



"You loved me without wanting to fix me and that's what saved my life"

# ACET News

## Spring 2024

### Positive Youth Project Update Breaking New Ground

Positive Youth Project offers a space for young people growing up with HIV in Ireland, but we are still breaking new ground.

There is general enthusiasm for PYP's mission; however, there is caution around our work due to the stigma that still surrounds HIV. This stigma can create additional anxiety around safeguarding while working with this group of minors.

So far, we have received several referrals from adult HIV clinics in Dublin and Chiva, UK. These young people are adjusting to the transition from children's care to the new adult clinic setting, which can be challenging and create anxiety. During this phase, they may struggle with taking full responsibility for their HIV care and clinic visits, along with other adult responsibilities like work, study, friendships, family obligations, and romantic relationships.

We understand that this transition period can make young people more vulnerable to decreased medication adherence and missed clinic appointments which is why the Positive Youth Project aims to support them during this vulnerable stage.

— Aishling McCormack, Positive Youth Project, aishling@acet.ie



Thank you for being part of our work!

We are excited to officially launch the Positive Youth Project (*updates this page and info on the launch page 3*). You can also read about the challenges in our care work (*page 2*) and mental health for migrants (*page 3*). Consider how presence is a first step toward delight, with some thoughts from Vivienne on page 4.





**Lessons from Ireland - challenges and opportunities in establishing a new national support service for young people living with HIV.**

Aishling McCormack, Yvon Luky, Vivienne Murtagh, Richard Carson (ACET Ireland)



Birmingham, 15th March 2024

**Introduction:**

Up to late 2023 Ireland had rare and sporadic support services for young people living with HIV with patients reliant on clinical settings for dedicated bio-psych-social support.

**Positive Youth Project (PYP)** addresses that gap as a new initiative of ACET Ireland, in partnership with Chiva. This study draws on a combined 200 years of experience working on HIV in the ACET Ireland team as well as ethnographic interviews with sectoral colleagues and patients, including as relates to volunteering with Chiva, to **identify contextual opportunities and challenges for establishing a new national service that seeks to fulfil the Chiva mission of young people growing up with HIV becoming healthier, happier and more in control of their own futures.**

**Ireland and HIV:**

- In 2022, there were 884 HIV notifications in Ireland giving a rate of 17.2 per 100,000 population.
- 85% of these were previously diagnosed outside Ireland.
- There were 17 diagnoses in 2022 where the probable route of transmission was attributed to vertical transmission.
  - Nine adult cases: all previously diagnosed outside Ireland
  - Eight paediatric cases: seven previously diagnosed outside Ireland and one a first-time diagnosis.
- The Rainbow Clinic in Children's Health Ireland reported that 60 babies were born to 59 women known to be HIV positive in pregnancy in 2022, all infants are HIV negative.
- Data on serostatus and HIV is not gathered in Ireland.

HIV in Ireland: Latest trends to end 2022. Health Protection Surveillance Centre, December 2023, p. 22

**Contextual challenges for young people living with HIV in Ireland:**



**Transition to adult services - a key contextualised issue:**

This transition from child to adult services for young people living with HIV can be tumultuous with risks of both poorer clinical attendance and medication adherence. Factors in Ireland which can add to this risk are: 1) **The Dublin-centric nature of children's care** which may lead to a profound geographical change when entering adulthood that may be further complicated by another subsequent change when entering higher education as well as the absence of both dedicated transition clinics and large all-age clinics in Ireland, with the same school attended from aged 12 to 18, means that the clinical transition will likely take place without the educational transition experience of the UK peer; 2) **A positive experience of children's HIV care** can be followed by an anxiety that adult care, with its new relationships and new responsibilities, will not offer the same positive experience. In this regard, PYP is breaking new ground with **little established legacy in Ireland of an age-appropriate, peer and community-level support.**

**Recommendations:**

PYP must operate as a contextually tailored service for young people living with HIV, constructing local theories in such a way that is sensitive to changing social and political circumstances. Accessibility to the service is itself a challenge informed by these contexts and service adaptations have been made through PYP's emphasis on:

- patient trust building with stakeholders
- the late-teen stage for young people - before, during and after transition to adult services
- highlighting the need for age-appropriate supports to sectoral colleagues

PYP's development demonstrates differences and similarities to the UK which create opportunities for international comparative learning, further research and emerging pedagogies.

**Come and find us. We look like this:**



### Chiva Conference, UK

Aishling and Richard were in Birmingham in March for the 18th annual Chiva Conference. The day covered a range of vital issues and updates, from understanding HIV-related stigma, to engagement in care, youth involvement in Chiva's work, and the latest HIV research.

We had the opportunity to share a poster presentation (*left*) on the setting up of Positive Youth Project, our partnership with Chiva supporting young people growing up with HIV in Ireland.

## Care Work 2024

The start of 2024 has been challenging, a far contrast to the fresh renewed start that is often hoped for as a new year begins. **Levels of violence, intimidation and unrest have affected nearly every family and community we are working in.** Many clients have experienced increases in violence in their local area in the past months and there is a notable rise in clients' exposure to online forms of aggressive behaviour and intimidation. This has resulted in many not leaving their home unless absolutely necessary and with concerns for their own or family members' safety. While our care continues within the home space we have seen some clients withdraw from other local supports and services, which is concerning. Domestic violence has also had a significant impact on a client family in the early months of the year: we have worked alongside them and other relevant agencies to prioritise safety, protection and intervention for all involved.

The cost of living crisis continues to bring increasing pressures. **Some clients have talked about making decisions to either heat their home or cook a meal.** Others have discussed missing appointments or not attending community groups because of financial constraints. Our support to clients experiencing these pressures has included keeping welfare supports up to date, signposting to food banks and advocating on their behalf with utility providers, but it also goes beyond budgeting support. We constantly review the supports we can provide during care calls; at times this could involve bringing some staple groceries or a meal to a client home. At other times it is using community spaces as a positive resource for a walk and coffee out together. Our hope is to find a discerning balance to meet the need for safe local care spaces and subsistence, neither of which should have to be compromised.

For HIV specific care most clients are attending clinics 2-3 times a year. Because this is less frequent than a few years ago, we have found our support within the home and community space in the interim period has become particularly important. We work with clients on medication adherence between appointments, support them with other clinic and hospital visits and liaise with community health support teams to advocate on their behalf. This support is very individual to each client but has become more of our care focus as clients spend less time engaging with staff in a formal hospital setting. Many we work with still have complex ongoing HIV care needs that can be supported within the community.

These challenges can feel enormous. They are complex and have to be navigated with practical care and patience. **The past few months we have been prioritising safe spaces to work in, ensuring basic needs are being met, adapting to challenging circumstances while remaining present and focused on the care we provide.**

— Olivia Corbett, Adult support worker, [olivia@acet.ie](mailto:olivia@acet.ie)

*"I'm ready to get rid of all this junk I don't need anymore, I'm sick of it! Its taking over my head and my house."*

### Decluttering our Spaces

This winter has been very challenging for many, where concerns like the cost of living, poor health and isolation can compound and create a very overwhelming place to be. With spring in the air — a season of hope and renewal — there has been a natural opportunity to declutter and take stock of what is not needed in our spaces anymore. In the care world, this happens in the physical spaces of both home and head, spending time exploring what 'junk' does not belong in either place anymore.

In a home, this looks like DIY house projects, transforming spaces that need some TLC and creative re-organising, which helps create new spaces for rest, privacy, cooking, studying, playtimes or spending time as a family. It also includes some goal planning, creating structures or useful tools to manage health appointments, medications or budgets.

Decluttering mentally looks like identifying and working therapeutically to prune through (and support) distress such as anxiety, shame, depression, grief, loneliness, addiction relapse and disrupted relationships.

— Hansi Chisnall, Family support worker, [hansi@acet.ie](mailto:hansi@acet.ie)



## World Health Organisation themes for migrant mental health: Migrants are exposed to mental health problems that are often overlooked

On World Mental Day 2023, the WHO published a document that organises in five themes different risk factors and barriers refugee and migrant groups experience. We think that these themes are relevant to the case of migrants living in Ireland, and could help promote an active partnership between mental health public services and migrant communities.

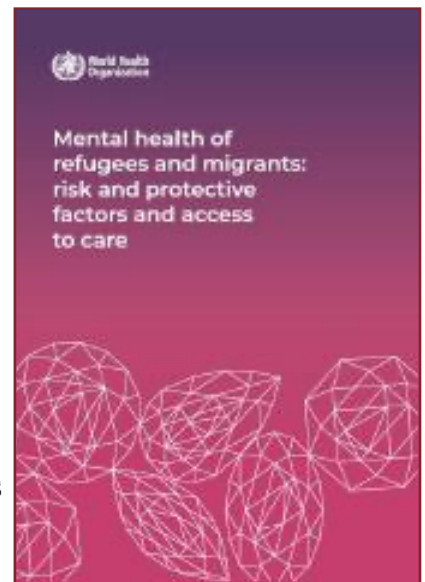
Here are the themes:

- **Community support:** it lowers rates of mental disorders.
- **Basic needs and security:** for example, an insecure legal status can contribute to poor mental health.
- **Stigma:** experiences of racism and discrimination are consistently associated with adverse mental health outcomes.
- **Adversity and trauma:** for example, extended detention is associated with increased rates of depression and PTSD.
- **Access to services:** refugees and migrants often do not prioritize their mental health because they are not aware of the services available free of charge or do not accept health care due to language barriers and concerns around confidentiality.

The WHO document recommends urgent action by policymakers cutting across all the five themes in order to improve migrant access to mental health care. The urgent action includes:

- **Promote refugees' and migrants' participation in society** and reduce discrimination by adopting refugee- and migrant-sensitive mental health policies.
- **Address the non-medical factors that impact mental health** in migration policies and prioritise basic needs, such as food, housing, safety, and education or employment.
- **Strengthen community capacity for and access to mental health care** by providing information about services, engaging with migrant groups, and offering community-based referral pathways.

— Yvon Luky, Migrant Plus, luky@acet.ie



### Trustee News

We would like to say thank you to **Juliet Amamure** who served as an ACET trustee from 2020 to the end of 2023. Juliet's keen interest in advocating and promoting social

justice, global health, and holistic and alternative medicine made her an asset to our board. We wish her all the best as she starts a new chapter in Uganda.



The official launch of Positive Youth Project takes place on Thursday, 4 April at 6.30 pm in the Exchange, 50 Lower Gardiner Street, Dublin 1, D01 VC03.

## Delightedness: from presence, to contact, to reflection and response

I recently attended a course with the wonderful Bonnie Badenoch, where she was talking about early attachment. She set out what to her were some of the most important components of safety in attachment. This made me ponder not only about early years but how we do relationships now. I thought about our care team in ACET and how they exemplify many of Bonnie's indicators for safety in connection.

**The first thing that the care team brings is presence**, that ability to be with someone in whatever state they are in, without agenda. Just being, not preoccupied with possible interventions or platitudes. Seeing and being with, offering a safe haven and meeting the profound human need for connection.



**From presence flows contact**, often contact without touch. With their eyes and their quality of being, our clients are held in a steady presence in the many storms and terrifying experiences that many of them face.



Photo by [Tony Detroit](#) on [Unsplash](#)

And **from contact comes reflection**: I see you and I reflect you. Their nervous system hosts the client's nervous system and this creates a coherence, an intimacy. Like the moon and its reflection on the surface of a lake: the moon up there looks exactly like the moon on the surface. I reflect that you are precious to me, that you are this wonderful and tender being who is also precious to God. The God who 'sees into you', (just like Hagar, the castaway, in the old testament scriptures, when she names God 'the one who sees into me') and loves you with an everlasting love.

And **from reflection comes the dance of response**: I reflect you and you respond and so it goes on and in the beautiful dance of relationship, deep safety and connection are formed. **Out of this emerges the most wonderful thing of all, Delight**. I delight in you, you delight in me and together is birthed - delightedness.

— *Vivienne Morrow Murtagh, ACET counsellor*

ACET's 2024 AGM will be held on Tuesday, 28 May in The Exchange, Dublin 1 where we will launch our 2023 Annual Report. Contact the office if you would like to receive a copy; it will also be available to read on our website.

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