing some broader issues around youth health before focusing on the topic of transition from child to adult services.

In 2013, the former Commissioner, Michelle Scott, began a project to consider whether more could be done to improve youth health policies and services in WA.

This was prompted by concerns from some young people, parents and clinicians about the way health services were being coordinated and delivered – concerns that were similar to those previously raised in the office's mental health inquiry.

The Commissioner began a project to consult with young people and stakeholders and review previous research about youth health.

The project focused on health policies and services to give it a feasible scope, although clearly there are other very important youth health issues, such as around

the social determinants of health and the illnesses and conditions affecting young people.

As part of the youth health project, the office consulted more than 1,000 young people from diverse backgrounds in WA about their experiences with health services, their views on what works well and where they would like to see improvements.

We ran eight focus groups and an online survey for young people aged 13 to 18 years, in line with the Commissioner's legislative mandate, which extends to people up to 18 years.

We recognise that health policy and service issues for adolescents extend beyond 18 years and into their 20s, and the project's findings and outcomes are relevant to this broader age group.

As well as consulting with young people, my office spoke with clinicians and other stakeholders in the public health and community sectors about their views and priorities around youth health.

We contracted the Telethon Kids Institute to provide us with a comprehensive literature review that identified policies and programs that have been shown to improve health outcomes for young people.

This work culminated in several publications that I released earlier this week, including a position statement on youth health, a publication that captures the views of young people we spoke with, and a report from our consultants, the Telethon Kids Institute and the Social Research Group.

My position statement on youth health advocates for improvements in five priority areas.

At a health policy level, the position statement calls for a stronger focus on young people's needs and a recognition that adolescence is an important and distinct developmental phase.

There is clear evidence that positive physical and mental health during adolescence provides a foundation for lifelong wellbeing.

Young people have specific health needs that stem from the rapid developmental changes they are experiencing.

We also know that young people form health-related attitudes and behaviours that can stay with them for life.

In many respects, adolescence provides a window of opportunity and a 'second chance' to shape positive health behaviours and attitudes that will endure for the remainder of the life course.

At a broader social level, investing in young people's health protects earlier investments into child and maternal health, is socially and economically more effective than dealing with problems in adulthood, and supports the future wellbeing of the population.

This is being recognised increasingly around the world, with growing attention on youth health in global reports, national plans and strategies, and peer-reviewed journals.

In WA, there has not been a strong focus on young people as a distinct target group in public health policy.

In the main, young people continue to be largely grouped with either children or adults when health policies or services are being developed.

There are some exceptions, such as WA's mental health policy, *Mental Health 2020*, which promotes a 'new and comprehensive youth stream approach' for young people up to 24 years.

At a health service level, one example of a dedicated youth service is specialist cancer treatment for 15 to 25 year-olds in some major public hospitals.

While these examples provide useful models for future health service planning in WA, we need a broader youth health framework to nurture a health system that is responsive to young people's holistic needs.

This could be achieved through a stand-alone state youth health policy, which is something the WA Clinical Senate has called for on two occasions, as have other stakeholders.

Such a policy would be based on the principles of effective, youth-friendly health services that are well established in the literature.

The seven 'ACCESS' principles that shape the New South Wales youth health policy provide an example. They include:

- youth participation in service design
- accessibility of services
- collaboration between health care providers
- professional development for clinicians and support staff
- sustainability of services
- evidence-based practice, and
- ongoing evaluation.

The second priority issue my office identified is supporting health professionals to deliver youth-friendly services.

In our consultations, young people said they had generally positive experiences with health services, with around three quarters saying they were helped and treated well and with respect.

When young people highlighted concerns, they mostly focused on discussions about confidentiality, receiving enough information, being linked to other services, being welcomed and made to feel comfortable, and being encouraged to voice an opinion.

There are many factors that influence young people's experiences of services, which either empower them or present barriers to getting help.

Some of the main practical considerations include transport, cost, opening hours, availability of appointments and access to a Medicare card.

Other factors include knowledge about services, discomfort about disclosing health issues, concerns about confidentiality and worries about not being taken seriously or treated with respect.

Of interest, general practitioners were the health professionals seen most by young people, who reported positive interactions with doctors who spoke directly with them and made them feel comfortable.

One young person said, "Independence is a big driver for me. That's the one main reason I love to go, because suddenly you go by yourself and you're the adult. You're now the person they speak to about what is going to happen, not the dummy that gets tested."

Positive experiences for young people can be achieved through a friendly and welcoming approach by service providers, treating young people respectfully, building trust and a relationship, and providing a relaxed physical environment.

Delivering culturally appropriate services is also a consideration for Aboriginal young people and those from culturally and linguistically diverse backgrounds.

There are many examples of training and resources to support health professionals to deliver youth-friendly services.

My position statement highlights the Australian Medical Association's 'Youth Friendly Doctor' Program, the Royal Australasian College of Physicians' *Working with Young People* training resource, and toolkits for general practitioners produced by New South Wales under its youth health policy.

These resources often emphasise taking a holistic approach to young people's wellbeing.

Our research confirmed that holistic wellbeing is an important consideration for service providers, not only because it is a current public health priority, but also because young people consistently express a view of their health that includes physical, mental, emotional and social dimensions.

The integration or co-location of services and effective referral pathways between service providers are other important factors that promote young people's wellbeing.

The third priority area we identified for youth health is information and education to help young people and their families stay healthy, identify problems early, navigate the health system and access services.

Many young people told us they would like more information about health services and resources, and more education about how to access health care on their own.

Young people say they want to receive information in a way that preserves their anonymity, such as online or through school and other group settings.

Families are also an important target for information and education as parents and siblings strongly influence health care decisions for young people.

The fourth priority highlighted in the position statement is the use of data to drive health policies and services.

Some stakeholders have suggested we can improve the way data is collected, shared and used.

Jurisdictions such as New Zealand are setting high benchmarks in this area.

New Zealand's Adolescent Health Research Group has been conducting broad-based youth health and wellbeing surveys since 2000, with the latest survey in 2012 gathering data from more than 10,000 young people.

The New Zealand survey covers a wide range of issues that contribute to the health and wellbeing of young people.

Some of the less obvious topics include ethnicity and culture, spirituality, school achievement and participation, and neighbourhood environment.

The New Zealand data is disseminated widely and used to inform policy and service delivery at both a national and local level.

It is important that we continually review whether our data collection and use are in line with international best practice.

The fifth priority area I would like to discuss with you today is the care of young people in hospitals and other services, which includes issues around transitioning from child to adult care.

In our research, we identified many factors that contribute to young people receiving high quality care.

Young people say that the most important factors are the skills, attitudes and values of the staff they interact with, which includes clinicians as well as administrative and support staff.

Donald Payne, who will be on this morning's panel, highlighted this issue in a recent paper and argued for a greater emphasis on young people in training programs for medical, nursing and allied health professionals.

My position statement also advocates for providing clinicians and support staff with training and resources to help them achieve optimal health outcomes for young people in all settings.

Research shows that other important factors for young people who receive care are social and peer support, appropriate facilities and equipment, referral pathways and integration with other services, and processes for transitioning from paediatric to adult services.

Western Australia is currently investing \$5 billion in health care building projects, including two new hospitals, and this provides a unique opportunity to review our approach to providing care to young people.

To achieve best practice, we need a stronger focus on adolescent health and tailored approaches to the care of young people in hospitals and other relevant health services.

In relation to the transition of young people from child to adult services, we know that adolescence is a challenging time for young people and it can be made more difficult by worries about ongoing health care.

The transition from child to adult services is a key point of vulnerability for young people, as well as their families and service providers, and there are risks if not done well that we lose them during the process.

Problems with transition are known to be associated with poor health outcomes later in life, such as preventable complications and co-morbidities.

For the health system, problems with transition can increase costs and the pressure on resources, and there are also longer term social and economic costs.

In WA, there is evidence that young people have experienced challenges with transitioning to adult services in the past.

Some young people and clinicians have raised this with my office directly.

The challenges are acknowledged in WA Health's *Paediatric Chronic Diseases Transition Framework*, which aims to help health services provide planned and appropriate transition of care.

The Transition Framework states that "paediatric and adult health services frequently fail to meet the needs of young people with chronic illness and disability as they move from one service to another."

It goes on to suggest that the child system does not adequately recognise the growing independence and autonomy of the adolescent, while the adult system does not adequately take into account the physical, psychological and emotional changes young people are experiencing.

Historically, the transition to adult services was regarded as a matter for children's services, but this is no longer the case.

More children are now surviving into adulthood with complex chronic conditions and it is important for adult services to be engaged much earlier in planning for the transfer of care.

The WA *Paediatric Chronic Diseases Transition Framework*, which was developed in 2009, outlines best practice processes and a range of strategies to promote effective transition.

I sense there is an urgency now to get this right and priority needs to be on implementing the Framework.

I would encourage WA Health to continue the work it has begun on developing an implementation plan.

To conclude, I would like to emphasise a key principle for promoting effective transition and, more broadly, for building a youth-friendly health system - which is to involve young people in the making of decisions that affect them.

Young people have unique insights into issues, can offer creative solutions to problems and can help ensure decisions are relevant and sustainable.

It is not rocket science – I think you will find that often solutions are put forward that are relatively simple to implement.

Young people also have the right to say what they think should happen to them and to have their opinions taken into account.

This is explicitly recognised in the United Nations Convention on the Rights of the Child.

For clinicians, this means involving young people in a meaningful way in their health care planning, including the development of transition plans and choice of services.

For service providers and policy makers, young people should be included in planning and decision-making processes to achieve better policies, services and outcomes.

As you move forward with your discussions about improving the transition of care and the health system more generally, I encourage you to seek young people's contributions as a priority.

Thank you.