# IIMHL Youth Match -
# Feedback and Conclusions

**Background**

The IIMHL Youth Match brought together representatives from six different countries (Sweden, Canada, UK, Ireland, USA and Denmark). The group comprised thirteen young advocates and twelve professionals, many of whom were in their early career. Swedish youth mental health organization Tilia were local hosts of the match, bringing a youth voice to the partnership with FRAYME (Canada) and the Mental Health Foundation (UK).

The match sought to provide an interactive space for youth and professionals to have meaningful discussions about youth engagement in service design and delivery, policy, research, campaigns and advocacy. To ensure that the match resulted in practical outcomes, the agenda was coproduced through pre-match questions and joint planning during the two-day meeting.

A detailed social programme of shared meals and sightseeing within Stockholm allowed relationships to be built and sustained around the match workshops. Participants also had an identified clinical support lead and access to practical support from hosts throughout the match and Network Meeting.

Over the two days of the youth match, four "breakout" discussions formed the backbone of the coproduced work. These four discussions covered topics identified by hosts and participants via a pre-match survey:

- Service design and delivery
- Research
- Advocacy, campaigns and policy influence
- The "how to" of youth engagement

Small groups discussed the topics together and participants were asked to feed back to the larger group from these conversations, identifying:

- Key challenges for youth, and for effective youth engagement
- Key opportunities to do better e.g. promising innovations or shifts in thinking
- One "how to" or best practice tip

This summary brings together this feedback across the two days of the match and highlights commonly recurring themes. The final section of this summary brings together the practical "best practice" guidance for engaging youth identified by the group.

## Service design and delivery

***Challenges***

**Mental health literacy** is not high enough amongst youth, their families and professionals. This includes systems literacy – how does the mental health system work, from whom can (or should) you receive help and how can you access it, what rights do youth and families have?

**Risk aversion** amongst professionals to youth and para-professionals providing care/ support, peer support initiatives. This is a huge untapped resource that could provide much of what youth want from services but needs careful planning to make sure it is safe and effective.

**Services are not integrated** within or between sectors (health, housing, addictions, welfare, employment etc.) and organisations (NGO's, govts, health services). Services are not sufficiently aware of each other (particularly between sectors and organisations) to signpost effectively and ensure that people are able to access all the support that could be beneficial to them.

**Lack of standardisation** in terms of quality, duration and nature of care provided. This includes responses from other professionals such as teachers, as well as more clinical standards. It also includes criteria for access, although rigid criteria can also be a deterrent if youth don't feel they are "ill enough." Too often such criteria represent policy barriers to access.  This is particularly problematic for transitional-aged youth that fall between various age criteria.

**Lack of options** in terms of what care and support for mental health looks like. This should be a continuum or "stepped" approach, rather than a one-size-fits all model.

**Continuity of care** is something that young people consistently say that they want, but they are often unable to build relationships with those supporting them as they don't see the same person each time, or their care is strictly time-limited.

**Insufficient funding** (and security of funding in the long term) to provide any or all of the above.

**Stigma** – including self stigma and stigmatising attitudes amongst professionals – makes young people reluctant to seek help.

*Opportunities*

**Mental health awareness** is higher than ever before, with more and more focus on people's lived experiences. We have an opportunity to build on this to increase knowledge and co-operation, and to reduce stigma.

**Youth are an untapped resource**, both for advocacy around mental health and providing support to their peers. This could be an opportunity to meet the increasing levels of demand in an appropriate way.

**Online approaches** also offer ways to increase the capacity to offer information and lower-level support in an instant way, that does not rely on geography.

**The building blocks of good care are already there** – the major challenge for many is in making sure youth reach the right services at the right time. A single point of contact to help youth and their families navigate the system could make a huge difference.

---

**Case Study – Tilia (Sweden)**

Tilia is a youth-led mental health charity supporting young people across Sweden. Its two-tiered mental health support service allows youth to access resources when and where they need them.

The website, social media accounts, podcasts and videos – all created by young people – provide accessible information about mental health and wellbeing, as well as sources of support.

If youth need more support, they can access the charity's online support services – via chat, email or in person at the wellbeing camps. Support is always provided by other youth, mostly young volunteers who have used the service themselves in the past.

All these services are open to youth from anywhere in Sweden, meaning that those in rural communities can also access peer support. Chat support and camps are scheduled when youth most need them – weekends, evenings and school holidays.

Tilia also campaign on issues important to young people, as identified by the youth who use their services. They sit on national committees and influence policy on youth mental health, education and services.

Tilia provides a meaningful alternative to clinical care for those young people who are struggling but may not be "ill enough" to access traditional mental health services.

---

**Case Study: Advocacy Service in Galway CAMHS**

**By Ciara Gillespie, Psychiatric Nurse, Advancing Recovery Ireland**

Under the Mental Health Act 2001, adults admitted to an inpatient psychiatric ward in Ireland have access to advocacy services in the form of a mental health tribunal. No such provision exists within the child and adolescent mental health public services sector. The Mental Health Commission, during their inspections, have regularly commented negatively on the lack of independent advocacy available to young children and adolescents. This is a problem that is faced in CAMHS all over Ireland. CAMHS Galway as a team decided they were going to try and tackle this problem and they have done so with success.

To start the process, the Executive Clinical Director of CAMHS Galway undertook a literature review to highlight the need for an advocacy service with CAMHS. They then set up a scoping group involving young people who are experts by experience, staff within the CAMHS Galway unit, mental health business managers and a current advocate. A business proposal was then sent on to the Health Service Executive who are responsible for the provision of health and personal social services for everyone living in Ireland. When this proposal was approved a tender was sent out to advocacy providers who were independent of the HSE. When a suitable provider was chosen by the scoping group both the scoping group and the advocacy providers set up information sessions for both staff and young people who were currently using the services. From this a reference group comprising of young people was set up. This reference group developed the leaflets and posters for the advocacy services that would be available. This process took some time, but it leads to a service that was well thought out and one that would be of a high-quality.

So where are we at now? The advocacy providers YAP have been given access to the unit and continue to visit it on a weekly basis. They spend time with the young people on the unit and are beginning to gain their trust. The team are continuing to promote the service on the unit to the young people and a discussion on the advocacy services available is now part of the assessment process for every young person who is referred to the CAMHS service. Although, the advocacy service is initially being piloted in the inpatient unit, there is plans to phase it out to the community in time. This is a project that CAMHS Galway are very proud of and are very keen on ensuring that their service users are receiving the best quality care that is available.

## Research
***Challenges***

**Research design** often takes place without youth / families in mind or being involved in the coproduction of the research. Factors such as who sets the questions, the measures used, what constitutes a "good result", research ethics impact on whether the findings are meaningful or useful. In qualitative research, research design needs to look at what to do with conflicting narratives from youth, parents, professionals about the same issues.

**Qualitative research** is undervalued – gives you the "why" as well as the "what" of illness care, wellness /wellbeing etc. Need a balance of both.

**Long timelines in traditional research** models take a long time to produce results. Youth grow quickly and the context changes. Alternative or "less rigorous" models are needed to give us actionable results quicker. These long timelines and short shelf-life of timings mean that research is often conducted but outcomes / recommendations are not actioned.

**Youth are not a homogenous group**, and this should be represented in both research design and any youth engagement around it. Diversity needs to be meaningful and representative. Lack of diversity perpetuates stereotypes and stigma. Younger age groups are often not included (e.g. under 16s)

**Youth have to make space to present their views**. This is challenging and most youth don't have the resources to do so. Research should be looking to youth and making space for them, rather than asking them to "take space" for themselves.

**Families** are often not included in research. Families, and wider social networks, are often key both to understanding the causes of poor mental health in youth and providing the environment in which recovery can happen. Research into mental health interventions and preventative initiatives should take this into account.

***Opportunities***

**Lots of good work is happening** that is not evaluated. Making evaluation part of everything we do increases the amount of information available for ourselves and others to use. The evaluation process should be coproduced.

**Increasing use of user-informed/ co-created metrics.** Involving youth/ families in a coproduction process can identify the constructs of most relevance to their own contexts and the most appropriate tools and methods to collect such information.

**Alternative research designs** are sometimes used, particularly in programme evaluations. In particular, iterative research (e.g. as part of PDSA cycles) offer more immediate, actionable results than more traditional methods (e.g. RCT's). Mixed methods research designs are more commonly used in some sectors e.g. nursing, with qualitative findings included to bring research to life. Action research methods represent a particular opportunity to involve youth and family members and to quickly put findings into action.

## Campaigns and Policy
*Challenges*

**The public focus** of anti-stigma campaigns is laudable, but we should look at professionals, too. Many young people highlight the stigmatizing attitudes of professionals towards their distress as barriers to getting help – this might be diminishing their experience due to their age, or overly rigid criteria making youth feel "not ill enough" to get help.

**Public opinion** is changing, but those of us in the mental health world, even those who are advocating from our lived experience, can lose touch with how it looks on the ground. We also need a system responsive to attitude changes – increased awareness of, and more positive attitudes about, mental health are likely to lead to increased demand. If there is no accompanying increase in capacity – or creative thinking about how needs can be met - this is a problem

**Long term funding** and resources for campaigns – it takes time to change minds and results often won't show up in the first year or so. Advocacy work is often not evaluated or valued, so it can also be hard to show that interventions are in fact changing minds, and thus ensure future resourcing.

**Mental health education** of all kinds is needed, for students, staff and the general public. This education needs to strike a balance between mental health promotion, recovery education for all on one hand, and education about illness and crisis on the other hand, both for those experiencing it and those who may be supporting people. Education should be context-focused, too e.g. teachers need training to manage mental health in school environments, managers need training on supporting mental health in the workplace, etc.

**Youth movements** often lose momentum as people "age-out", or when progress is not made. Youth do not control change-making processes, so can often come up against barriers they find it hard to move beyond. Opportunities for youth to continue their advocacy work – particularly opportunities to develop their skills – beyond their time as "youth" are highly valued when they are available. On the other hand, we also need to ensure new voices are joining the conversation, reflecting the reality of being a young person today.

**Personal cost of advocacy** - many of those who are motivated to get involved in mental health advocacy are those with lived experience of mental ill health. They are often asked to share their personal story without fully understanding the implications of this, how it may be sensationalized or how their recovery may be portrayed, unhelpfully, as linear and final.

*Opportunities*

**Co-ordinated and co-produced policy asks** between countries make them more powerful. Furthermore, showcasing the good work being done in other countries can compel governments to replicate that good work.

**Lived experience** is increasingly at the forefront of public, but we still need to ask who's NOT at the table. There are marginalized groups that aren't part of these conversations, both in shaping the campaigns and recipients of the messages. Families and carers are also often missing from this conversation,

**Mental health conversations are happening!** We have a huge opportunity to guide and shape these, e.g. we could incorporate more messages about services into these campaigns, re-focus the conversation on mental health as a resource rather than a cost, health promotion strategies rather than illness-focused messages.

**Youth need training** in how to be the best possible advocates including (but not limited to) project management, community organizing, media engagement and public speaking training. Organizations using youth advocates need to commit to support plans for the young people they work with, during and beyond their time as advocates, whether this is public-facing or not.

**Adult champions can open the door for CYP**, making it easier for them to deliver their messages, whether that's in policy or in the public sphere. By linking up with adult champions, work may be more productive. Genuine coproduction, whereby each group brings their experience and skill to the table, is the best way to effect change.

**Beyond stigma reduction.**  A consequence of reduced stigma is increased help-seeking. Without significant adjustments to our care systems we may inadvertently increase demand that can't be met by our current capacity or models of care.  This can create a negative first experience for youth seeking care, resulting in their disengagement from future help seeking. Attention must be given to consider our collective capacity to meet the actual demand and to transform our systems of care to meet the needs that exist. These solutions may well lie in the community as well as our traditional healthcare institutions.

**The recovery model** was valued for its holistic view of people's needs. A shift in organizational cultures towards a recovery-focused model, driven by staff training, was seen as potential way to improve attitudes amongst professionals.

**Case study: the work of Jack.org, Canada**

**by Sarah Mughal, Director of Programs & Evaluation**

"Jack.org is a national youth mental health advocacy charity that supports relevant, youth-led advocacy work across Canada. Young people have the passion, drive, insights and experience to make real and substantive changes in local, provincial, and national systems - but they're rarely invited to the decision making tables. At Jack.org, we put youth action at the centre of this work in two main ways. First, to support localized advocacy, we focus on capacity building so passionate young people can build the knowledge and skills required to do effective work in their diverse communities across Canada. We teach systems literacy, mental health literacy, environmental scanning, community reflection, action planning, and public speaking to ensure young people will not only have the knowledge they've accumulated in their own lives and experiences, but they'll be empowered as strong, informed, powerful advocates. We also provide ongoing training and mentorship to provide sustainable support along the way.

We also focus on connecting young people to each other and our national network.  Every community is different in Canada and requires localized youth leadership, but in addition we see it as incredibly valuable to synthesize youth voices and efforts and allow young advocates to move together, learn from each other, and push forward a powerful youth-led voice for national systems change work.

We support this work with our three programs in every province and territory in Canada. With just over 3000 young leaders, we're just getting started"

**Focus on: Personal stories**

Many youth advocates taking part in the match had been asked to use their personal story of mental ill health and recovery as part of their advocacy. The topic of personal stories arose as a priority in all the breakout discussions.

**Personal impact**

Whilst many agreed that personal stories can be powerful ways to illustrate larger issues, there was widespread agreement that youth are rarely fully informed about the long-term impact of advocating using their own experience. Participants cited examples of ways that being a mental health ambassador had done harm to their mental health – from negative feedback online to their story being "spun" in a different way than they had anticipated.

For those young people who had had negative experiences, support from the organization they were representing was crucial. These negative experiences were also less likely to happen amongst youth who had received media training or preparation from mental health organizations.

**The purpose of personal stories**

Regardless of their experience of telling their story, many participants questioned the value of personal stories, particularly given the way that these stories are often reported in the media.

For many young people, journalists or other professionals imposed an artificial narrative of recovery onto their story, implying that change had been linear and that they were now "well". This was at odds with people's real experiences of recovery, which were complex and, for many, a lifelong process.

The concern within the group was that telling personal stories in this way gives those reading an unrealistic picture of mental illness and treatment. For those experiencing mental ill health themselves, consistently hearing stories of seemingly straightforward recovery can be discouraging, rather than inspiring. This effect seems to be all the stronger when those in the public eye tell stories of mental ill health, with their professional success another barrier, rather than an inspiring achievement.

Youth were clear that telling a personal story needs a clear aim from the outset. Knowing what we hope to achieve by sharing our experiences – and what we can't hope to achieve – is essential for managing our expectations.

**"Your story is rarely just yours"**

Youth also talked about the very public nature of their advocacy for those around them. For the families and friends of youth advocates, having these stories told publicly could be invasive and uncomfortable. Many young people spoke of the challenges they had experienced balancing their right to be private with a sense of pressure or "duty" to be open about their experiences.

Other young people saw a larger community impact of telling their story. Whilst youth often did not identify the services they were talking about, small town or rural environments made those details identifiable. Youth expressed concerns about the way that their constructive criticism or accounts of their experiences negatively impacted those services.

**Open, honest and informed**

The clear message from the youth at the match was that preparation, training and support to manage the media was essential to safeguard young advocates and those around them. Starting with a clear purpose for telling a personal story, and what that story might achieve, is crucial to doing this well.

But the conversation also asked challenging questions about the purpose of personal stories in raising awareness, promoting good mental health and improving systems.

## *Best practice tips*

*Services*

- Be prepared to respond to mental health problems, both as individuals and organisations
- Share knowledge, both within and between sectors
- Look at the whole person when addressing mental health needs – are there accompanying physical health, housing, financial, education, etc. needs that are also impacting on them?
- Work towards a stepped care approach – right level of care, provided by the right person at the right time.
- Coproduce services with youth, their families and carers.

*Research*

- Involve youth in research design, starting as early as the research question, target group, recruitment process and outcome measures.
- Ensure that your samples are representative, to avoid the risk that results are "normed" on any subgroup.
- Publish what doesn't work, as well as what does.
- Make a commitment to act on results gathered – demonstrate that the information was used to make change.
- Ensure choice and support for young people participating in research, as co-researchers or participants.

*Advocacy, campaigns and policy*

- Use the evidence – we have a lot. You might find good practice examples in other countries, too.
- Peer deliver your campaigns whenever possible – it's more attractive and more likely to meet the needs of your audience.
- Train young people alongside adults to be good advocates with a clear role. Be prepared to support them before, during and after that process.
- Be responsive, adopt a "trial and error" way of working.
- Think carefully about how and why personal stories are used.
- Advocate for each other in areas where we excel. Give up power in areas where we don't. Work together whenever we can.
- Think about the larger systemic consequences of stigma reduction and advocacy and mitigate and negative outcomes

*In general…*

- Don't ask for youth approval after the fact, get them involved from the very start.
- Seek out youth perspectives, don't wait for them to come to you.
- Many forms of youth engagement are valid – it doesn't have to just be a panel.
- Be mindful of diversity - don't assume anyone you engage can speak for all youth.
- Make sure youth benefit from the process, as well as the organization engaging them.
- Make sure people are in the right place to do effective engagement
- Remember the positives –engagement doesn't just need to be a forum for complaints.

# Game Changers

Matches were asked to summarise their conversations to share with other IIMHL attendees. Specifically, matches were asked to identify "game changers" in their area.

The Youth Engagement match jointly identified six game-changers. These are six things that, if implemented, would drastically improve the way youth are engaged in services, research and policy. These same game-changers would also have a dramatic impact on young people's mental health.

1. Effective training and support for youth (build capacity and capability in an ongoing way)
2. Mental health, systems and research literacy
3. Person-centred, rather than professionally focused, practice
4. Co-ordinated response within and between countries
5. Fail forward – talk about what doesnt work as well as what does
6. Prevention, mental health promotion and early intervention