

Review of Youth Best Practice

**AUG
15**

A review of the best approaches to providing social support and development for young people living with HIV in Australia and internationally.



ACKNOWLEDGEMENTS

This review would not have been possible without the involvement of all those who generously gave up their time, expertise and experience to help inform Living Positive Victoria's approach to supporting and developing young people living with HIV. The openness, willingness and patience they showed despite collaborating within pressing schedules and the occasional frustrations of long distance communication is warmly acknowledged.

Thank-you to the following individuals and organisations:

Consultant and Writer

Timothy Krulic

Consultation Participants

Body and Soul Charity (UK)

The Institute of Many (AUS)

The AIDS Committee of Toronto's Positive Youth Outreach (CDN)

Youth Co, (Vancouver CDN)

Morningside Clinic's Young Adults Program (USA)

Project STAY at the Harlem Health Center (USA) and

Body Positive. (NZ)

The author also wishes to thank all of the staff at Living Positive Victoria for their involvement and encouragement while conducting this review. Special thanks is reserved for the Manager of Health Promotion, Suzy Malhotra and Chief Executive Officer Brent Allan, for their generous and understanding supervision, guidance and mentorship through what was a steep learning curve.

© Copyright 2015 Living Positive Victoria

Living Positive Victoria

Suite 1/111 Coventry Street

Southbank VIC 3006

Tel: 03 9863 8733

Web: www.livingpositivevictoria.org.au

LIST OF ABBREVIATIONS

ACT AIDS Committee of Toronto

AIDS Acquired Immune Deficiency Syndrome

BAY Bay Area Young

CALD Culturally and linguistically diverse

HIV Human Immunodeficiency Virus

LGBTI Lesbian, Gay, Bisexual, Transgender, Intersex

MSM Men Who Have Sex with Men

NAPWHA National Association of People with HIV Australia

OBB Outstanding Beautiful Brothers

PLHIV People Living With HIV

PYO Positive Youth Outreach

TIM The Institute of Many

STAY Services to Assist Youth

YAP Young Adult Program

TABLE OF CONTENTS

Acknowledgements	i
List of Abbreviations	ii
Executive Summary	1
1.0 Introduction	5
1.1 Young People and HIV in Australia and Victoria	5
1.2 Living Positive Victoria and Young People	6
1.3 Current Youth Programs and Services	6
1.4 Review Overview	7
1.5 Review Aim	8
1.6 Review Objectives	8
2.0 Methods	9
2.1 Region Selection	9
2.2 Evaluation Framework and Questions	9
2.3 Data Sources and Collection	10
2.4 Challenges and Limitations	11
3.0 Findings	12
3.1 Overview of Social Support for Young People Living with HIV aged 18-30.	12
3.2 Services under Review	12
3.3 Key Evaluation Question 1: Accessibility	15
3.4 Key Evaluation Question 2: Appropriateness	18
3.5 Key Evaluation Question 3: Effectiveness	21
3.6 Key Evaluation Question 4: Capacity Building	22
4.0 Conclusion and Recommendations	25
4.1 Key Recommendations	25
References	27
Appendices	28
Appendix A	28
Appendix B	30

EXECUTIVE SUMMARY

This review into youth best practice was inspired by Living Positive Victoria's commitment to enable and empower all people affected by and living with HIV in Victoria, including young people. A report of this nature necessarily focuses on the successes of other organisations working in a diverse range of regions, priority populations and contexts to achieve these aims. Yet it also provides opportunity to reflect on how they can be most effectively realised in Victoria. It follows that several of the initiatives and interventions employed by Living Positive Victoria are consistent with the best practices identified in this report. However, there remains scope for improvement as many present themselves as highly transferable to young people living with HIV in Victoria.

A broad survey of organisations embodying the greater involvement and meaningful engagement of people living with HIV and AIDS within the selected regions reveals that relatively few provide social support services specifically catered to young PLHIV aged between 18-29. Most incorporate young people within their general support services for PLHIV, or do not recognise young PLHIV as having separate needs or requirements to at risk populations of young people.

Of the services providing social support specifically for young PLHIV identified by this survey, several were unable to contribute to the review citing a lack of resources and time. The remaining organisations were subjected to an evaluation that focused on how successfully they provided social support for young PLHIV that is accessible, appropriate, effective and builds capacity. These criteria are recognised as essential for health promotion interventions and reflect Living Positive Victoria's development of programs and services in relation to the goals outlined in the strategic plan 2014-2017.

Information was generated through semi-structured interviews with key program coordinators and facilitators, or their responses to surveys as well impact and annual reports. Quantitative secondary resources supplemented the qualitative data gathered in interviews where necessary to add rigour and to address differences in priority populations between regions and contexts. What follows is a summary of the key findings from these data sets, separated into the designated evaluation criteria.

Accessibility

- Strong partnerships with sexual health services alongside streamlined referral systems were common among services that were best able to reach young PLHIV. Diagnosis is also recognised as a prime opportunity to connect young people to services.
- Initial one-on-one peer support and orientation into group-based services for young PLHIV with high needs creates better awareness of the type of support available while reducing stigma and fear of disclosure as barriers, with participants reporting young people are much less likely to return to or even make contact with a large group on their own.
- Communicating and extending support groups online through social media significantly increases access, as young people are open to engaging with and are easy to reach on sites such as Facebook, while they also reduce temporal, spatial and geographical barriers.
- Applying strict restrictions on age limits access to young people with high needs.
- Subsidising the cost of activities, food and travel represents a strong incentive to attend and reduces barriers for priority populations with high economic needs.

Appropriateness

- All contributors recognised peer led and based as key to ensuring services remain appropriate to the needs of the priority population.
- Spaces where young people feel comfortable and safe are confidential, non-judgemental and driven by peers.
- Screening and induction of new members into services helps foster spaces that remain peer based, inclusive, safe and appropriate to their needs.
- Young people are comfortable using social media, for whom sites such as Facebook are a routine part of daily life, offering a high level of privacy within “secret group” settings.
- The negative perception of traditional support groups leads young PLHIV to believe they are inappropriate to their needs.
- Advertising and promotional material featuring videos, photographs and testimonials of young people of diverse gender and cultural appearance promote inclusivity and provide faces and voices with which young PLHIV can identify.

Effectiveness

- Group peer support was recognised by all contributors as an effective way of achieving increased and sustained social inclusion, resilience and engagement with community, enabling young PLHIV

to create their own support networks and focus on the issues most relevant to them.

- Online extensions of support groups on social media sites such as Facebook effectively promote social inclusion, with a high level of engagement, emotional and social support, social networking and relationship building behaviour evident within groups utilising them.
- Peer discussion effectively communicates health promotion messages and can be complemented by guest speakers, who provide variety and the assuredness of expert opinion.
- Training young PLHIV to perform peer education and outreach effectively builds confidence and engagement with community, empowering young PLHIV to become educators and encouraging collaboration with peers and service providers.

Capacity Building

- Training programs focused on leadership and developing a greater understanding of LGBT and other at risk communities and priority populations are highly transferable to young PLHIV, add value to their experiences with services and encourage engagement with the HIV and sexual health sector.
- Volunteer, work placement and internship opportunities within both services and matched external partners provide practical and tailored professional experience and skills development for young PLHIV.
- Peer outreach and education training builds confidence and engagement with community but is also recognised by several contributors to effectively develop leadership capacities.
- Practical workshops on professional, CV writing and interview skills, as well as financial management recognise and address the added barriers young PLHIV with high needs face to becoming productive members of the community.

Recommendations

1) Strengthen partnerships with sexual health clinics and HIV sector services to develop greater awareness of Living Positive Victoria's youth services, encourage further access to priority populations and enhance referral pathways.

2) Formulate standards for assessing the needs and suitability of new members of the support group, one-on-one orientation for new members with high needs and a code of conduct to promote a space that remains peer based, safe, confidential, non judgmental and inclusive.

3) Develop promotional material that emphasises peer driven

approaches, avoids the perception of traditional support groups, is inclusive of diversity, features voices and faces of young people and utilises online and social media. This includes promoting the Facebook group as a primary means of internal communication and online extension of the support group to increase reach, access and engagement.

4) Provide volunteer and mentor opportunities, especially peer outreach and education at Living Positive Victoria and develop internship and work placements with external partners to provide tailored professional experience and skill development.

5) Explore Totally OutRIGHT as a model to develop a sexual health leadership program for young PLHIV to encourage greater involvement with the HIV and sexual health service sector.

1.0 INTRODUCTION

1.1 Young People and HIV in Australia and Victoria

In comparison to other regions within the scope of this review, Australia maintains relatively low levels of HIV infection, with an estimated 27,150 people living with HIV at the end of 2014¹. The epidemic is predominantly concentrated among gay men, with smaller but significant epidemics emerging among people travelling and working in high prevalence countries, some culturally and linguistically diverse communities, injecting drug users, sex workers and their clients and Aboriginal and Torres Strait Islander communities.²

Young people do not only span these at-risk groups, but for a number of factors such as increased duration between sexual debut and the formation of long-term partnerships, low rates of condom use, and poor access to services, they are particularly vulnerable to sexually transmissible diseases, including HIV.³ As such, they have been recognised as a priority group since the 2010 National Sexually Transmissible Infections Strategy and remain a target population of the Victorian Department of Health and Human Services.

In Victoria, by the end of 2013 there was an estimated 6,885 people living with HIV.⁴ The state has had the largest increase in new diagnoses over the last 10 years (40 per cent), and although the rate has remained stable in this time, a rise to 5.5 cases per 100,000 population in 2013 represented a 16 per cent increase over the previous year.⁵

The median age of men who have sex with men (MSM) at HIV diagnosis increased steadily from 34.5 years in 2000 to 38.8 years in 2007 across the state. However, a significant decline in 2008 to 35.3, which was sustained in 2009 at 35, represented the first observed decline in age at the time of HIV diagnosis in Australian since the introduction of HAART, suggesting increased levels of HIV

¹ "Annual Surveillance Report 2015: HIV, viral hepatitis and sexually transmissible infections in Australia" (The Kirby Institute, 2015).

² Department of Health and Human Services, Victoria, Australia, "Sexual Health Delivery: Sexual Health," guidelines, accessed September 7, 2015, <http://www.health.vic.gov.au/sexualhealth/priority.htm>.

³ Ralph J. Di Clemente et al., "Psychosocial Predictors of HIV-Associated Sexual Behaviors and the Efficacy of Prevention Interventions in Adolescents at-Risk for HIV Infection: What Works and What Doesn't Work?" *Psychosomatic Medicine* 70, no. 5 (June 2008): 598–605,

⁴ "Victorian Prevention Epidemiology and Surveillance - HIV Update" (Department of Health and Education, Victoria, Australia, July 2014).

⁵ "Annual Surveillance Report 2014 HIV Supplement."

transmission and risk-taking behaviour among younger MSM.⁶ In the years following 2010 this decrease has continued, and remained at 34 years in 2013 before dropping to 31.5 in 2014.⁷

1.2 Living Positive Victoria and Young People

Living Positive Victoria is a not for profit, community based organisation representing all people living with HIV in Victoria since 1988, and is committed to the advancement of human rights and wellbeing of all people living with HIV.

Living Positive Victoria shares the vision of the National Association of People Living with HIV Australia (NAPWA) of a world where people living with HIV live their lives to their full potential, and their mission is to enable and empower all people affected by and living with HIV in Victoria to be part of the response that seeks an end to the HIV epidemic.

Inclusion is a core principal of the organisation, implementing the following statement into the 2014-2017 Strategic Plan:

*Living Positive Victoria represents all people living with HIV in Victoria, regardless of gender, sexuality, age, disability, ethnic group or national origin. We work to unite all people living with HIV in our common cause.*⁸

So too, are the core principals of involvement and engagement, including a declaration that 'people living with HIV have a right to be directly involved in the response to HIV in Australia' and a commitment to 'provide leadership to the HIV response, informed by the experience of living with HIV'.⁹

These principals, vision and mission commit Living Positive Victoria to not only provide support and representation for young people, who contribute to the diversity of people living with HIV in Victoria, but to also empower them to meaningfully participate at all levels of the organisation's response to the epidemic, including governance, staffing, volunteer and community structures.

⁶ Carol El-Hayek et al., "The Changing Age Distribution of Men Who Have Sex with Men Diagnosed with HIV in Victoria," *Medical Journal of Australia* 193, no. 11 (2010),

⁷ The Department of Health and Education, Victoria, Australia (Unpublished, October 2015).

⁸ "Strategic Plan 2014-2017" (Living Positive Victoria, 2014).

⁹ Ibid.

As such, Living Positive Victoria has endeavoured to achieve representation of young people within its board of directors and favours peer-led approaches in providing support for young people through a support group for young gay men, Generation Next Guys, facilitated by peers.

1.3 Current Youth Programs and Services

Young people are welcome across all of Living Positive Victoria's program areas, however, the only program targeted specifically towards young people aged 18-29 is Generation Next Guys. This support group for gay and bisexual men in their 30's or younger was developed in response to the expressed needs of younger members of Living Positive Victoria for a space of their own with their peers.¹⁰ A high proportion of young PLHIV are represented in Phoenix, a workshop for the newly diagnosed, as well as the Positive Leadership Development Institute Australia, suggesting demand exists among young PLHIV for these services.

Generation Next Guys provides peer support, facilitating social events, health promotion, and a safe and confidential space for young members where they can feel included and talk about issues relating to the disease and their diagnosis which they might feel uncomfortable discussing with health professionals or their existing support networks who are often unfamiliar with the lived experience of HIV and its stigma.

Meetings are held monthly and consist of both structured discussions facilitated by volunteers who identify as peers, and social gathering and events organised by participants. A "Secret" Facebook group is used primarily for administrative purposes, while the main medium of contact for the group is via email communication.

1.4 Review Overview

In May 2015 Living Positive Victoria commissioned an independent contractor to conduct a survey of initiatives for supporting and developing young people living with HIV and to assess their effectiveness, as well as the viability of translating these initiatives to the Victorian context and the agency's priority populations.

¹⁰ Kate Maddaford, "Needs Assessment Report" (Living Positive Victoria, June 2014).

Living Positive Victoria is committed to providing excellent health promotion programs and services that inform and enable wellbeing and support the diversity of people living with HIV in Victoria, including its young people. The agency is also committed to basing its programs on evidence and investing in innovation and practices that show promise for change. In line with these commitments this review will inform the development of Living Positive Victoria's approach to providing social support and development to young PLHIV.

Based on the agency's strategic aims and objectives, this review has focused on innovative and leading peer-driven organisations that support the development and leadership of young people living with HIV within Australia, New Zealand, Canada, the UK, the San Francisco Bay Area, and New York.

1.5 Review Aim

To determine what are the most effective interventions Living Positive Victoria can make to provide social support and leadership development for young PLHIV.

1.6 Review Objectives

- 1 – To gain an overview of current programs and approaches to supporting young PLHIV in Australia and internationally.
- 2 – Identify which programs and their target populations are most relevant to Living Positive Victoria's aims and priority, and what interventions they employ.
- 3 - Assess the outcomes of these interventions and identify possible improvements.
- 4- Identify and explore potential barriers in translating interventions to the Victorian context
- 5- Determine how Living Positive Victoria's current programs could benefit from implementing more effective interventions
- 6- Provide recommendations on what new programs and interventions Living Positive Victoria should consider to further develop personal growth and leadership capacities of young PLHIV.

2.0 METHODS

This review's methods were developed through ongoing consultation with the health promotion manager with input from the board via the executive officer. The review consisted of a broad survey of services advertised online targeting young people living with HIV aged 18-29 within the selected regions. In line with Living Positive Victoria's mission and strategic objectives, this focused on peer-driven organisations that support the development and leadership of PLHIV. This was followed by the collection of qualitative data through semi-structured interviews and survey responses from service providers, as well as published impact reports and annual reports. Quantitative data was drawn upon when necessary to provide rigour and address differences in regional contexts and priority populations. Evaluations were then performed based on this information. This approach allowed for this review to gain both an overview of the types of interventions and practices used to support and develop the leadership capacities young PLHIV in a range of regions, as well as an in-depth evaluation of their accessibility, appropriateness, effectiveness and capacity to develop young PLHIV.

2.1 Region Selection

For the purposes of identifying the most effective initiatives for supporting young PLHIV relevant to Living Positive Victoria's priority populations, this review has focused on community health and people living with HIV organisations pursuing established peer-led efforts to support and develop young PLHIV.

2.2 Evaluation Framework and Questions

The review implemented an evaluative framework to assess which initiatives worked best to provide support and development for young PLHIV. The framework is divided into the broad themes of accessibility, appropriateness, effectiveness and capacity building to make judgements about selected programs and services. These dimensions are recognised as essential for health promotion interventions directed towards enabling people to take action, with the purpose of strengthening the skills and capabilities of individuals and groups.¹¹ They also reflect Living Positive Victoria's goals for the development of its health promotion programs outlined in the strategic plan 2014-2017.

¹¹ Don Nutbeam, "Evaluating Health Promotion—Progress, Problems and Solutions," *Health Promotion International* 13, no. 1 (January 1, 1998): 27-44.

1. Accessibility: How do programs and services most effectively reach young people living with HIV?
2. Appropriateness: What makes services suitable to young people living with HIV?
3. Effectiveness: How do programs and services achieve their expected goals and objectives for providing social support for young PLHIV?
4. Capacity Building: Do programs and services accommodate for further/graduated personal growth and developed capacities of young clients?

The questionnaire that was either completed by participants or formed the basis of interviews was based on these questions and can be found in Appendix A.

2.3 Data Sources and Collection

Data was collected from both online resources and published impact and annual reports made available by agencies, as well as from staff working directly with young PLHIV through services and programs.

The initial survey of programs was conducted through a broad online search of peer-led services, groups and programs providing social support and leadership development catered specifically to young PLHIV aged 18-29 within the selected regions. Google.com was the search engine used, and search terms included "youth," "young," "HIV services," "HIV support groups" and the names of various cities and states within the selected regions. Following online searches, local agencies were also contacted for referral of suitable services for young PLHIV to cover services that may be missed or do not have a large online presence.

Contact was made with key personnel at agencies with either direct involvement with services for young PLHIV, or an in-depth knowledge of their operation via email. The evaluation questionnaire was then either completed by respondents (see Appendix A) or a semi-structured interview was conducted based on the questionnaire either in person or over video call. Correspondence of the questionnaire and interviews were conducted throughout June and July 2015. Interviews were then transcribed for accuracy by the interviewer. Impact and annual reports provided further data about programs. Key themes and best practices and initiatives were identified in this way, as well as providing a thorough description of how each service operated. Quantitative secondary resources supplemented the qualitative data gathered in interviews where necessary to add rigour and to address differences in priority populations between regions and contexts.

2.4 Challenges and Limitations

Conducting searches online posed the risk of overlooking suitable services and programs for review without a large online presence or were missed by the search terms. This was mitigated by seeking referrals from key contacts in local agencies and peak organisations.

Contact with service providers internationally posed a significant challenge. The majority of communication was contained to email correspondence due to the challenges time zones and costs such large distances created. This notably delayed responses, and the lack of personal contact further discouraged service providers from participating in the review. Phone calls were made in order to counter these difficulties if key personnel were unable to respond.

Several service providers expressed difficulty in responding to the questionnaire, citing a lack of time and resources to spend on its completion given the underfunded and volunteer reliant environment many non-for-profit and community based organisations work within. To accommodate for these pressures, a shorter questionnaire (Appendix B) and short Skype interviews were offered as alternative contributions to the review. A number of services identified through online searches were also uncontactable, further limiting the number of programs providing additional information. Of the ten services under review, only six were able to provide further information by responses to surveys or an interview. An additional two agencies contacted about advertised services for young PLHIV also advised these services were no longer available and were excluded from the review.

Finally, this review draws selectively from regions, as well as organisations that are peer-driven and support the development and leadership of PLHIV. It offers an assessment only of what are the best practices for supporting young people in line with Living Positive Victoria's mission and objectives for program and service development, rather than an exhaustive or comprehensive assessment of all programs available to young PLHIV.

3.0 FINDINGS

The findings from the broad survey of services providing social support for young PLHV within Australia and internationally is presented as an overview, which briefly sketches the approaches towards youth taken by community health, and people living with HIV and AIDS organisations, followed by descriptions of selected services under review. Analysis is grouped into designated evaluation criteria, drawing selectively from data to provide an in depth assessment the best practices for supporting and developing young PLHIV in line with Living Positive Victoria's strategic objectives for the development of programs and services.

3.1 Overview of Social Support for Young People Living with HIV aged 18-30.

Of the community health and people living with HIV and AIDS organisations within the selected regions, relatively few provide support services or groups specifically targeted towards people PLHIV aged 18-29. Most incorporate young people within their general group or one-on-one peer support services, or do not differentiate this population as having separate needs or requirements for accessible, appropriate and effective support.

To a lesser extent, agencies address this gap in youth-specific services through partnerships with community groups specialising in either general services for at risk youth, or peer support for LGBTQI identifying or questioning youth. For instance, Queensland Positive People maintains partnerships with the Brisbane Youth Service and YEAH, although neither provide social support specific to youth living with HIV.

Similarly, various AIDS councils and committees run programs for young LGBTQI community health and other at risk communities, such as ACON's brilliant range of workshops for young gay men aged 18 -26. However, workshops, peer education and outreach are often focused on HIV education and prevention rather than the support of development of young PLHIV.

3.2 Services under Review

What follows are brief descriptions of the ten peer-driven services providing social support and development for young PLHIV under review.

Positive Youth Outreach (PYO) – AIDS Committee of Toronto (Toronto)

The ACT has a well-established Positive Youth Outreach program, which has been running for 25 years. The PYO provides for young people living with, affected by, at risk of, and concerned about HIV and other STIs aged 16-29 with a range of services, including:

- Social gathering and support activities
- Structured peer discussion support group
- One-on-one peer support for young people by appointment or drop-in basis
- Assistance connecting young people to other health services
- Community outreach and peer health promotion and education
- PYO Recharge, the PYO zine, created by and for young people living with HIV
- Totally OutRIGHT, external workshops held in community settings for both young people living with HIV or affected or at risk, focusing on sexual health leadership.

Youth Co (Vancouver)

Youth Co is an entirely youth led and run organisation providing a variety of workshops for young people focused on sexual health education and HIV prevention. All programs are inclusive of young PLHIV, and they are supported specifically through leadership and peer education and outreach opportunities, scholarships and summer camp for youth.

Outstanding Beautiful Brothers (OBB) – Gay Men’s Health Crisis (New York)

Gay Men’s Health Crisis caters for gay, bisexual, questioning and MSM of colour aged 16 to 29 regardless of HIV status through their Outstanding Beautiful Brothers program, including group and one-on-one peer services, and mental health and substance abuse counselling.

OBB provides a peer discussion group, Many Men Many Voices, focused on making short-term interventions with topics including creating a healthier sex life, making decisions, responsibly choosing sexual partners, and gaining a deeper understanding of power dynamics in relationships.

A leadership program called Fraternity House of Taking Ownership of Prevention is also provided to graduates of the discussion group

where members are empowered and motivated to live healthy lives through creative expressions, self-discovery, and projects that promote HIV awareness and build community.

Young Adult Program (YAP) – Morningside Clinic (New York)

Situated within a clinical environment at St Luke's Presbyterian Hospital, the Young Adult Program provides social support for young PLHIV aged 18-26 in addition to the medical care provided by the clinic. This includes a weekly peer support group, which is supplemented an online Facebook group, as well as counselling and case management work. Discussion topics include adolescent health issues, substance abuse and risk reduction, medication adherence, disclosure of HIV status to friends/partners, relationships, employment and job assistance, housing and education. Recent YAP projects have included new media projects and use of poetry and prose as a means of creative expression. Guest speakers are invited to address various topics. Group members are invited to attend monthly off-site social/recreational activities

Project Services to Assist Youth (STAY) – Harlem Center for Health (New York)

Project STAY provides comprehensive health services for high-risk and HIV-positive adolescents and young adults 13 – 24, within a clinical environment. Social support is provided through a peer support group, social workers and councillors.

Bay Area Young (BAY) Positives (San Francisco)

BAY Positives is run entirely by young people living with HIV under 26. Operating for over 25 years, the organisation provides social support through:

- Youth and Family Counselling
- Drop-In Centre
- Linkage and Referral Services
- Individual Risk-Reduction Counselling
- Prevention Case Management
- Social and Recreational Events
- Support Groups
- Weekend Intensives

BAY Positives provides opportunity for further personal and professional development, including leadership skills through training as public speakers, facilitating HIV/STI prevention workshops, off-site program consulting and youth provider training.

Body and Soul (London)

Body and Soul caters for young PLHIV with dedicated program areas for children aged 0-13, teens aged 13-19 and young adults 20-29. Social support includes structured peer support sessions, individual assessment for newly registered clients, and group, family and one on one support specifically focused on relationships and communication, and involving young PLHIV in anti-stigma campaigns. Their adults program provides a separate support group for young adults aged 20-29 to provide peer support most relevant to them as well as separate groups based on gender and cultural sensitivities.

Positively UK (London)

Positively UK is a peer led and run organisation. The range of peer support activities for young PLHIV include a youth group, one on one support, workshops and events.

Y+ - Body Positive (Auckland)

Y+ is a group for younger PLHIV under the age of 35 run by Body Positive to provide peer support and discussions centred on health promotion and HIV. In person meet ups are supplemented by an online extension of the group on Facebook.

The Institute of Many (TIM) (Australia)

TIM provides an online forum for peer support for PLHIV through a secret Facebook group. The collective is peer driven, and although open to PLHIV of all ages, has a diverse membership, including a large proportion of people under 30.

3.3 Key Evaluation Question 1: Accessibility

How do programs and services most effectively reach young people living with HIV?

Young PLHIV face a multitude of barriers within the diverse range of regions and social and economic contexts in which the services under review operate. However, several strategies and interventions consistently overcome common barriers, presenting themselves as not only effective ways to reach young people, but also highly transferrable.

Strong partnerships and referral systems with sexual health clinics, services and professionals, as well as other social services and

community health organisations characterise all of the services who were able to effectively reach their priority populations. Several reported liaising with partner organisations and health professionals, as well as having promotional material in the form of flyers and cards at these sites effectively raises awareness of programs and builds referral patterns. YAP, Body Positive and Body and Soul report having peers speak directly with staff or young people was the most effective way to overcome irregular referral patterns. A facilitator from Y+ stated clinicians often “do not recognise [how the] skills of having been in the community [helps] these young boys at that time,” demonstrating the importance of building close relationships with sexual health clinics and services to ensure greater awareness of the type of support available to the newly diagnosed from community organisations. Emphasising the importance of streamlined referrals, a social worker from YAP said “making young people wait even a week, [means] they’ll just disappear. That immediate connection makes a difference”. Both of these statements also locate recent diagnosis as a key time to connect young PLHIV to support services.

Initial one-on-one peer support was also shown to effectively transition young PLHIV with high needs into peer group services. Significant barriers for young people to group peer support services, especially the newly diagnosed, were consistently identified by respondents as feelings of isolation caused by stigma and the fears of disclosing to, and meeting a large group of other young people living with HIV. Several respondents pointed out that young people would choose to access support groups in time. But there was also broad agreement initial one-on-one peer support made them feel more comfortable and likely to do so. Two facilitators were able to describe how this happened in practice, firstly from Y+,

“[I] just meet them for coffee and let them know that, you know there is support for them ... not pressuring them to actually join into the group- that’s a step that they’ll take when they’re ready - and usually they come in.”

And secondly from YAP,

“I do that in a casual way; get one of [the group members] to drop something by, ‘Oh and this is so and so’. I ask a lot of people when they first come in: ‘do you know anyone with HIV?’ And they say no. And I say, ‘you probably do, they just haven’t told you.’...for some people in those first few weeks it’s way too intense to just walk into a room.”

Both of these examples show initial one-on-one peer support not only lessens feelings of isolation, but is also effective at transitioning

into support groups because it increases awareness of the nature of the group as a safe place and the sort of support available to them through groups.

There was broad agreement among respondents that communicating with young people through online and social media makes it much easier to reach them. The PYO provides a particularly strong example, with the AIDS Committee of Toronto utilising Facebook, Twitter, Instagram, Youtube, online media pieces and their webpage to promote the program, reporting that these avenues are a major way to attract young people to the program. TIM reports similar success, explaining new members “hear about us on the web, they find us through the public Facebook page that we have. They find us through [online] articles.” Moreover, the success of TIM and other support groups to exist as primarily digital platforms for peer support on Facebook speaks to how easily these sites facilitate communication for a broad range of PLHIV. A YAP facilitator reports this is particularly true of young people, explaining that it is difficult to get hold of members via phone or email, “but [that] they’re always on Facebook – without that I would lose them.” Further, TIM, Body Positive and YAP all report the use of a Facebook group, or Skype in the case of Body and Soul, as online extensions of support groups help to deliver peer support to members who face temporal, spatial, geographical and financial barriers to physical meetings. In particular, Body Positive and YAP reported the Facebook group helped alumni from their support groups to remain connected with the friends and networks they had made. While a facilitator from Y+ commenting that it also allowed them to connect with young PLHIV in other cities and rural areas, addressing shortcoming of services outside of the city highlighted by the 2010 Review of Services for People Living with HIV in New Zealand.¹²

Strict age targets limit access to services for young PLHIV with high needs. The Morningside Clinic reported that many service users aged out of YAP and the support group, which strictly limits access to PLHIV aged 26 and under due to financial limitations. This suggests young PLHIV may be exiting services without having their needs met, which is supported by a statement from a facilitator who reported clients with high needs struggled to transition to adult services. On the other hand, a facilitator from Y+ reported the group maintained a degree of flexibility with their target ages to ensure member felt their needs had been met before leaving the group. Moreover, services such as the P.Y.O. report being able increase the attendance of underrepresented priority populations by having

¹² David Miller, “Review of Services For People Living With HIV in New Zealand” (Ministry of Health, November 2010).

flexible limits on age. Trans* female, heterosexual male, aboriginal and CALD populations face the added barriers of being non-typically associated with the ACT and English being the primary language used by the PYO. Flexibility reportedly encourages larger attendance from these demographics, allowing their peers and pre-existing networks to participate.

The provision of free or subsidised activities and services was also common among services. A facilitator from YAP described providing free food, activities and subsidising travel costs as essential for their priority population to attend services, considering their high economic needs. However, the provision of free services and social events was common among respondents from a range of regions, suggesting that it represents a significant incentive to attend.

3.4 Key Evaluation Question 2: Appropriateness

What makes services suitable to young people living with HIV?

There was a broad consensus among contributors that spaces where young people felt safe, comfortable and satisfied were confidential, inclusive, non judgemental and driven by peers.

Every organisation under review utilises peer-based approaches as part of the social support they offer. Moreover, all that were able to submit further information about their services demonstrated peer-driven approaches, or ongoing meaningful engagement and involvement of peers in the development and implementation of their programs were key methods of ensuring their services remained appropriate to the needs of young PLHIV. All peer support groups were facilitated by young PLHIV, or practiced rigorous evaluation and consultation with group members, encouraging them to choose topics of discussion or social activities. Further, organisations were able to demonstrate participants were highly satisfied with the social support they received from peers. Facilitators from YAP and Y+ provided anecdotes of members describing their support groups as "family". Meanwhile, 82 per cent of clients from Project STAY rated the peer support group as excellent to good, opposed to the 48 per cent who said it was not easy to talk to a psychiatrist and felt they did not care about their feelings and problems.

Meaningful involvement of young PLHIV was also achieved in other program areas by ensuring they are represented in the leadership and governance of organisations. While Youth Co and BAY Positives are entirely youth led and run, Body and Soul maintains a Youth Board of Directors, and Gay Men's Health Crisis and the ACT ensure the OBB and PYO are, respectively, youth led and run.

The screening and induction of new members into support groups, as well as codes of conduct not only ensure groups remain peer based, but also aids in fostering inclusive, non-judgemental and confidential spaces. For instance, a facilitator from YAP described how

"There was so much homophobia among the prenatally infected kids who grew up in urban areas, saying 'This [contracting HIV was] not my fault, this is your fault' –we're way beyond that now, which is great ...we have all people of all sexual orientations here, so we do a lot of prescreening [sic] to make sure that we're not going to have too many issues and patients know what they're going to be walking into."

Although this anecdote suggests stigmatising and anti-social behaviour reduces with engagement with the group, it also shows that a diverse group benefits from the initial promotion of appropriate behaviour and the greater awareness of group dynamics fostered through screening and induction. A submission from TIM also showed that screening and inducting new members aided in creating the perception that the group was safe and confidential, as one of the greatest fears of being in TIM for members was that HIV negative people might join. YAP, TIM and Y+ also all promote codes of conduct within the group, detailing what the group is not for, rules regarding confidentiality and privacy, and guides encouraging non-judgemental, positive engagement. For instance, TIM's guidelines for posting suggests members should "try and end with how you can combat the problem instead of dumping it on the group" to promote positivity. Body Positive also reported the promotion of sex-positive and non-judgemental behaviour in Y+ helps make members feel safe and included. As one facilitator stated, "you can see them all relax [when] they know I'm on their side and they know I'm not there to make any judgement calls".

Young people were also comfortable using social media as an online extension of support groups. Although concerns about confidentiality remains an issue for a small amount of members, the reportedly high uptake of members joining the private Facebook groups of YAP and Y+ suggests most are comfortable with the level of confidentiality provided by 'secret group' settings which ensure no content within the group is visible to anyone outside of it. Submissions from TIM and facilitators from YAP an Y+ also suggest young people, for whom sites such as Facebook are a routine part of daily life, are very open to engaging with each other in online spaces, checking in, 'liking' and posting regularly. This is also supported by a content analysis of YAP's Facebook group, which

found that there was not only administrative communication, but also a high amount of spontaneous and voluntary activity.¹³

There does, however, exist a negative perception of traditional support groups among young people, leading many to believe they are inappropriate to their needs. A social worker from YAP explains that she often needs to correct this perception,

"A lot of people will tell me that the group isn't for them or that it's not something they'd do, but then they ask me about disclosing – and then I say to them, 'well this is something [the support group] talked about last week, I think it could be really helpful. I could talk to you about this, but I haven't experienced this; no one could do a better job talking to you about this than someone who's been through the same thing as you.'"

The young person's focus on disclosure in this exchange, a common theme in YAP's support group, makes clear that it is largely the negative perception of support groups which is misleading, rather than any particular element of group peer support. This point is also powerfully underscored by a submission from TIM:

"I try not to use the word 'support' where possible, mainly because I think that word has been tarred by the notion of support groups and support services, and 'support' creates an image of people sitting in a circle and talking with tissues – it's not – but people, especially young people reject the idea that they need support (or a) support service or group."

This submission picks up on the negative connotations of the term 'support' within the Australian context, which suggests excessive emotional neediness and structured therapy, although neither accurately characterise peer support.

Finally, advertising and promotional material featuring a diversity of young people's faces and voices is appropriate to the widest range of young PLHIV. All of the services under review, except for OBB which is specifically targeted to young men of colour, use language which is inclusive and not specific to gender, race or ethnicity in the name of their programs or to describe services. If photos are used, they feature a diversity of young people. Body and Soul and the PYO also report involving young PLHIV in the production of videos and testimonials to promote programs helps ensure they remain

¹³ Anna Gaysynsky, Kathryn Romansky-Poulin, and Stephen Arpadi, "My YAP Family': Analysis of a Facebook Group for Young Adults Living with HIV," *AIDS and Behavior* 19, no. 6 (September 4, 2014).

appropriate and provides faces and voices with which priority populations can identify.

3.5 Key Question Evaluation 3: Effectiveness

How do programs and services achieve their expected goals and objectives for providing social support and health promotion for young people living with HIV?

Group peer support was confirmed as an effective means of providing social support, enabling young PLHIV to create support networks for themselves. Not only did every organisation under review incorporate an element of group peer support into their services, there was broad agreement among those who were able to provide an interview or a survey response that group support was the most effective means of providing social support. Describing her ability to transition young PLHIV into their support group as a key skill, a social worker from YAP said this was because

"[O]nce they're in the group they have this instant network of young people. And they talk about themselves as though they're family. And these are people who don't have functional families, so this is like the only family they have – you know a lot of our young gay guys have been disowned from their parents or abused by parents or kicked out of their houses, so this is really the only place that they can come."

Although young PLHIV come to YAP with minimal support networks, this anecdote highlights it is the opportunity to create them, which makes group peer support effective. Within the Australian context, TIM reported that the Facebook group 'absolutely' enables PLHIV to create their own support networks, providing the level support they need, from information and daily check ins, to building close knit relationships in face to face events. This suggests that group peer support is highly transferable to priority populations with different levels of social support needs as it enables to determine the level of support suitable to them.

TIM's ability to provide this support also speaks to the effectiveness of social media and online groups on sites such as Facebook. This was also confirmed by other services utilising online extensions of support groups. A facilitator from Y+ said,

"Now, we've got our own private Facebook page. So I've watched some of these boys – I really have – when they've been diagnosed sort of go through that sort of closed up, sort of scared 'how do I tell my family?' 'What's going on in my life?' sort of thing. And I've watched them go through that

journey with the group and blossom into beautiful people again and engage with the life again and the community. And they actually support each other a lot on that Facebook page.”

This statement shows Y+'s Facebook group complements the effectiveness of the peer support offered by in person meetings; the facilitator emphasizes both that she had observed supportive behaviour occurring online, rather than just administrative communication, as well as suggesting it was part of the cause for the journeys she had witnessed. Indeed, a content analysis of the interactions on YAP's Facebook group also showed social, emotional and tangible support was often exchanged, while companionship and relationship-building interactions were highly prevalent.¹⁴

Peer discussion groups were also shown to be effective spaces for health promotion activities. Several organisations reported the transferal of knowledge between peers in discussion groups significantly aided in meeting HIV and AIDS sexual health and wellbeing education outcomes, as participants felt empowered to be educators and take control of their own health. The use guest speakers, such as HIV specialists, general practitioners, dieticians, lawyers, and other PLHIV with experience in public speaking was also reported by three organisations using peer discussions to aid in health promotion. This was reportedly due to providing both variety in content and speakers, and the trust group members placed in opinions of experts.

3. 6 Key Question 4: Capacity Building

How do programs and services best accommodate for further personal growth and developed capacities of young people living with HIV?

Several of the organisations under review have experienced demand for further development and opportunities for personal and professional growth among the young PLHIV who have engaged with the social support services. However, the way agencies provided for this varied.

Volunteer, work and internship opportunities, including training for these positions, were the most commonly utilised methods to address further development needs. BAY Positives, Youth Co, Body Positive, Body and Soul and the ACT all provide opportunities and encourage young PLHIV to volunteer in various capacities, either as facilitators of peer services or in a position that interests them or

¹⁴ Ibid.

suits their skill sets. The following describes the experience of a member of the ACT's PYO, who said

"[I] started off looking for information and wanting to make friends while gathering emotional support and confidence around living with HIV...[and] after a while hit a plateau, and we had to relook at [his or her] role in the program. The individual now is a staff volunteer and has taken on a leadership role in the program, offering knowledge ... helping to run the group and encouraging other/new participants to go back to school, get a job/work, talk about their status/disclosure, or volunteer. [He or she] still identif[ies] as a member of the program, but views [HIV] status, health, and [the] future [through] a more confident and resilient lens."

This example shows that the skills and greater emotional resilience and confidence young PLHIV gain through engagement with social support services enables them to further develop their capacities when given the opportunity in volunteer and work placements. Indeed, Body Positive, Body and Soul and the ACT were all able to demonstrate anecdotally that these opportunities effectively build leadership capacities and encourage engagement with community.

Further, Body and Soul reported external internship opportunities with matched partner organisations allowed them to provide placements tailored to the needs of individual young PLHIV, their skills sets and capacities. As entirely youth led and run organisations, BAY Positives and Youth Co are able to provide work opportunities at all levels of the organisation, including leadership and governance rolls. Youth Co also provides scholarships for young PLHIV based on community involvement and demonstrated need. Several organisations highlighted peer education, outreach and public speaking opportunities as particularly valuable ways to develop young people. Youth Co and the ACT both provide these opportunities, reporting they empower young PLHIV to become educators and encourage connections between other young people in the sector, leading to greater engagement with community and more developed leadership skills.

The only organisation that provided a standalone leadership program for young PLHIV was the ACT through a series of sexual health leadership workshops, Totally OutRIGHT. Several organisations provided workshops focused instead on practical skills such as resume writing, interview skills, and financial management. However, this was in response to the high economic needs of the

priority populations of Body and Soul, Project STAY, and YAP, and the added barriers they face to employment and becoming productive members of the community. The ACT was nonetheless able to demonstrate the success of Totally OutRIGHT in Toronto with young PLHIV, after adapting it from the Community Based Research Centre for Gay Men's Health in Vancouver. The program prioritises young gay/bi and queer men aged 18-29, and welcomes HIV-positive participants. Confidentiality training is provided and a code of conduct based on the agency's mission and values is followed to help with issues of HIV disclosure. The program consists of a series of workshops covering general leadership skills and information to understand priority populations that enable participants to pursue a career or leadership roles in the LGBT and HIV/sexual health sector.¹⁵ This broad focus, as well as the emphasis on confidentiality and codes of conduct ensures the inclusion of both HIV negative and positive participants remains appropriate.

¹⁵ A full description of workshop curricula with descriptions of subject matter can be found at <http://www.actoronto.org/home.nsf/pages/toqa>, accessed 19/08/2015

4.0 CONCLUSION AND RECOMMENDATIONS

This review has cast a critical eye over approaches to supporting and developing young PLHIV within a broad and diverse range of regions, priority populations and contexts in an effort to find what out works best.

Often, this threw into sharp relief the stark differences, rather than the similarities, of the social, economic and public health contexts in which community health and people living with HIV and AIDS organisations work so hard to empower and enable the health and wellbeing of young people. Indeed, the needs of young PLHIV in Victoria and what community means to them may be changing, and are certainly different to some the populations under review.

Yet as borne out by this report, certain solutions, interventions and initiatives were consistently effective across these contexts in supporting and developing young people living with HIV most in need, providing strong evidence that they are highly transferable, as well as the opportunity for Living Positive Victoria to benefit from the successes of other organisations in these areas.

As such, the recommendations that have been made offer practical solutions that seek to bring Living Positive Victoria's organisational approach to young PLHIV into further alignment with best practice.

4.1 Key Recommendations

- 1) Strengthen partnerships with sexual health clinics and HIV sector services to develop greater awareness of Living Positive Victoria's youth services, encourage further access to priority populations and enhance referral pathways.
- 2) Formulate standards for assessing the needs and suitability of new members of the support group, one-on-one orientation for new members with high needs and a code of conduct to promote a space that remains peer based, safe, confidential, non- judgmental and inclusive.
- 3) Develop promotional material that emphasises peer driven approaches, avoids the perception of traditional support groups, is inclusive of diversity, features voices and faces of young people and utilises online and social media. This includes promoting the Facebook group as a primary means of internal communication and online extension of the support group to increase reach, access and engagement.

4) Provide volunteer and mentor opportunities, especially peer outreach and education at Living Positive Victoria and develop internship and work placements with external partners to provide tailored professional experience and skill development.

5) Explore Totally OutRight as a model to develop a sexual health leadership program for young PLHIV to encourage greater involvement with the HIV and sexual health service sector.

REFERENCES

- "2013 HIV/AIDS Annual Summary Slides." The Department of Health and Education, Victoria, Australia, March 2015.
- "Annual Surveillance Report 2014 HIV Supplement." The Kirby Institute, July 2014.
- Department of Health and Human Services, Victoria, Australia. "Sexual Health Delivery: Sexual Health." Guidelines. Accessed September 7, 2015. <http://www.health.vic.gov.au/sexualhealth/priority.htm>.
- DiClemente, Ralph J., Colleen P. Crittenden, Eve Rose, Jessica M. Sales, Gina M. Wingood, Richard A. Crosby, and Laura F. Salazar. "Psychosocial Predictors of HIV-Associated Sexual Behaviors and the Efficacy of Prevention Interventions in Adolescents at-Risk for HIV Infection: What Works and What Doesn't Work?:" *Psychosomatic Medicine* 70, no. 5 (June 2008)
- El-Hayek, Carol, Isabel Bergeri, Margaret E. Hellard, Alisa E. Pedrana, Nasra Higgins, Alan Breschkin, and Mark Stoové. "The Changing Age Distribution of Men Who Have Sex with Men Diagnosed with HIV in Victoria." *Medical Journal of Australia* 193, no. 11 (2010).
- Gaysynsky, Anna, Kathryn Romansky-Poulin, and Stephen Arpadi. "'My YAP Family': Analysis of a Facebook Group for Young Adults Living with HIV." *AIDS and Behavior* 19, no. 6 (September 4, 2014)
- Maddaford, Kate. "Needs Assessment Report." Living Positive Victoria, June 2014.
- Miller, David. "Review of Services For People Living With HIV in New Zealand." Ministry of Health, November 2010.
- Nutbeam, Don. "Evaluating Health Promotion—Progress, Problems and Solutions." *Health Promotion International* 13, no. 1 (January 1, 1998)
- "Strategic Plan 2014-2017." Living Positive Victoria, 2014.
- "Victorian Prevention Epidemiology and Surveillance - HIV Update." Department of Health and Education, Victoria, Australia, July 2014.

APPENDICES

Appendix A

Evaluation Questionnaire

Section 1, Accessibility: This section will focus on how well your services or programs reach young people living with HIV most in need of them.

- a) What age groups do your youth services target?
- b) Who else is attending your services and can you think of why?
- c) What do you think are the major barriers young people face in accessing your services, and what have you found are the most effective methods of attracting them to your services?
- d) Within that age group, are there any demographics (gender, sexual orientation, cultural or linguistic) who are not participating in your services?
- e) Can you think of any specific barriers these groups might be facing from accessing your services, or what aspects of your program have increased participation of these demographics?

Section 2, Appropriateness: This section will focus on how suitable your programs and services are to young people living with HIV.

- a) How do you know your programs cater to the needs of young people living with HIV? Please include an outline of what you provide
- b) How do you think current perceptions and understandings of your agency influence engagement with your services?
- c) Do participants report satisfaction with your youth services? If you have conducted satisfaction surveys are you willing to share the results?
- d) What part of your program or service do participants find the most satisfaction in? Would you like to provide an example
- e) What are the main reasons for people exiting your services? If you have conducted exit surveys are you willing to share the results?

Section 3, Effectiveness: This section will focus on how well your services and program achieve their expected goals and outcomes.

- a) What are the expected outcomes for young people who have engaged with your services? Do they include: social inclusion, increased resilience, greater engagement with community, and greater understanding of safer sexual practices and the effects of HIV on their health?
- b) Do you test for improvement in these areas? Are you willing to share your results?
- c) What aspects of your services and programs do you think have had the greatest impact in meeting them? Would you like to provide an example?
- d) Do you conduct follow up in these outcome areas and how long after? Are they sustained?

Section 4, Personal Growth and Development: This section will focus on how your programs and services accommodate for further/graduated personal growth and development of young clients

- a) Have you found a need for demand for the further personal development of young people living with HIV after engagement with primary support services and programs?
- b) How have you accommodated for this and has it focused on leadership development? Please provide an outline of these services
- c) Are these programs specifically catered towards young people living with HIV? If not, how have you dealt with issues such as disclosure and HIV stigma within a mixed environment?
- d) What areas of growth and development do your services focus on, and do you test for improvement? Would you be willing to share your results?
- e) Please provide an example of how your agency has built the capacities of a young client (e.g., leadership and public speaking skills, personal resilience, professional experience etc.) – feel free to include testimonies.

Appendix B

Short Survey

1. What do you think are the biggest barriers for young people accessing your services and how do you overcome them?
2. How do you know that your organisation's services and programs are appropriate for young people?
3. What are the interventions/initiatives your organisation makes to provide social support for young people? Please identify which you think have make the most difference.
4. What do you expect a young person to gain from your organisations social support services? can you provide an example of how this was achieved?
5. How do you think your organisation could better develop and support young people living with HIV?
6. How does your organisation maximise the potential of young people living with HIV? (E.g., Leadership development, professional skills training, mentorship, workshops, internship/employment opportunities, resilience and confidence building?)



