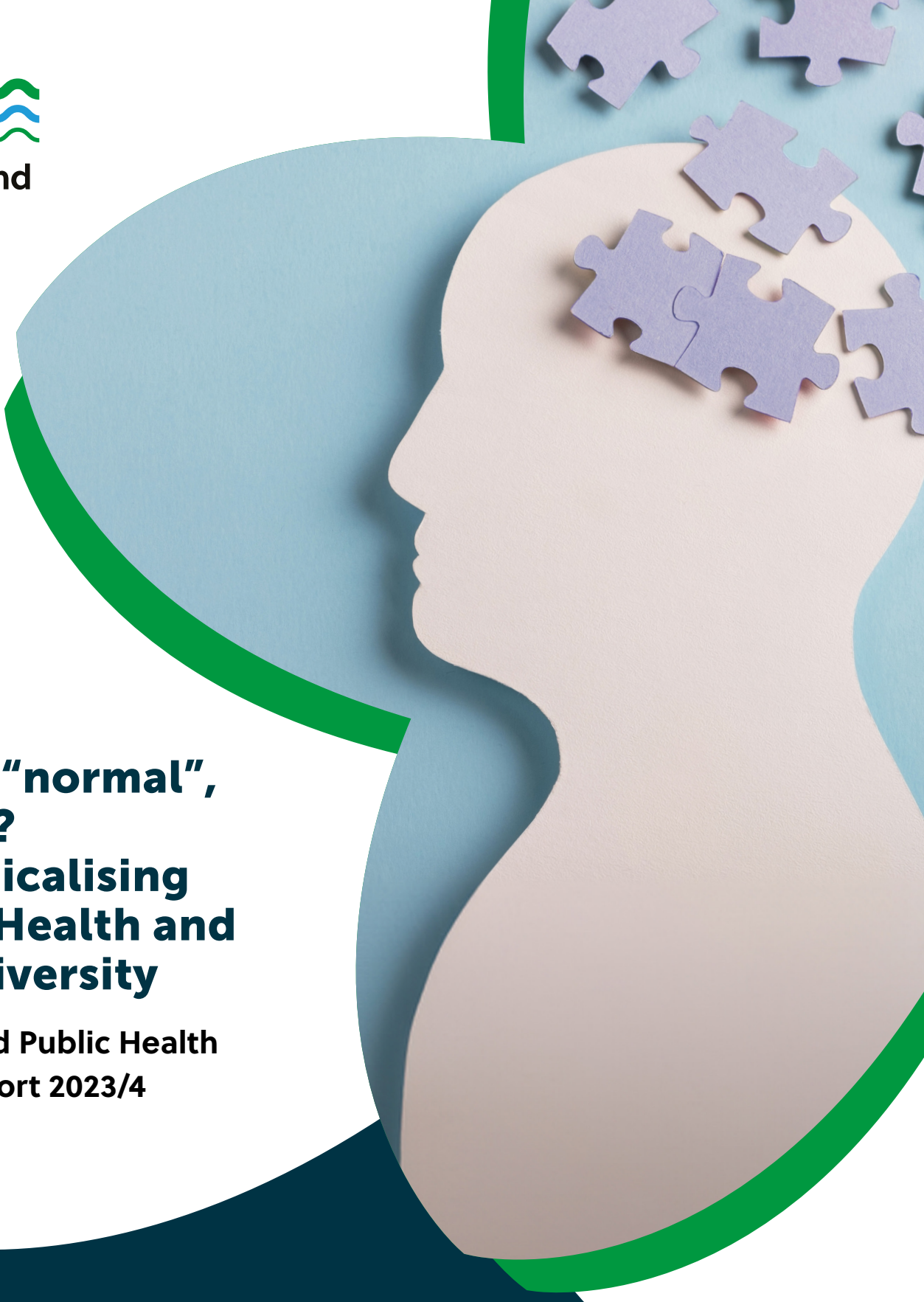
Cumberland Council



What is “normal”, anyway? De-medicalising Mental Health and Neurodiversity

Cumberland Public Health Annual Report 2023/4

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Contents

Foreword

"We are now cruising at a level of two to the power of twenty-five thousand to one against and falling, and we will be restoring normality just as soon as we are sure what is normal anyway."

Douglas Adams, ***The Hitchhiker's Guide to the Galaxy***

I am delighted to be able to present the latest Public Health Annual Report for Cumberland – the first to be produced since 1973, when the County Medical Officer, Dr John Leiper, presented his final annual report to Cumberland County Council before that body was subsumed into Cumbria County Council and the public health function transferred to the NHS. Forty years later public health was transferred back to local government, and now, fifty years later, Cumberland has itself returned.

You might think that a lot has changed in those fifty years. However at a time when we are seeing a measles outbreak across some parts of England it is notable that in the preface to his 1972 report, Dr Leiper reflects on the success of using "the County Council computer" to help achieve a 91% vaccination rate that "is slowly bringing under control those widespread outbreaks of measles which we have suffered from every alternate year in this country in the past" (our vaccination rate today is around 95%). He also reflects on evidence that the fluoridation of water supplies was already bringing improvements in dental health, an issue which remains live today, and bemoans the fact that "doctors, nurses and social workers are increasingly frustrated in that adequate arrangements cannot from time to time be found for the care of some of the diagnosed [psycho-geriatric] cases". Some things, alas, remain challenges fifty years on.

Dr Leiper also reflects that "the care of the mentally disordered is in a state of great change, with increasing emphasis on community care both in cases of subnormality and mental illness and the year has seen wide ranging multi-disciplinary discussions about the implementation of this policy." The outdated language notwithstanding, it is clear that challenges around mental health are also long standing – and this is the focus of this Public Heath Annual Report.

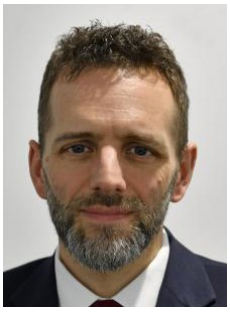
In some ways this report feels like the latest step on a long journey for me. My undergraduate degree was in psychology, and at the time I was particularly interested in the courses on what was then called "abnormal psychology", and "social cognition" – which I later realised was a bit like undergoing a course of cognitive behavioural therapy, and which undoubtedly changed the way I saw the world. I was also interested in the course on addictions, and it was this that led me into working in drug policy; the rest, as they say, is history. In 2018 I focused the Cumbria Public Health Annual Report on the importance of adverse childhood experiences; in 2022/3 the focus was on our Health and Wellbeing Coach service, a team designed to take a different approach to supporting people to deal with the challenges they face. This current report can to some extent be seen as a logical progression from that personal history. It reflects on the rising rates of mental distress (as measured by demand for services) and challenges our

tendency to medicalise many things that could in fact be seen as normal human experiences, or as reactions to abnormal situations. One inspiration for this report came when I started hearing about young people being diagnosed with "climate anxiety". Being anxious about the environment may be distressing but it is not a mental health disorder: it's a perfectly reasonable and rational response to our climate emergency, and the "treatment" is activism, not Prozac.

"Abnormal is so common, it's practically normal"

Corey Doctorow, Little Brother

While tackling the social and economic factors that are driving what can be seen as a current mental health crisis is far from easy, the good news is that there is some strong evidence on what can be done to intervene. It will take a radical reimagining of what "normal" is, and of what mental health and neurodiversity support can look like but I believe that in Cumberland we are ready to rise to that challenge.



Colin Cox

Director of Public Health and Communities

Introduction: Embracing a paradigm shift in mental health and neurodiversity

If the demand for services is any indicator, society appears to be going through a growing mental health crisis. Mental health services both for adults and children and young people (Child and Adolescent Mental Health Services, or CAMHS) are facing unprecedented demand, a pattern which has been developing for many years, with ever-growing waiting lists for diagnostic assessment and treatment services. This pattern is echoed in learning disability services, particularly those focused on Special Educational Needs and Disabilities (SEND) in children and young people; demand for diagnostic assessment is rising, as is the number of children subsequently receiving a Statement of Special Educational Needs and therefore additional support in schools.

Aside from the difficulty of meeting this rising demand, from a public health perspective this prompts the question of what is causing it. Most medical disorders have relatively clear (though sometimes complex) causes. They can be genetic; however in this case the changes in demand are too rapid to be explained by genetic changes in the population. They can be communicable diseases, which can of course spread rapidly; but these are not. They can be caused by biochemical changes created by factors such as smoking and poor diet; while there is evidence that lifestyle changes can improve mental health and wellbeing, it is far from clear that such factors can specifically cause diagnosable mental disorders.

More pertinently, they can be caused by biochemical changes brought on by psychosocial factors. This is closer to the likely mechanism behind many or most mental health problems. Even here an emphasis on the biochemical changes rather than the psychosocial factors can distort the understanding of the individual experience and the response to it, but psychosocial factors can change rapidly enough that they are a credible reason for the rapidly rising demand for services. Such factors can include trauma and adverse experiences, which are at the heart of many mental health problems; social structures that encourage people to seek diagnoses (e.g. benefits and educational support systems that require medical diagnosis before help is offered); and changing patterns of expectation in the public of what sort of range of experience is considered to be "normal" and healthy.

There is a long history of critiques of biomedical approaches to mental health, most notably going back to RD Laing and the antipsychiatry movement that came to the fore in the 1960s. Most psychiatrists would now endorse what is known as a "biopsychosocial" model of mental health, recognising the importance of psychological and social factors in addition to biochemical ones. However this still sees mental health and learning disability in a medical framework – there is a defined disorder that can be diagnosed and treated, at least with the aim of mitigating the symptoms. But if psychosocial factors are indeed driving the increase in demand, the appropriate response is to tackle those factors that are affecting on people's lives and experiences in a profoundly negative way, rather than to see the individual's experience as the problem.

If that is to be achieved, the landscape of mental health and neurodiversity support needs a radical transformation, moving away from traditional diagnostic-centric approaches to a more inclusive, nuanced, and holistic understanding of individual experiences. And a new emphasis is needed on public mental health – on promoting those factors that protect people from poor mental health, and on tackling factors that cause it. This report sets out some of the key ways in which this transformation could be achieved.

Chapter One begins with an overview and critique of mainstream medical models of mental health and learning disability.

Chapter Two delves into the pattern of mental health problems in Cumberland, at this point utilising mainstream diagnostic categories – as this is how the data are currently collected. It shows the demand for services and the poor outcomes we see in Cumberland, including through high mortality associated with substance misuse and suicide.

Chapter Three illuminates the profound impact of trauma on mental health. It explores trauma theory, the prevalence of traumatic experiences, and the imperative to transition from diagnostic and treatment-oriented models to trauma-informed care. By emphasising safety, trust, compassion and healing, this chapter advocates for services that support individuals in processing trauma rather than solely focusing on clinical diagnoses and treatments.

Chapter Four considers societal expectations surrounding mental health. It unpacks the prevalent misconceptions that lead individuals to seek clinical support for emotions and thinking patterns that fall well within the spectrum of normal human experiences. This chapter advocates for a more inclusive approach that encourages the recognition of everyday emotional struggles as normal, with support offered outside of professional interventions.

Chapter Five extends this thinking to some categories of learning disability, neurodiversity and special educational needs. It provides an overview of patterns of demand for SEND services, then goes on to explore why individuals seek clinical diagnoses for traits that could be seen as part of normal cognitive diversity. This chapter advocates for mainstream services such as schools to adopt inclusive approaches that support diverse thinking styles and personalities without solely relying on diagnostic labels.

The implications of implementing these progressive approaches within local mental health services are far-reaching. **Chapter Six** therefore offers recommendations on reshaping services to adopt trauma-informed care, strengths-based assessments, recovery-focused models, inclusive practices, and collaborations with diverse stakeholders to create supportive environments that accommodate diverse learning and mental health needs without rigid diagnostic boundaries.

In essence, this report calls for a substantial focus on public mental health in Cumberland, and a seismic shift in how mental health and neurodiversity support are approached – a shift that prioritises empathy, compassion, inclusion, empowerment and individual strengths, creating pathways to wellbeing that honour the diversity of human experiences.

There are two crucial caveats to what is set out in this report. First, nothing in this report should be read as an absolute. It does not apply to several health problems that fall under the general heading of mental health or learning disorders, notably degenerative brain disorders including dementia, acquired brain injury, and profound learning disorders that

have a significant impact on people's ability to function independently – though some, like Foetal Alcohol Syndrome, can present in very similar ways to some neurodiverse characteristics. While it argues for an approach that resists over-medicalisation and the dependence on diagnostic categories, some people find diagnosis extremely helpful in aiding their understanding of their experiences; and pharmaceutical interventions undoubtedly have their place in supporting people. The aim is to promote an alternative view where this would be helpful, not to reject the role of medicine altogether.

And second – nothing in this report is intended to suggest that any mental health or learning challenge is in any way invalid, not "real", or the fault of the people experiencing it. The distress and difficulties that people face are very real, and usually driven by external factors; the question is how we help people to respond to these, and how we can change society to reduce the negative external factors. This is the essence of public mental health.

Chapter 1: Mainstream medical paradigms and critiques

ICD-11 Classification 06: Mental, behavioural or neuro-developmental disorders

"Mental, behavioural and neurodevelopmental disorders are syndromes characterised by clinically significant disturbance in an individual's cognition, emotional regulation, or behaviour that reflects a dysfunction in the psychological, biological, or developmental processes that underlie mental and behavioural functioning. These disturbances are usually associated with distress or impairment in personal, family, social, educational, occupational, or other important areas of functioning." Sub-headings are defined as:

- Neurodevelopmental disorders (including Autism Spectrum Disorder, ADHD, and a range of learning disorders)
- Schizophrenia or other primary psychotic disorders
- Catatonia
- Mood disorders
- Anxiety or fear-related disorders
- Obsessive-compulsive or related disorders
- Disorders specifically associated with stress
- Dissociative disorders
- Feeding or eating disorders
- Elimination disorders
- Disorders of bodily distress or bodily experience
- Disorders due to substance use or addictive behaviours
- Impulse control disorders
- Disruptive behaviour or dissocial disorders
- Personality disorders and related traits
- Paraphilic disorders
- Factitious disorders
- Neurocognitive disorders
- Mental or behavioural disorders associated with pregnancy, childbirth or the puerperium

"Acute stress reaction" and "Uncomplicated bereavement" are excluded from diagnosis under this category; "Sleep-wake disorders", "Sexual disfunction" and "Gender incongruence" are noted as potentially related but coded in different sections.

Box 1: Mental health classifications under ICD-11

Mainstream medical paradigms

The prevailing medical paradigms in mental health and neurodiversity often revolve around the identification and categorisation of various conditions through standardised assessment tools and diagnostic criteria. These paradigms tend to use clusters of symptoms to assign diagnoses, aiming to classify and treat mental health conditions and neurodivergent traits within established frameworks.

The two key established frameworks in this area are the Diagnostic and Statistical Manual (DSM) and the International Classification of Diseases (ICD) (see Box 1), which both provide diagnostic criteria for mental health disorders and neurodevelopmental conditions based on symptom presentation. Assessment of symptoms may be supported by various psychological assessments, interviews, and questionnaires that are used to evaluate an individual's behavioural, emotional, and cognitive patterns. These assessments often contribute to forming diagnostic impressions and guiding treatment plans. In some cases, tools such as brain scanning and genetic testing may complement diagnostic processes, offering additional insights into brain functioning and potential genetic factors associated with certain conditions.

These approaches often emphasise biological factors, such as genetics, neurochemistry, and brain structure or function as primary contributors to mental health conditions and neurodiversity. Research in fields like neuroscience and genetics is used to identify biological markers and mechanisms underlying these conditions. The frontline biomedical treatments include medications such as antidepressants, anti-anxiolytics and anti-psychotics, all of which are aimed at alleviating symptoms or correcting

perceived biochemical imbalances in the brain, and various forms of psychotherapies ("talking therapies" which aim to help people identify and change their thought processes. Somatic interventions such as electroconvulsive therapy are now much more rarely used than they once were due to concerns about effectiveness, long term effects and ethical considerations. Practical support such as skills training and various assistive technologies can also help people overcome specific barriers that they face.

Further important considerations in the context of this report are the link between mental health and addiction, and the connection with suicide. While "Disorders due to substance use or addictive behaviours" falls within the heading of "Mental, behavioural or neurodevelopmental disorders" under ICD-11, conventionally addictions are treated as being somewhat separate to other mental health problems, though it is recognised that many people who suffer as a result of addictions also have other mental health disorders – so-called "dual diagnosis". Likewise, while many people who take their own lives do have a mental health diagnosis, many do not, and therefore suicide is not necessarily seen as a result of "mental illness". Within the confines of the biomedical approach, this is entirely appropriate. However alternative approaches can help bring greater coherence to these perceived relationships, as described further below.

Critique of biomedical paradigms

Critiques of this biomedical paradigm have existed for many years. Biomedical approaches to mental health, particularly those reliant on traditional psychiatric diagnoses, have faced growing scrutiny regarding their validity and potential arbitrariness. Several critiques challenge the objectivity and scientific grounding of these diagnostic categories, highlighting the following key points:

1. **Lack of objective biomarkers:** While poor mental health can undoubtedly manifest through physiological symptoms, traditional psychiatric diagnoses often lack clear, objective biological markers. Unlike many other medical conditions with identifiable physical indicators, mental health and learning disability diagnoses rely heavily on reported symptoms and subjective assessments. The absence of reliable biomarkers raises questions about the objectivity and scientific validity of psychiatric diagnoses. It underscores the challenge of establishing a clear biological basis for many mental health conditions.
2. **Arbitrary diagnostic boundaries:** Diagnostic criteria for mental health and learning disorders are often defined by a set number of symptoms or behaviours, leading to diagnostic thresholds that may seem arbitrary and even circular (for example: hearing voices – auditory hallucinations – leads to a diagnosis of schizophrenia, which is then given as an explanation for the hallucinations). The shifting nature of diagnostic criteria over time adds to the perception that these boundaries lack a solid scientific foundation.
3. **Overlap and comorbidity:** Many individuals receive multiple diagnoses simultaneously, indicating a high degree of overlap and comorbidity among different disorders. The co-occurrence of various diagnoses suggests that the discrete categories may not accurately capture the complexity and interconnectedness of mental health conditions. This challenges the idea of clear and distinct disorders.
4. **Reliability issues in diagnosis:** Studies reveal inconsistencies in psychiatric diagnoses, with different clinicians sometimes providing different diagnoses for the same individual. The lack of consistent reliability in diagnoses raises concerns about the robustness of psychiatric

categories, including the potential conflation between the presentation of neurodiversity and complex trauma. The subjective nature of diagnostic assessments and potential clinician bias contribute to the variability observed in practice.

5. **Heterogeneity within diagnoses:** Many psychiatric diagnoses encompass a wide range of symptoms and presentations, leading to considerable heterogeneity within diagnostic categories. Critics argue that this heterogeneity challenges the validity of overarching diagnostic labels, as individuals within the same category may exhibit vastly different symptom profiles and trajectories.
6. **Cultural and contextual bias:** Psychiatric diagnoses may reflect cultural biases and be influenced by prevailing societal attitudes. Perhaps most notoriously, homosexuality was included as a mental disorder in the Diagnostic and Statistical Manual of the American Psychiatric Association until 1974, and even then it was still referenced in the DSM until 1987; more broadly, it has been argued that many diagnostic definitions have been developed by a profession that has historically been predominantly white and male, who clearly bring a certain perspective to interpreting others' experiences. The cultural specificity of certain diagnoses and the potential for pathologising normal variations in behaviour highlight the influence of societal factors on diagnostic frameworks.
7. **Reductionist approach with limited emphasis on social and environmental factors:** The biomedical model can be inclined to focus on biochemical and neurological differences without always considering the impact of social and environmental factors on the experiences of individuals. A more comprehensive understanding should account for the complex interplay between biology, environment, and individual experiences, challenging the reductionist view of solely biological causation.
8. **Pathologisation of neurodivergent traits:** Traditional psychiatric diagnoses may pathologise neurodivergent traits, such as those associated with autism, ADHD, or dyslexia, by framing them as disorders rather than natural variations in cognitive functioning. Neurodiversity advocates argue that many traits classified as disorders are part of the natural spectrum of human diversity, challenging the appropriateness of medicalising these differences, and recognising that efforts to "mask" these traits can in fact create additional challenges for people.
9. **Overemphasis on deficits:** Biomedical models often focus on deficits associated with neurodivergent conditions rather than recognising the diverse skills and capabilities neurodivergent individuals may possess. Critics argue that framing neurodivergence primarily in terms of deficits perpetuates a deficit-based model, neglecting the positive aspects of neurodivergent thinking and potentially hindering opportunities for neurodiverse people.
10. **Pharmaceutical industry influence:** The influence of the pharmaceutical industry on psychiatric research and practice has raised concerns about the potential over-reliance on medication-based interventions. Critics argue that the close relationship between pharmaceutical companies and psychiatric research may contribute to a medicalisation of normal human experiences, with an emphasis on pharmacological solutions.

In conclusion, the critique of biomedical approaches to mental health and learning disability centres on the arbitrary nature of traditional diagnoses and the failure to recognise the validity of the breadth of human experience. The lack of clear biological markers, overlap between diagnoses, reliability issues, and cultural biases all contribute to questions about the scientific validity and objectivity of the current diagnostic framework.

Alternative perspectives

While mainstream medical paradigms try to offer systematic approaches to mental health and neurodiversity, a critical lens suggests that a significant portion of diagnoses may be adaptations to adversity or represent variations within the broad scope of normal human experiences. This perspective urges a re-evaluation of diagnostic frameworks to encompass the nuances of adversity responses and the diversity of human cognition and behaviour.

As Peter Kinderman puts it in his recent book *A Manifesto for Mental Health:*

> "We are born as natural learning engines, with highly complex but very receptive brains, ready to understand and then engage with the world. As a consequence of the events we experience in life, we develop mental models of the world, including the social world. We then use these mental models to guide our thoughts, emotions and behaviours. Our social circumstances, and our biology, influence our emotions, thoughts and behaviours – our mental health – through their effects on how we have learned to make sense of, and respond to, the world...Seeing our mental health as the consequence of normal, understandable, psychological processes, rather than ill-defined and elusive "illnesses", offers an opportunity radically to re-conceptualise mental health services."

Such a re-conceptualisation would need to take significant account of two key factors. First, the impact of trauma and adversity. A growing body of research suggests that numerous mental health conditions may stem from experiences of trauma or adversity, which includes inadequate attachment in childhood. These factors can significantly affect an individual's mental and emotional well-being, potentially leading to symptoms that align with various diagnoses. Their effects might manifest as symptoms resembling traditional mental health conditions such as anxiety, depression, or dissociation. These manifestations often represent adaptive responses to overwhelming experiences rather than inherent disorders. And second, diversity of experience. Many traits and behaviours encompassed within diagnostic criteria exist on a continuum within the normal spectrum of human experiences. Varied cognitive styles, emotional responses, and personality traits may not inherently signify pathology but rather reflect diverse ways individuals engage with the world. There is therefore a risk of over-pathologising common variations in human behaviour, where certain traits or reactions that deviate slightly from societal norms are labelled as disorders or deviations from the norm.

Within this broader approach, both addictions and suicide can clearly be seen as responses to or outcomes of mental distress brought on by a range of psychosocial factors rather than as separate phenomena. Addiction in particular is clearly not a choice, and nor is it helpfully seen as a disease; as the American psychiatrist Gabor Maté puts it, *"Addictions represent, in their onset, the defenses of an organism against suffering it does not know how to endure. In other words, we are looking at a natural response to unnatural circumstances, an attempt to soothe the pain of injuries incurred in childhood and stresses sustained in adulthood."* The same could be said of many experiences currently defined as mental disorders.

Chapter 2: Mental health in Cumberland

Given some of the uncertainty surrounding mental health diagnoses previously described, it is perhaps inevitable that getting a clear picture of the prevalence of mental health challenges in Cumberland is not easy. However a range of data can be used to give an indication of relevant patterns.

Primary care data

Data from GP Registers paints a dramatic picture of changes to some categories of mental health demand. Across the whole of England, the number of people being recorded by GPs as having a diagnosis of depression has nearly doubled in 10 years. While some of this may reflect improved recording and reporting, it is stark that in 2022/3, over 40,000 people in Cumberland – 18% of the adult population – was recorded as having depression, a rate that is over a third higher than the England average (Figure 1). This rising trend is less dramatic with some other mental health disorders (Figure 2) but even here there has been a 15-20% rise in 10 years, with over 3,000 people in Cumberland recorded as being diagnosed with schizophrenia, bipolar disorder or other psychotic disorder, around 10% higher than the England average.

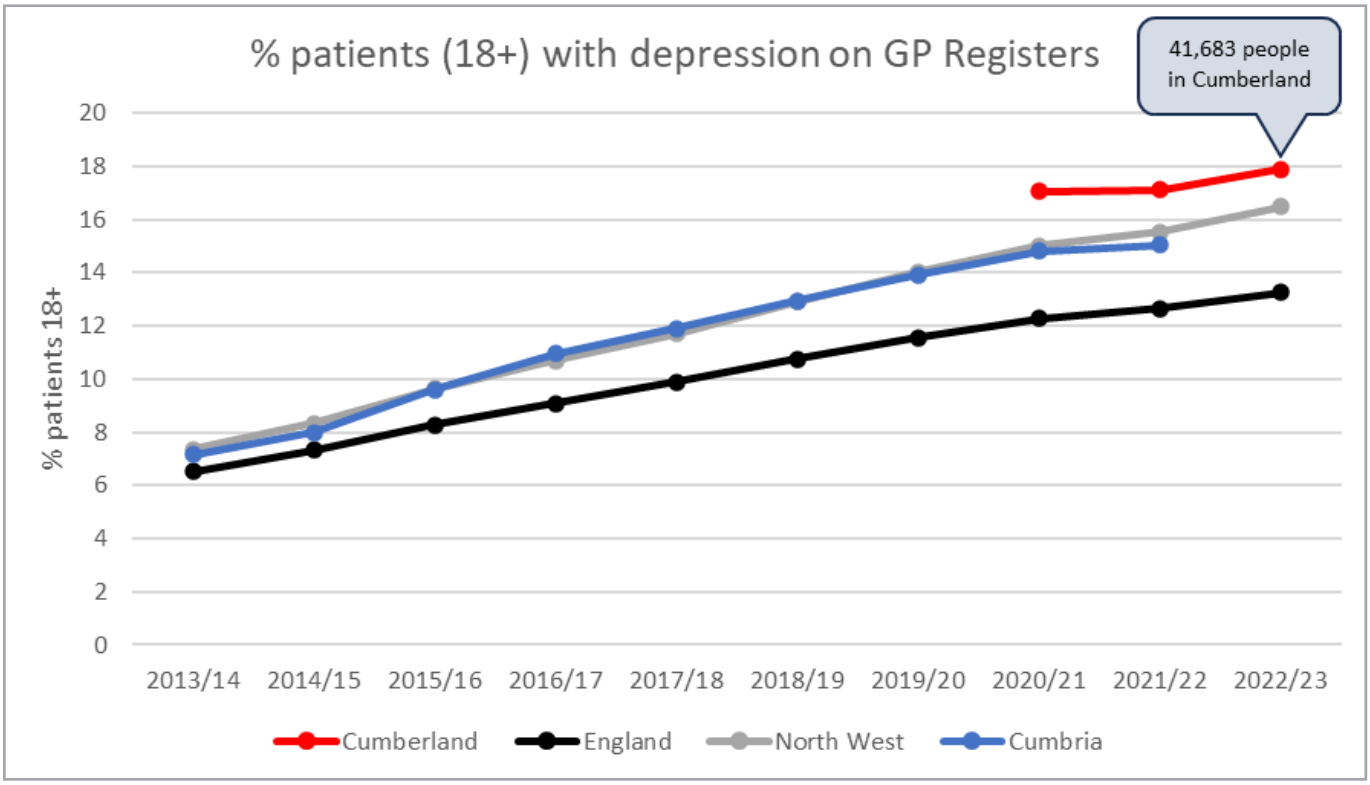


Figure 1: Rising rates of recorded depression over the last 10 years

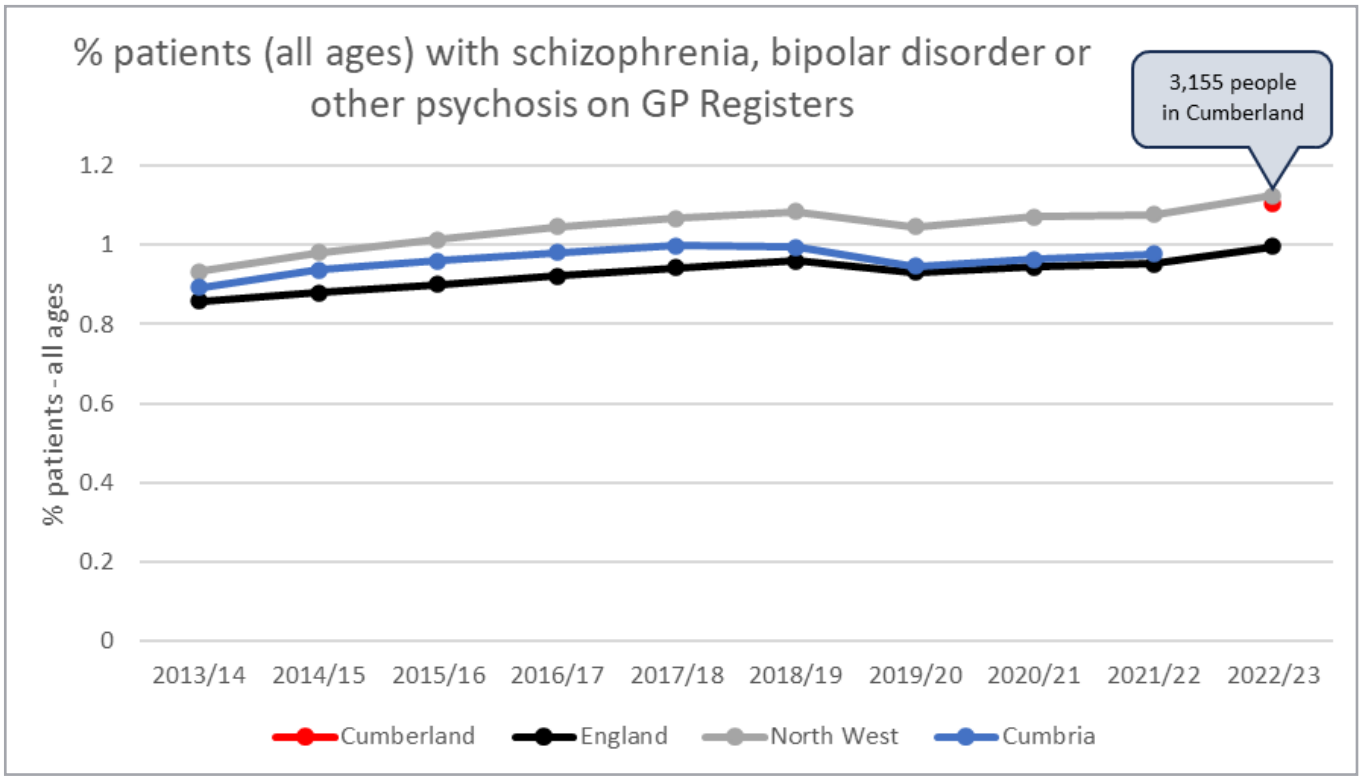


Figure 2: Trends in selected mental health disorders

These data can be valuably cross-referenced to prescribing data (OpenPrescribing.net, 2024). In NHS North Cumbria, which covers the vast majority of Cumberland but also includes the former Eden District in Westmorland and Furness, antidepressant (British National Formulary section 4.3) prescribing was around 160 items per 1,000 patients in November 2023 (Figure 3); this is again a third higher than the England average of 120 items per 1,000 patients. Figure 3 also show the increase in prescribing over time: the England average in December 2018 was only 100 items per 1,000 patients, indicating a 20% rise in prescribing over the last five years. And this prescribing does not come cheaply; in the year to November 2023, in NHS North Cumbria the 622,078 items prescribed under the category of antidepressants cost £1,391,345.

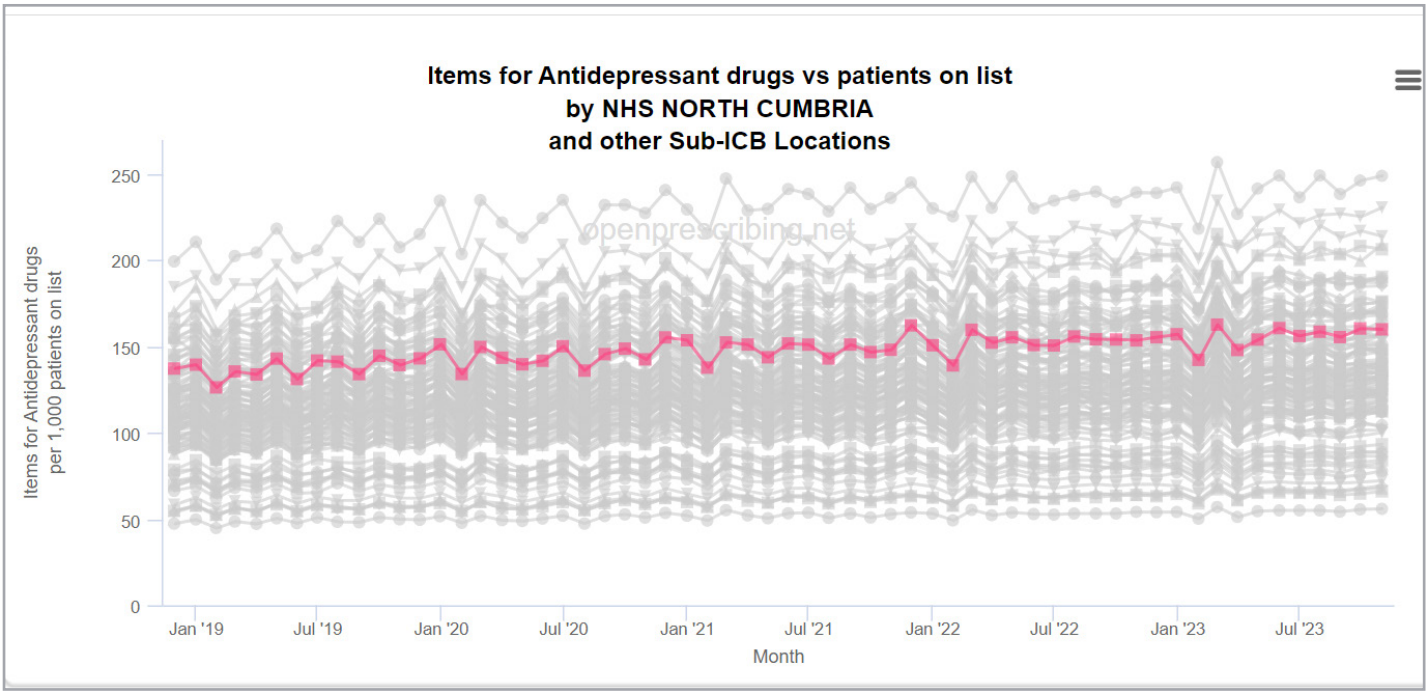


Figure 3: Antidepressant prescribing over time (North Cumbria figures highlighted)

The prescribing picture is slightly different for other mental health conditions. Prescribing of hypnotics and anxiolytics (anti-anxiety drugs – BNF Section 4.1) has been falling in recent years, and is low in North Cumbria compared to the national average, at about three quarters of the national rate (Figure 4). Despite that, the year to November 2023 still saw 53,041 items prescribed in this category, at a total cost of £448,668

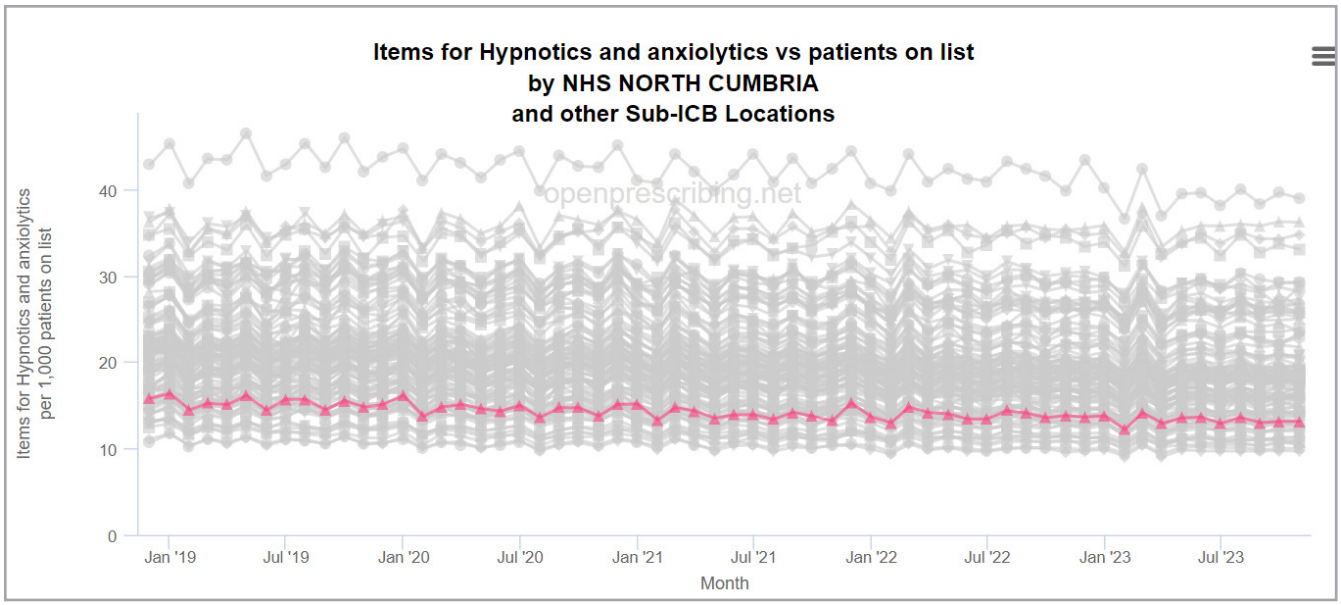


Figure 4: Prescribing of anti-anxiety drugs over time (North Cumbria figures highlighted)

The picture for anti-psychotics (BNF section 4.2) has been quite stationary for the last five years (Figure 5) at around 10% higher in North Cumbria than the national average – relatively consistent with the GP Register data shown in Figure 2. In the year to November 2023, there were 74,866 such items prescribed at a total cost of £887,301.

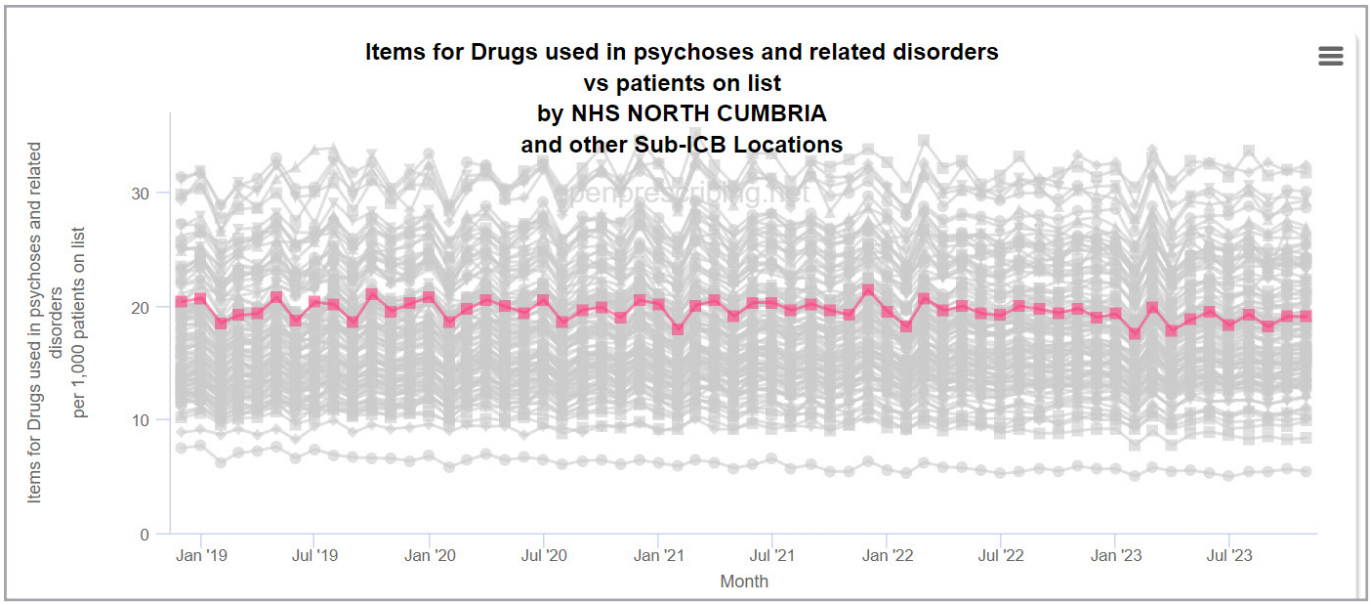


Figure 5: Antipsychotic prescribing over time (North Cumbria figures highlighted)

In total, the cost of primary care prescribing across these three categories of mental health medications in North Cumbria in the year to November 2023 was £2,727,315. Note that this is only the prescribing carried out in primary care – it does not include prescribing done in secondary care or specialist mental health services.

As an important side-note, prescribing of these drugs show a predictable pattern across the country: it is higher in northern and coastal communities and areas of higher socio-economic deprivation, as can be seen in Figure 6.

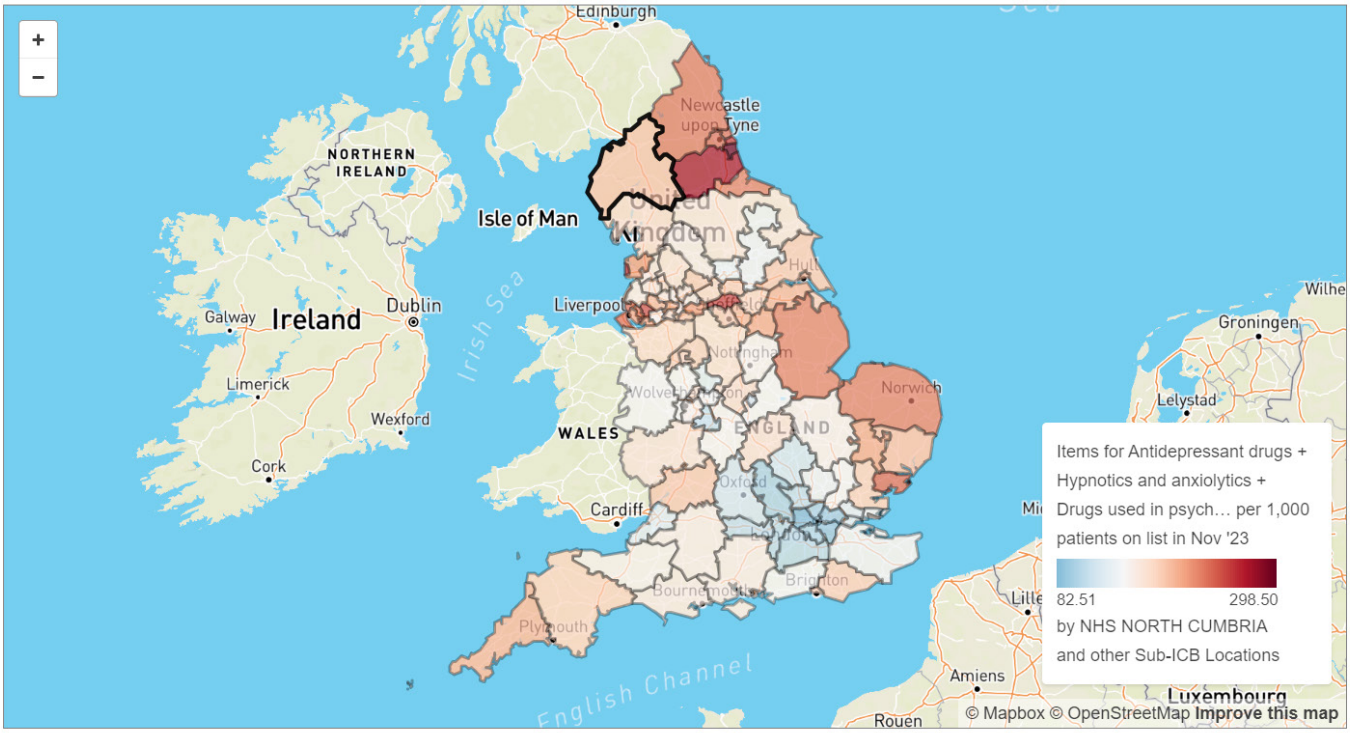


Figure 6: Prescribing of mental health medications by ICB sub-region (North Cumbria highlighted)

There is also considerable variation within Cumberland, as shown in the breakdown by GP Practice in Figure 7, with the highest prescribing practice issuing nearly twice as many items per patient as the lowest.

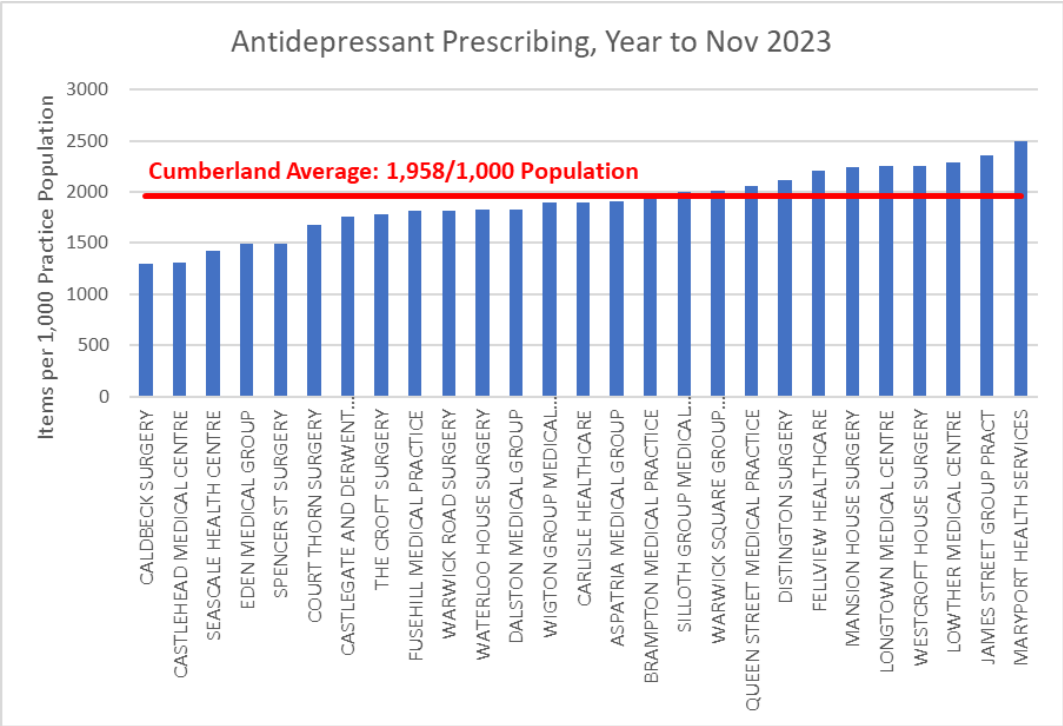


Figure 7: Antidepressant prescribing by Practice

Specialist mental health services

In Cumberland, specialist mental health services are primarily provided by Cumbria, Northumberland, Tyne & Wear NHS Foundation Trust (CNTW). The number of referrals to CNTW has increased by more than 50% over the last three years alone (Figure 8), putting huge and unsustainable pressure on the system.

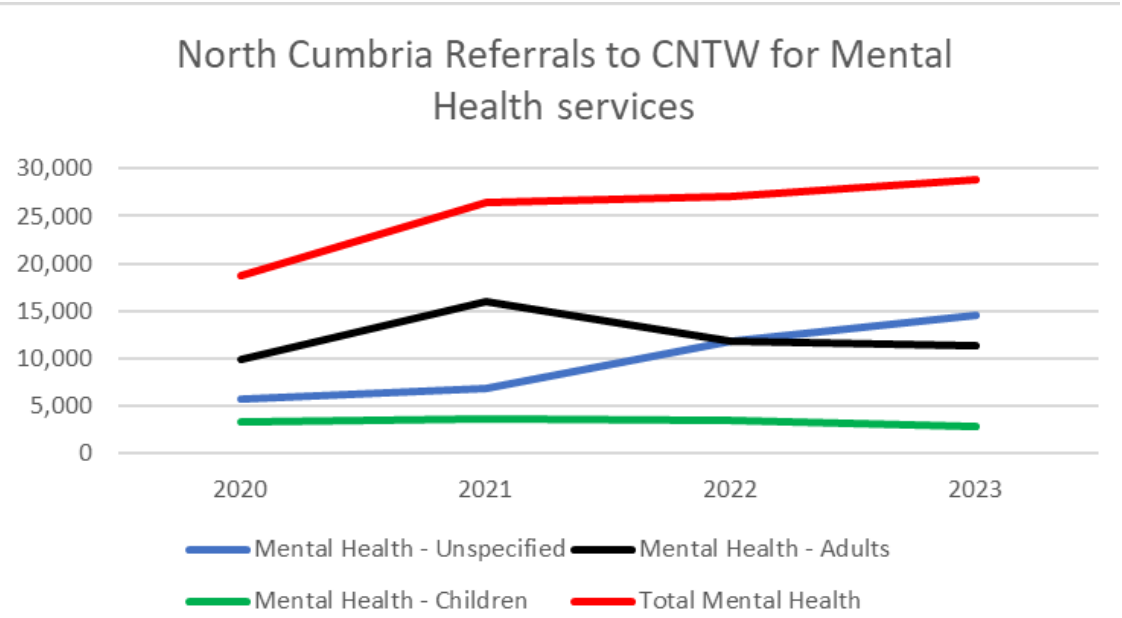


Figure 8: North Cumbria referrals to specialist mental health services

Within specialist mental health services, the number of people taking up talking therapies (mainly cognitive behavioural therapy) has increased by around 15% since 2020, rising from 6,730 to 7,706 in 2023. Figure 9 shows how the use of talking therapies is highest in younger age groups, progressively decreasing after the age of 35; it also illustrates how this type of intervention is predominantly taken up by women – though this discrepancy reduces with age until middle age, after which it rises again.

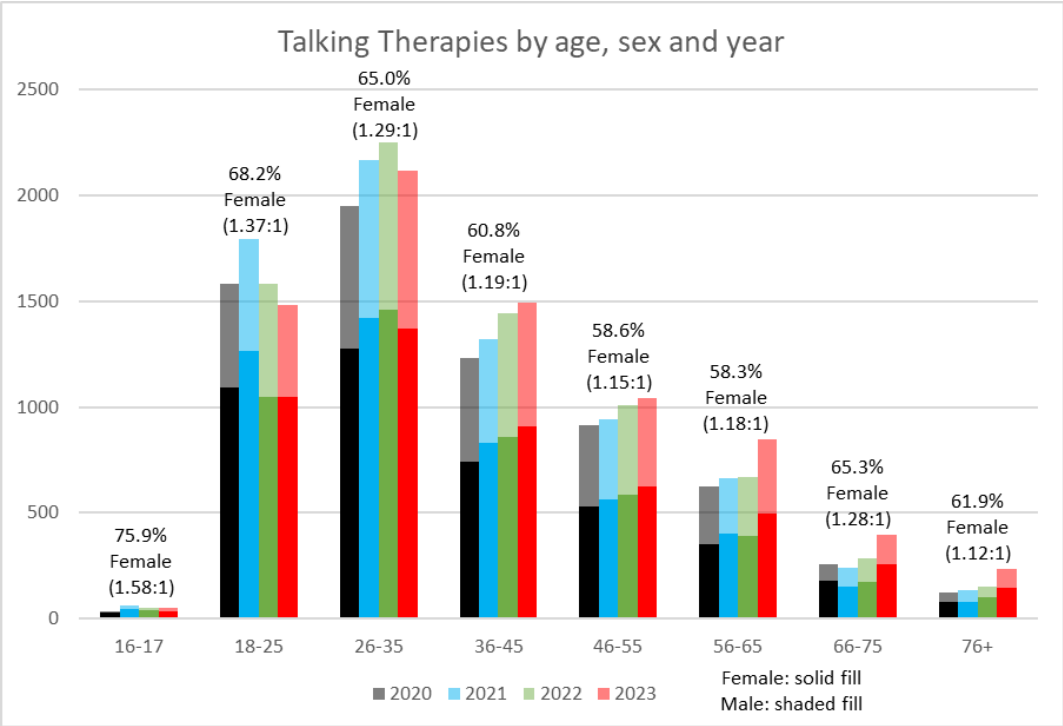


Figure 9: Talking therapies by age, sex and year

Demand on services means that waiting times for talking therapies in North Cumbria are challenging. While the vast majority of referrals (4,985/5,050 in 2022/3) are seen for a first time within 28 days, with an average waiting time of 5.8 days, the time between first and second appointments is considerably longer – an average of 44.9 days, with 415 people waiting more than 90 days for a second appointment. This matters because these therapies can be highly successful, with the majority of people seeing clinically and socially significant improvements across a range of mental health and wellbeing scores and very high levels of satisfaction with services.

In wider specialist mental health services it is now far from unusual to wait for more than 18 weeks before receiving services. Figure 10 shows the rapid rise in waiting times for general adult community mental health services since 2021; the comparison with older adults services is instructive as the latter are mainly driven by dementia diagnoses, which are not so susceptible to the socio-cultural pressures described in Chapter 1.

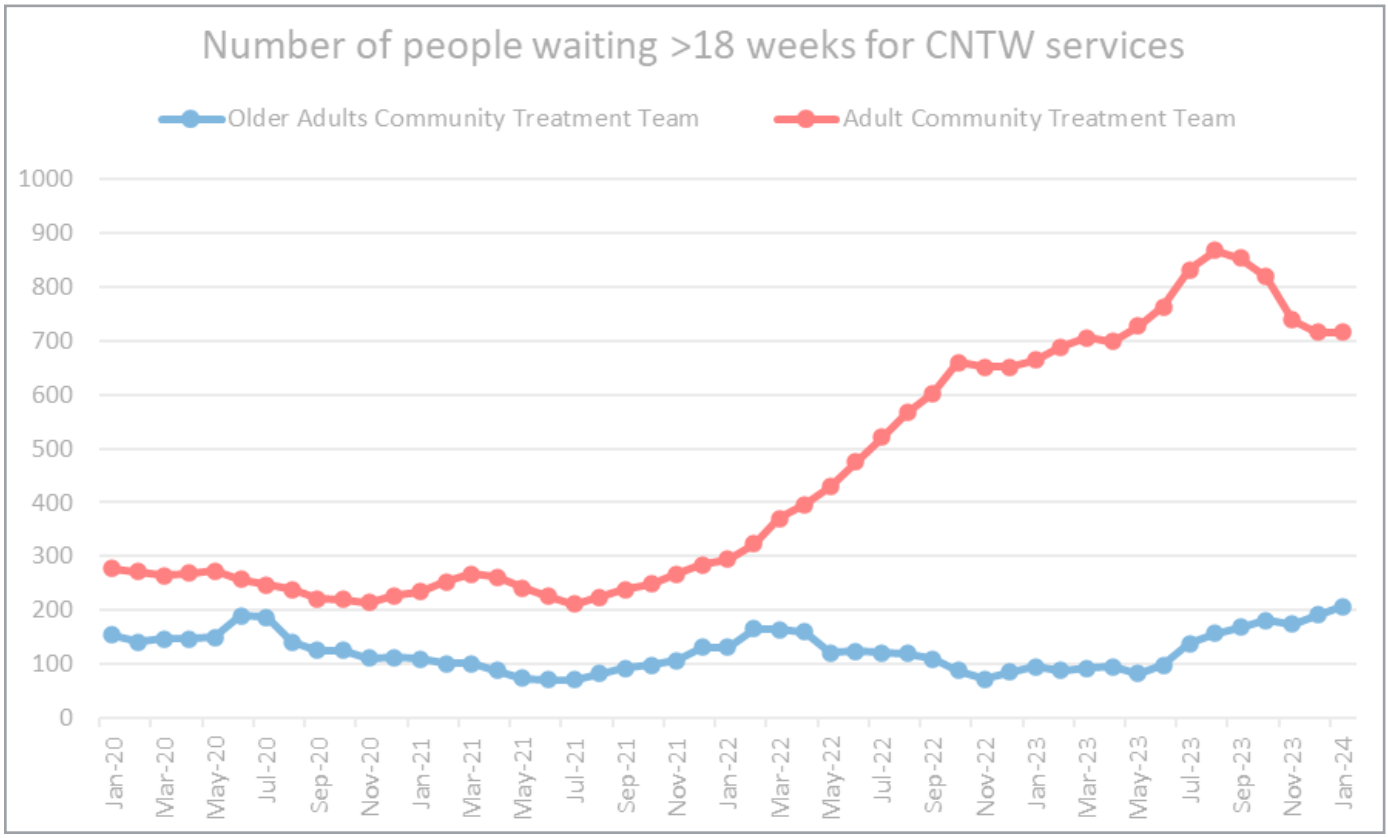


Figure 10: Waiting times for community mental health services

Consequences of poor mental health and wellbeing

As noted in Chapter 1, there are several health-related behaviours that can usefully be seen not just as separate phenomena but as symptoms of a broader mental distress – not themselves mental health problems, but consequences of them. These include self harm, addictions, and suicide. And across all three, Cumberland has significantly high rates. Emergency admissions for intentional self-harm are significantly above the England average in all three of Cumberland's former Districts, as shown in Figure 11, and follow a close relationship with deprivation, as shown in Figure 12.

	Count	Rate
Allerdale	170	197.9*
Carlisle	240	225.6*
Copeland	160	258.3*
North West	14,275	190.3
England	93,895	163.9

Figure 11: Emergency hospital admissions for intentional self-harm (Directly Standardised Rate per 100,000), 2021/22. * Statistically significantly worse than England average, p<0.05

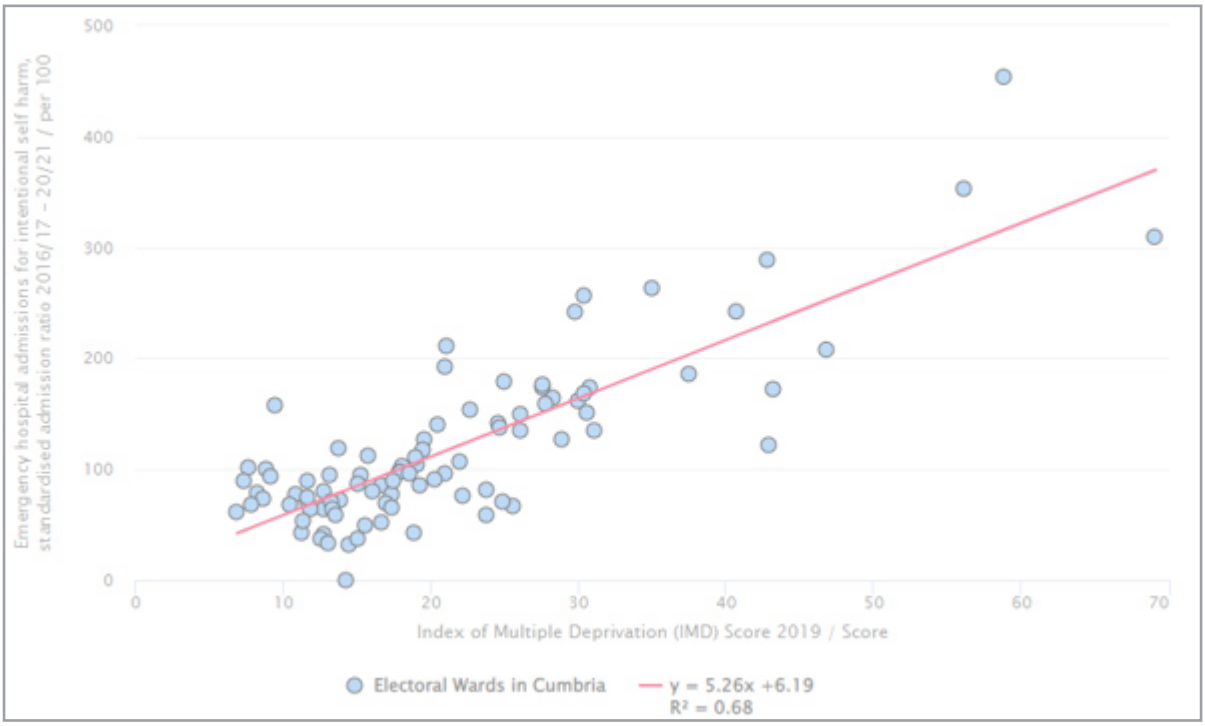


Figure 12: The relationship between self-harm and deprivation

One very recent (February 2024) analysis of so-called "deaths of despair" (those related to alcohol use, drug use, or suicide) has highlighted the significant geographic differences in such deaths, and shows clearly the much higher rates in many parts of the North of England – including in Cumberland – as shown in Figure 13.

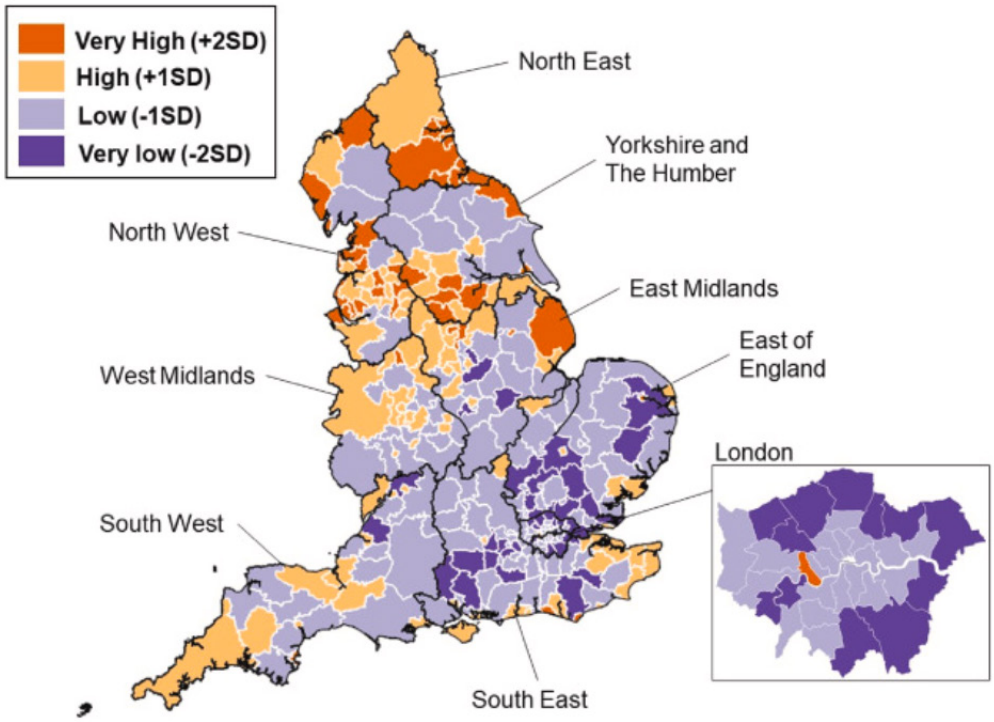


Figure 13: Standardised rates of "deaths of despair" (relating to alcohol, drugs or suicide). Camacho et al (2024)

Looking at Cumberland in more detail, some very worrying recent trends can be seen. Our alcohol specific mortality data is somewhat out of date, with the most recent figures available being for 2017-19, but this shows rates below the England average in Allerdale and Carlisle, but higher in Copeland (Figure 14). Our drug-related deaths (Figure 15), and suicide rates (Figure 16), on the other hand, are rising rapidly and are substantially higher than the England average.

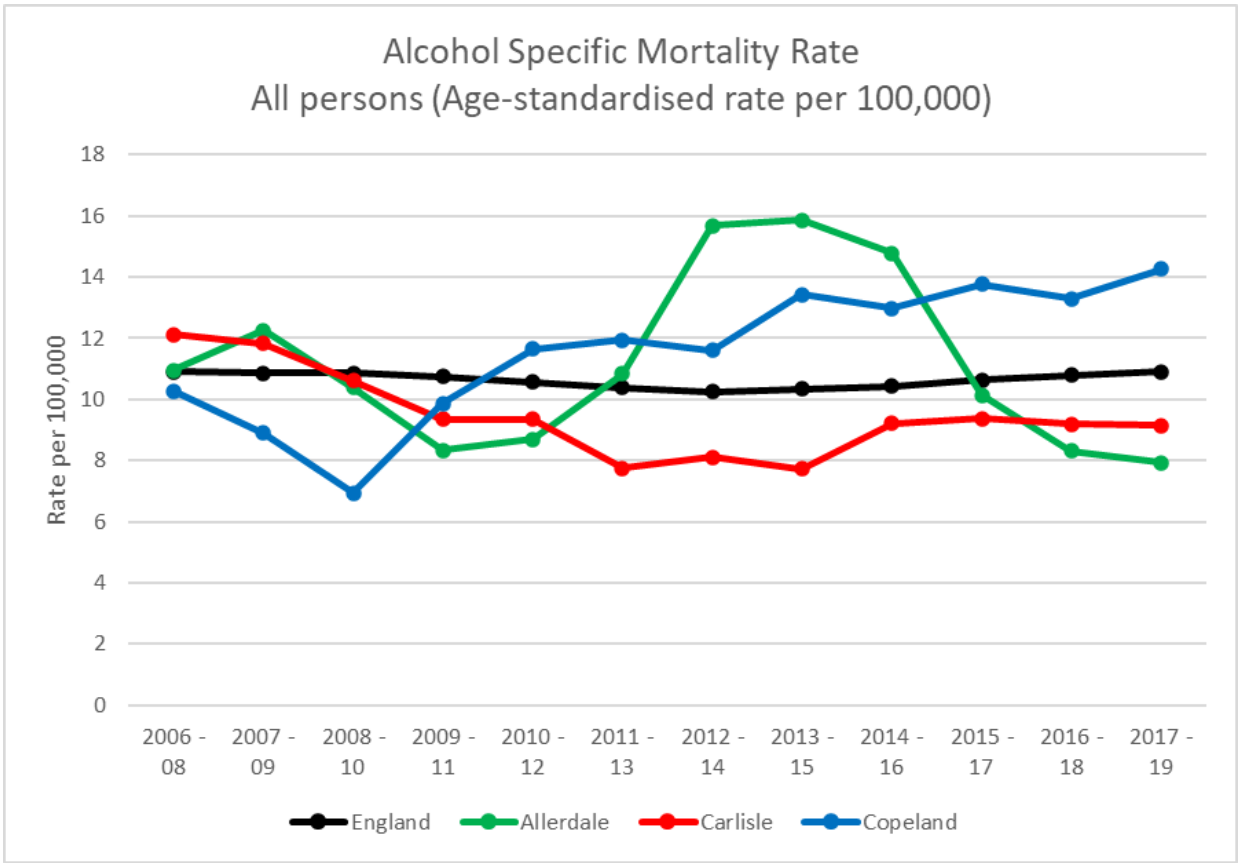


Figure 14: Alcohol specific mortality rates

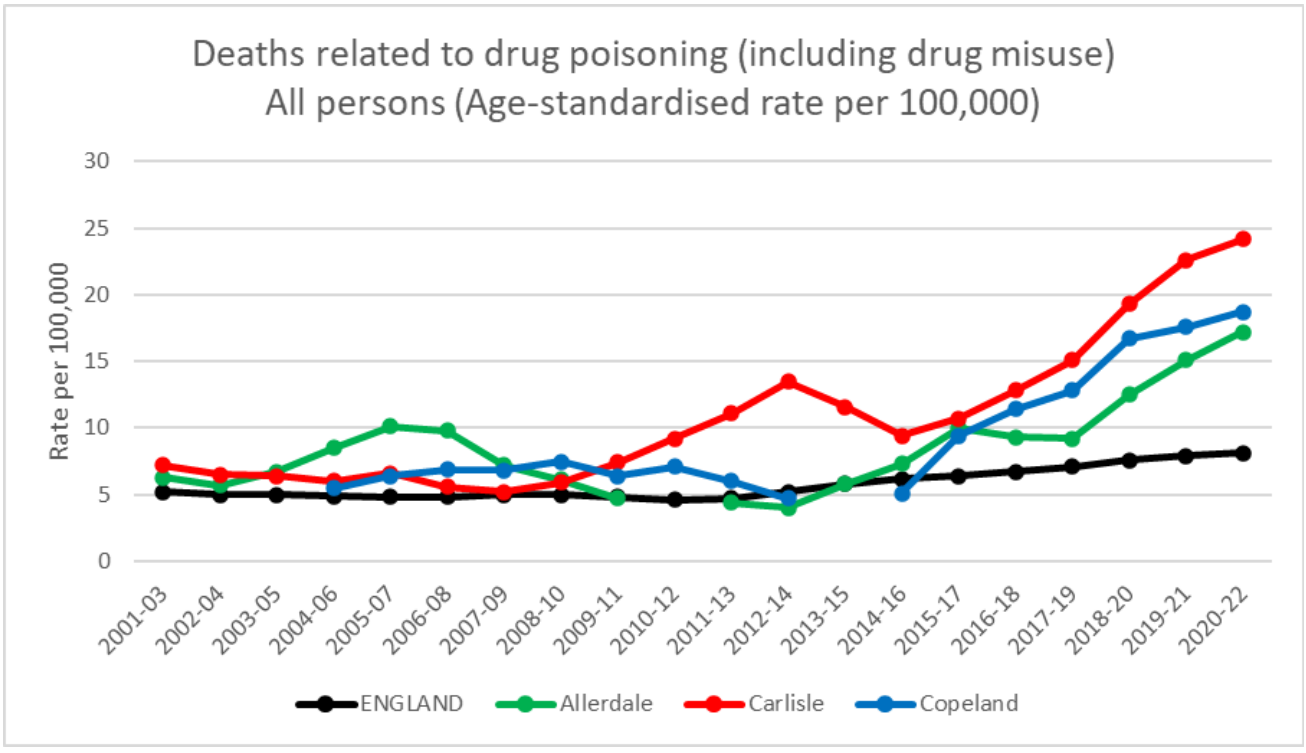


Figure 15: Deaths due to drug poisoning (including drug misuse)

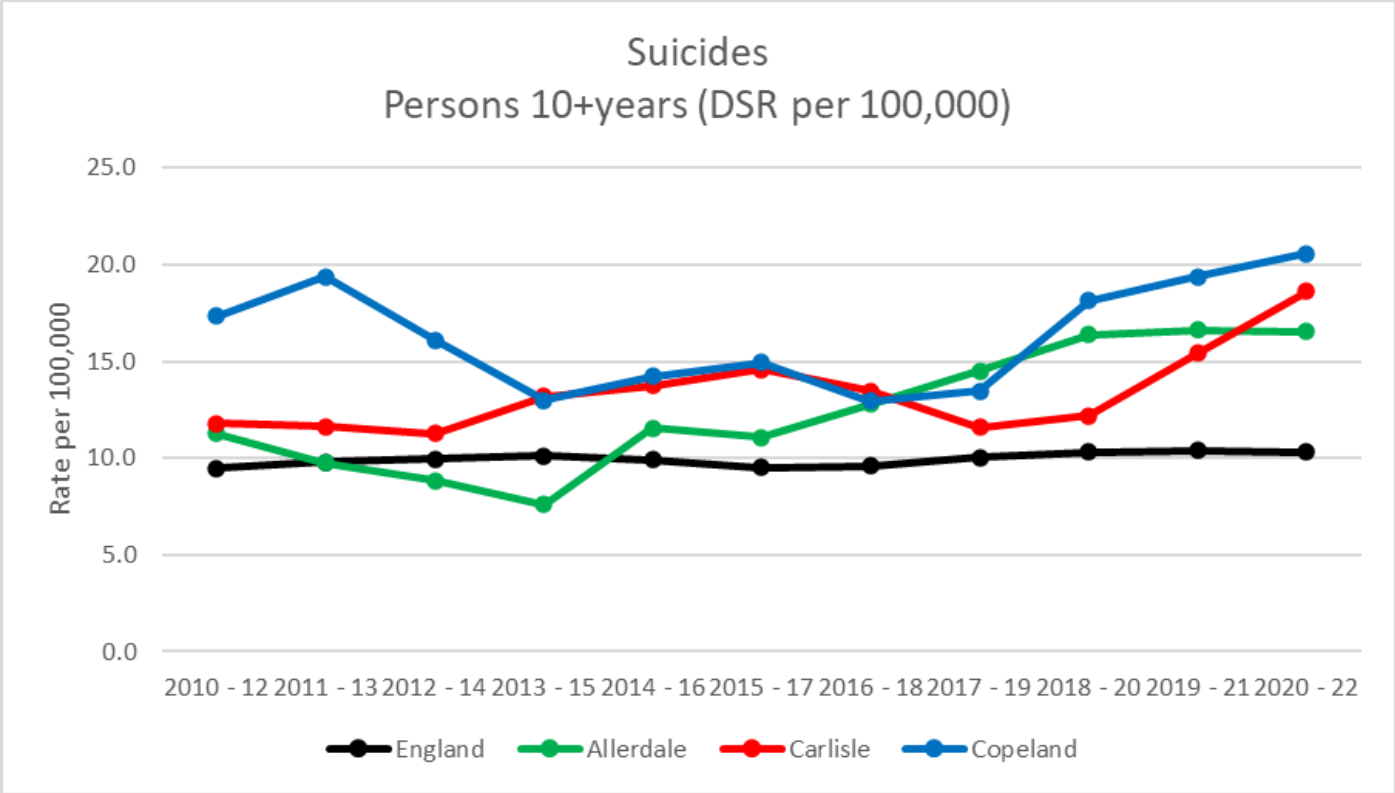


Figure 16: Suicide rates

Worryingly, more recent unpublished data indicates that our suicide rate has continued to climb substantially over the last two years.

Summary

However you look at it, it seems clear that mental health challenges in Cumberland are higher than the national average, and getting worse – or at least, demand for support, and the negative consequences of poor mental health, are increasing. And these challenges, like most other health concerns, are worse in our more deprived communities. The impacts of this are profound, both for human suffering and the ability of local services to respond; these rising rates of demand are simply unsustainable for our current services. Even if increased funding was available – which is extremely unlikely, at least to the extent that would be required – we would struggle to recruit the qualified staff to run our current service model. An alternative approach is desperately needed.

Chapter 3: Understanding trauma and adversity's impact on mental health

Trauma can be defined as an individual's emotional, psychological, and physiological response to an overwhelming, distressing event or a series of events that exceed their ability to cope, leading to a profound disruption in their sense of safety, security, and well-being. This experience often challenges the individual's ability to integrate and make sense of their emotions and perceptions, leaving a lasting impact on their mental, emotional, and physical health.

It is arguable that the word "trauma" has recently been over-used to the extent that it has become devalued as a descriptor, with even relatively low-level adverse experiences sometimes being described as traumatic. It can be helpful to see trauma and adversity in four different categories:

1. **Event-based trauma:** This encompasses single, discrete traumatic incidents, such as accidents, natural disasters, or acts of violence. These events are typically intense and acute, leading to an immediate stress response that may result in post-traumatic stress symptoms.
2. **Developmental trauma:** Developmental trauma involves experiences of chronic stress or adverse events during critical periods of childhood development. These ongoing adverse experiences, such as poor attachment, neglect, abuse, or chronic instability, can significantly affect a child's neurological, emotional, and social development, leading to long-term consequences in adulthood.
3. **Complex trauma:** Complex trauma encompasses prolonged, repeated, and often interpersonal traumatic experiences, such as chronic abuse, neglect, or exposure to community violence. This form of trauma can result in multifaceted and enduring consequences, affecting various aspects of an individual's functioning including their sense of self, relationships, emotional regulation, and cognitive processing.
4. **Continuous or low-level trauma (adversity):** This category acknowledges long-term exposure to lower-level stressors or adverse conditions, such as ongoing discrimination, poverty, or environmental stressors. Although these experiences may not be characterised by acute trauma, their cumulative impact over time can lead to significant psychological distress and contribute to mental health difficulties.

These categories are of course not entirely independent of each other, and can layer up for some people. Poor childhood attachment may, for example, be connected to family poverty and domestic violence, and those experiences may in turn lead to someone experiencing a range of complex traumas as they grow up. Trauma can, sadly, breed further ongoing trauma. And different traumatic experiences can interact; someone may experience both poverty and (unrelated) discrimination as a result of having a marginalised minority characteristic.

While the importance of trauma is to some extent recognised in conventional biomedical approaches to mental health, being explicitly the trigger for Post Traumatic Stress Disorder, for example, many theorists have argued that it is fundamental to many or most mental health conditions.

Trauma theory serves as a foundational framework for understanding the profound impact of traumatic experiences on an individual's mental health and overall well-being. It describes how exposure to distressing, life-threatening, or overwhelmingly distressing events can significantly shape one's psychological and emotional responses. The impact of trauma can manifest across various domains, and its effects often transcend singular diagnoses, contributing to a broad spectrum of mental health challenges. Key facets of trauma theory include:

1. **Types of trauma:** As described above, traumatic experiences can encompass a wide array of events, including but not limited to physical or emotional abuse, neglect, natural disasters, accidents, combat exposure, loss of a loved one, or witnessing violence. The subjective nature of trauma implies that an event's impact can vary significantly based on an individual's perception and response.
2. **Disruption of safety and coping mechanisms:** Trauma disrupts an individual's fundamental sense of safety, stability, and control over their environment. It overwhelms an individual's coping mechanisms, leaving a lasting impact on their emotional regulation, cognitive functioning, and interpersonal relationships.
3. **Post-traumatic stress responses:** Traumatic experiences often lead to a range of post-traumatic stress responses, which can include intrusive memories, flashbacks, nightmares, hypervigilance, avoidance of trauma-related stimuli, negative alterations in mood and cognition, and alterations in arousal and reactivity.
4. **Complex trauma stress responses:** In cases of prolonged or repeated traumatic experiences, known as complex trauma (such as in childhood abuse or neglect), the cumulative effect can result in complex post-traumatic stress responses. These responses often entail difficulties in emotional regulation, disturbances in self-concept, relational challenges, and disruptions in cognitive processes.

It is essential to recognise that traumatic experiences can influence mental health across diverse spectra and may not always neatly align with specific diagnostic categories. Trauma theory underscores the need for a comprehensive, trauma-informed approach to mental health care that prioritises understanding an individual's history, experiences, and coping mechanisms to provide appropriate and effective support and treatment.

One helpful way of visualising the impact that trauma can have on mental health – and how people can be supported to cope with this – is with the "window of tolerance" model, illustrated in Figure 17. This recognises that people's ability to remain emotionally well-regulated, or mentally healthy, can increase or decrease dependent on a wide range of external and internal factors and behaviours, and that moving outside of the space in which they are able to manage their own mental health can take the form of either hyper- or hypo-arousal – ether a "fight or flight" response, or a "freeze" response.

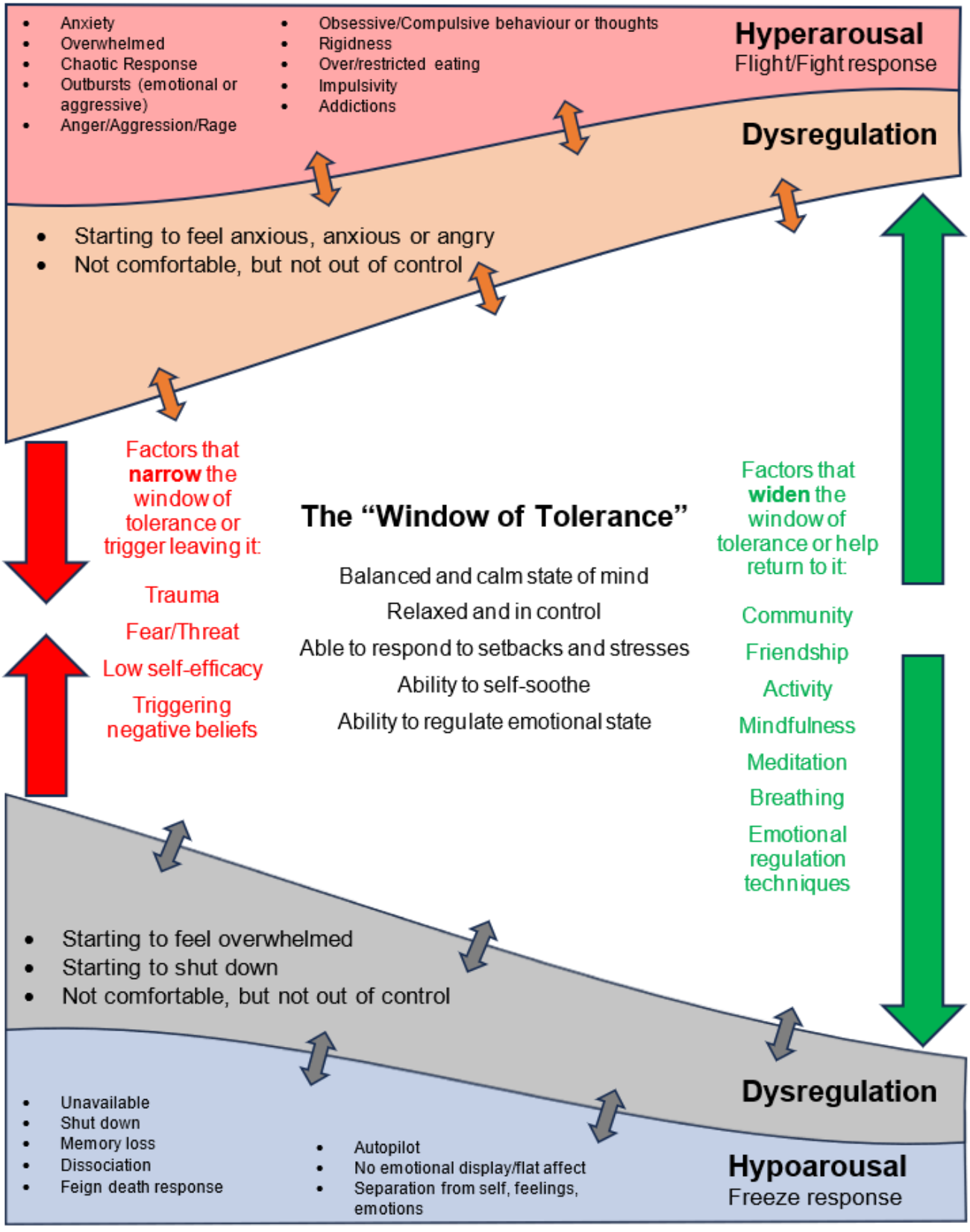


Figure 17: The "Window of Tolerance" concept

Fundamentally, the symptoms of many conventional mental health diagnoses can be seen as either being characteristic of hyper- or hypo-arousal; given that the experience of trauma can significantly narrow someone's "window of tolerance" this can arguably be a sufficient explanation for a wide range of traditional mental health diagnoses, including but not limited to:

- **Post-traumatic stress disorder (PTSD):** Characterized by persistent symptoms following exposure to a traumatic event, PTSD is often associated with re-experiencing, avoidance, negative alterations in mood and cognition, and alterations in arousal and reactivity.
- **Depression and anxiety disorders:** Trauma can significantly contribute to the development or exacerbation of depressive and anxiety disorders, manifesting as persistent sadness, anxiety, panic attacks, or phobias.
- **Substance use and addiction:** Individuals may turn to a wide range of coping mechanisms to alleviate trauma-related distress, leading to substance use and/or other addiction issues including gambling, gaming and pornography addiction.
- **Dissociative disorders:** Severe trauma can lead to dissociative symptoms, where individuals may feel disconnected from their thoughts, emotions, or identity, such as in Dissociative Identity Disorder (DID).
- **Personality disorders:** While personality disorder is a highly contested concept even within traditional psychiatry, there is no doubt that trauma can contribute to symptoms and experiences that can result in diagnosis of personality disorders, particularly those linked to interpersonal and emotional dysregulation such as Borderline Personality Disorder (BPD).

It is important to note that not everyone who experiences trauma develops a psychiatric diagnosis or long-term mental health problems. Trauma can affect people in different ways, depending on a range of factors such as the nature, severity and duration of the trauma, the availability of support, the individual's personality, coping skills and previous history of trauma. Some people may be able to overcome trauma with minimal or no professional intervention, especially if they have adequate protective factors and resources, such as supportive relationships, social networks, self-care practices and positive beliefs. Some people may even experience post-traumatic growth, which refers to the positive psychological changes that can occur as a result of facing and coping with trauma. These changes can include increased appreciation of life, enhanced personal strength, improved relationships, greater spirituality and a recognition of new possibilities or opportunities. People who experience post-traumatic growth may develop considerable resilience, skills, insights and attributes that can be used to great effect in their personal and professional lives. This does not mean that they do not suffer or struggle, but rather that they are able to find meaning and value in their traumatic experiences and use them as a catalyst for positive change.

Implications for public mental health

The aim of a public mental health approach is to improve mental health and wellbeing at a population level. While treatment services can be part of this approach, it includes a key focus on preventing mental health problems from arising in the first place, and on putting protective measures in place to mitigate their effects when they do occur. The impact of trauma – particularly when extended into broader adversity – has clear implications for public mental health, which, like so many physical health problems, can be seen to be closely linked to poverty, discrimination and inequality. In addition, it becomes impossible to overstate the importance of childhood experience, which – even in the absence of acute trauma – is where a person's way of interpreting the world is forged. A refreshed approach to public mental health in Cumberland would include:

- **Tackling social and economic determinants:** In the long term, of course, the aim is to prevent people from experiencing so much trauma in the first place. This is a significant societal challenge, given the variety of adverse experiences that people can have and the impact of wide social, economic and cultural factors. However a particular focus on tackling poverty, discrimination, domestic violence and substance misuse (which can cause trauma as well as being a symptom of it) is likely ultimately to have the biggest impact on people's experience of trauma, and therefore on their long term mental health and wellbeing.
- **Early intervention and support for children and families:** Children and young people are particularly susceptible to the impact of trauma because it shapes their brain development and the way in which they interpret and interact with the world. A comprehensive programme of universal, early intervention, and children's social care services aimed at developing secure attachment and supporting all families to bring children up in a stable and loving environment is crucial in building public mental health over the long term.
- **Resilience training and education:** While being brought up in a secure and loving environment is one important factor in developing resilience to life's challenges, there are other ways in which this can be taught and practiced. Programmes such as Decider Skills – which uses the principles of cognitive behaviour therapy to teach people how to monitor and manage their own thoughts and emotions – can build valuable skills for preventing adversity from triggering mental health problems.

The Well Communities

The Well Communities is a nationally renowned Lived Experience Recovery Organisation (LERO). While it formed around substance misuse, none of its members come with just one presenting problem – addiction, mental health, homelessness and criminal behaviour often go hand in hand, with past trauma being the common factor in most cases, and the approach is just as suited to mental health recovery where no addictions are present. The Well Communities uses the lived experience of its members to create a trauma safe environment that is focussed on connection (back to self and with the community), creating meaning and purpose and inspiring hope, enabling people to overcome and recover from their presenting issues.

The community-led LERO "reach one teach one" approach provides co-produced meaningful and purposeful mechanisms of support which place the client front and centre. Clear benefits are derived from the knowledge that the individual delivering the intervention has experienced the difficulties themselves and managed to regulate and overcome them. LEROs do not view discharge after short-term treatment as a measure of success as they understand the relapsing nature of the condition, hence the intentional community led structure of such organisations.

"I believe that People Of Lived Experience give people that first glimmer of HOPE they need to overcome their presenting issues. I formulated the idea for a hub in the heart of the community, a lighthouse where visible recovery from trauma, addictions and mental illness was happening in the open, not hidden inside traditional services. I knew that addiction was contagious; if you hang around with people using drugs, you eventually do the same. I reasoned that recovery could be infectious too."

Dave Higham, Founder, The Well communities

Box 2: Lived Experience Recovery Organisations

- **Community engagement and collaboration:** Many people with adverse experiences cope with them on their own or with the support of family, friends and peers – and many others could be helped to do so. Involvement of wider communities in recognising these issues and responding sensitively to diversity could help to create a network of support for individuals affected by trauma.

Implications for services and interventions

This recognition of the importance of trauma on people's mental health and wellbeing has a number of important implications for how services function. These include:

- **A shift to a trauma-informed approach:** Mental health services in particular could shift from a diagnostic and treatment-focused approach to a trauma-informed model that prioritises understanding a person's history and experiences. One such approach is the Power/Threat/Meaning Framework described in Box 3; adoption of such a model could be transformative for services and service users. More broadly, a wide range of services would benefit from becoming trauma-informed, shifting from asking "What's wrong with you?" to "What happened to you?" This completely changes perceptions of what support might be appropriate.

The Power Threat Meaning Framework (PTMF) is a conceptual framework that offers an alternative perspective to the traditional diagnostic model of mental health problems. Instead of focusing on symptoms and diagnoses, the PTMF explores how power imbalances, adverse experiences, and societal influences contribute to individuals' distress and behaviour. It considers the impact of social, cultural, and environmental factors on mental health, emphasising the importance of understanding individuals' experiences within broader contexts. The PTMF encourages a narrative-based approach, where individuals' stories and meanings are central to understanding their distress, rather than applying diagnostic labels. It aims to empower individuals by validating their experiences, promoting self-understanding, and supporting meaningful pathways to recovery. Overall, the PTMF provides a comprehensive framework for understanding mental health difficulties that integrates psychological, social, and political perspectives.

Box 3: The Power Threat Meaning Framework

- **Increased access to trauma-specific services:** Cumberland has a significant gap in services specifically skilled in helping people cope with trauma, both for children and adults. While more trauma-informed general services would help many people, specialist services are also needed in some cases.
- **Emphasising resilience and coping models:** A key insight of this model is that what people are dealing with is not necessarily an illness to be cured, but an experience to be overcome or coped with. Supporting people to develop their coping mechanisms can therefore help build resilience as a key aspect of recovery.
- **Provision of training and education:** Understanding the impact of trauma is critical for a very wide range of service providers. A comprehensive programme of training and education in trauma recognition and trauma-informed care is therefore needed to ensure that they understand the principles and how to implement them effectively.
- **The importance of holistic support services:** The things that people find supportive in coping with and overcoming trauma are very varied and individual. Holistic support services that focus on empowerment, safety, compassion and healing are crucial; these may or may not be explicitly part of mental health provision.
- **Lived experience as support:** The value of support provided by people with shared lived experience has been increasingly recognised in recent years, particularly in the field of substance misuse but applicable more widely. Cumberland is fortunate to be home to some exceptional Lived Experience Recovery Organisations (LEROs) – see Box 2 – and broadening support for these into mental health recovery could transform local services.

There is some excellent work already underway in Cumberland that aims to support this transition to trauma-informed services, both at individual organisation level and collaboratively, such as through the Trauma Informed Cumbria initiative (see Box 4), but this could be significantly accelerated to make a difference more quickly.

Trauma Informed Cumbria

Trauma Informed Cumbria is a collaborative of local organisations aiming to create a movement of change amongst Cumbrian professionals, raising awareness of trauma and improving everyone's response through partnership working and sharing best practice.

Becoming trauma informed can have such a transformative impact on the lives of local people, enabling individuals to turn improve their mental and physical wellbeing, It can lead to higher levels of service user engagement, improved retention rates and better outcomes. By signing the Trauma Informed Cumbria pledge organisations are committed to:

- Working with others to put trauma-informed and responsive practice in place across Cumbrian services.
- Delivering services that are actively informed by people with lived experience of trauma.
- Recognising the central importance of relationships that offer collaboration, choice, empowerment, safety and trust as part of a trauma-informed approach.
- Responding in ways that prevent further harm, and that reduce barriers, so people affected by trauma have equal access to the services they need, when they need it, to support their own journey of recovery.

In Cumberland, Trauma Informed Cumbria is co-ordinated by Safety Net, a third sector recovery organisation. Professionals can contact them directly for more information at office@safetynetuk.org or check out the Trauma Informed Website for training and event information and to sign up to the pledge. https://www.traumainformedcumbria.org.uk/

Box 4: Trauma Informed Cumbria

Conclusion

The importance of the impact of trauma on mental health and wellbeing cannot be overestimated; it is arguably the key factor driving the majority of poor mental health. As such a comprehensive, trauma-informed approach is needed in mental health services and much more broadly. Preventing it is extremely challenging, but the good news is that there is significant potential for positive outcomes when individuals are supported in their journey of healing and recovery from trauma. Lots of work is already underway to move services in this direction, but this needs to be given a substantial boost to embed it rapidly throughout all relevant services.

Chapter 4: The impact of expectations in mental health

It is clear that the spectrum of normal human responses to various life events and stressors can be very broad, covering many emotional experiences and thinking patterns. Individuals can and do respond very differently to the same events depending on their past experiences, their current situation, their personalities, and the way in which they are used to thinking about things; and the same individual may respond very differently to the same event on different occasions. There can hardly be said to be a single "normal" human response to challenges. Returning to the "window of tolerance" concept outlined in the previous chapter (see Figure 17), mental health problems occur when people regularly move beyond their window of tolerance into dysregulation and hypo- or hyper-arousal. And among the factors that can narrow or widen that window of tolerance, or change the likelihood of moving out of it, are individual and social expectations.

Cultural attitudes to and beliefs about mental health can be powerful driving forces. Shaped by media (including social media) representations, they can influence the extent to which poor mental health is recognised, stigmatised, or supported. They can affect the perceptions people have about their own experiences, how they interpret them, how likely they are to seek support, and what sort of support they look for. For example:

- Diagnosed rates of depression and anxiety tend to be higher in more individualistic cultures than in more collectivist cultures, where community support and social cohesion may serve as protective factors.
- In cultures where poor mental health is stigmatised or seen as a sign of weakness, people may be less likely to admit to it (even to themselves). Conversely, where mental health is more openly discussed and recognised people may be more likely to see themselves as having specific mental health problems. This could have the beneficial effect of encouraging people to seek support, but could also drive medicalisation of a broader part of the spectrum of human experience.
- Cultural ideals emphasising achievement, success, and social status may contribute to feelings of inadequacy and self-doubt. Social comparison processes particularly related to pressure to achieve certain standards of success, beauty or wealth, fuelled by consumerism and the pervasive influence of social media, can exacerbate feelings of inferiority and contribute to the development of dissatisfaction and distress.
- This focus on success can also contribute to an expectation of positive experience, reducing people's tolerance of normal negative emotions. Sadness, anxiety, anger, a sense of helplessness – all can be an entirely reasonable and healthy response to the situation in which people find themselves; they can also be deeply unhealthy and have a significant effect on people's day to day lives for extended periods of time. The question of where to draw the line between "normal" and "pathological" responses is largely subjective and could be interpreted very differently by different individuals.

This is not to suggest that we should be returning to a culture where poor mental health is stigmatised and the expected response to difficulty is a stiff upper lip – far from it. Such a culture might have significantly lower rates of diagnosis and demand for treatment services, but it would not have lower rates of distress. Our current openness about mental health and the recognition that many people need support from time to time can only be a good thing, but it can bring challenges with it. One such challenge is when it interacts with an

individualistic and materialistic culture to create an expectation that (a) we should be happy all the time; so (b) if we're not there's a problem; and (c) that medicine should be able to providethe solution. It is possible that the pendulum has now swung so far away from the previous culture of stigmatisation that we have lost sight of the normality of experiencing a wide range of emotions (sometimes including conflicting emotions at the same time), and of the ways in which we can live with those. Perhaps a better balance is needed.

> "We are now a few years after the pandemic and the increase in the number of parents/families that schools are supporting with their mental health and wellbeing has increased. Schools are faced with some parents/ carers who are disengaged with schools life and their expectations around working with the schools to support behaviour and attendance is a challenge. While on the other hand schools across Cumberland are also supporting high levels of parents and families who seek mental health support and are in crisis which in turns affects their child, schools have seen an increase in the lack of school readiness over the last few years.
>
> "Poverty and the cost of living crisis has had an impact across many families and this has contributed to the support they are seeking. Schools are a familiar place, a familiar face and are for many their "go to" for support as they don't know what to do. However, the demands on schools can be overwhelming and the expectations from parents/carers unmanageable a lot of their support is not an education specific area."
>
> Headteacher, West Cumbria

Implications for public mental health

Challenging this culture will certainly not be easy. It is driven by a wide range of factors including an economic, cultural and media landscape that is global in its reach, and a social media world that thrives on negative social comparisons. And some of the push-back against this culture that exists already is potentially deeply unhelpful and divisive – sneering tabloid headlines about a "snowflake generation" are hardly likely to support a respectful dialogue about the right balance between personal resilience and support. However some work at local level could start to shape a different approach in Cumberland. This should include:

- **Campaigning and normalisation.** While campaigning in the face of such prevalent cultural and media messaging may struggle to cut through, a local focus on awareness and education initiatives that encourage people to recognise the healthiness of experiencing a wide range of emotions and mental states could be the starting point for a wider discussion with the public that challenges mainstream culture and builds a greater sense of belonging and acceptance of difference.
- **Building mentally healthy communities.** Fundamentally there is a need to develop a culture in Cumberland that recognises, values and supports approaches that protect and promote good mental health. There is a vital role for our universal services that provide access (and where necessary, supported access) to social and community-based activities such as physical activity, arts and culture, connecting with nature, and volunteering, where the emphasis is on kindness, belonging and wellbeing.
- **Building individual resilience.** Developing resilience to life's challenges begins at a very early age, and is influenced strongly by early family experiences. Universal and early help services are therefore crucial in supporting families to raise resilient children and young people. There is also a role for teaching resilience mindsets and skills in schools, and building a co-ordinated and systematic approach to this is essential for the future.

- **Providing accessible support services.** Promoting greater individual resilience does not mean that people should not need support. Easily accessible support that caters to the everyday emotional needs of individuals – particularly through self-help, family and friendship groups, but also through strength-based coaching services – is crucial.
- **Promotion of mindfulness and self-reflection practices.** As part of building resilience, mindfulness practices and other self-reflection exercises can empower individuals to build their acceptance of who they are and to understand and manage their emotions effectively.
- **Supporting realistic engagement with social media.** Social media is here to stay, and it has some potential benefits as well as the downsides already mentioned. As such it is important to help people – particularly young people – to engage with it while recognising the way it can present a distorted view of reality and not falling victim to its more negative aspects.

Conclusion

Reshaping social expectations surrounding mental health support is a crucial part of delivering the change that we need to see in Cumberland. We need a shift in perspective to acknowledge the everyday emotional experiences of individuals, to recognise that most people are actually very resilient in the face of life's challenges, and to support everyone to become more so. Changing culture takes a long time and is not easy, but we already have the foundations for many of the suggestions above and many assets we can make use of locally to shape some more realistic expectations of what has an impact on mental health and what can be done to support it.

Chapter 5: Learning disability, neurodiversity and special educational needs

This chapter considers data on patterns of some aspects of learning disability, neurodiversity and special educational needs across Cumberland. It does not attempt to cover all learning disability or special educational needs; the former includes several clearly organic brain conditions, and the latter includes these but also incorporates needs associated with physical or sensory disability. The focus of this chapter is therefore narrower, focusing on those areas where it is plausible that there is a more significant sociocultural dimension to the current situation: where, consistent with the earlier discussion about mental health, there is a risk that we are significantly over-medicalising the situation.

Estimates of the proportion of children who have some additional learning support need range from approximately 1% (those clinically diagnosed) to around 20% (based on lived experience). In Cumbria in 2022-23, 17.3% of pupils received some sort of Special Educational Needs support. The challenge is that current clinical diagnostic systems are designed and scaled to respond to the lower number, and there is no way in which they could realistically be expanded to meet the demand of the higher proportion (Ginns, 2024). This leaves many people desperate for support and unable to access it. An alternative approach is desperately needed.

Data on Special Educational Needs

Data from the Cumbria Special Educational Needs Dashboard reveal some interesting patterns. Figure 18 shows that the number of children in receipt of some support for special educational needs is rising, and that Cumbria as a whole is effectively no different to the rest of the country

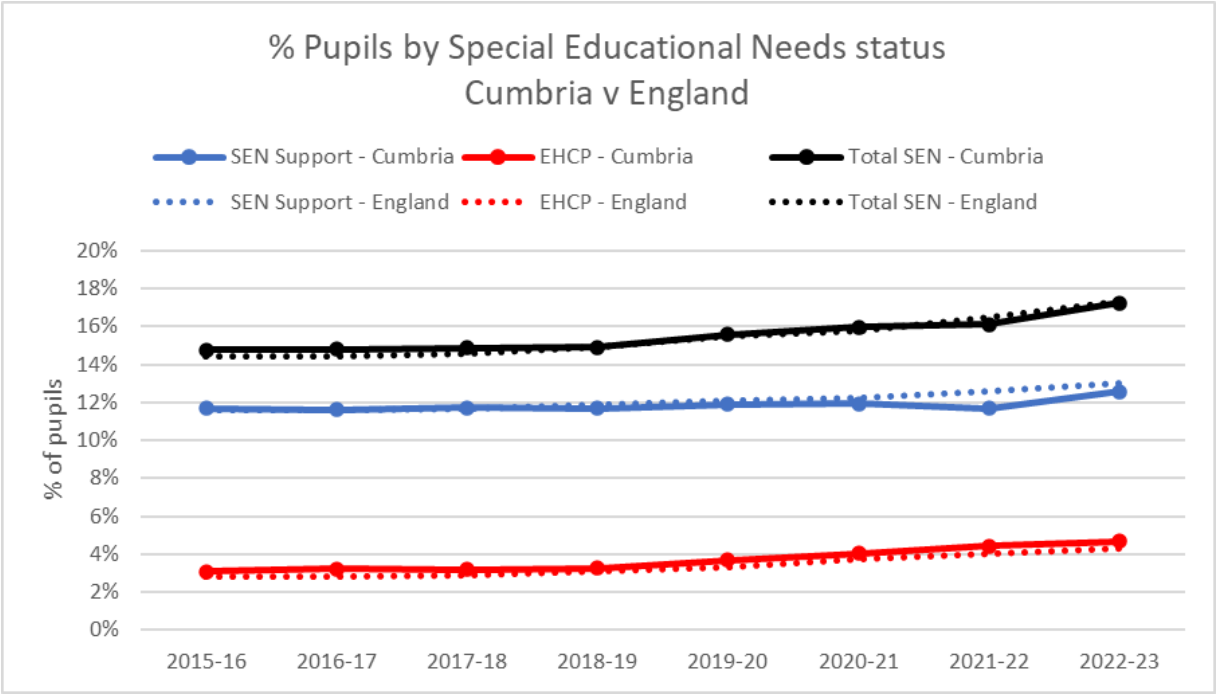


Figure 18: Rate of special educational needs identified

Drilling down into some particular categories of special educational need, as can be seen in Figure 19, the number of pupils identified as having a moderate or severe learning difficulty has remained broadly stable over recent years, as would be expected where conditions are predominantly neurodevelopmental. Specific learning difficulties (dyslexia, dyspraxia, dyscalculia, and dysgraphia) have risen substantially, by around 20% in total since 2015-16, as have speech, language and communication needs (by around 25%) – though here the dramatic difference is pupils receiving an EHCP. Autism spectrum disorders and social, emotional and mental health needs, on the other hand, have more than doubled. Such rising trends suggest changes that are socio-cultural rather than bio-medical. This does not mean that these special educational needs are "not real" – improved recognition of neurological differences is likely to be playing a role here, for example.

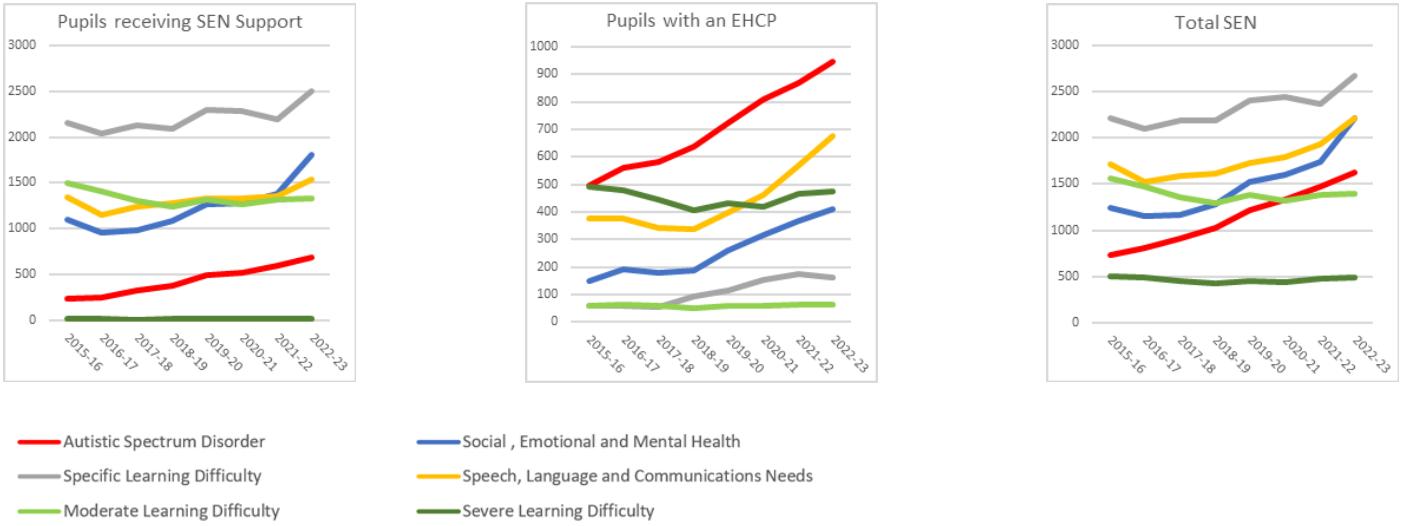


Figure 19: Numbers of pupils in Cumbria identified with particular Special Educational Needs

Secondary care data

Unsurprisingly, the rising rates of special educational needs are translating into rising demand for clinical support. Figure 20 shows the change in referrals to North Cumbria Integrated Care paediatric services for Autism Spectrum Disorders and speech and language problems; while no clear trend is seen in the latter, the number of ASD referrals has increased six-fold in the last three years. The pattern in our specialist mental health services provided by Cumbria, Northumberland, Tyne & Wear NHS Foundation Trust is slightly more complex (Figure 21): here referrals for learning disability have dropped slightly, while for neurodiversity the number has increased four-fold, with the two combined more than doubling in three years. This may reflect some of what was once referred to as learning disability being more recently described as neurodiversity; this may be a positive development, as described later in this report, but the fact of the rise in demand remains a challenge for services.

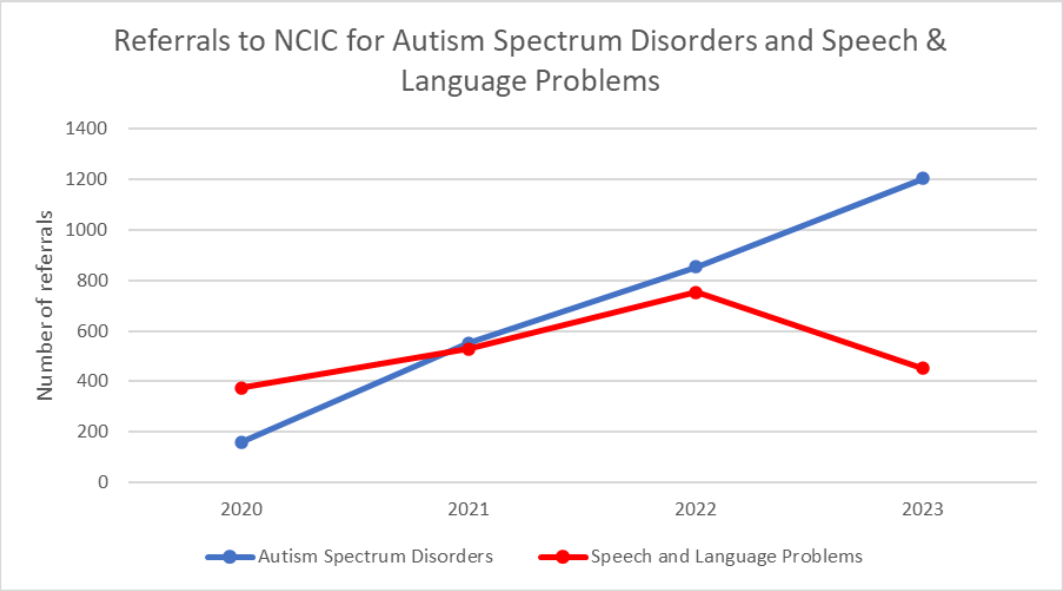
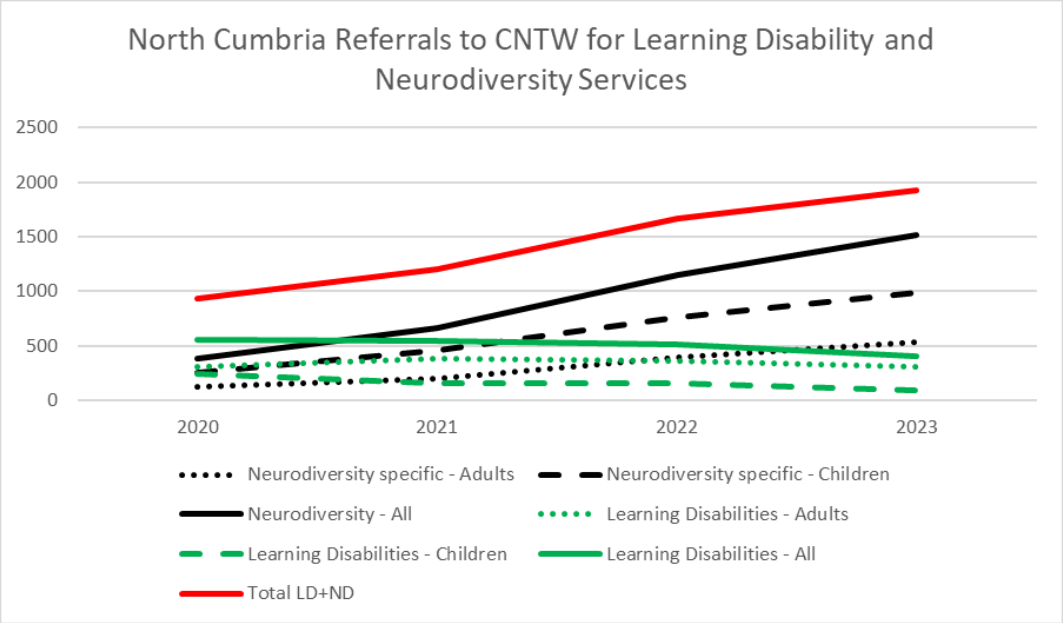


Figure 20: NCIC paediatric referrals for ASD and Speech & Language Disorders



Needless to say, just as for mental health services this rise in demand has led to a rise in waiting times, as illustrated in Figure 22. Figures for ADHD in children are particularly startling, with numbers waiting for more than 18 weeks for services rising ten-fold in two years, but there is also pressure on adult focused services, with numbers waiting for adult autism services doubling in the last four years.

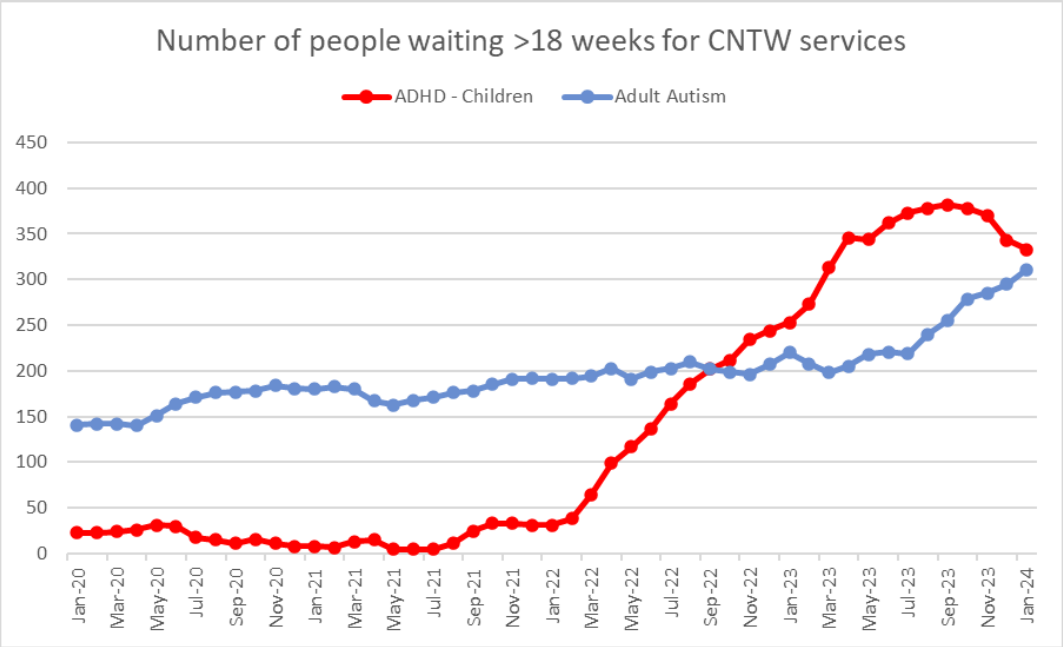


Figure 22: Increasing waiting times for key services

All these figures indicate a real rise in the number of people who feel that they (or their children) are struggling in some way. The key question, as with mental health, is what is causing this rise.

Understanding the rising demand

In conventional terms these rises are likely to be ascribed to two main factors:

- **Changes in patterns of need.** While the changes we are currently seeing are too rapid to be explained by things like genetic factors, there are social and environmental factors that could bring about a genuine shift in patterns of need, particularly in young children. The Covid-19 pandemic, for example, resulted in significantly reduced opportunities for social interaction; it is entirely plausible that infants who were not so widely exposed to other people at an important stage of their development could experience greater levels of social anxiety and challenges with speech and language as they get older and therefore to display behavioural patterns that overlap with autism. Foetal Alcohol Syndrome is another condition that can present as overlapping with autism or ADHD and may well be under-diagnosed as a result.
- **Advancements in awareness and improvements in services:** Even without real changes in patterns of need, increased awareness and understanding of neurodiverse conditions among both professionals and the general public could have played a significant role in driving demand for support services. As information about neurodiversity becomes more accessible, inclusive policies and legal protections for neurodiverse individuals get put in place, and healthcare and diagnostic services strive to respond to this growing awareness, so individuals and families are more likely to recognise and seek assistance for neurodiverse traits and challenges.

It is of course likely that these factors have played a part in the changing patterns of demand that we are seeing. However there are other, perhaps more challenging, explanations that also seem to be at play. These include:

- **Changing social norms and expectations.** There are considerable social pressures, particularly but by no means exclusively, on children and young people, to behave in particular ways and to be successful – as identified by conventional measures such as exam results and earning potential. There is therefore a motivation, both for individuals and for parents who want the best for their children, to try to "fix" any individual differences that could reduce such success, which leads to the medicalisation of these differences.
- **Perception of diagnosis as a gateway to support.** Linked to this is a sense that a diagnosis is a requirement in order to get support. Individuals and families may pursue diagnosis with the hope of accessing specialised therapies, educational accommodations, and community support networks tailored to their neurodiverse needs. As awareness of available resources grows, so too does the incentive to seek formal diagnosis and support. Sometimes this perception is accurate – for example in the case of disability-linked benefits – but at other times either there is in fact limited support even post-diagnosis, or support could in fact be available without such a formal categorisation.
- **A search for meaning and explanation.** For some people, a diagnosis can be a reassuring explanation for their (or their children's) experiences or behaviour. In a society where parenting practices are often scrutinised, some parents may feel pressure to explain or mitigate their child's differences to avoid judgment or criticism. Seeking a diagnosis and accessing appropriate support services can provide reassurance to parents, affirming that their child's differences are not solely attributable to parenting choices but are instead part of their inherent neurodiversity. Likewise for adults who may have faced challenges throughout their lives, a diagnosis can offer a sense that these difficulties may have been caused by something almost external to themselves. For some people this may help reduce the responsibility they feel for their experiences and add to their sense of self-understanding, which in turn helps improve their wellbeing.

Challenges to diagnosis-driven approaches

As in the field of mental health, for many years there have been critiques of biomedical approaches to learning disability. Emerging from the disability rights movement from the 1960s onwards, the social model of disability emphasised that societal barriers and norms often contribute more to people's experience of disability than the inherent traits themselves do. To take an obvious example, someone who uses a wheelchair for mobility is "dis-abled" by split levels and steps; an environment with ramps and level access is enabling for that person, and while there is undoubtedly a very long way to go, society has made considerable progress in recognising this and putting measures in place to accommodate a wide range of physical and sensory challenges. A similar argument can be made for many learning difficulties: without conscious intervention, it is inevitable that society is designed around what works best for the "neurotypical" majority, leaving others potentially disadvantaged. If this can be overcome, however, strengths-based approaches recognise the unique strengths and abilities of neurodiverse individuals rather than pathologising their differences.

These alternative ways of looking at things, however valuable, often do not fundamentally challenge the centrality of diagnosis in categorising and identifying specific types of learning disability. As in mental health, however, there are some more fundamental challenges arising from this conventional approach. These include:

- **Diagnostic Overreach:** The diagnosis-centric model may lead to overdiagnosis, pathologising traits that may simply be natural variations in cognitive functioning. This tendency can contribute to medicalising normal aspects of human diversity.
- **Stigmatisation:** Focusing on diagnoses can perpetuate stigmatisation by reinforcing a binary distinction between 'normal' and 'abnormal' cognitive functioning. Individuals with neurodivergent traits may experience social prejudices that can impact negatively on self-perception and acceptance.
- **Individual Variability:** A critical issue with diagnosis-driven approaches is their tendency to oversimplify complex neurodivergent experiences. Within a single diagnostic category, there exists significant individual variability in cognitive profiles, strengths, and challenges.
- **Psychosocial Impacts:** The psychosocial impacts of a diagnosis-centric model are far-reaching. Individuals may experience lowered self-esteem, identity challenges, and heightened societal expectations, which can contribute to stress and mental health difficulties.

The neurodiversity paradigm: recognising cognitive diversity

The neurodiversity paradigm introduces a fundamental shift in our understanding of neurological variations. It emphasises that differences in neurological functioning, such as those associated with ADHD, autism, dyslexia, and other neurodivergent conditions, are not necessarily deviations or disorders; rather, they are integral aspects of the broader spectrum of human cognitive diversity. Key features of this model include:

- **Natural Variability:** Neurodiversity contends that the human brain is naturally diverse. Rather than adhering to a standardised model of cognitive functioning, it acknowledges the existence of a wide range of neurological variations.
- **Cognitive Styles:** In embracing a neurodiversity paradigm, conditions traditionally viewed as deficits or disorders are reframed as unique cognitive styles. For instance, ADHD might be seen as a cognitive style marked by high energy and creativity, while autism might be recognised as a cognitive style characterised by attention to detail and pattern recognition.
- **Celebrating Diversity:** Central to the neurodiversity paradigm is the celebration of cognitive diversity. It challenges the notion that a singular, 'normal' cognitive profile should be the benchmark, urging society to appreciate and value the richness that diverse cognitive styles bring to the human experience.

In summary, the neurodiversity paradigm challenges traditional views by recognising the inherent variability of human cognition and celebrating diverse cognitive styles. Simultaneously, it overcomes the limitations of diagnosis-driven approaches, urging a more nuanced and individualised understanding of neurodivergent experiences.

As things stand, however, society seems to be operating a strange mix of increasingly validating neurodiversity (and even celebrating it to an extent, with the contribution of neurodiverse people to a range of fields being recognised in popular culture, albeit sometimes in a somewhat stereotyped way), while simultaneously continuing to medicalise it and failing to respond to it in that nuanced and individualised way. In part this may be because there is an unfortunate cycle here: when society as a whole does not respond to neurodiversity in a nuanced way, it can present as highly challenging, disruptive behaviour that can be extremely difficult to manage on a day to day basis, particularly for parents and schools, which are trying to support everyone effectively and do not have the resources necessary to tailor their response appropriately. A society that truly embraced neurodiversity would better support

educators to identify individual learning styles and needs, without the need to diagnose and categorise people, and enable them to tailor education accordingly: this would include widespread availability of things like sensory-friendly classrooms, appropriate assistive technology, and personalised learning plans. It would celebrate different thinking styles in the workplace, make flexible working and what are currently seen as "reasonable adjustments" standard practice available to all, and provide wider opportunities for neurodiverse thinking styles to be recognised and rewarded as valuable talents. And it would ensure that health and care systems were responsive to a wide range of needs, with broad understanding of neurodiversity needs and support and information available in multiple formats

Improving services (and society) for neurodiverse people

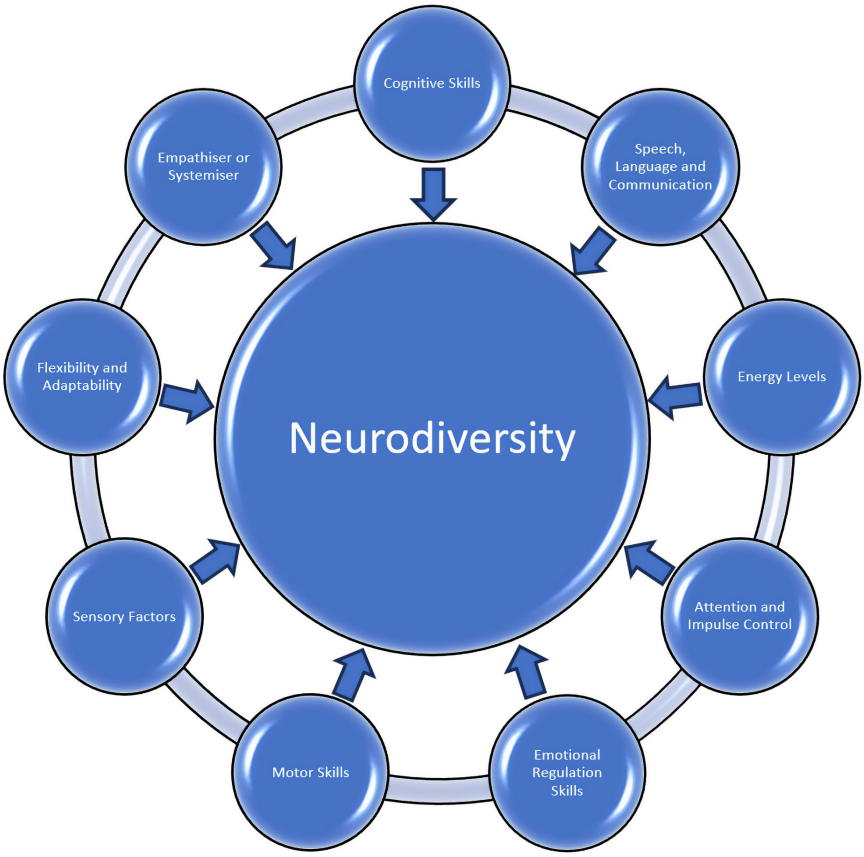
Becoming a society that recognises and celebrates cognitive diversity as normal will take time and effort. Much of the work is likely to have to take place in schools, to set the culture and approaches at an early stage; our workplaces are the other key setting for establishing a change in culture. The sort of action required includes:

- **Mainstreaming strengths-based approaches:** Educational settings and workplaces could use strengths-based assessments that focus on identifying and utilising the strengths and talents of neurodiverse individuals rather than solely identifying deficits. Training on recognising and supporting diverse styles could support this.
- **Universal design for learning (UDL):** UDL principles aim to ensure that teaching methods, materials, and assessments are accessible and cater to diverse learning needs without the need for specific diagnoses.
- **Early intervention and support:** Development of early intervention and support programs that are accessible to all students, irrespective of diagnostic labels. These programs can offer tailored assistance based on individual needs and strengths.
- **Promoting inclusive cultures:** Promoting inclusive school and workplace cultures that celebrate diversity, foster empathy, and reduce stigma associated with neurodiverse traits. Peer support programs and awareness campaigns can help to promote understanding and acceptance.

Some excellent practice already exists in Cumberland and beyond: the Portsmouth ND model, for example (see Box 5) shows considerable promise in helping to transform support for neurodiverse children and young people. A co-ordinated and systematic approach to improving services and changing culture is needed

Portsmouth ND Model

In 2019, Portsmouth was experiencing exactly the same sort of challenges that we currently face in Cumberland: long waiting times for diagnosis, with limited support afterwards, very frustrated and distressed families, and many children not getting the support they needed. Working with families they designed a new approach, including a neurodiversity profiling tool, based around nine domains, which can be used by a wide range of professionals to identify strengths, skills and areas of challenge that can then be responded to directly without waiting for a formal diagnosis.



Since implementing the model, early indications are that demand for diagnostic services has reduced by 89% and that children and families are receiving support much more quickly. Initial work has begun to plan implementing this approach in Cumberland.

Box 5: The Portsmouth ND Model

Conclusion

The culture around neurodiversity has been changing for the better in recent years. More people understand and accept that different brains work differently, and that this is not something to be ashamed of. But many parts of society still lag behind this change, and this creates a lot of frustration and difficulty for people who need support. The current systems of healthcare and education, especially, are not able to meet the demand or address the problems that people face. Many people have to wait a long time for diagnoses that, when they come, don't actually help them much. But there are also some great opportunities to rethink our current ways of doing things and to try to make services and society in general more aware and respectful of neurodiversity.

A society that truly appreciated neurodiversity would make sure that everyone had equal opportunities, access, and inclusion in all areas of life, and that the unique talents and views of neurodiverse people were valued and celebrated. By seeing neurodiversity as a natural part of human diversity and focusing on strengths and individualised support, rather than treating it as a problem that needs to be fixed or cured, society would create a more compassionate and supportive environment for everyone.

Chapter 6: Conclusion and Recommendations

The current situation regarding mental health and neurodiversity is simply untenable. Too many people are suffering in one way or another, and existing services are unable to meet their needs. Doing nothing is not an option, and doing more of what we're currently doing is unsustainable. Implementing the approach outlined in the previous chapters within local mental health and neurodiversity services requires a shift in perspectives, policies, and practices across a wide range of sectors.

Some of the most comprehensive work on the effectiveness of public mental health interventions has been done recently by the Royal College of Psychiatrists Public Mental Health Implementation Centre (2022). These recommendations draw heavily on their reviews.

Recommendations for all national and local governmental agencies

1. The fundamental factors underlying our crisis in mental health are no different to those underlying a wide range of other health and social challenges. All agencies need to work systematically and consistently to address poverty, poor living and working conditions, social power imbalances, abuse and trauma, prejudice, marginalisation, exclusion and exploitation. I recognise of course that this is a very broad recommendation, the detail of which is outside the scope of this report; however it is crucial to recognise that while these factors remain, even full implementation of every other recommendation in this report will only scratch the surface of the problem.

Recommendations for public health and prevention services

2. The importance of secure and loving childhood environments cannot be overstated for long term mental health and wellbeing. The forthcoming redesign of Cumberland's children and families universal services and early help system, including the Healthy Child Programme, should invest heavily in work to help develop attachment, build parenting skills, and support families from a very early stage of them starting to show signs of struggling. This should be established as an integrated and holistic response that families can interpret positively rather than being seen as stigmatising or punitive.
3. Changing culture at a local level in the face of national and global forces is extremely challenging. Nonetheless Cumberland should conduct community-based campaigns and educational programs aimed at encouraging people to recognise the normality of a diverse range of experiences both in mental health and neurodiversity; the potential for some of these to be responded to without clinical support; and the way in which Cumberland could truly foster a sense of belonging among those with very diverse experiences.
4. One specific challenge in changing culture is the sometimes pernicious influence of social media. Consideration should be given to local campaigns and support for schools to delay the start of social media use and to ensure that children and young people are prepared to have realistic expectations of what social media is.
5. While experiencing mental health problems should never be seen as being in any way an individual weakness, there is no doubt that people can respond differently to similar stressors as a result of their previous experience and their cognitive styles, and that more resilient approaches can be learned. Further development of widely available resilience programmes should therefore be considered.

Recommendations for health services

6. Like (and often linked to) the childhood environment, the importance of trauma as a driver of mental health problems can hardly be overstated. Trauma-informed principles should therefore become infused into a wide range of health services. Staff should be trained in recognising the signs of trauma and responding sensitively and compassionately, and services should be provided in trauma-informed spaces that prioritise safety, trust, and empowerment for individuals seeking support.
7. There is a specific gap in Cumberland regarding the specialist therapeutic response to trauma, and particularly to complex trauma. While trauma-informed services can go a long way to supporting many people, in some cases considerable expertise is required and such a service should be commissioned as part of the wider transformation of local services.
8. Traditional diagnostic models are clearly not adequately meeting the range of needs and demands currently being placed on services. Service offerings should therefore be expanded beyond these traditional diagnosis and treatment models. Within mental health services a programme of training and development around the Power/Threat/Meaning Framework should be put in place to enable it to be widely adopted and to support a transformation of the local approach to identifying and supporting mental health problems.
9. Changing the way we think about things can change the way society responds. Health professionals should therefore adopt assessments based on social challenges rather than solely relying on diagnostic labels. Imagine how powerful it would be if a GP, rather than diagnosing someone as having "mixed anxiety and depressive disorder" (which in electronic patient records would use the SNOMED code 231504006), instead "diagnosed" them as suffering from the effects of being financially poor (11403006), a victim of domestic violence (1279539006) and having a history of being a victim of child sexual abuse (288411000119107); the appropriate service response would be very different, and so eventually would our understanding of the epidemiology around demand for services.
10. One implication of becoming more clearly trauma-informed is that strength-based approaches to supporting people have the potential to be more successful than traditional treatment models. Services should therefore focus on identifying individual strengths and resources to tailor interventions that support personal growth and well-being. Coaching models are a good example of this, and the success of Cumberland's Health and Wellbeing Coach service (see Box 6) should be further built on to enable such services to be more widely accessible.

Health and Wellbeing Coaching

Cumberland Council's Health and Wellbeing Team consists of Health & Wellbeing Coaches and Officers who provide Coaching support to individuals aged 16 years + who would like to make positive changes in their lives. The team works with seven key principles:

- To challenge traditional services and cultures.
- To adopt a person-centred strength based coaching approach.
- To build greater independence and resilience into individuals and communities.
- To help transform lives rather than being a transactional service provider.
- To reduce demand on statutory services and prevent further dependency.
- To have customer-led, evidence based outcomes.
- No artificial cut-off times or appointments for working with people.

"At the end of 2023 I reached out for help regarding my gambling problem, this was shadowed by my compulsivity, my poor discipline and my overall lack of consistency in maintaining a healthier and positive lifestyle, as well as being ably to keep on top of my addictions and self destructive behaviour (Gambling, excessive spending on games, porn). All of the aforementioned having had a hugely negative impact on my life, family and relationship for a long time. I had never been in contact with the council before this and was given a HAWC to help me identify my issues and develop realist and achievable strategies to reach my goals. The help I have received thus far has been nothing short of invaluable and has help me outline and construct a routine that I've been able to stick to and manage for the first time ever, not to mention provide me with the tools I now have to managed my addiction. I am both surprised and proud in regards to my achievements over the past few months and hope to continue to work toward creating and achieving future goals. I'm not 100% there yet - it seems to be just a matter of remaining consistent and trying different methods of making these goals work. Overall I have really surprised myself as to what is achievable for me and look forward to seeing where my consistency and efforts take me, because as of now, I'm in a much better place."

Box 6: Health and Wellbeing Coaching

11. Given that people's experience of mental health will be highly individual, influenced by their very specific experiences and thinking patterns, their support needs will be equally variable. A wide range of interventions should therefore be provided, including trauma-focused therapies, mindfulness-based approaches, support groups, and psychoeducation programs that address everyday emotional experiences and promote mental wellness.

12. The approach to mental health outlined in this report has significant optimism behind it: it strongly endorses the view that recovery should be at the heart of our service response, and that this is absolutely achievable for many or most people. Support should therefore be given to increasing the capacity of Lived Experience Recovery Organisations (see Box 2) and the Recovery College (see Box 7) to provide community-based opportunities for people to take greater control of their own recovery.

The Recovery College concept

A recovery college is a place – sometimes a virtual or online one – that supports individuals in their journey of recovery from mental health difficulties. These colleges focus on learning and education, which are co-produced by people with lived experience and professionals with expertise in mental health.

The North Cumbria Recovery College, which opened its virtual doors in 2021, hosts a number of co-produced courses delivered by individuals with lived experience. The courses develop an individual's understanding and skills base of their mental and physical health. The courses focus on symptoms of conditions being on a continuum of impact to the person throughout their life. Courses are not based on diagnosis: instead they encourage skills acquisition and connections between people with similar symptoms. This creates a recovery community and builds hope for an individual to manage their symptoms throughout their life. NCRC also develops those individuals wanting to develop their own peer led groups by equipping them with the skills and mentoring to do this.

This example, drawn from a real case study, shows how the recovery college can be impactful and hope filled, and builds resilience.

"I've had problems with my mental health and physical health for a few years now. I have engaged with the NHS mental health services but have found the recovery college to be one of the most beneficial. Having engaged with the NCRC I have been better able to manage my mental health in particular. I have worked on being able to stop worsening symptoms sooner, talk to others with similar experiences and learn skills to manage my symptoms. This has meant I has accessed my GP, A&E and my services less often and faster than I used to. I feel supported and empowered to manage my mental health, without feeling alone."

Box 7: Recovery Colleges

Recommendations for multiple agencies

13. Cumberland should fully embrace the Portsmouth ND Model, adopting this approach systematically across mental health services, education, and children's services. This should be done in full partnership with parents and carers of children currently within the Special Educational Needs system.

14. People with (sometimes protected) minority characteristics are more likely to experience adversity and trauma, and to find that available services are not adequately designed to meet their needs. Relevant services should therefore review their approaches in the light of community and service user feedback about equality, diversity and inclusion.

Recommendations for the education sector

15. A lot of the pressure around neurodiversity support falls on schools, which find themselves under-resourced to respond to the increasing demand. While resources will remain challenging, educational institutions should be supported to implement inclusive practices and provide resources for neurodiverse individuals without the need for clinical diagnoses. This will require investment in ongoing professional development as well as the widespread adoption of Universal Design for Learning principles.

16. The role of trauma in shaping mental health and behaviour in children and young people is clear. Trauma-informed principles should therefore become infused into schools and further and higher education institutions as much as they should be in health services. Staff should be trained in recognising the signs of trauma and responding sensitively, and services should be provided in trauma-informed spaces that prioritise safety, trust, compassion and empowerment for individuals seeking support.

Recommendations for employers and workplaces

17. Diversity is a strength in the workplace, and employers should promote inclusive cultures that celebrate diversity, foster empathy, and reduce stigma associated with neurodiverse traits. This should include peer support programs and awareness campaigns to help to promote understanding and acceptance.

Recommendations for research

18. The agenda set out in this report could, if fully embraced, be a radical departure from the mainstream approach to mental health and neurodiversity, and it is crucial that it should be rigorously evaluated to ensure that it is actually improving mental health and wellbeing, and the experience of neurodiverse individuals. Cumberland Council's new Health Determinants Research Collaborative should therefore adopt mental health and neurodiversity as a key theme of its research programme. This research should be used to continuously improve service delivery, ensuring that the approach remains responsive and effective for diverse populations.

Conclusion

Mental health and neurodiversity are posing substantial challenges to society at the moment, both in terms of the scale of the distress and suffering being experienced, and the inadequacy of our response. This report has presented a vision for a new approach to mental health and neurodiversity in Cumberland, based on the principles of human rights, social justice, and empowerment. It has outlined the challenges and opportunities facing local services, and made a number of recommendations for policy and practice changes that could make a positive difference for the wellbeing of the community. The report has also highlighted the need for further research and evaluation to ensure that the proposed changes are evidence-based and effective.

None of this will be easy: however the "burning platform" of unsustainable demand is widely recognised in Cumberland and there is therefore a real opportunity to lead the way in creating a more inclusive and supportive environment for people with diverse mental health and neurodiversity needs, and to demonstrate the benefits of such an approach for the whole society.

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