Living Well

Mental Wellbeing and Public Life in the North East

A Report by the Tyne & Wear Citizens Commission on Mental Health

TYNE & WEAR citizens

Acknowledgements

The Commission is indebted to all those who came forward from across Tyne and Wear to give testimony. We are honoured to have borne witness to each and every powerful story.

The Commission is also deeply grateful to Catherine McKinnell MP, the Rt Revd Christine Hardman, Dr Esther Cohen-Tovée and John Lawlor for their invaluable contributions to our public hearings.

Furthermore, the Commission is grateful to the following individuals and organisations for ensuring the smooth running of our public hearings:

Jon Banwell, Karisma Music and AV Hire
Mining Institute, Newcastle
The Quayside Exchange, Sunderland
Lindisfarne Centre, St Aidan's College, Durham University

Finally, the Commission expresses its thanks to Professor Eileen Kaner and Liam Spencer of the Institute of Health and Society at Newcastle University and Fuse, the Centre for Translational Research in Public Health for making this report possible.

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ISBN: 978-1-5272-3151-1

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Foreword

Tyne & Wear Citizens established the Citizens Commission on Mental Health to identify practical solutions to the mental health challenges facing people in our region.

Through our listening campaign and public hearings held in Newcastle, Sunderland and Durham, we received over 300 unique testimonies about mental health, ill-health and wellbeing from across our region.

We could not fail to be moved by what we heard. While some of these stories span decades, many perceive a more recent decline in our health and public services. Most powerful of all are those stories that end with the loss of a loved one.

Many of these testimonies, however, are stories of hope and of the will to make a difference. We heard of communities seeking to nurture the emotional wellbeing of their children. We heard of young people wanting to ensure that none of their peers suffer in silence. We heard of healthcare professionals wishing to break down procedural barriers to better treatment and support. We heard of citizens longing to share joy and connection.

We know that there were many more stories that we did not hear. Stigma and the fear of discrimination continue to prevent too many in our communities from speaking up and seeking help. The Commission acknowledges the struggles of those who did not feel able to come forward as much as those who did.

In recent years, the North East has experienced the worst of austerity, and its effects have only exacerbated the challenges facing both those living with mental ill-health and those who are trying to help. But our local traditions of resilience stretch much further back into our history than these more recent episodes and they serve as a source of inspiration as we work to reweave the social fabric for future generations. We believe that there is an opportunity for everyone to participate in public life and improve the wellbeing of our society.

As Commissioners, we have come to appreciate that the mental health challenges facing people in our region are often the result of systemic factors that lie beyond the control of the individual person. This does not mean, however, that we in civil society are powerless. Rather, we believe that it is from those living with mental health challenges that innovative solutions will come and that, together, we can build the power required to hold key decision makers to account. To this end, we outline in *Living Well* a series of practical 'Actions' for decision makers in healthcare, statutory services and civil society to address a range of mental health issues at the local, regional and national level.

As a result, our report is not merely an account of the mental health challenges facing people in the North East but a snapshot of change in action. For this reason, we hope that our findings will resonate with a readership far beyond our region and that our solutions encourage all those working towards public wellbeing and the common good.

Claire Robinson
Chair of the Citizens Commission on Mental Health

Executive Summary

Through its listening campaign, the Commission received over 300 testimonies about mental health from across the North East. The Commission analysed these testimonies and identified the common issues that underpinned them before grouping together related issues into the key themes summarised below. Each theme was further explored at the public hearings of the Commission held in Newcastle, Sunderland and Durham, and is discussed in more detail in the main body of this report. A full account of the Commission's methodology can be found on page 34.

Early Intervention

The Commission heard from young people whose mental health worsened because their school, GP or local mental health service did not intervene early enough. However, their testimonies also identify ways to better embed the practices that would aid early intervention in schools and primary care.

Systems that Serve People

The Commission heard from a range of service users whose encounters with processes and procedures left them feeling as if they, the patient, were the problem. While some of these stories speak to systemic issues, others identify problems that are much more local – though no less consequential – in character. Crucially, these testimonies also identify specific ways to reposition the person at the centre of their care.

No Choice, No Control

The Commission heard from individuals whose experiences of treatment and recovery range from freedom of choice to no choice at all. Their stories outline how inconsistencies in approaches and protocol, as well as limited treatment options, can further disempower the person in their moment of need. However, the Commission also heard how flexibility and choice of treatment can play a key role in helping the patient take control over their recovery.

Suicide

The Commission heard of how suicide affects families and communities from across the North East. Testimonies illustrate the immense pressures that individuals and institutions face when trying to help someone in crisis or cope with the effects of a person taking their own life. However, these stories also identify specific ways to better share the skills and

resources needed to assist both those trying to prevent suicide and those trying to deal with its impact.

Engaging Families and Carers

The Commission heard of the challenges that families and carers face as they try to support their loved ones during their assessment and treatment. While these testimonies point to the complexities of involving families and carers in the assessment process, they also identify effective models for engagement and opportunities to further expand them.

Being Well, Staying Well

The Commission heard from patients and practitioners alike whose understanding of mental health and wellbeing extend far beyond the medical model. These testimonies not only identify a range of non-medical solutions but suggest opportunities for healthcare providers and civil society to promote ways of living well together.

Social Determinants

The Commission received a range of testimonies that identify key social determinants of mental ill-health. These testimonies demonstrate the impact that the benefits system and living conditions can have on personal wellbeing. In so doing, they emphasise the importance of strengthening relationships within civil society and empowering communities to nurture their own wellbeing.

Actions

The Commission applied the methods of broad-based community organising to discern practical solutions to the issues it identified through its listening campaign and public hearings. Each of these solutions is framed as an 'Action' to be put to a key decision maker in local statutory services, NHS Trusts, and civil society organisations.

Will you, **Northumbria Healthcare NHS Foundation Trust**, work with students from St Thomas More Roman Catholic Academy, North Shields to re-design the CAMHS clinic at Albion Road, North Shields?

Will you, **Northumberland, Tyne & Wear NHS Foundation Trust**:

- release fifteen of your clinicians to participate in a pilot to promote mental health and emotional resilience in schools?
- work with Tyne and Wear Citizens to excel in your practice of engaging families and carers in line with the Carers Trust Triangle of Care?
- implement the CRAFT Model within the Trust for families and carers?

Will you, **Newcastle Upon Tyne Hospitals NHS Foundation Trust**:

- ensure that the signs for the Emergency Department at the Royal Victoria Infirmary show that the service is for mental health as well as physical health emergencies?
- work with Northumberland, Tyne and Wear NHS Foundation Trust to develop mental health training for all your staff who have patient contact?
- develop a best practice protocol for distressed patients needing to travel home from A&E following assessment?
- apply to the Department of Health for permission for the Lloyds pharmacy Royal Victoria Infirmary to be open 100 hours across a seven-day week?
- work with Tyne and Wear Citizens and local pharmacies to ensure that a pharmacy is available 24/7 in Newcastle City Centre?

Will you, **Catherine McKinnell**:

- ensure that the Health and Social Care Committee consider mandatory provision of a counsellor for every English school, and work with us to pilot and evaluate such provision locally?
- work with Tyne & Wear Citizens to highlight in Parliament the need for consistency across CCGs regarding dual GP registration and continuity of care for students and others with multiple addresses?

Will you, **Durham University**:

- provide funding and time for staff from the University Counselling Service to train as Mental Health First Aid Trainers and deliver training to groups of student leaders and staff within your Colleges?

Actions

- ensure that your telephone and email points of contact (at both University and collegiate level) signpost to local out of hours support for students who are seeking help during a time of mental health crisis?
- work with Tees, Esk and Wear Valleys NHS Foundation Trust, Durham County Council, Durham Constabulary and other partners to develop a suicide protocol, which includes debrief and local support for your respective staff?

Will you, **Newcastle University Student Health and Wellbeing Service**, work with Tyne & Wear Citizens and Newcastle University students to improve the waiting system for students with mental health appointments?

Will you **Newcastle Central Mosque**, run an Open Door Meal by the end of January 2019 and commit six or more of your members to undertake mental health awareness training?

Will you **Northumbria Quakers, All Saints, Newcastle, the College of St Hild and St Bede at Durham University,** and **St John the Baptist, Newcastle, support Newcastle Central Mosque** by sharing the resources you have to assist with running the Open Door Meal and developing Open Door Meals in other institutions?

Will you, **Byker Community Trust**, work with Tyne and Wear Citizens and partners to ensure that all rubbish, litter and items which have been fly-tipped are disposed of appropriately on the Byker estate?

While many of these Actions offer solutions to the specific problems that emerge from the testimonies that the Commission received, they do not tackle the deeper systemic issues that these testimonies also demonstrate. To this end, the Commission envisions several of the Actions outlined above, such as the provision of clinicians in schools, as pilots which can be evaluated and implemented on a wider scale.

In addition, the Commission has also identified issues that it has thus far been unable to address through specific Actions. These issues include the effects of punitive sanctions in the benefits system, social determinants such as noise pollution, and lack of choice for patients who would prefer face-to-face counselling. However, the Tyne & Wear Citizens Mental Health Action Team will continue to build relationships and power within civil society to explore and address these issues. The Commission invites interested readers of 'Living Well' to participate in its work going forward.

Context

Defining 'mental health'

A recent index of 301 diseases reported that mental health problems are "one of the main causes of the overall worldwide disease burden" and the "primary drivers of disability worldwide" (Vos et al., 2013). A recent commission on global mental health concluded that "mental health problems kill more young people than any other cause around the world" and rising levels of mental ill-health constitute a "global health crisis" which "results in monumental loss of human capabilities and avoidable suffering" (Patel et al., 2018).

What is meant by 'mental health' in such contexts, however, requires some clarification. On the one hand, mental health can be understood with regards to mental disorders; that is, in terms of the presence or absence of "a clinically recognizable set of symptoms or behaviour associated in most cases with distress and with interference with personal functions" (World Health Organization, 1992).

On the other hand, mental health can also be understood as denoting not just an absence of mental disorders but, rather, a "state of wellbeing" in which a person might flourish (World Health Organization, 2004). Given its title, it should come as no surprise that *Living Well* adopts and contributes to this latter understanding of mental health, even though it discusses the treatment and diagnosis of specific mental disorders.

Mental health in the UK

In its "No Health without Mental Health" strategy, the UK Government appeals to this broader understanding of mental health as "the foundation for wellbeing and effective functioning both for individuals and for their communities" and "a positive state of mind and body, feeling safe and able to cope, with a sense of connection with people, communities and the wider environment" (UK Government, 2011).

It does so in challenging circumstances. In the UK, mental disorders that reach diagnostic thresholds exceed the prevalence, impact and persistence of all other health conditions in the country (Friedli & Parsonage, 2007). Approximately one in four people experience a mental health problem each year (McManus et al., 2009), though only one in eight receives treatment (Lubian et al., 2016). The annual economic and social cost of mental illness in the UK is estimated at £107 billion; a figure which approaches that of the entire annual NHS budget (UK Government, 2017).

Young people and students

While mental health problems span all age ranges, the highest burden is felt among 14 to 29-year-olds (Office for National Statistics, 2005, Whiteford et al., 2013). Two of the most common diagnostic categories for this age group are anxiety and depression (Department for Health, 2013), the rates of which have increased by 70% among young people between 1989 and 2004 (Mental Health Foundation, 2005). In 2016, *The Times* reported a 68% increase

in students using counselling services at Russell Group universities since 2011 (Sandeman, 2016). In addition, a recent international study found that the rate of suicide amongst UK students increased by 32% between 2012 and 2016 to overtake the suicide rate of young people in the general population for the first time; a trend the researchers concluded "cannot be explained by changes in the student population, or by factors affecting the general population" (Pinkney & Kwok, 2018).

Social determinants of mental health

The World Health Organization defines social determinants as the factors impacting upon physical and mental health which pertain to "the circumstances in which people are born, grow, live, work and age". In terms of mental health, existing research identifies employment as "one of the most important determinants of physical and mental health", with the long-term unemployed facing "a lower life expectancy and worse health than those in work" (Public Health England, 2017). Research demonstrates that certain factors associated with low-pay and low-skilled work can contribute to mental ill-health, with "lack of control and reward at work" identified as "crucial determinants of several stress-related disorders" (The Marmot Review, 2010). More generally, there exists "a strong association" between poverty and health outcomes (Public Health, 2017); poor housing, for example, is associated with a range of health conditions including mental disorders (Krieger et al., 2002).

Groups identified as experiencing a higher prevalence of mental health problems include Black, Asian and minority ethnic communities (Bhui & McKenzie, 2008); refugees and asylum seekers (UNHCR, 2015); homeless people (Homeless Link, 2014); carers (Shah et al., 2010); people with learning disabilities (Raj et al., 2016); people who have experienced domestic abuse (Howard et al., 2009) and people with a history of substance misuse (Roberts et al., 2016).

Adults who identify as lesbian, gay or bisexual are "twice as likely as heterosexual adults to suffer from anxiety or depression" (Semlyen, 2016). In addition, a recent report found that "there is some evidence" of UK practitioners "pathologis[ing]" the gender identity of transgender mental health patients (Hudson-Sharp et al., 2016). This report also pointed towards "a lack of mental health inpatient provision for transgender people [and] evidence of long waiting times in first referral to a gender identity clinic, with consequences for mental health."

North East England

Many of these mental health challenges are felt acutely in the North East. A 2018 YouGov survey commissioned by the Mental Health Foundation revealed that the North East has the highest percentage of people reporting mental health problems in the UK. Of those surveyed, 77% of people had been "overwhelmed or unable to cope" at some point in the last year, 40% had suffered with depression, 32% had experienced panic attacks, and 4% had suffered post-natal depression (Evening Chronicle, 2018). According to the Office of National Statistics, the highest suicide rate in the country is found in the North East, with 13.2 deaths by suicide per 100,000 population (Office for National Statistics, 2014). A report by the Office for Science found that in the UK "women in the North East have one of the highest prevalence of mental ill-health, with men in the region ranking towards the middle" (Jagger, 2014).

Data from Public Health England finds that the prevalence of mental health disorders in children and young people aged between 5 and 16 in the North East is, once

Context

again, higher than the national average (Public Health England, 2017). In 2015, Health and Social Care Information Centre data showed that young people in the region self-harm more than anywhere else in the country, while data from Sunderland showed a 13% increase in self-harm admission amongst children and young people between 2007 and 2013 (Public Health England, 2017). Finally, a local study of mental health and substance use among 14 and 15-year-olds in seven schools in one area of the North East found that 30.5% of children and young people screened positive for signs of low mood using the Warwick Edinburgh Mental Wellbeing Scale (Newbury-Birch et al., 2014).

Mental healthcare in the UK: challenges and responses

These issues highlight existing structural challenges in healthcare. Although there has generally been a divide between physical and mental healthcare in the UK, there has in recent years been "an increasing call on healthcare professionals to consider psychological wellbeing when treating the physical symptoms of a condition and vice versa" (Mental Health Foundation, 2018). Research carried out by the King's Fund concluded that the "separation between physical and mental health has a high human cost", demonstrating that "the life expectancy for people with severe mental illness is 15 to 20 years below that of the general population, largely as a result of physical health conditions" (King's Fund, 2016).

Recent media coverage of mental health challenges has focused largely on strains on the NHS, with stories of stretched statutory services speaking to a much deeper societal anxiety about the growing challenge of mental ill-health. Once again, the North East features prominently in these national narratives. Reports of mental health patients being sent hundreds of miles away from home due to bed shortages, for example, include local examples, with the Tees, Esk and Wear Valleys NHS Foundation Trust having to send hundreds of patients as far as 180 miles away between June 2017 and May 2018 (*The Guardian*, 2018), and Northumberland, Tyne and Wear NHS Trust treating patients from NHS Lothian, Scotland (*Daily Record*, 2017).

In response to these challenges, the UK Government announced in 2017 a range of measures designed to "make mental health an everyday concern for every bit of the system" (UK Government, 2017) and, more recently, has signalled its intention to prioritise the retention and expansion of the NHS mental health workforce. In 2015, the Government pledged £1.25 billion for investment in mental health services, though, "in 2015, only £143 million was released instead of £250 million expected" (Bennett, 2018).

In January 2018, the UK Government appointed the world's first Minister for Loneliness. In October 2018, in response to reports from GPs of seeing between one to five patients a day suffering with loneliness, the Government announced its ambition to ensure that every primary care network in England will have access to social prescribing connector schemes by 2023 (Bostock, 2018).

Mental health research

While quantitative approaches are an established method for understanding various mental health challenges, qualitative methods have received increasing recognition in health research (Al-Busaidi, 2008). Involving "experts by experience" is becoming a core component of mental health research (AMHRF, 2018) and is increasingly recognised as essential in ensuring that research is focused on the needs of service users (Ghisoni et al., 2017).

However, mental health research has lagged behind many other areas of healthcare in using qualitative methods (Peters, 2010) and qualitative research is rarely published in high impact general medical, health services, or policy research journals (Gagliardi & Dobrow, 2011).

The relationship between mental health research and mental health policy can be fraught. Research outcomes often fail to have an impact due to problems associated with timeliness, presentation, and manner of communication, with policy makers often not considering research findings as central to their decision making (Stone, Maxwell & Keating, 2001).

A community organising approach to public wellbeing

As the product of a Citizens Commission informed by the methods of broad-based community organising, *Living Well* is uniquely placed to respond to some of these challenges. Community organising asserts that innovative and winnable solutions to specific social problems must emerge from the testimonies of people who face these challenges in their daily lives.

As such, the testimonies that form the core of *Living Well* come from people in the North East with lived experience of mental wellbeing and ill-health. Participants were not selected through randomised sampling, but rather, chose to make their voice heard through the existing relationships they hold within civil society, be it as school or university students, church or mosque congregants, users of a voluntary sector service, social housing residents, or simply as friends or family members. In other words, these testimonies are the product of conversations of a kind that simply would not take place in the more formal environment of the consultation exercise. Indeed, in some cases, these testimonies represent the voices of those who have not engaged with clinicians about their mental health challenges, let alone public health researchers.

The discussion that follows brings these unique testimonies to bear upon the challenges outlined throughout this section. In many cases, these testimonies point towards specific, practical steps to take to address manifestations of these issues at the local, regional, and national level.

Early Intervention

The Commission heard from young people whose mental health worsened because their school, GP or local mental health service did not intervene early enough. However, their testimonies also identify ways to better embed the practices that would aid early intervention in schools and primary care.

The Commission received testimonies about the importance of early intervention not just from young people themselves, but also their parents, teachers and counsellors. In many of these stories, however, 'early intervention' is purely hypothetical: something that should have happened but did not. The Commission heard from a mother in Newcastle whose son has severe anxiety, obsessive compulsive disorder and possible autism spectrum disorder. **"My son saw his GP about bullying and gender issues"**, she explains. **"The GP didn't make a referral until after the third appointment and it was to a gender service in Leeds with an 18-month waiting list."** While waiting for this appointment, her son's symptoms worsened to crisis point:

"He was screaming and hitting out - the police were called and told him if he did this again he would end up in a cell. The next day it happened again, the GP visited and made an urgent referral to CAMHS (Child and Adolescent Mental Health Services)."

As the mother suggests, there are multiple points at which speedier referrals **"could have prevented things from escalating"**, but in her case this only happened after the police threatened her son with arrest. Her story also points towards missed opportunities to embed interventions at school with regards to the bullying her son experienced, while the punitive response of the police highlights the importance of rolling out mental health training across all constabularies in the North East to ensure that officers working with individuals in crisis are equipped to act appropriately.

The Commission also received testimonies which identify the potentially tragic consequences of a school being unequipped to support students in emotional distress. The Commission heard from a secondary school student in Whitley Bay who, despite being subjected to bullying by her peers, felt unable to approach her teachers. She recounts that **"I had a really bad day at school; no one had talked to me all day, yet I could hear my name being whispered everywhere. I blamed it on myself and I decided that I would end my life"**. Following a suicide attempt that same evening, her family took her to see a GP, who made an urgent referral to CAMHS. Reflecting on the support she received following her referral, the student explains:

"What worked was my urgent referral to CAMHS, the cognitive behavioural therapy (CBT) and being taken seriously. What didn't help was that I received no support from anyone in school. I had no one to go to when I had panic attacks."

The mental health risks of schools not intervening in cases of bullying are clear, with one meta-study finding that the odds of suicidal ideation and suicide attempts more than doubles among students who report bullying (Van Geel, 2014). The student did not just stress the importance of being listened to, however, but specifically having **"someone to speak to in school who was independent"** of school staff, the need for **"a group class on wellbeing skills"** and **"being taught peer support"** so that young people can develop better emotional resilience.

Early Intervention

The Commission also heard from young people and their teachers who explain that, even when schools notice symptoms, they are faced with barriers to making discreet and timely interventions. One student from North Shields highlights how their CAMHS appointments at the Albion Road Clinic were often scheduled during the school day, causing considerable disruption to her studies. She suggests that having CAMHS workers visit her school would be far more beneficial as the appointment would take place discreetly **"in an environment where we're more relaxed and comfortable, and we'd only miss a short period of work"**.

In its recent Green Paper, the Government outlines plans to train existing school staff as **"designated senior leads"** for mental health and increase the number of mental health professionals working in and "near" schools (Department for Health and Social Care and Department for Education, 2018) as well as making mental health education compulsory from 2020 (Department for Education, 2018b). Taking its lead from the testimonies above, the Commission believes that these measures do not go far enough; as the head teacher of one Newcastle school puts it, **"schools are often best placed to provide the support but do not have the funding or budgets to provide this"**.

The Commission heard from a counsellor working with students at Sunderland University who argues that approaches to early intervention must begin **"with an understanding that supporting anyone with a mental health difficulty is not an expense but an investment"**. For this reason, the Commission recommends that the UK Government follows the lead of the Northern Ireland Assembly and National Assembly for Wales and introduces statutory provision for school-based counselling in compulsory education in England. In the meantime, the Actions below also outline how schools in Tyne & Wear can lead the way.

ACTIONS

Will you, **Northumberland, Tyne & Wear NHS Foundation Trust**, release fifteen of your clinicians to participate in a pilot to promote mental health and emotional resilience in schools?

Will you, **Catherine McKinnell**, ensure that the Health and Social Care Committee consider mandatory provision of a counsellor for every English school, and work with us to pilot and evaluate such provision locally?

Systems that Serve People

The Commission heard from a range of service users whose encounters with processes and procedures left them feeling as if they, the patient, were the problem. While some of these stories speak to systemic issues, others identify problems that are much more local – though no less consequential – in character. Crucially, these testimonies also identify specific ways to reposition the person at the centre of their care.

In its mandate to NHS England for 2018/19, the UK Government outlines the desire to see "measurable progress" towards the achievement of "parity of esteem for mental health [as] enshrined in the NHS Constitution, particularly for those in vulnerable situations" (Department for Health and Social Care, 2018). While progress undoubtedly has been made towards addressing the divide between mental and physical care, the testimonies that the Commission heard suggest that listening to, and learning from, patient experiences will prove central to realising this ambition.

The Commission received testimonies that do not merely identify the gap between physical and mental health care services, but powerfully illustrate how it feels to fall through it. The testimonies point towards this divide being felt most acutely in urgent and emergency care. One woman from Newcastle, for example, told of how she experienced a mental breakdown during an overnight stay in A&E. No one enquired about her wellbeing, or even offered her a cup of tea, until the following morning. The experience left her with the sense that **"A&E was not geared up"** to help those in mental health crisis.

The Commission heard from a university student whose testimony about visiting the Royal Victoria Infirmary (RVI) in Newcastle shows how, in the most extreme instances, this divide can feel like a void. The Commission heard how, on one occasion, the student was feeling suicidal and had self-harmed. Feeling nauseous, dizzy, and alarmed by the severity of their cuts, the student called NHS 111. The 111 worker advised that the student visit A&E but as the student could not afford transportation to the hospital, the 111 worker ordered a taxi. The student arrived at A&E Reception in their pyjamas, unsure if they were required to pay for the taxi out of which they stepped:

"Once I arrived at A&E, the receptionist told me that the waiting time was several hours. I wanted to die at that moment and I was not able to quickly talk to a mental health professional [...] if the NHS had the opportunity for those in crisis to speak to a mental health professional, even just to

book a crisis appointment or to speak to someone for 5 minutes, it would have helped."

On another occasion, the student visited the RVI because they had run out of antidepressants and had begun to experience withdrawal symptoms. Upon arrival, staff informed them that the hospital's outpatient dispensary service could not accept their prescription. As a direct result, they had no choice but to leave the RVI and travel out of the city centre to a late-night pharmacy. Doing so after dark, in unfamiliar surroundings and in an already vulnerable state, the student was "left shaken" after being groped by a stranger.

At the time of writing, the Newcastle Psychiatric Liaison Service that works with the RVI is resourced to operate a 24/7 service. Irrespective of whether this was the case at the time of the student's experience, their testimony points towards the need for the RVI to better communicate these opportunities for assessment and treatment to patients in mental health crisis.

The Commission also heard from those whose experiences of risk assessment models left them feeling excluded from a healthcare system that appeared to have other priorities. One young man from Durham reported feeling "brushed off" by his GP who, having established that he was not suicidal, suggested that he should "just ring" his local counselling service. Another young woman from Seaham was told by the local Crisis Team that she was "not appropriate" for their services because, although she had self-harmed and experienced suicidal thoughts, she had not yet attempted suicide. As John Lawlor explained at the Sunderland hearing of the Commission, these testimonies illustrate the problem of merely stratifying a patient as 'low risk' without also providing guidance about how to access more appropriate support.

This issue was most powerfully illustrated in the testimony of a mother from Newcastle who first managed to "coax" her son to see a GP in 2010. **"He had shown frequent signs of anxiety and depression"**, she explains, **"but like a lot of males had been reluctant to accept help"**. The GP prescribed antidepressants and referred him to counselling which proved unsuitable and only heightened his anxiety. Eight years since his initial appointment her son is yet to receive a referral to a clinician qualified to make a diagnosis that might lead to more effective treatment. In the meantime, he has become increasingly withdrawn. **"All that he has been offered is pills that clearly don't work"**, she adds. **"He often stays awake all night in his room on his own, sleeping all day which makes him even more isolated."** This experience has left his mother **"with the feeling of going around in circles, a dog chasing its tail"**.

Given that this mother's testimony outlines how her son had already "spoken of suicide" before his first appointment, it points towards the importance of the quality of these initial interactions with primary care in assessing how a patient should be supported along the Stepped Care Pathway. While clinical guidelines exist for identifying and assessing common mental health disorders (NICE, 2011), the Commission recommends that serious thought is given to the question posed by Dr Esther Cohen-Tovée in response to this testimony at the Newcastle hearing of the Commission: **"What else can we do to help push someone up the Pathway?"**.

Moreover, with NHS targets for access to psychological therapies set at 25% of patients per year by 2020/21 (NHS, 2016), the Commission reiterates the importance of early intervention measures to ensure that fewer young people's first interactions with primary care do not take place when, as in the case of this woman's son, they are already "at crisis point".

Systems that Serve People

The waiting area is an integral but often overlooked aspect of the healthcare system that can feel like "a containment space of inevitable frustration" for patients (Sherwin et al., 2013). The Commission received testimonies that illustrate how, in the context of mental health care, ill-designed waiting areas have the potential to increase patient anxiety and impede the therapeutic process. The Commission heard from several secondary school students who had been referred to the CAMHS service at Albion Road Clinic in North Shields. One student compares the atmosphere at Albion Road to **"a hospital waiting room, which made me feel nervous"**, while another remarks that **"it felt too clinical, the place smelt like bleach [...] CAMHS made me feel uncomfortable so it was hard to talk."**

These testimonies also point towards a perceived lack of age-appropriate provision for adolescents at the clinic, leading one student to question their CAMHS referral: **"They got it so wrong. I am a teenager, not a small child. Yes, I know there should be toys for younger kids, but what about teens?"**. One student compares the atmosphere at Albion Road with that of the Gender Identity Development Clinic to which they were subsequently referred, noting how the **"laid back atmosphere [...] put me at ease and meant I felt more comfortable to talk"**. Another student suggests that Albion Road should be **"less formal, with [...] bright colours and good decoration"**. Taken together, these testimonies raise the question of whether the NHS should consider the provision of a dedicated adolescent mental health service that could also provide holistic care for issues relating to sexual and gender identity.

The Commission heard how these experiences are not limited to the clinical context. The Student Health and Wellbeing Service at Newcastle University provides a free drop-in counselling service which operates out of an open-plan portion of Level 2 of the University's Kings Gate building called Student Services. Students wishing to speak to a counsellor about a wellbeing issue report to the general Student Services Helpdesk where they are given a colour-coded card indicating their place in the appointment queue before being asked to sit in a shared waiting area alongside students awaiting appointments on a range of other issues such as accommodation, visas and finances.

The Commission heard from one student who sought counselling to address symptoms of anxiety and obsessive compulsive disorder which she was concerned had worsened since moving to university. The Commission heard that, while the student's experience of the University's counselling sessions was highly positive, her experience of the layout and procedure of Student Services itself simultaneously trivialised and stigmatised her wellbeing issues.

She explains that, **"when you get to Level 2 of Kings Gate, it just makes you feel like**

Systems that Serve People

your problems aren't very significant, because you're there with people who've got housing problems or other things that they'd go to Student Services about [...] it's just not very tailored to wellbeing". In addition to this sense of trivialisation, the student remarks that the colour-coded appointment cards heightened her sense of vulnerability by marking out her wellbeing issues in a public space, which **"made me feel a lot more vulnerable, as if everyone was judging me [...] which didn't help as I was trying to seek help for anxiety."** To address these issues, the student recommends a separate waiting area for students with wellbeing appointments which might be discreetly delineated from the more general waiting area by a screen.

At the Newcastle hearing of the Commission, both Dr Andrew Cole and Dr Esther Cohen-Tovée spoke of the need for service user involvement in care design. The Actions outlined below draw upon the principles of co-creation and personalisation in mental health (NTDi, 2013) to address these specific examples of disabling environments.

As the Rt Revd Christine Hardman noted at the Durham hearing of the Commission, there is an urgent need for "systems which serve people" to prevent people from being damaged by inflexible approaches. While solving these systemic issues will require a good deal of coordination at the national level, the Actions below offer concrete steps to placing the person at the centre of their care.

ACTIONS

Will you, **Newcastle Upon Tyne Hospitals NHS Foundation Trust:**

- ensure that the signs for the Emergency Department at the Royal Victoria Infirmary show that the service is for mental health as well as physical health emergencies?
- work with Northumberland, Tyne and Wear NHS Foundation Trust to develop mental health training for all your staff who have patient contact?
- develop a best practice protocol for distressed patients needing to travel home from A&E following assessment?
- apply to the Department of Health for permission for the Lloyds pharmacy Royal Victoria Infirmary to be open 100 hours across a seven-day week?
- work with Tyne and Wear Citizens and local pharmacies to ensure that a pharmacy is available 24/7 in Newcastle City Centre?

Will you, **Northumbria Healthcare NHS Foundation Trust**, work with students from St Thomas More Roman Catholic Academy, North Shields to re-design the CAMHS clinic at Albion Road, North Shields?

Will you, **Newcastle University Student Health and Wellbeing Service**, work with Tyne & Wear Citizens and Newcastle University students to improve the waiting system for students with mental health appointments?

No Choice, No Control

The Commission heard from individuals whose experiences of treatment and recovery range from freedom of choice to no choice at all. Their stories outline how inconsistencies in approaches and protocol, as well as limited treatment options, can further disempower the person in their moment of need. However, the Commission also heard how flexibility and choice of treatment can play a key role in helping the patient take control over their recovery.

Despite painting a complex portrait of mental health assessment and treatment in the North East, the testimonies received by the Commission demonstrate the importance of having some choice over treatment and the resulting sense of control over recovery that this choice provides.

The theme of choice and control is most common in testimonies about attempts to access talking therapies. The NHS uses the term 'talking therapies' to encompass a range of psychological therapies such as CBT and guided self-help. The Commission received testimonies that both make general reference to talking therapies and specific reference to individual psychological treatments. It is important to emphasise, however, that there is no clear preference within the testimonies regarding specific therapies. Clearly, these therapies appear to be highly appropriate and effective for some patients and far less appropriate and effective for others. Rather than engage in debates around the general efficacy of particular psychological therapies (Rizq, 2012), then, the testimonies invite us to focus on how, if at all, patients are made aware of the options available to them.

While access to talking therapies has increased as a result of the Adult Improving Access to Psychological Therapies (IAPT) programme (Clark, 2011), the testimonies received suggest that they remain elusive for some patients in the North East. The Commission received a range of testimonies which identify assessment at the primary care level as the point at which they lose out on other treatment options.

In particular, these stories express a frustration at being prescribed antidepressants in lieu of psychological therapies. One mother from Newcastle describes her son as being "automatically" prescribed antidepressants, while one Byker resident laments that **"I've been on repeat prescription from my doctor for antidepressants for years and has never been assessed"**. One drug and alcohol support service user points towards **"GPs freely prescribing too much medication"** in a manner which fails to consider their

No Choice, No Control

history of substance use. While these testimonies sometimes acknowledge the benefits of antidepressants, they also point to how treatment stagnates when clinicians **"just kept prescribing [and offer] no other help or support"**. As one woman explains:

"If you're prescribed antidepressants in the first instance and have to wait two to three months for an appointment with a mental health professional, the symptoms you were exhibiting when you first approached a GP aren't there anymore. They aren't cured, they're merely managed."

While many of these testimonies make unfavourable references to GPs, the Commission also recognises the burden placed on GP surgeries with regard to mental health assessments. The Commission heard from one GP from Sunderland who observes that discussions about choice in treatment "hugely underestimate" just how many patients, especially the elderly, will only engage with their local GP about their mental health challenges. With this in mind, the GP asks, **"what should we expect GPs to do?"**.

The GP appointment's guarantee of a face-to-face interaction might partly explain why some vulnerable patients facing mental health challenges might feel unable to seek help beyond their local surgery. Indeed, the testimonies demonstrate the sense of powerlessness patients feel when their only option is to interact remotely with a mental health professional via telephone. One patient who was referred to phone-based talking therapies explains that:

"I had to speak to someone about my thoughts and feelings while sat in a car park as I couldn't see someone face to face. I found the whole thing awful and it was really hard to hear the worker on the phone."

She concludes that her experience was so alienating that it became a "barrier" to

No Choice, No Control

seeking further support. The testimonies also identify how inflexible processes can impede the progress of both practitioners and patients. The Commission heard from one woman from Sunderland who lost her job following repeated periods of sick leave due to depression and anxiety. She began high-intensity CBT sessions, during which she raised issues from her childhood which she felt were relevant to her condition. Her CBT worker was also a trained psychotherapist and as such was able to acknowledge the importance of these experiences. However, she could not record these discussions in her session notes for future reference as **"she was not allowed to deviate from the [CBT] protocol"**. Reflecting on this experience, the patient argues that a **"less restricted and more flexible approach to therapy would benefit many workers and clients in primary health care"**.

Testimonies also point towards confusion among students regarding GP registration. The Commission heard from the Lead Mental Health Advisor at Durham University Counselling Service who explains how students registered with a GP at their place of study can **"easily fall off waiting lists"** when they return home for the summer. The Commission also heard from one young woman living in County Durham who was hospitalised when she experienced a psychotic episode in a London airport upon returning from a holiday. After a decision was made that she should be detained under the Mental Health Act, she was transferred to a psychiatric hospital in Manchester, rather than the North East, requiring her family to stay in a nearby bed and breakfast until she was discharged. She attributes this decision to the fact that she was still registered with the GP from her time at Salford University. It is not currently common place for students to be registered with both their home and term-time GP surgeries despite it being recommended by the Higher Education Policy Institute (Brown, 2016) as a measure to improve student mental health and wellbeing. At the Durham Hearing of the Commission, John Lawlor suggested that dual GP registration "should be possible" although there are procedural and technical barriers that firstly need to be addressed at the national level.

Patient control over recovery is particularly important in the context of abuse-related trauma, in which even minor decisions over treatment options can begin to give power to a person who feels that they otherwise can exercise little. This is powerfully illustrated by a testimony the Commission heard from a woman from North Tyneside who was diagnosed with complex post-traumatic stress disorder (C-PTSD), anxiety and depression after having been raped. After relying heavily on antidepressants to function for nearly eight years, she resolved to **"actually treat the cause of my C-PTSD and not dull it with meds"**. She explains how a programme which included counselling, CBT, and eye movement desensitisation and reprocessing (EMDR) allowed her to stop taking medication and manage her own triggers.

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Pivotally, she attributes this to her therapist's flexibility regarding the number of weekly sessions provided, which made her feel recognised and supported during her recovery process, rather than being made to feel as if she **"was always on the clock"** as was the case with previous counsellors and therapists:

"Learning to take responsibility [...] for my recovery and learning to be open about the process has been instrumental in me being able to function as a 'normal' person. Having a service that was prepared to work with me and for me instead of creating barriers and time restrictions on the number of sessions, allowed me to relax into the process and 'grow' naturally and organically with my therapist. Talking therapies have not only saved my life but have given me back the part of myself that was taken 9 years ago."

As Dr Andrew Cole pointed out at the Sunderland hearing of the Commission, **"there are campaigns within statutory services to give workers time and support to be more compassionate in the service and care they give"**. While there is the need to honour the expertise of professionals in this 'hierarchy' of decision making, Dr Cole also acknowledges the **"need to improve patient knowledge generally so that they have the confidence to disagree with the prescriptions they're given"**. As this discussion has outlined, there are many challenges in ensuring that patients have some choice and control over their treatment, particularly with regards to providing face-to-face counselling. Such questions also have to consider the context of the mental health assessment burden on GP surgeries and what additional support might be offered.

While the Action below addresses the issue of dual GP registration, the Commission has not yet identified practical solutions to address the issues of professional inflexibility in treatment or lack of choice for patients would prefer face-to-face counselling. As such, the Commission acknowledges the need to undertake further listening, reflection and action to identify solutions that give patients in the North East greater choice and control over their treatment.

ACTION

Will you, **Catherine McKinnell**, work with Tyne & Wear Citizens to highlight in Parliament the need for consistency across CCGs regarding dual GP registration and continuity of care for students and others with multiple addresses?

Suicide

The Commission heard of how suicide affects families and communities from across our region. Testimonies illustrate the immense pressures that individuals and institutions face when trying to help someone in crisis or cope with the effects of a person taking their own life. However, these stories also identify specific ways to better share the skills and resources needed to assist both those trying to prevent suicide and those trying to deal with its impact.

The testimonies powerfully illustrate how suicide touches all corners of the North East, irrespective of age, class or community. However, a clustering of interrelated testimonies led the Commission to focus on the context of universities generally and Durham University in particular. This focus has proven timely; less than a fortnight after the Commission's public hearing session on suicide at Durham University in June 2018, the Universities Minister Sam Gyimah convened a student mental health summit at Bristol University at which he announced a "new deal on mental health provision" (Department for Education, 2018a). This follows on from Universities UK's call for higher education institutions to implement a "whole university approach" to tackling institutional barriers to greater student wellbeing (West, 2017).

The Commission heard from a student leader at Durham University who told of how two students at her College died by suicide during her year as College President. The University asked her to organise a memorial event for the deceased student; at the event **"University staff came along and then left me with this girl's parents on my own"**. While the University offered her counselling, she declined, observing that she **"didn't need counselling, I needed help to talk to my students"**. This "help" need not necessarily extend to comprehensive training, she explains, but rather basic mental health awareness skills and knowledge of who to call in a crisis. In an environment in which it has **"almost become so normal"** to experience low level anxiety and depression, she adds, what is needed are the skills to support for peers who **"need a cuppa, not counselling"**.

In addition, the student leader at Durham demonstrates how, if unchecked, the culture of excellence at elite universities can become a source of anxiety and alienation for students:

"You've probably been above average at school, and you turn up at this place where everyone is good and all of a sudden you feel substandard [...] if you then add any financial implications, family difficulties or relationship worries then you've got a recipe for disaster."

While the Commission also learned of the cooperation between Durham University Counselling Service, Durham Constabulary and the local NHS, it also came to appreciate the continuing challenges all services face in meeting an ever-increasing demand. The Commission heard from the Lead Mental Health Advisor at Durham University Counselling Service who explains how, despite increased outreach and low-level intervention work, **"we face increased demand for our services year-on-year"**. She adds that Durham City "badly needs" an open-access 24-hour mental health crisis centre akin to the adult mental health inpatient services at Roseberry Park hospital in Middlesbrough.

Durham Constabulary's University Liaison Officer points out that the police are often the only service able to respond to students in crisis but are often not best placed to help. Her testimony illustrates the frustration that police officers in the city

face during crisis callouts when, unable to secure a student with an immediate appointment with a mental health professional, they have no choice but to take them home. **"Because we're not trained"**, she explains, **"we have to take that person back to their college [...] it feels like we're dumping them."**

As the testimonies in 'Early Intervention' and 'Systems that Serve People' illustrate, it can be all too easy for a person in crisis to isolate themselves from their support network and find themselves at the mercy of inadequate procedures. This can have tragic consequences. The Commission heard from one woman who told of how her friend died by suicide after being left alone by the police following a crisis callout. During this callout, the police asked the suicidal woman whether there was anyone who could stay with her. The police contacted one of the woman's friends, who was unable to come and stay. The police did not attempt to contact anyone else and left her alone. After the police left, the woman took her own life. This testimony not only raises the question of whether there was a protocol in place at the time for crisis callouts, but also whether there were post-suicide debrief and support measures in place for the officers and whether this might have influenced their decision making.

As the Right Revd Christine Hardman noted at the Durham hearing, universities are "no different" than any other organisation when it comes to meeting the challenges of caring for its members or employees, engaging with the NHS and statutory services, and reaching out to the wider community. While these testimonies on suicide have focused on universities, the Commission believes that many of the issues identified above, and the Actions outlined below, can be applied in other contexts.

ACTIONS

Will you, **Durham University**:

- provide funding and time for staff from the University Counselling Service to train as Mental Health First Aid Trainers and deliver training to groups of student leaders and staff within your Colleges?
- ensure that your telephone and email points of contact (at both University and collegiate level) signpost to local out of hours support for students who are seeking help during a time of mental health crisis?
- work with Tees, Esk and Wear Valleys NHS Foundation Trust, Durham County Council, Durham Constabulary and other partners to develop a suicide protocol, which includes debrief and local support for your respective staff?

Engaging Families and Carers

The Commission heard of the challenges that families and carers face as they try to support their loved ones during their assessment and treatment. While these testimonies point to the complexities of involving families and carers in the assessment process, they also identify effective models for engagement and opportunities to further expand them.

The testimonies received illustrate how, without adequate support or knowledge, families can be taken by complete surprise when their loved one presents acute symptoms of mental ill-health. The Commission heard from a man from Newcastle whose daughter developed severe post-natal depression. The father explains how his daughter's condition deteriorated without her family noticing. One day, **"she had left me with her 3-month-old baby while she ostensibly went for a jog. When she failed to return, I raised an alert with the police and other agencies"**; her deterioration had **"culminated in a suicide attempt and missing person's search for two days"**. After a psychiatrist in Newcastle collated and reviewed the uncoordinated notes of her interactions with services in Newcastle and her home near London, she was referred to the Mother and Baby Unit in Morpeth, where she stayed for five months. He explains that it was only after this traumatic experience that **"we realised we'd been trying to cope without adequate knowledge of her condition and without the specialist support we needed."**

Recent research into the benefits of family involvement in mental healthcare points towards the necessity for improved staff training (Dirik et al., 2017). The testimonies received appear to reflect this need. The Commission heard from a mother from Newcastle whose teenage daughter was referred to CAMHS. **"We were extremely worried about her and so we were relieved to go along to the appointment to get some support"**, she explains. Over the course of an hour-long appointment with two CAMHS workers:

"My daughter disclosed feeling suicidal, self-harming, feeling that life was pointless. It was quite a distressing interview as I had not heard some of this information myself and it was a shock to hear just how poorly she was."

At the end of the appointment, the CAMHS workers decided not to progress her daughter's case and argued that she was "low-risk" and required no further interventions. Feeling as though she had not been believed by the CAMHS workers, her daughter **"sank into a further depression"**. Meanwhile, having received no practical guidance on how to support her daughter, the mother struggled to help and began to receive visits from the school attendance officer and **"letters threatening me with court"**. The mother believes that her presence at the appointment played a role in the CAMHS workers' decision; **"because my daughter had a supportive parent with her"**, she says, **"she was seen as needing less support"**.

Not all of the stories from families and carers were negative, however, and the testimonies also identify examples of good practice when including families. For example, one mother from North Tyneside whose daughter has been diagnosed with Asperger's and attention deficit hyperactivity disorder (ADHD) outlines how a combination of a learning mentor at school and help from Northumberland, Tyne & Wear NHS Foundation Trust's Children and Young People's Intensive Community Treatment Service (ICTS) ensured that both patient and family received the support they needed. While

Engaging Families and Carers

"we had previously felt alone in trying to manage the symptoms", she explains, **"having the input of a learning mentor has been keenly felt"**. The presence of the learning mentor at school also meant that her daughter had **"someone to talk to or just a quiet place to be by herself"**.

The Commission also heard from a Family Intervention Worker from PROPS North East, an organisation which supports individuals living with alcohol and substance misuse alongside their families and carers. She explains how the Community Reinforcement and Family Training model (CRAFT) allows the family to go through the recovery process alongside their loved ones. She argues that families are **"an untapped resource of information"** about the person in recovery: **"no one knows us better than our loved ones"**. Moreover, she emphasises how structured interventions can instil the skills and tools which families need to support their loved ones without being co-dependent on statutory or voluntary services. While this model has been developed for substance use, clinicians have considered applying the model for other diagnoses such as eating disorders (Gianini et al., 2009).

There is a growing evidence base for the benefits of family-based interventions in mental health treatment (Eassom et al., 2014). At the Sunderland hearing of the Commission, John Lawlor pointed out that Northumberland Tyne & Wear NHS Foundation Trust already follows the Carers Trust 'Triangle of Care' approach to including families and carers and is also piloting the Finnish 'Open Dialogue' model which enables the patient to consistently include family members or other loved ones in their treatment. He added that while NHS Mental Health Trusts need to do more to **"think family, think carer"** when providing treatment, there are instances when patients, including young people, **"do not want their family to be involved in those conversations"**, which can create "significant tensions".

As Dr Andrew Cole argued at the Sunderland hearing of the Commission, given the existence of these models and the organisational aspiration to embed and expand them within the NHS, the question regarding engaging families and carers is **"'How do we do it better?' rather than 'Should we do it or not?'"**. Dr Cole pointed out that Northumberland Tyne & Wear NHS Foundation Trust already has a Carers Charter; the challenge, then, is how to ensure that the Trust is held to account on the commitments it makes in this Charter. The Actions below identify practical ways to hold the Trust to account and further involve carers and families.

ACTIONS

Will you, **Northumberland, Tyne & Wear NHS Foundation Trust**:

- work with Tyne and Wear Citizens to excel in your practice of engaging families and carers in line with the Carers Trust Triangle of Care?
- implement the CRAFT Model within the Trust for families and carers?

Being Well, Staying Well

The Commission heard from patients and practitioners alike whose understanding of mental health and wellbeing extend far beyond the medical model. These testimonies not only identify a range of non-medical solutions but suggest opportunities for healthcare providers and civil society to promote ways of living well together.

In recent decades, the UK Government (2011) has broadened its definition of mental wellbeing to account for a fuller sense of personal and interpersonal flourishing. The testimonies received demonstrate that many patients and doctors share this deeper understanding of what it means to be and stay well. The Commission heard from a woman from Newcastle whose bouts of severe depression included hearing voices and two suicide attempts. While her experiences of talking therapies have varied widely, she points towards the importance of being offered alternative therapies to complement her counselling:

"Sitting in a dingy smelly room listening to condescending counsellors is not always helpful so alternative therapies should be optional. Reiki, yoga, walks and gentle exercise should be offered as therapies, discounted gym memberships, discounted swimming [...] teaching and advising people to look after their wellbeing, meditation methods and skills - all these can be part of a mental health and wellbeing programme."

This practice of frontline healthcare professionals referring patients to local community services is known as 'social prescribing'. A recent systematic review found that social prescribing referrals resulted in an "average 28% reduction in demand for GP services" and "24% fall in A&E attendance" among patients (Polley et al., 2017). NHS England is currently in the process of developing an agreed model of social prescribing and an attendant quality assurance framework (NHS England, 2017). The Commission heard from a retired GP from Newcastle who explained her approach to social prescribing:

"Many of the patients I saw were unhappy and were looking for pills. We know that antidepressants do help. So do other things, like talking, taking a walk outside, exercise, learning, seeing people, sharing with people. I recommended all these as well."

Reflecting on her experience of treating patients from a range of socioeconomic backgrounds, however, she observes that the ability to be well and stay well is often determined by the facilities to which a person has access. In particular, she notes that cuts to public services have reduced **"the ability to access places like libraries, affordable swimming pools and gyms,**

parks and open spaces, flowers, community facilities" for patients in less affluent parts of Newcastle.

At the Durham public hearing of the Commission, Catherine McKinnell MP echoed these comments when she spoke of the role that community facilities play in upholding public wellbeing by explaining how her constituency office is based in the Lemington Centre, a community centre which **"really embodies what a hub should be: it is a place to find a balance, a healthy lifestyle, and a community spirit."**

Despite these positive examples, barriers to greater wellbeing remain. In particular, the Commission heard how fear of discrimination by employers can hamper attempts to be and stay well. The Commission heard from one woman who confessed that **"I've never, *ever* openly told an employer about my mental health issues as I feared I'd lose my job or be treated differently"**. She adds that **"if we can challenge the stigma, we can reach a lot more people"**. She emphasises that the key to this is ensuring that the kinds of approaches are **"translated into working environments, with employers better supporting mental health in the workplace"**.

As Revd Timothy Ferguson put it at the Durham hearing of the Commission, **"just waiting for the 'professional' to meet the needs of the patient neglects civil society's own gifts and skills."** The Actions below outline how individual Tyne & Wear Citizens member institutions can take some responsibility in meeting this challenge by committing to host Open Door Meals open to all residents in their local surroundings. As some of the testimonies explored in this section were received from Newcastle Central Mosque, the Actions below ask the Mosque to lead the way.

ACTIONS

Will you **Newcastle Central Mosque**, run an Open Door Meal by the end of January 2019 and commit six or more of your members to undertake mental health awareness training?

Will you **Northumbria Quakers**, **All Saints, Newcastle**, **the College of St Hild and St Bede at Durham University**, and **St John the Baptist, Newcastle**, support Newcastle Central Mosque by sharing the resources you have to assist with running the Open Door Meal and developing Open Door Meals in other institutions?

Social Determinants

The Commission received a range of testimonies that identify key social determinants of mental ill-health. These testimonies demonstrate the impact that the benefits system and living conditions can have on personal wellbeing. In so doing, they emphasise the importance of strengthening relationships within civil society and empowering communities to nurture their own wellbeing.

As many communities across the North East grapple with health inequalities (Public Health England, 2017) stemming from decades of deindustrialisation, unemployment and underinvestment, it is impossible to overlook the impact of particular social determinants of mental ill-health.

The testimonies received identify the benefits system as one such cause of stress and anxiety. The Commission heard from a recovery coach working for a psychological therapies service in Ashington who describes the effects of **"a benefit system that is broken and not fit for purpose"** on people with mental health challenges. He explains how **"time and again people are refused Employment and Support Allowance (ESA) and Personal Independence Payment (PIP) because no points are granted for mental health issues"**. He implores the DWP **"to come and see the real suffering and hardship that mental health issues can cause and change the way they assess these problems in future"**.

In addition to punitive assessment processes, the testimonies received also point towards the stresses of trying to navigate complex services that communicate poorly with one another. The Commission heard from a man from Newcastle whose wife has mental health issues. He explains that **"as my wife's carer, it is normally me who deals with the administrative side of interacting with mental health services"**. As a self-employed musician, his income was highly variable. He explains how, when his income increased:

"I filled in the appropriate 27-page document and sent it to the DWP. They suspended our ESA payments while processing. This lasted for 6 months when it should have been a maximum of six weeks. In this time, I had to make multiple phone calls in which I discovered that the DWP had received my documentation but not put it on the system. Newcastle City Council is unable to distinguish between a suspended payment awaiting processing and a terminated claim for ESA so they stopped Housing Benefit and Council Tax Reduction. Once resolved the back payment took my savings over the threshold that would affect the ESA amount and further complications ensued."

He concludes that **"I have been forced to abandon my musical career and am now seeking full time corporate employment to remove myself and my wife from this extremely stressful system"**. Since then, he notes:

"When I rang Newcastle City Council about my wife's ESA payments changing I became aware that I could receive these benefits without being on ESA. This raises the question of why these benefits were stopped in 2016".

In addition to the benefits system, the testimonies received demonstrate how one's immediate environment can be a source of alienation and distress, especially for those who have no direct control over its development or maintenance. The Commission heard from an elderly resident of the Byker Wall estate who has experienced bouts of depression

throughout her life. She reflects that **"later in my life I think that the environment around me has impacted my mental health"**:

"There is a lot of rubbish out in the street and in people's gardens, and people fly-tip sofas and mattresses, and they are there for ages. If you go out your front door and you see all these things it gets you down, and it makes you feel, 'Well, why should I bother?'"

She adds that Byker Community Trust, the housing association that owns and manages the estate, are slow to make repairs to properties, which only contributes to residents' sense of powerless:

"They are more likely to do repairs near to their office, in my opinion. They have a very smart office with a large cabinet full of awards. They say this is the best neighbourhood to live in? I would say to them, 'Come and try living here!'"

The resident also points towards noise pollution from the nearby Tyne Bank Brewery, a popular microbrewery and venue which operates out of a warehouse opposite the estate:

"this keeps me awake sometimes, especially when there are parties which finish late at night. Sometimes all these things can add up; and even if you are taking medication they can stop you from feeling better, and from moving forward with your health."

While the Action below addresses the issue of litter and fly-tipping, the Commission has not yet identified practical solutions to the issues regarding the benefits system as highlighted in the testimonies. The testimonies received characterise the experience of using the benefits system as one of powerlessness. Similarly, the challenge currently facing the Commission as it attempts to address such a systemic issue is also one of insufficient power and influence. The Tyne & Wear Citizens Mental Health Action must respond to this challenge by building the relationships and power required to address these issues. Readers of *Living Well* are invited to join Tyne & Wear Citizens in this crucial work.

ACTION

Will you, **Byker Community Trust**, work with Tyne and Wear Citizens and partners to ensure that all rubbish, litter and items which have been fly-tipped are disposed of appropriately on the Byker estate?

The Commissioners

Claire Robinson is the Chief Executive Officer of PROPS North East, a charity that works directly with families and young people affected by the use of alcohol and drugs across Newcastle and North Tyneside. Born and raised in the North East, she has a deep passion for the people and communities in the region. Claire feels exceptionally privileged to Chair the Citizens Commission on Mental Health because she believes that community organising provides a real opportunity to cut across systems and achieve real and lasting change.

Catherine McKinnell MP is the Labour MP for Newcastle North. Having previously served in several Shadow Ministerial posts between 2010-2016, including Shadow Attorney General, she currently holds a number of roles in Parliament. These include membership of the Treasury Select Committee and the Petitions Committee as well as Chair of the Northern Group of Labour MPs. She is also Chair of All-Party Parliamentary Groups on Apprenticeships, Children Who Need Palliative Care, and CAFOD. Catherine has campaigned on a range of concerns in relation to mental health including leading a Parliamentary debate on compulsory mental health education in schools.

Rt Revd Christine Hardman is the Anglican Bishop of Newcastle and a member of the House of Lords. She has served the Church of England in a number of roles including Archdeacon in the Diocese of Southwark and as a Church Commissioner. Bishop Christine joined the Citizens Commission on Mental Health because human flourishing is at the heart of her faith and she sees mental health as a significant issue facing our society today. She is particularly concerned about mental health issues among young people.

John Lawlor is the Chief Executive of Northumberland, Tyne and Wear NHS Foundation Trust (NTW). He is passionate about mental health and mental health services, both as a Chief Executive and as someone who lives with a mental health condition. John joined the Citizens Commission on Mental Health as it offers NTW an opportunity to work in partnership with the local communities that it serves.

Abdul Basith Mohammed is the Imam of Newcastle Central Mosque. Born and raised in India, and with degrees in both Islamic and secular disciplines, he has grown Newcastle Central Mosque into an active Islamic centre which attracts thousands of worshippers and visitors and builds bridges with the wider community. Through his role as Imam he supports many social causes and was eager to join the Citizens Commission on Mental Health.

Our Commissioners at the Durham Hearing of the Citizens Commission on Mental Health. Left to right: John Lawlor, Jeremy Cripps, Michael Thompson, Alisdair Cameron, Claire Robinson, Leah Harneshaug, Neave Miller, Tim Ferguson, Christine Hardman

The Commissioners

Alisdair Cameron is Team Leader at Launchpad, an organisation which promotes the voices of mental health service users in Newcastle, and co-creator of the Recovery College Collective, a mental health charity in Newcastle which puts service users in charge. He is also a guest lecturer at both Newcastle University and Northumbria University, where he is responsible for modules on involvement, engagement, Mad Studies, and mental health systems. Before this he has been an historian, a lawyer, a user of mental health services and a community activist.

Dr Andrew Cole is a consultant psychiatrist at Northumberland, Tyne and Wear NHS Foundation Trust. He has worked in North East NHS Trusts for 26 years and also sits on Mental Health Tribunals. He joined the Citizens Commission on Mental Health because he wants those affected by mental health problems to be better heard, accepted and supported. Andrew is affiliated to Tyne & Wear Citizens through All Saints' Church in Gosforth, Newcastle.

Dr Esther Cohen-Tovée is a Consultant Clinical Psychologist and Director of Allied Health Professionals and Psychological Services at Northumberland, Tyne and Wear NHS Foundation Trust. She is also Vice-Chair of the British Psychological Society's (BPS) Division of Clinical Psychology and Co-Chair of the BPS Accreditation Programme for Psychological Therapy Services. Esther has worked professionally with people with mental health difficulties throughout her 19-year career in the NHS. She is committed to the values and aspirations of the Citizens Commission on Mental Health both professionally and personally as a practising Roman Catholic.

Jeremy Cripps is the Chief Executive of Children North East, a charity about growing up that supports children and young people, their parents, and schools. He previously worked as a social worker with children and families for 42 years and is also a trained counsellor. Jeremy is alarmed by the epidemic of emotional health and wellbeing difficulties experienced by young people today. He joined the Citizens Commission on Mental Health to help to prevent and alleviate that distress.

Michael Thompson is the lay School Chaplain at St Thomas More Roman Catholic Academy in North Shields. He has experience of working with young people in the context of faith since 2009. Michael joined the Citizens Commission on Mental Health because he wants to see a change in how we talk about mental health and emotional wellbeing. He hopes that one day when any person struggles with how they are feeling, they will know where to go and be offered the holistic and appropriate support that they need.

Revd Tim Ferguson is the Anglican Chaplain of the College of St Hild and St Bede at Durham University. He was ordained in the Diocese of Newcastle in 2005 and served in Ponteland and Benwell before coming to Durham in 2015, where he also works to help churches address poverty in their local area. Tim developed an interest in mental health as a result of his work as a priest and a chaplain, which has brought him face to face with both the mental fragility and resilience in people from all areas of our society.

Bethanie Ashton Smith, **Hannah Baldwin**, **Leah Harneshaug**, **Neave Miller**, **Rebecca Crow** and **Sophie Blackett** are students at St Thomas More Roman Catholic Academy in North Shields.

Methodology

The work of the Citizens Commission on Mental Health is informed by the principles of broad-based community organising. Broad-based community organising seeks to build power within civil society to work towards the common good by prioritizing "personal relationships, membership of institutions rooted within the community and a pragmatic approach to influencing people who hold power in government, business or public life" (Citizens UK, 2018).

Two tools central to community organising are the one-to-one conversation and the public testimony (Burbridge, 2015). In one-to-ones, two participants develop a mutual understanding of one another's self-interest by telling stories which articulate their personal motivations and concerns. In a public testimony, an individual tells a personal story which breaks down a widely-felt issue into human-scale components which can be addressed by targeted solutions. Both tools also help individuals to develop their voice as citizens and leaders.

The Citizens Commission on Mental Health applied these principles in a cycle of listening, reflection and action. Between June and September 2017, Tyne & Wear Citizens held over 1000 one-to-ones across its member institutions which sought to answer the question "what is putting pressure on you, your family and your communities?" Leaders from the member institutions shared their findings and identified five common issues, one of which was mental health. In September, the member institutions voted to prioritise three issues for future campaigning. Mental health received the greatest number of votes.

In response, interested leaders formed the Citizens Commission on Mental Health, whose first task was to launch a listening campaign to explore this issue more deeply. Between February and April 2018, the Commission received over 300 individual written testimonies from across Tyne & Wear Citizens' broad membership.

In April and May, the Commission's Core Team analysed these testimonies and identified the common issues that underpinned them. The Core Team then grouped related issues together into the key themes which are explored in *Living Well*.

In May and June, the Commission held public hearings in Newcastle, Sunderland and Durham to further explore these issues and potential solutions. At each hearing, a panel of Commissioners (see Commissioner Profiles) discussed these key themes in front of a public audience. Individuals who submitted testimonies that the Commission found to be particularly illustrative were invited to share their testimony with the panel and engage in a roundtable discussion. Some of these testimonies were delivered in person while others were pre-recorded or read by a friend, colleague, or Commission volunteer.

In June and July, the Commission held two workshops in which leaders from member institutions reflected on the findings of the hearings, further discerned the precise character of the issues identified thus far and generated nearly 50 potential solutions to them. Participants then narrowed this list by prioritising the solutions which were the most representative, impactful and winnable.

In August, the Commission's Core Team continued to further hone these solutions and frame them as 'asks' of key decision makers in local statutory services, NHS Trusts, and civil society organisations.

In September, the Commission agreed on which 'asks' it would pursue over the short and medium term and established campaign teams to undertake the research and relationship building required to realise them. The 'asks' are presented as 'Actions' at the end of each of *Living Well's* chapters.

References

Please note that the bibliography below is abridged. A complete list of the works cited throughout the report can be found online at https://www.citizensuk.org/tyne_wear

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Who are Tyne & Wear Citizens?

Tyne & Wear Citizens is a broad-based alliance of civil society organisations committed to working together for the common good.

Our Members

All Saints, Newcastle, Church of England • Catholic Parish of the Durham Martyrs • Cedarwood Trust, North Shields • Citizens Advice Newcastle • College of St Hild and St Bede, Durham University • Consult & Design, Sunderland • Children North East, Newcastle • Islamic Diversity Centre, Newcastle • Newcastle Central Mosque • North East Wellbeing • Northern Saints C of E Primary School, Sunderland • Northumbria Area Quaker Meeting • Park View Academy, Chester-le-Street • PROPS North East, Newcastle • St Chad's College, Durham • St Cuthbert's RC Primary School, North Shields • St Gabriel's, Newcastle, Church of England • St John the Baptist, Newcastle, Church of England • St Michael's with St Lawrence, Newcastle, Church of England • St Thomas More Roman Catholic Academy, North Shields • Together Durham • Together Newcastle • Walker Parish Church, Newcastle, Church of England • West End Women and Girls Centre, Newcastle

Our Founding Partners

Church of England Diocese of Durham • Church of England Diocese of Newcastle • Newcastle University Faculty of Humanities and Social Sciences • Newcastle University Institute for Social Renewal • Newcastle Quakers • Roman Catholic Diocese of Hexham and Newcastle

Our Community Organisers

Sara Bryson (Community Organiser)
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Wendy McConnell (PACT Parent Organiser)
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Follow us on Twitter @tynewearcitizen & Facebook @ TyneWearCitizens

Tyne & Wear Citizens is an alliance of Citizens UK,
developing leaders and effective citizens, strengthening civic institutions
and creating systemic change.
Registered charity number: 1107264
www.citizensuk.org