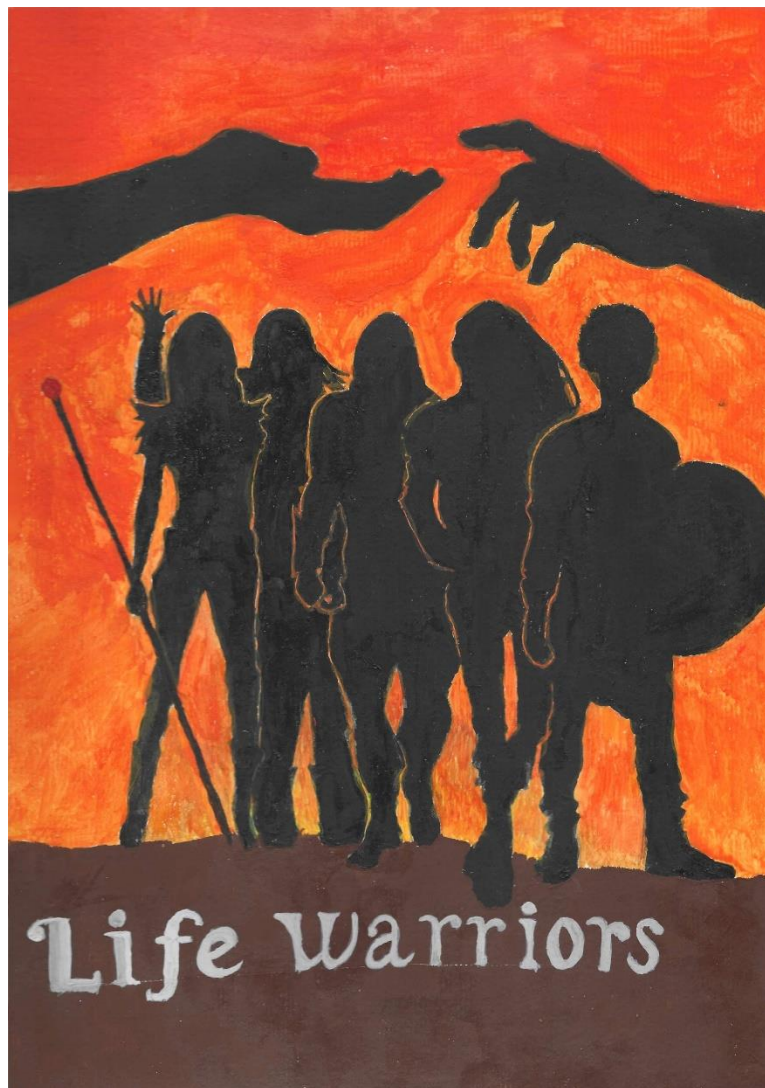


Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [anghydraddoldebau iechyd meddwl](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [mental health inequalities](#)

MHI 17

Ymateb gan: | Response from: Life Warriors



Evidence to Support the Welsh Parliament Committee for Mental Health Inequality in (North East) Wales

Lived experience narratives - Highlighting the need for change, for those experiencing stigma and challenges due to identifying with, the characteristics of, or having a diagnosis of 'personality disorder. February 18th 2022.

Authors of this report

Name of member and Author	Role within the group
Pam Watkinson	Chairperson
Scott Bloomer	Vice Chairperson
Simon Fielding	Vice Chairperson
Alix Douglas	Event's Organiser
Jennifer Jones	Motivating Specialist
Alex Flannery	Note taker/Agenda/LGBTQ+ Rep
Santana Crofts	Spokesperson
Peter Jones*	Timekeeper
Facilitators	
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Aims of the Report & Consent

- We aim to highlight inequalities in mental health services in Flintshire, including access to services, stigma and judgement from services, lack of resources and other topics that are relevant to your committee's inquiry.
- We will be using the four headings provided on the inquiry website:

<p>1. Which groups of people are disproportionately affected by poor mental health in Wales?</p> <p>What factors contribute to worse mental health within these groups?</p>	<p>2. For the groups identified, what are the barriers to accessing mental health services? How effectively can existing services meet their needs, and how could their experience of using mental health services be improved?</p>
<p>3. To what extent does Welsh Government policy recognise and address the mental health needs of these groups? Where are the policy gaps?</p>	<p>4. What further action is needed, by whom/where, to improve mental health and outcomes for the groups of people identified and reduce mental health inequalities in Wales?</p>

- All the narratives within this report are collective written accounts of the Life warriors meetings and discussions around their lived experience. These accounts have been merged and transcribed by Amy Luckhurst, (Coordinator for Life Warriors and Registered Local Authority Social Worker - Wellbeing and Recovery Adult Mental Health Social Services).
- Coordinator is over 18 years old, as are all authors/group members and staff. Coordinator's contact details are provided above and can be utilised to communicate with Life Warriors. All group members welcome any contact from committee members and have offered invitation to committee members, to visit the group and further discuss and elaborate on evidence provided.
- Lived experience voices of the Life warriors can be heard throughout the report. Amy has full consent from the group members to use their

individual quoted narratives within the report, although the majority of the writing will be a collection of views discussed by all members, of which have common themes and patterns experienced by each individual. The group consents to this information being published in its entirety.

- We are happy for the committee to use our names as the author of this report and for the committee to publish our evidence to inform their recommendations for change within mental health services in Wales.
- Although the Authors are listed, they are not named individually within the report to protect their rights to confidentiality.

The Life Warriors Story, History and Development

Life Warriors is a peer-led therapeutic support group for people with a diagnosis of, or people who identify with the characteristics of 'personality disorder' (PD). Members have varying diagnosis such as: Borderline (BPD) and Emotionally Unstable personality disorder (EUPD), Attention Deficit Hyperactivity Disorder (ADHD), Turners Syndrome (TS), Anxiety, Depression, Complex Post Traumatic Stress Disorder (PTSD) and Autistic Spectrum Disorder (ASD). The group provides members with a regular and therapeutic, peer led safe space for people to share their experiences around struggling to maintain relationships, risk taking and emotional regulation. This was created by and is facilitated by Flintshire County Council Wellbeing and Recovery (Adult Mental Health Social Services) and North East Wales Mind Community Wellbeing, as part of the transformation project.

Specialist support for people experiencing complex trauma and/or with a 'personality disorder' diagnosis was provided in Flintshire and Wrexham by BCUHB for many years. The services (Shards and Taith) were based on a therapeutic community model and were supported by a multi-disciplinary team of paid and volunteer staff, led by a psychologist. They were very well received. Once the services ended due to staffing cutbacks, there was no specialist support available for people with these experiences.

In 2019, BCU bid for Healthier Wales funding from Welsh Government to set up pilot mental health 'hubs' (ICAN hubs) in community buildings. Aura Libraries, FCC Mental Health Services and North East Wales Mind succeeded with a partnership bid to run a hub in the newly refurbished Flint Library. The bid included a substantial budget for recovery learning and training activities to support self-development and resilience. It was agreed that part of this money be used to develop specific services for those experiencing CPTSD/PD (in line with Learning Partnership priorities) and Rhian Evans (Team manager – FCC mental

health support services/Chairperson of learning partnership) suggested using the therapeutic community model.

In April 2020, consultants were appointed to help develop the service in a safe and sustainable way and it was agreed that a member of staff from North East Wales Mind and another from Flintshire County Council would work with the consultants to develop the group. These members of staff were Steph Phillips and Amy Luckhurst.

The group began in April 2021 and has been delivered remotely due to restriction around Covid 19 and working from home rules. For the first three months the group were supported by an Occupational Therapist/consultant, a lived experience consultant, Amy and Steph and participants learnt the basics of running the group. At that point it was decided that, in order to ensure longer term sustainability for the Life Warriors, the staff would continue to support the group with the help of specialist supervision from an experienced psychotherapist, with a background of managing therapeutic communities within a specialist service.

Last year in 2021, Coordinator for Life Warriors Amy Luckhurst was a participant in of the Community Resilience Programme, Research Project looking at gaps in services and inequalities in local and wider society. Working in adult mental health services for over 20 years, Amy (working in statutory services) and her third sector colleagues providing mental health support across North East Wales, recognised there was a cavernous gap in provision for people with BPD in North Wales. She saw that people were suffering as a consequence and wanted to take action to do something about it. Using tools and techniques learnt through the Community Resilience programme, Amy developed a public narrative to make the case for investment, support and action: why the issue matters, how it impacts local communities and how the issue can be addressed.

Working with people with lived experience of PD, Amy and her colleagues developed a group that would support their needs. It was important that her and staff members roles were to facilitate rather than lead; that the group would be run by people with BPD for people with BPD and that members should decide the group's name, rules and roles. They chose Life Warriors as a name for the group, as they feel that it summed up their struggles and their courage and determination to live well with PD and others conditions that create emotional dysregulation.

The group meets weekly for two hours, online, and creates a space where people feel heard and supported by peers with lived experiences of BPD. The experience of feeling understood often for the first time has been transformative for group members.

Here are some quotes from a recent case study (text above authored by R, Robinson 2021, edited A Luckhurst, 2022) and review undertaken with the Life warriors, by Independent Evaluator: Rosa Robinson (Frame CIC) in September and December 2021, evidencing how group has helped members:

"I'd just been diagnosed with BPD and I was asked if I'd like to join this group. And so I did because there's nothing else out there and the NHS don't seem to have anything. This was the first thing that's actually helped me...it's helped me because there are other people in my situation that understand. My confidence has grown tremendously. All these wonderful people in this group are my family. Whenever I'm struggling in the week, all I've got to do is hang on until Wednesday...it helps me stay a bit more stable than I normally would".

"It took them a while to diagnose me with this disorder (BPD). I'd tried all sorts of things [to manage it] before that just weren't helping...I love everyone in the group so much. They are so amazing and strong. I'm definitely glad that I'm part of the group and can see them every week"

“There’s not really any other support I’ve been offered other than this group. I was a bit apprehensive coming because nothing else I’ve tried has been any use. But it’s been so nice to meet people who are similar to me and understand the struggles that I go through, because a lot of other people don’t understand. It always brightens my week”.

“I’ve suffered with poor mental health for a very long time. I was told that this is the only therapy that’s available...it’s like a family; we all get on well and support each other and I look forward to every week”

“I’ve been part of this group for a few months now and I find it helpful in that if I feel like I’m going to have troubles at home or something, instead of going into crisis, I know I can get support on a Wednesday. I find it helpful not to get down to the lowest point like I would have got to before”

“I was diagnosed about two years ago for BPD...and I didn’t really know much about the condition. I remember I was nervous speaking in the group because I didn’t know anyone. I had a little spiral one time and spoke about how I was feeling...I thought that people might reject me but everyone was so supportive. They were able to give examples of when they’d have the same experiences. And it’s nice to have that support because friends and family outside of the group, they mean well but they don’t understand unless they’ve been through it themselves. But people in the group can tell you what they would have wanted and needed to hear in that moment”

“It’s made such a difference to my life. I’ve suffered with my mental health for years and years and I’ve never really been listened to or been helped...and I didn’t feel like I could ask for help. But with this group, I felt I can cope more”.

“The group’s impact is created by the open, honest, non-judgmental space it offers its members: It’s just being able to talk honestly, about how you’re actually feeling...And being able to come out and say, I think I’m a bad person or I think this or that, and these are the reasons why. But when we talk, people say, this is why you’re not a bad person or a bad mum or whatever’s going on in our heads. You know? And they understand. And that’s huge. We suffer with that constant battle in our heads, continuously, and it’s so tiring...24/7, continuously analyzing things. When people understand that’s huge”

Rosa suggested in her case study that: “Crucially, the group shows potential to resonate beyond the impact on individuals’ lives and to create broader societal outcomes”:

“For me, I’ve not been aggressive since joining the group and that was quite a regular thing for me before. And because I’ve been more stable, I’ve been able to get a job. My whole frame of mind is just changed”.

Which groups of people are disproportionately affected by poor mental health in NE Wales? What factors contribute to worse mental health within these groups?

- **People who have a diagnosis of, or identify with the characteristics of personality disorder. Borderline (BPD) or Emotionally Unstable (EUPD) personality disorder.**

The Life warrior group discussed how it feels that every depiction of personality ‘disorder’ within the mainstream media, will be portrayed as evil, split personality, manic, unstable and cruel individuals. This information feeds through into the psyche of society, including professionals. Nothing could be further from the truth. We have further discovered this, by meeting each other that we are caring, loyal people who are largely misunderstood, due to us experiencing events in life that trigger an emotional response based on past traumas. This can lead to our reactions being misconstrued, rather than understood by professionals and society. Instead we will be labelled as “attention seekers”, “hysterical” or someone with “poor coping skills”. All of us as life warrior members have experienced varying degrees of trauma in our lives, whether that be as children, as adults, or both. Often, there is no specialist support or help offered, to allow us to manage that trauma and its effects. As a result, we find it hard to trust people and that they will not leave us, abandon or reject us. This makes it very difficult for us to believe that we can have safe and secure attachments with people. Often instead we will want constant reassurance that we are loved and needed and will not be abandoned and forgotten. This is easily misunderstood by people who are not familiar with our struggles.

- **Parents needing Peri and Post Natal mental health support**

A Life Warrior stated: “When I was a young parent and I was struggling greatly with my mental health and managing my emotions, I was passed off with having the ‘baby blues’ and given anti-depressant medication and discharged. They took a total blanket approach to my struggles and I was not listened to and did not feel supported or valued as a person or a mum”.

- **Men, in particular young men.**

A male Life Warrior stated that he will “never want to admit how bad it is to doctors or professionals, as I find it almost impossible to trust other people. I have always been aware that if I say too much, I might get sectioned and lose my rights and liberty. Instead I’m left feeling unsafe and that impacts on my wider family as well as me”.

- **Survivors of Childhood Sexual Abuse and Domestic violence**

One Life Warrior experienced significant childhood abuse and trauma, then domestic violence as an adult and was for a time a looked after child and until recently, she has not been offered or received any support for this. She believes this is why she experiences low self-esteem and lack of confidence, often struggling to leave the house due to crippling anxiety, prior to joining group. Due to not receiving early intervention (other than short term ‘fixes’ and offers of medication) she was left to “fend for myself” and often felt she did not know how to cope or where to turn, she now feels she has “passed on” the issue to her wider family, who experienced the trauma with her. She feels if she had been offered specialist support things would look very different now.

- **Adults and Children with Adult ASD and/or ADHD** - Young people and children under 18 who are unable to access CAMHS – Child and Adolescent Mental Health Services or Neuro Developmental Services (NDS).

“I have been finally diagnosed with ASD and ADHD in my early 30’s, after experiencing all the difficulties the symptoms present since childhood. The reason I ended up having a diagnosis myself, was because I had identified the same traits in my young child. I am now in a position where I am trying to get professional advice and support around this and it is proving to be impossible”.

Another Life Warrior stated that she has experienced significant issues with her own mental health since childhood. She came from a diverse background with strong and fixed belief system about “keeping problems in the family” and lived with an elderly relative, who she found deceased at a very young age. She was not offered support with this and as a result, became unable to manage emotions and trauma responses as she would like to. She feels if she had received support as a child and young person, she “would not be here now in this position”.

One account from a parent within Life Warriors suggested that their child is experiencing difficulties with mood and self-esteem and they as a parent have been asking for support with this for some time. They want early mental health intervention for their child, so they do not “repeat history and end up like I did

struggling alone”. After being confirmed as ‘open’ to the Flintshire CAMHS team, the family are still awaiting intervention from the service after 2 years of waiting.

“Professionals don’t generally recognise when young women ‘masking in ADHD’ and I struggled throughout my education. It wasn’t until I had a psychiatric admission that I finally felt understood and listened to. It shouldn’t get to that”.

- **People who are diagnosed with Post and Complex Traumatic Stress Disorder.**

We could argue that each Life Warrior member can identify with the symptoms of PTSD/CPTSD and will be evidenced throughout.

- **Anyone applying for benefits such as Universal Credit or Personal Independence Payment (PIP) for mental health issues preventing them from working.**

One Life Warrior suggested that the PIP system is “damaging, terrifying and demeaning”. When this individual was assessed by the private company employed by DWP, they were forced to disclose that they are not able to use a bath or shower without easily getting triggered, due to previous trauma in childhood. She describes the assessor dealing with this disclosure “with disgust and sarcasm and with no regard for my feelings whatsoever”. As a result, this is directly affecting the person financially, as they were refused PIP support and feel too “frightened” to apply for it again, despite evidence of need.

For the groups identified, what are the barriers to accessing mental health services?

“I have had a condition all my life that has a dedicated society attached to its cause, yet for my ‘personality disorder’ the only available service is Life warriors. Statutory services (MH Teams) have huge long waiting lists and I am personally seeing how that is having an impact on the third sector (mental health organisations) trying to bridge the gap”. When you do see them (MH Teams) after going “round and round in circles trying to gain support” they simply tell you “there is no correct support for you”. They will say, “What you need is not out there” and they are right. Other than group we don’t get any other support (with PD symptoms). “I love group and all my friends, it has really helped me”

Judgement - “Appearances can be deceptive, just because I am wearing makeup and I look nice, does not mean that I am okay. It more likely symbolises

the fact that I have had to put makeup on to feel able to leave the house that day, using it as a 'mask' to the world, to help me cope with the anxiety it brings me. Despite presenting as incredibly distressed on arrival to the doctor on this one occasion, I was merely taken on face value and they have decided I am "well kempt" so I must be okay, so I didn't get the right support".

Most members talked about "masking my difficulties", "damping down personal experience" and "trying to hide how they really feel", so they will not be penalised in some way by professionals. Examples given where parents have done this whilst dealing with children's social services. Immediately you are made to feel that they question your ability to be a parent due to your mental health, rather than offer you help when you need it. This is a "double edged sword" as at the time I really needed the help but I was terrified if I said the wrong thing they would remove the children". If this individual had access to a MH advocate, this could have been avoided.

One member tragically lost their father as a child, after their father sadly took his own life. Following this the individual attended the GP and opened up about how it made them feel and think, whilst displaying emotion after the tragedy occurred. They were told that they were using "attention seeking behaviour". This individual has experienced issues ever since and has found it difficult to trust medical professionals following this incident.

Discrimination – "Recently I was refused life insurance because I have a diagnosis of Borderline personality disorder so was deemed too risky". When I visited the GP to discuss what I was told was "run of the mill depression", deep down I knew it was more than that because it kept getting worse. I rang the GP to ask about medication advice and was "told over the phone that I had BPD". "No one had told me to my face at any point but there it was on my medical records".

Another member talked about how they applied for a job within the prison service and got through all the tests, only to be rejected due to evidence from his medical records. They did raise an appeal under the grounds of discrimination, but it was not taken further.

Police – the group collectively think that North Wales Police (NWP) officers are not offered appropriate training around mental health. This is evident from the accounts we discuss in group sessions. Following concerns raised, Amy visited NWP training over two days and was shocked to see that aside from the poor quality of training provided, there was no representation whatsoever of the voice of those with lived experience of any form of mental health issues, including personality disorder. We have as a result of this, offered to work alongside the

Crime Prevention unit and NWP in improving and updating their training program. We are yet to hear from them or witness any positive change within the police forces knowledge around complex mental health issues. The police force will argue that they are “not mental health professionals”, however they are most often first responders to someone in mental health crisis, so do need those specialist skills to remain person centred at times where people need help the most. “In moments of crisis, I am vulnerable and frightened, yet I am thrown in the back of a van and treated like a criminal, not explaining where we are or where we are going”. “If they understood us, they would be much kinder than they are”.

Dual Diagnosis – One person disclosed that they have had a long term battle with alcohol and mental health issues, including (past) eating disorder, current BPD, ADHD and PTSD. This person uses alcohol to cope when they feel that they are not. Having mental health issues sometimes causes extreme distress and without support for this, “how will I ever stop drinking either as it is all connected together”. “My wider family are all affected by my issues and we all want me to get better, so why can’t I get the help I need?”

Another member talked about how they experience chronic pain, which is often worse if their mood is affected. “This has not been connected as a whole issue by medical professionals and I think that needs to change as it is all connected”.

Mental Health Services in Crisis in North Wales

In the last few years due to underfunding and understaffing and increasing service demand, there has been a real downturn in primary and secondary NHS services provided for people experiencing mental health issues. Most recently staff team members are leaving the teams in large numbers in our local area, meaning that staff retention is becoming even harder to manage than previously as the job/caseloads are reported to be too stressful to manage.

Specialist mental health services such as Psychological therapies in Flintshire are almost impossible to access. Psychology services can only be accessed if someone meets criteria for Tier 2 (Community Mental Health Team - CMHT input), and has an approximate four year waiting list for patients, if they are lucky enough to make it to Tier 2. Most people with BPD or EUPD will likely never meet Tier 2 criteria, due to the firm belief within the health services that PD is “not a mental disorder”, despite it being in the diagnostic manuals (DSM-5 ICD-10) under mental health disorders.

As a result of this, members reported that they have received appointments that they have waited weeks sometimes months for, such as counselling or assessment, just for it to be cancelled at the last minute and not reinstated. Others report that they have received letters to say they are being discharged from MH team as they did not attend appointments, when they have attended appointments on the phone. "They (the MH team) will then write to your GP and tell them that you did not attend, so the GP will not re refer you to them". This leaves us with "nowhere to turn". Wait times continue to increase for all services.

How effectively can existing services meet their needs, and how could their experience of using mental health services be improved?

As stated above, mental health teams in Flintshire are facing a current staffing crisis and it is having a direct impact on those individuals who use services.

Suggestions for improvements included:

- Police to attend scene with a mental health professional when responding to a mental health crisis situation, so it can be led by them rather than officers.
- Allow funding for more staff in Flintshire and Wales' mental health NHS and Local Authority teams (PCMHT, CMHT, CAMHS, CRT, SMS, Support services), across all tiers including acute hospital care.
- 24 hour access to mental health support when it is needed, rather than teams offering a service "5 days a week on a 9 to 5 basis".
- Make triage accessible in the community outside A&E and s.136 suites without procedures or fear of Mental Health Act (MHA, 1989) assessment.
- Government to identify where all the advertised "extra funding for mental health services" is and how it is being spent/will be spent.
- Create new person centred peer led projects across the country
- Fund existing and developing groups to expand, including Life Warriors so specialist, continued support can be made available to those who need it.
- More focus on long term diagnosis being supported by long term practical and flexible support, "when we need it". Rather than "offer short term support for a lifelong issue" where "everything is a fight to our rights".

- Better, adequate multi-disciplinary working to provide people with better outcomes.
- Robust and informative training should be offered to any professional that might come into contact with someone experiencing mental health distress or crisis.
- Allow more funding for mental health advocates, so peoples voices are not ignored and can be heard, to allow positive change in their lives.
- Allow more time and autonomy for professionals to work with individuals so continuity and validation occur.
- Provide childcare access and or crèche facilities to parents needing to access mental health support, so they can engage fully in a therapeutic process.
- Make benefits claim forms and assessments specific to mental health and separate to physical health assessment.
- No postcode lottery, make all services available in all areas.
- Offer transition or signposting to other services where possible, rather than leave a person with no support at all.
- Reduce waiting times for services and allow other support to take place whilst waiting for services.
- Allow flexible access to mental health social work support, “Having a social worker has made such a difference, I actually feel listened to now and that things are moving on for me”.
- Stop putting people in “checklists”, look at the whole person and those around them.
- Remember that we are all human beings regardless of our issues and should be treated as such.

To what extent does Welsh Government policy recognise and address the mental health needs of these groups? Where are the policy gaps?

We feel as a collective, that we have provided you with a plethora of information that you can use, to cross reference and scrutinise the appropriate policies gaps. The policies we have considered during debate are:

Mental Health (Wales) Measure (2010), Together for Mental Health <https://www.northwalescollaborative.wales/transformation-programme/mental-health/>, Mental Health Delivery Plan 2019-2022 - <https://gov.wales/mental-health-delivery-plan-2019-to-2022> and The (SSWBA, 2014) population Needs Assessment, which although is not published yet, but is in draft form.

Coordinator and facilitator Amy said: The Life warriors have worked incredibly hard in recent weeks to bring you this information and they are looking forward to witnessing, how members of the committee will use this information, to address the inequalities of mental health services in Wales, particularly for those who identify with or have a diagnosis of 'personality disorder'.

The group are particularly interested in their voices being heard in relation to funding of specialist services for those who experience 'personality disorder', also to those who experience similar issues and don't "fit in the statutory tick boxes". If we are allowed to expand on these crucial and valuable networks of support, the outcome could well be a huge saving for Welsh government and the NHS, on stat services, with possible reductions in waiting times for individuals. Whilst vitally, we would be removing the unnecessary stress for those who fear abandonment and rejection due to past trauma, being rejected by those they should be able to trust.

"I think there should be more of these groups...the community feel you get. It's such a simple thing and it's changed our lives; it's changed how much we are all in crisis. I wish the people who hold the purse strings could understand that something so simple like this, in the long run, saves them money because we're not going in and out of A&E every five minutes or needing to be back on the books at the Mental Health team every couple of months because nothing's been sorted. I think this group is so simple and yet effective".

What further action is needed, by whom/where, to improve mental health and outcomes for the groups of people identified and reduce mental health inequalities in Wales?

During an independent review of Life Warriors in September 2021, we asked the question: Has there been any changes in your relationships since you joined the Life Warriors Group? Here are some answers from the members:

I have had a positive change as I now have an outlet to discuss things rather than tell family members. Have the group to discuss stuff with and get advice.

Would like to get a few groups going and maybe 2 groups coming together (in the future).

Took pressure off my kids. Having someone to talk to. My son said it's nice to have my mum back

Taken some pressure off mum and dad

Important as people may think of suicide of they didn't have the group to talk to and having someone to understand.

Without the group we would have all been left by the mental health service stuck on tablets and that's it

Please do pay reference to our review document from September 2021 (sent with this report), which gives a lived experience overview of the benefits of being part of a therapeutic community. If policy reflected the gaps in services, then it would likely acknowledge that this is an area that needs development now. We intend to expand in the next few months, but we are aware even then, we are only scratching the surface of what is actually needed across Wales, to provide an appropriate level of support to those who need it most.

Thank you for allowing us this opportunity to work alongside you on this important issue.

The Life Warriors

February 18th 2022

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All the contents of this report remain the property of The Life Warriors. All members have given full permission for members of parliament to use this document to inform their call to Welsh Government to improve services for people experiencing mental health issues.