

Infiltrating the Mainstream – the Queensland Experience

By Chris Howard and Karen Porter

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“I needed some dental work done and decided to go to my local dentist, instead of the one 100km away from the small town I live in. I completed the form that asked me about medical conditions, including whether I was HIV positive. When I handed the form over I asked the receptionist what their policies for privacy and confidentiality were, with the added warning my form contained information that was very ‘private and confidential’. The receptionist assured me such policies existed and were adhered to. I felt somewhat confident in the protection this afforded me. That the receptionist was also my neighbour however was not reassuring. It struck fear in me.”

In the current climate of fiscal conservatism, it is possible to foresee HIV-specific service delivery in Queensland impacted by reduced public health spending and retracted human and financial resources. It is timely, therefore, to examine ‘mainstreaming’ HIV service delivery in light of the factors likely to influence successful mainstream service engagement, at different social-ecological levels of the health care system. An increase in referrals to mainstream services in Queensland may call for a new focus on ‘mainstreaming’ HIV.

Positive Directions, A program of Anglicare Southern Queensland, was formed in October 2004 as a result of St Luke’s Nursing Service successful tender for the client care and support tender of Queensland Health (QH). This was one of nine new tenders developed by QH in response to changing needs in the HIV community sector and was the first time QH had opened funding for these services to competitive tender (prior to this, these activities were undertaken by the then Queensland AIDS Council (QuAC) through direct grant).[1]

At that time, Queensland was the only state in Australia that opted for such a model of care for individuals living with HIV and since then Positive Directions has remained the only organisation of its type in Australia.[2] Our model is a collaborative, coordinated and integrated approach to service provision, operating with a person-centred service culture that delivers outcomes for people living with HIV through a suite of holistic supports that include individual and group self-management education; referral to other services based on identified needs; and care coordination services that aim to facilitate a seamless transition along the care and support continuum.

The nature of the HIV epidemic is changing: people are living longer with HIV due to increasingly effective combination antiretroviral therapies. As the epidemic evolves, so do the clinical and social support needs of people living with HIV. As a result, the focus of care for many has shifted to managing co-morbid conditions associated with long-term HIV infection, such as stroke, cardiovascular disease, kidney and liver diseases.[3]

The current model for the delivery of HIV treatment is based on accessing prescriptions for combination antiretroviral therapy through three major routes: GPs in the community who are trained s100 prescribers; HIV

specialists providing outpatient or inpatient care; and doctors at sexual health clinics.[4] While complicated clinical care is best provided by specialist and experienced HIV clinicians, traditional health care that builds largely on acute, episodic models of care is ill equipped to meet the long-term and fluctuating needs of those with chronic conditions. The complex management of chronic conditions requires prepared, informed and motivated individuals, multidisciplinary health care teams, and broader community supports.[5]

Positive Directions is tasked to develop care coordination responses to facilitate access to a range of services that are appropriate to the complex health and welfare needs of people living with HIV throughout Queensland. For people with HIV, a lived experience of stigma and discrimination and the fear of public exposure and vilification can negatively impact the willingness to engage with mainstream services.[6] The protection that private and confidential HIV-specific services afford HIV-positive people is highly valued by those who are particularly fearful of and vulnerable to social alienation, including those living in regional, rural and remote communities.[7]

In recent years researchers have also examined existing and potential trends in the location of the HIV-positive population in Queensland and warned of the implications for service delivery and development. Their findings suggest that while differences in service use appear to be related to geographic accessibility of different service types, there may be other important social, economic and cultural factors, such as ageing and socio-economic pressures involved. [8]

Chronic conditions require complex models of care, involving collaboration among practitioners, professions and institutions that have traditionally worked independently of each other.[9] Accordingly, Positive Directions responded to this need through the development of an integrated, more coordinated approach to service delivery informed by the Social Ecological Perspective.

The Social Ecological Perspective is a theoretical framework that considers the inter-relationship and multiple influences of elements in society on the individual at four levels: the individual level (including biological factors and personal history); the interpersonal level (a person's peers/social circle), organisational and community (such as a person's workplace and neighbourhood) and systemic factors (including societal/cultural norms).[10],[11] When HIV service delivery is viewed through this perspective it is clear that a broad range of environmental factors directly affect the individual; all these need to be considered to achieve more effective and better coordinated services across the continuum of care.

Using this perspective as its foundation, Positive Directions constructed a service model that aims to integrate education and action on the different social ecological levels to ultimately achieve continuity of care and better health and wellbeing outcomes for our clients. This approach seeks to ensure that support and education is delivered to people and practitioners operating on different levels of the system in a logical, connected and timely manner.

Self-management education focuses on the skills, knowledge, self-efficacy, motivation, resources and information required for an individual to self-determine and actively work towards and achieve health and wellbeing goals.[12] This core component of our service delivery model works to provide people living with

HIV information that will assist them to self-manage their chronic condition and adopt health and wellbeing enhancing behaviours. To bring about the best possible outcomes for people living with HIV we are skilling staff to deliver a range of Chronic Condition Care Models including the Health Change Australia's Model of Change, the Stanford Model (HIV Adaption), and Brief Interventions for Chronic Conditions (an initiative of Anglicare Southern Qld) that are complementary models suited to different service delivery and cultural contexts (i.e. individual/group; clinical/psychosocial support).

Positive Directions has begun work to implement this self-management programming model across Queensland with the aim to provide individuals with flexible, individually tailored packages of support that can include: individual self-management support; group self-management courses; group wellness programs (mental health; nutrition and exercise); and other community-based life-skill orientated activities. A *Coordinated Activity Plan* is developed in response to the identified needs of each individual, ensuring engagement is structured towards developing the skills, knowledge, self-efficacy and motivation required for self-determination. Grounded in and driven by the principles of self-management, the goal of service delivery is to empower and prepare individuals to manage their health and health care.

On interpersonal and organisational levels, the interdisciplinary members of Positive Directions work to provide information to relevant mainstream agencies/service providers on HIV issues and service provision, ensuring such information will enhance sensitivity and understanding.

In 2002, UNAIDS declared 'mainstreaming' an essential approach for expanding multi-sectoral responses to HIV/AIDS [13]. The concepts of mainstreaming were in use in other spheres (such as education and gender) but were relatively new to the area of HIV/AIDS and most proponents of the approach were quick to point out mainstreaming is not an end in itself, but a means to an end. Mainstreaming is a range of strategies implemented to ensure HIV is central to all programmatic activities – policy development, research, advocacy, resource allocation, and planning, implementation and monitoring of programs and projects.[14] The objective of mainstreaming efforts is to stimulate all entities within the health system to take HIV into account in program development and delivery. In this way, mainstreaming is defined as a strategy for making the concerns and experiences of people living with HIV an integral dimension of the design, implementation, monitoring and evaluation of policies and programs in all political, economic and societal spheres.

The bulk of the literature examines the success of mainstreaming HIV into development and humanitarian programs in developing countries to enable the expansion and acceleration of HIV/AIDS responses. In under-developed countries mainstreaming processes ensure HIV/AIDS shapes and influences the core activities of its institutions, agencies and programs.[15] In Queensland the concept of mainstreaming can be applied as a way of modifying the operational practices adopted by those working at the different levels of policy and practice in a wide variety of sectors, such as aged care, education and employment.

Appropriate HIV mainstreaming is required in key Queensland sectors, particularly education, employment and aged care to engage more people, practitioners, program developers and policy makers. The intensification of mainstreaming efforts in Queensland will assist to bring greater clarity to roles and

responsibilities within the national response to HIV. Mainstreaming also requires sufficient funding, and there must be the necessary commitment of appropriate human and financial resources to realistically undertake mainstreaming efforts at all levels. There must be the commitment to partnerships and building positive relations amongst the various sectors and levels in this regard.

In 2010, researchers from the Australian Research Centre in Sex, Health and Society, called for a balance to be struck between mainstreaming HIV service delivery and increasing the accessibility of HIV-specific services.[16] To achieve this balance, a proportion of service delivery must transfer to mainstream providers, and this successful transition requires an increased focus on 'mainstreaming' HIV. Mainstreaming cannot develop of its own accord. Systemic advocacy, wide-spread sensitisation and individual capacity building must occur in order to place people in a better position to undertake 'mainstreaming'.

Mainstreaming highlights the importance of broadening and strengthening strategic collaborative partnerships between government sectors, community and health service providers and professional practitioners' at all social ecological levels of the system. It is anticipated the mainstreaming efforts of Positive Directions can ensure mainstream services in Queensland are better positioned to respond to an expected growth in the number of people living with HIV who may be experiencing chronic co-morbid conditions that require complex levels of care and support.

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