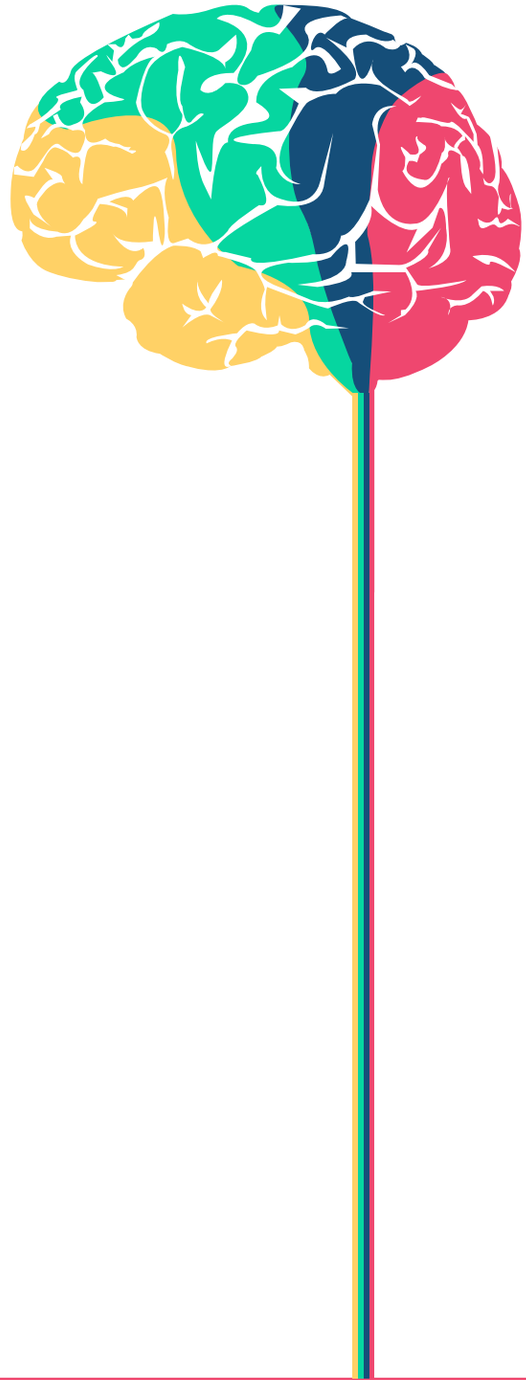
Northern Ireland Personality Disorder Conference 2018

Conference Report

Prepared on behalf of the Northern Ireland Personality Disorder Network



Kindly supported by

Mental Health UK

Working together

Rethink Mental Illness.

support in mind scotland

hafal

Wind Wise

The Northern Ireland Personality Disorder Network is made up of representatives from:

- Belfast Health and Social Care Trust
- CAUSE
- Health and Social Care Board
- Inspire
- Mindwise
- Northern Health and Social Care Trust
- People with Direct Experience of Personality Disorder
- Praxis
- Royal College of Psychiatrists
- South-Eastern Health and Social Care Trust
- Southern Health and Social Care Trust
- Western Health and Social Care Trust

C/O MindWise,
46 Newforge Lane,
Belfast, BT9 5NW
E: info@mindwisenv.org
T: 028 9040 2323

Report compiled by Chambré Public Affairs LLP

Table of contents

Introduction

On 21 June 2018, the Northern Ireland Personality Disorder Network held its first ever conference in the La Mon Hotel and Country Club. Over 140 people attended the event, contributing their perspective and experience to help improve outcomes for those with a diagnosis of Personality Disorder. The conference was chaired by Scope NI Editor Nick Garbutt.

Personality disorders are a serious issue, estimated to affect 1 in 20 people in the UK, according to the Royal College of Psychiatrists. Though we in Northern Ireland have already put effective systems in place to help those with a diagnosis, there is still more that needs to be done.

In the first session of the conference, we heard from Chris Matthews, Director of Mental Health, Disability and Older People at the Department of Health, about the work currently being done in Northern Ireland. We also heard from four experts from outside of the region. Dr Alex Stirzaker, The Rt Hon Norman Lamb MP and Sue Sibbald talked about work that had been done to establish a consensus on how the treatment of personality disorder could be improved in England and Wales. Finally, Dr Rex Haigh talked about his innovative approach to relational practice in the treatment of personality disorder.

In our second session, we heard about the human cost of personality disorders from three people with a diagnosis. Steven Millar, Nicole Devlin and Jemimah Armstrong showed incredible courage in sharing their intensely personal and moving stories. They were joined on stage by Dr Iain McDougall and Nuala Cassidy, who outlined what front-line clinical work is being done in Northern Ireland.

The conference then split into 5 breakout sessions. In the main hall, we heard a talk which aimed to dispel the stigma of mental health by examining its links to creativity. The service user perspective and the carers' perspective were examined, respectively, by Harm-ED and CAUSE. The Police Service of Northern Ireland and Probation Board for Northern Ireland led a session looking at efforts they were making to improve their engagement with people with a diagnosis. Finally, the South-Eastern Health and Social Care Trust ran a showcase on Dialectical Behavioural Therapy with a mindfulness exercise.

When the conference reconvened in the main hall, we had a hugely productive afternoon session. A free-flowing discussion around the room saw great ideas coming forward about how we can make life better for those with a diagnosis and their families. This report has been produced to provide a record of these discussions, and of the wonderful presentations from the day. It is to be hoped that the legacy of this successful event will be greater understanding of personality disorder and better outcomes for those with a diagnosis in Northern Ireland.

Foreword by Dr Iain McDougall

In Northern Ireland we have a great starting point for the treatment of people with personality disorders. A genuine interest and concern in providing and developing services for people with personality disorders was apparent at the conference held by the Northern Ireland Personality Disorder Network on 21st June 2018. This interest has been present for many years. The initial investment in services began in the 2010 – 2015 pre-austerity era. This was followed by the development of The Northern Ireland Personality Disorder Strategy 'A Diagnosis of Inclusion' and the accompanying Personality Disorder Pathway, which saw all of Northern Ireland's Health and Social Care Trusts develop personality disorder services in line with NICE guidelines.

Mental health services and personality disorder services in particular have always been ahead of the times in relation to service user and carer input. This was seen at the conference itself with the high level of service user input on the day. I am very grateful to Jemimah, Nicole and Steven who spoke so openly, honestly and bravely about their journeys through life and treatment. This has continued post-conference and one of the next steps being planned is a service user and carer networking and strategy day.

One downside in recent years has been the financial climate making it impossible for the PD strategy to become fully funded leaving a gap between what Trust services would like to provide and what they are able to provide to service users. We were grateful on the day to have the Department of Health represented by Chris Matthews But I would further emphasise the need for the Department to fully fund the Personality Disorder Strategy as a priority. This is especially pressing given the high rate of suicide, loss of functioning life years and physical health co-morbidities shown through the Adverse Childhood Experiences (ACEs) literature which applies to the experiences of many patients with a Personality Disorder.

At the conference we emphasised the importance of the publication of the Personality Disorder Consensus Statement, to which the Rt Hon Norman Lamb, Sue Sibbald and Dr Alex Stirzaker spoke. Alongside their presentation, Dr Rex Haigh's presentation on Relational Practice, proved a focal point for the conference. It highlighted the most challenging aspects - both for mental health professionals and government funders - of the suggestion of no longer using personality disorder as a diagnostic term. While many clinicians working in the field agree with this perspective there are no accepted answer to wither the question of what term to replace it with, or how funding streams would be maintained if the label were to change. A particularly positive aspect of this session was the ethos of each patient having a trauma informed or developmentally informed diagnostic formulation. This means that if a diagnosis of Personality Disorder is made, while the framework of symptoms may help somewhat for an individual to understand what happens in their lives, it is the more descriptive links to an individual's life experience and relationships that may provide the starting point for understanding, treatment and change for the individual.

After the conference I was left in no doubt about the high quality maintained throughout the day with the enthusiasm and momentum palpable. This could not have happened without all of our invited speakers and Nick Garbutt as our chair. The incredible hard work of everyone involved paid off including all of our local speakers but particularly from Anne Doherty of Mindwise and all of those at Chambré Public Affairs to whom I am hugely grateful for their meticulous planning of the day. The remainder of the document summarises well all of the speakers contributions in the hope that had you not been there on the day you will be able to have enough information to carry forward your own interest in personality disorder.

Foreword by Anne Doherty

Anne Doherty – Deputy Chief Executive Officer, MindWise

Like many of the best ideas within the field of mental health, the inspiration for this conference came from those who were most closely affected by personality disorder. Those members of the network with direct experience of personality disorder told us that they wanted to shine a light on the issue in Northern Ireland, highlighting the region's successes, shortcomings and - most importantly - building a consensus to improve services.

Inspired by this vision and informed by the rest of the network's expertise, we decided that holding a major conference would be the best way to achieve these aims. For over a year, we in the Northern Ireland Personality Disorder Network worked to make the conference a reality. When the day came, it did not disappoint.

I was thrilled by the quality of the discussion we saw on the day. Not only did we hear inspiring presentations from renowned experts, but we also heard inspirational stories about developing best practice in Northern Ireland. Finally, and most importantly, the service users in attendance contributed constructively and with great enthusiasm - demonstrating both the expertise and the desire to improve services that exists among this group. As well as the valuable insights and learnings the conference produced, it also demonstrated a shared desire to make things better - we are hoping to build upon this at our Service User Strategy Day in March 2019.

More generally, I believe our key challenges going forward are:

- Refreshing our Personality Disorder promises as previously laid out in the NI Personality Disorder Pathway 2011
- Galvanising service user and carer peer lead support systems, structures and cultures
- Raising awareness of the impact of Personality Disorder on the health and wellbeing of the NI populace
- Together creating a sustainability plan which addresses the real needs of people directly affected by personality disorder, their families and carers and the range of health care professionals (community, voluntary, statutory and independent) who are challenged with meeting those needs.

On behalf of the NI Personality Disorder Network, MindWise were delighted to drive through the Conference in partnership and collaboration with the very many experts by experience and professionals who made it a success. A debt of gratitude is owed to all.

Session One - Chairman's Introduction and Welcome

Nick Garbutt – Editor, Scope NI

Nick opened the conference, saying that the day's core focus would be on how we can work together better to improve outcomes for people with a diagnosis. There is an urgent need for this, since personality disorders affect a surpisingly large segment of the population and those with a diagnosis are often very unsatisfied with the support available.

However, he pointed out that this is an area beset by many complications. One is the term 'personality disorder' itself, which many with a diagnosis complain is stigmatising. This stems back to the fact that personality disorders are still poorly misunderstood, and it is not very long since the diagnosis was widely considered to be untreatable. There is therefore a perception among service users that, among some of those in the health system, a diagnosis of personality disorder connotes patients who are 'difficult'.

Improving outcomes for those with a diagnosis will require joined-up working between the wide range of services with which those with a personality disorder come into contact. For instance, some people experiencing difficulties may first present to their GPs, ambulance services, or the police. On the other hand, some people's symptoms may not come to the attention of professionals until the individual is in prison, or has experienced a major crisis.

Ensuring that these public services have the necessary experience to provide suitable help to those with a personality disorder is a key challenge, requiring support from government. The Programme for Government makes no specific mention of Personality Disorder – however, one of its indicators was the improvement of mental health. The key measurement for this indicator was the percentage of the population with GHQ-12 scores less than or equal to 4 – signifying possible mental health problems.

Personality disorder, as a range of conditions, raises a number of fascinating questions. For example, how to address the challenge of providing appropriate pathways to care for a cohort of people who may first present to any number of public services and who may or may not have a diagnosis. The vast over-representation of people with a diagnosis in the prison begs questions about whether better care could be provided for these people earlier and whether prison is the best place for them to be. Finally, it raises questions about our society - though we have come a long way in our understanding and acceptance of mental health issues, it is right to ask how far we still have to go.

Nick invited delegates to consider these and many other questions as he opened the first session's discussions.

Personality Disorder - A Diagnosis for Inclusion

Chris Matthews – Director of Mental Health, Disability and Older People, Department of Health NI

Chris began by saying that there had been an increased awareness and understanding of personality disorder and the needs and issues of those with a diagnosis in recent years.

The 'Bamford Review of Mental Health and Learning Disability' was the first major government document to advocate that mental health issues should be treated on same basis as physical health issues. This led to the Department of Health undertaking its first ever review of the needs of people living with a personality disorder. The review team considered the stigmatisation and isolation of people with the diagnosis and recommended that that the support that they received from social services needed to improve.

'Personality Disorder: A Diagnosis for Inclusion' was Northern Ireland's first high-level strategy on personality disorder. It included plans for user and carer networks, training provision and increased access to acute psychiatric in-patient support. It also included provision for improving awareness and available support within the prison services. However, the strategy was introduced on the back of the 2008 financial crisis and lacked the required funding to fully implement it.

For those with a diagnosis, significant support is in place in Northern Ireland. A team dedicated to the treatment of personality disorder is based in each of Northern Ireland's five Health and Social Care Trusts. There is also a recovery college for people with mental health needs in each of the Trust areas. Despite this support, however, those with a diagnosis still have significantly shorter life spans than those without.

Personality disorders are often comorbid with other issues – so those with a personality disorder often present themselves to a wide variety of different services. This means that awareness-raising and co-operation between Northern Ireland's services – be they public, independent or community and voluntary – is especially important.

Looking ahead, the Department recognises that there should be a greater focus on recovery, as opposed to simply on correctly diagnosing the issues. The Department's focus on recovery was founded on three key principles:

- positive engagement
- autonomy and independence for the patient in deciding upon their own treatment
- working towards a future without a need for services or support.

Underpinning all of these principles is the Department's firm view that patients should take control of their own treatment. They should be allowed to make their own decisions – even if carers are concerned they might be poor decisions.

Shining a Light on Personality Disorder – Helping Public Services Work with those with a Diagnosis

Dr Alex Stirzaker – Clinical Psychologist and Editor, Consensus Statement

Alex opened by saying that she was "really pleased" to hear from Chris Matthews' address that Northern Ireland appeared to be much further ahead in responding to the needs of people with personality disorder than some other parts of the UK.

She explained that she had had edited the Consensus Statement for People with Complex Mental Health Difficulties who are Diagnosed with a Personality Disorder. This document was born out of the premise that there existed a huge disparity in the facilities and treatments available for this group of people across the UK. It outlined early intervention methods for preventing personality disorders developing and described ways to provide better "later in life" care. The document also addressed failings in the prison service when dealing with personality disorder.

A key focus of the Consensus Statement is to move from a model of treatment to one of prevention. Childhood trauma immediately imposes limitations upon a person's quality of life. For people who have experienced such treatment, special pathways of care need to be created – sensitive to their needs. A simple adjustment in approach is needed. Instead of asking "what's wrong with you", practitioners should ask "what has happened to you?"

One issue around the treatment of personality disorder is that the care is often paternalistic. This can limit its effectiveness. For policymakers and practitioners seeking to improve outcomes for those with a diagnosis, this approach needs to be avoided.

To improve care across the UK, the Consensus Statement calls for:

- A consistent and respectful therapeutic environment and network of services
- Psychologically-informed and bespoke treatment for each individual, administered by trained professionals with an understanding of the complexities of personality disorder.

Alex finished by outlining the work carried out so far off the back of the Consensus Statement. The document is being used to support local health commissioning services in areas including Somerset. It has impacted the major professional stakeholder bodies, with the British Psychological Society making printed copies available to its members and high-level discussions ongoing in the Royal College of Psychiatrists. The Department of Health and Social Care in England is also continuing to engage with the group around how to implement trauma-informed care.

Shining a Light on Personality Disorder – Helping Public Services Work with those with a Diagnosis

Rt Hon Norman Lamb MP (Liberal Democrat, North Norfolk) and Co-Chair, Personality Disorder Consensus Group

As Minister for Care and Support in the Coalition Government between 2012 and 2015, Norman explained that he came to the view that that "people with a diagnosis of personality disorder are probably the most neglected of anybody" within the NHS.

There is an "enormous personal cost" of the failure of the NHS to properly care for people with a diagnosis. Far too many people are confined in institutional care for long periods of time. These people are in effect "contained, with no ambition for their recovery or for getting them to a better place – but simply to keep them out of harm's way. Now that's no way to live a life."

The cost of this failure falls upon the individual in terms of their diminished life expectancy and experience. But it is also borne by the State, which must pay for the expensive, long-term institutionalisation of a large group of people. Too often, he said, people end up drifting into the criminal justice system – being treated as culpable for what has happened to them. He said he believed that this money could be used much better.

As an aside, Norman also took issue with the term 'personality disorder'. Said we needed to move on from this description "as soon as possible".

There is a growing understanding of the complex ways that trauma can impact upon people's lives. For example, there are many people who have experienced sexual abuse during childhood, who have then gone on to receive a diagnosis of personality disorder during their adult lives. This had led Mr Lamb, when he was Chair of the House of Commons Select Committee on Science and Technology, to initiate an inquiry into how children could receive the support they needed when they experienced trauma or neglect.

By bringing everyone involved in the treatment of personality disorder – including service users – together, it is possible to come to some conclusions about how the system needed to change. This evidenced by the Consensus Statement. Many of its recommendations do not involve additional resources – rather they are focused on better using the resources already in place. The aim is to create more personalised, more responsive and more dignified care for those with this diagnosis.

Shining a Light on Personality Disorder – Helping Public Services Work with those with a Diagnosis

Sue Sibbald – Peer Specialist and Co-Chair, Personality Disorder Consensus Group

"My name is Sue Sibbald and my personality *isn't* disordered."

Sue Sibbald explained that she had a traumatic childhood, with a mother who had been labelled as suffering from schizophrenia. She was often scared and didn't know who to trust. As a result, she found it difficult to form relationships and didn't learn how to manage her emotions.

She dropped out of education and worked in nightclubs, where she drank and took drugs. She broke down, self-harmed, lost weight and dissociated herself from those around her. She said she "lost her mind for a while." As a result, she got a diagnosis of Borderline Personality Disorder.

She got limited support – "just a care co-ordinator and a psychiatrist." The psychiatrist was kind – "that's what mattered". What helped her was finding people like her, who taught her Dialectical Behavioural Therapy (DBT). She used Twitter and Facebook to connect with people who had similar experiences to her. They were her peers online and taught her about validation.

Validation is "emotional first aid for those in crisis." It is about connection – showing that you understand what someone is feeling. It can bring down anger and help a person confront whatever bad experience they are facing. It is a "really useful skill".

With her friends online, Sue learned DBT skills. She also learned through books and using apps like Diary Card. She set up a chat on Twitter, so people who didn't have help and wanted to connect could support one another. It's called 'BPD Chat' and has run every Sunday for 6 years.

Sue said that "In any therapy involving trauma, relationships are key". She explained she was lucky to have a psychiatrist and care co-ordinators who were stable, kind and consistent. However, she had friends who weren't so lucky and had been unable to access the support they needed. Once, a friend of hers was turned away from hospital three times in one night and ended up taking her own life.

She emphasised the importance of early intervention. Had she received the help she needed earlier, the emotional and monetary cost of her illness could have been much less. As a society, we should engage sooner with young people who have experienced trauma – and extend compassion and understanding to them.

Stigma also needs to be addressed. People are often called manipulative because they self-harm, or need help managing emotions. This diagnosis is incorrect and fails to take proper account of the trauma those people may have suffered.

Sue's life was changed by the therapy she received, and she has since become a prominent campaigner for better services for others with a diagnosis. She was asked by NHS England to sit on a group formulating its Personality Disorder Strategy. And she has become a peer worker with her local NHS Trust, helping those facing similar challenges to her own.

Therapeutic Environments and Relational Practice

Dr Rex Haigh – Medical Psychotherapist and Enabling Environments Lead, Royal College of Psychiatrists Centre for Quality Improvement

Opened by describing himself as a "grumpy old psychologist" – in that throughout his entire career he had been dissatisfied with the way that people with Borderline Personality Disorder were treated. However, he said that he felt the tide was now turning.

Rex began by giving an overview of the history of the treatment of personality disorder from 2000 onwards. In 2001, the UK Government launched the Dangerous and Severe Personality Disorder Programme. This stemmed from a directive from then-Home Secretary Jack Straw that Personality Disorder could no longer be treated as an incurable condition – and provided £128m to improve treatment.

Some notable developments in this period included the establishment of Borderline UK – the first service-user organisation to start "shouting out that something was terribly wrong" in the treatment of those with a diagnosis. As a result of Borderline UK's pressure, the UK Department of Health produced 'No Longer a Diagnosis of Exclusion' in 2003 – the first personality disorder strategy.

Out of 'No Longer a Diagnosis of Exclusion', 11 pilot projects across England. The projects were hugely varied - service users within the project areas submitted ideas, and the best of these were selected for trial.

In 2007, a service user organisation known as 'Emergence' focused on creativity to provide therapy to those with a diagnosis.

The Knowledge and understanding Framework (KUF) – a national training programme for personality disorder – was launched in 2008. This was followed in 2009 by the NICE guideline on borderline personality disorder and by the NHS commissioning guidelines – 'Recognising Complexity'.

In 2011, the community side of the national personality disorder programme lost its funding – Rex described this as the "end of the flourishing of the movement."

In 2013, a book called 'Meeting the Challenge, Making a Difference' was published by Emergence (a service user network backed by NHS England). This "practical guide to personality disorder" was designed to help practitioners provide more effective care.

From all this, Rex said that a number of important principles could be drawn – though the Royal College of Psychiatrists wasn't fully on board with all of these. These were:

- "Diagnosis is never enough" - clinicians should work towards a "formulation" or, in other words, an understanding of both the symptoms and the cause (the problematic behaviour and the experiences the individual has had to cause them to act in such a manner), which can then be added to a diagnosis to become a "diagnostic formulation"
- Using the biopsychosocial model – not just a biomedical one
- Providing a long-term 'continuity of care' - ensuring some continuity in those providing care and treatment that allows relationships to be fostered and ensuring that all aspects of care are understood as linking in to the other parts of care (rather than pathways fragmenting into disconnected elements of service)
- Having networks of co-operation and collaboration – these can be far more effective than hierarchies of authority and control

Therapeutic Environments and Relational Practice

- Training carers and clinicians - putting the emphasis on "training for better attitudes" rather than knowledge and skills
- Those working with people with a diagnosis must accept complexity and uncertainty and enjoy spontaneity and creativity – something that was often not the case in "highly-focused, highly regulated pathways"
- Care should be cross-agency, rather than health-centred – an approach that appears to be practiced in Northern Ireland
- The ethos of the voluntary sector was most appropriate for care, "rather than the ethics of the private sector or the inertia of the public sector"

Rex encouraged practitioners and service designers to "treat risk positively, rather than being paralysed with anxiety about it." He also said the "only real way to contain risk is by relationship."

Looking ahead, he identified a number of relatively recent and upcoming initiatives, which he felt could have a positive impact on treatment and care of those with a diagnosis. These were:

- The Knowledge and Understanding Framework, which had been produced by the Department of Health and Social Care, Ministry of Justice and other, and is very much focused on relational practice
- The Royal College of Psychiatrists have created an award for creating and sustaining Enabling Environments, which has been running for seven years and has been particularly effective in the prisons system
- The Department of Health and Social's review of the 11 pilot projects ('Innovation in Action'), which found that no specific model (e.g. DBT, CBT or any equivalent therapy) emerged as superior, and the most successful pilots had several key features in common:
  - Employed treatments focused on long-term outcomes and creating a therapeutic environment
  - Employed recovery-based models
  - Addressed needs beyond symptom management
  - Did not try to 'fix' people
  - Gave back responsibility to people for their own well-being and safety
  - Involved service user partnership – not just input.

Rex noted that the latest edition of the International Classification of Diseases (ICD-11) appeared to point towards the first official recognition of 'trauma-informed care', in its section on Post-Traumatic Stress Disorder and Dissociative Disorder.

Summing up, Rex said that he was hopeful that there was a growing realisation that the way we treat personality disorder needs to change. He hoped that the path was being cleared for "a different way of doing 'mental health' – with people (not pathology) at the centre and relationships (not procedures) as the work".

Questions and Answers / Panel Discussion

Q: Should the term 'personality disorder be changed – and what should we change it to?

Alex Stirzaker: The risk is that if you take the term away, it makes it harder for people to access services. So, if we do anything differently, we need to make sure people can still access services.

Rex Haigh: The commonest alternative term he has heard used is 'complex trauma'. He has also heard the term 'compound trauma' – since traumas compound one another. About half the people who access his services are glad to hear that there's a term and that they're not alone in their experiences. The other half object strongly to the term and want to get rid of it. There appeared to be a growing understanding that the term 'personality disorder' wasn't acceptable.

Chris Matthews: From the perspective of a policymaker, terms need to be as precise as possible. However, changing a term is very complex in policy terms. Training, professional credentials and service access are all affected when one begins to change associated nomenclature. There's also a risk that a new term might exclude some people who come under the ambit of the old term. However, if there is a strong sense that the term is counter-productive – hindering the treatment of those it applies to – then the Department won't resist any change.

Q: In term of influencing public policy, how helpful has the Consensus Statement been? Do we need an equivalent in Northern Ireland?

Alex Stirzaker: I wouldn't wish to mislead people into thinking that the Consensus Statement has completely succeeded. One of the most important things that the team did was to bring Norman Lamb on board, since changing policy is so dependent on relationships. Where this was most useful was in opening doors to policymakers – permitting meaningful conversations, by giving policymakers a reasonable lay understanding of the issues.

Rex Haigh: The Consensus Statement is a really important document, but it won't lead to more funding for personality disorder services on its own. There are three things we're up against in realising all the changes listed in the Statement: the huge cost of full implementation; the major change in attitudes towards commissioning that would be required; and the fact that moving in this direction is contrary to the interests of the pharmaceutical industry, who will strongly oppose it.

Chris Matthews: The Statement itself is very similar to the approaches taken by the Bamford Review – so for a Northern Ireland policymaker it's heartening to see that "we were on the right track". A Northern Ireland version of this statement would be beneficial. But there are a lot of important lobbies asking for bigger cuts of a limited pot of money. The influence of any document in Northern Ireland may therefore be limited. The most important thing for any such document would be to set out a "really clear outline of what change is needed" and set out evidence for why this is necessary.

Questions and Answers / Panel Discussion

Q: Since the estimated number of people with a personality disorder is so much higher than the number being treated for it, how do we bring more affected people into the system?

Rex Haigh: In NHS England, personality disorder sits within a group of services, along with gender dysphoria and eating disorders. The other two conditions have massive public support, and are bolstered by very public campaigns – "why don't we?" The "time is becoming right" to start proper activism to raise awareness of the diagnosis.

Alex Stirzaker: I have "absolutely no doubt" that there are a lot more people who could be brought into the system. However, this isn't necessarily entirely a bad thing – since the description of 'personality disorder' could be stigmatising. The focus needs to be on ensuring people getting the help they need – not necessarily on giving them a diagnosis.

Q: How can we get away from the term 'personality disorder' without restricting access to services?

Chris Matthews: The starting point is to consider what alternative term should be used. So long as it's clear and covers a suitable range of conditions, it may meet with support from policymakers.

Session 2 - The Lived Experience of Personality Disorder

Jemimah Armstrong – Individual with lived experience

Jemimah lives with borderline personality disorder – but is now stable after learning how to manage her mental health well.

When Jemimah first started having issues, she initially tried to hide them from her family and friends. "Self-harm became an addiction for me", she said. "Any time I became stressed I needed to do it." This was made worse because, as she put it, her "anxiety was through the roof 9 to 5."

She found it difficult to cope and to function. She spoke to lots of specialists and was on a wide range of medications. But sometimes she simply felt like giving up – she tried to end her life many times. She is grateful that she didn't – she now has two boys who depend on her and who give her strength. She has learned that "suicide is a permanent solution to a temporary problem".

During her dark times, however, she lost a huge amount. She lost her two daughters to adoption. When this happened, she realised she had "hit rock bottom". She became involved in a new mental health programme, which led on to Dialectical Behavioural Therapy. This programme helped her to examine her negative behaviours and modes of thought and helped her get to a stage where life was worth living.

The most difficult part for Jemimah was the emotional regulation sessions. She had always bottled up her emotions - "No one, not even myself, knew what I was really feeling". Jemimah has now learned to control her emotions, with the help of her focus group.

She has come to understand that personality disorder doesn't define her as a person – she is still human and interesting. Though she has had severe struggles, she has come to see her diagnosis as part of her. For those who are currently struggling, she encourages them to reframe their feelings. Instead of saying "I'm damaged" or "I'm broken", say "I'm healing and discovering myself."

The Lived Experience of Personality Disorder

Nicole Devlin – Individual with lived experience

"Every story begins with a past. My past has been difficult, challenging, traumatic and hopeless."

Nicole experienced trauma in childhood, which was compounded when she was an adolescent. She was bullied at school, with other children calling her names, pushing her into doors and pulling her hair. She asked herself time and time again if there was something wrong with her – and always the answer she came up with was 'yes'. She also struggled with her sexuality.

She was 17 when she first tried to take her own life. Three suicide attempts later, she was admitted to a psychiatric hospital against her will. At age 18, she received a diagnosis of Emotionally Unstable Personality Disorder.

Her self-harm and suicide attempts got out of hand. "I began to self-harm daily – it was almost like an addiction." She experienced relief and felt empowered when she did – but then feelings of guilt, shame and anger would follow, feeding a cycle of repeated self-harm.

One day, Nicole decided to get a tattoo. The feeling of the needle going into her skin gave her the same relief as self-harming. Tattoos "became a new fix and a new means to self-harm". Her arms are covered in tattoos. They serve as a clear reminder of "how bad things really were." She is currently in the process of having them removed.

She spent months at a time in hospital. She knew that if she self-harmed or attempted to abscond she would be sedated. Being sedated meant escaping "the torture of my mind" so she absconded and self-harmed, knowing she would receive a jab and go to sleep.

Throughout her darkest years she felt in so much emotional turmoil, she felt as if "my heart was engulfed with fire." The pain was intolerable. She didn't really want to die – she just wanted to end her pain.

This continued from the age of 17 until she was 27. "It lasted ten whole years."

Her last suicide attempt was four years ago. A turning point for Nicole was the birth of her nephew. He "showed me the power of vulnerability, how it was ok to cry – ok to not be ok". She now embraces her vulnerability and is no longer scared to have her pain seen by others.

She has been in therapy for 18 months and "probably will be for the next 5 or more years". She finds it very tough – but she carries on.

For the past three years, she has worked with a mental health organisation in England and has recently begun delivering workshops on self-harm training to professionals. She returned to education three years ago and began a degree in Psychology at Queen's University Belfast last September.

She doesn't think of herself as 'cured' – but she is now in control and taking control of her life. Thanks to the support of her partner, family, friends and therapist she is still on the road to recovery.

Nicole has also begun speaking out about her experiences – "because I know how isolating these invisible illnesses can be. I know what it is like to feel desperately alone and wanting to be heard". Her hope is that, by telling her story, she can help change someone's life "because there are a few people out there who cared enough to change mine".

The Lived Experience of Personality Disorder

Steven Millar – Peer Support Worker, Belfast Health and Social Care Trust

Steven spoke from a very personal perspective about his recovery from the effects of life experiences on his mental health. He spoke passionately and informatively about his journey confronting addictions, self harm and his feelings inspiring everyone with his own tag line – "what you can feel, you can heal."

Steven described how through four years of intensive treatment programmes he learned to love himself, support himself and take care of his life. This has lead him to a position of being able to help others, initially through his work with Forum for Action on Substance Abuse (FASA), then as an addictions support worker and most recently as the Peer Support Worker at the Belfast HSC Trust Self Harm Personality Disorder service where in prior years he had received treatment.

He offers a unique version of support to patients through working alongside healthcare professionals. It allows him to use his experiences to give hope and inspire. As he put it, "it is about walking alongside the individual, helping them to accept themselves and realise they are not alone". Through this, he describes helping people to build relationships with mental health professionals and those around them. By being able to understand another's experience in a non-judgmental manner, he is able to help them build the confidence to engage in treatment and make better decisions about their lives.

The Northern Ireland Perspective: Where Are We Now?

Dr Iain McDougall – Consultant Psychiatrist, Belfast Health and Social Care Trust

Iain explained that the "journey" to improve personality disorder services in Northern Ireland began in 2010. Prior to this, services were sparse. Outside of Belfast, there were no other specialist services for personality disorder regionally. Then, if someone with a personality disorder presented to their GP, they would get placed into a general psychiatry pathway.

However, 2010 saw the launch of 'Personality Disorder: A Diagnosis for Inclusion', Northern Ireland's first personality disorder strategy. Out of this has grown a number of new initiatives, including the 'Regional Care Pathway for Personality Disorders', which was launched in 2014. There has also been a renewed focus on mental health care, in part driven by the 'Delivering the Bamford Vision – Action Plan 2012-2015'.

Looking to the future, Iain said that the 'Consensus Statement' will be "massive" – raising the profile of the issue and providing an accessible guide to policymakers. As the document suggests, the label of 'personality disorder' needs to change – but what it can change to is unclear. Likewise, relational practice is important – "therapy allows us to do our jobs, but the relationships with service users are most important."

Iain stressed the importance of a wide availability of different but evidence-based interventions being available. He also said that a trauma-informed, formulation-driven, whole-system approach to care is necessary. However, he said that Northern Ireland did do several things well – therapeutic environments were well-supported, and the region benefited from a highly-qualified workforce.

One of the biggest issues is that specialist services only treat "the tip of the iceberg." Reaching more people, earlier in their treatment journey, is a key challenge for specialist personality disorder services.

Additionally, there are challenges around the therapies used. While evidence-based treatments tend to involve groups, the role of counselling and psychotherapy in treating personality disorder is unclear. Additionally, recovery post-treatment can be hampered by a lack of available support. In this, community and voluntary organisations have a significant role to play.

Going forward, Iain said that co-production will be an increasingly important part of treatment. Service design needs to involve families, carers and loved-ones to an increasing extent. Patients need to have a greater role in co-producing their own formulations. And treatment models need to provide greater opportunities for work with service-users' families.

By 2025, Iain said he hoped to see a fully-funded personality disorder strategy. He also hoped that PD teams would be larger, multidisciplinary organisations, able to actively engage with community mental health teams and community and voluntary colleagues. He hoped that specialist treatments would be available earlier in the patient journey and that prison services would be improved. Finally, he hoped that there would be less need for treatment outside Northern Ireland.

The Northern Ireland Perspective: Where Are We Now?

Nuala Cassidy – Personality Disorder Service Manager, Northern Health and Social Care Trust

Nuala said the evidence continues to grow for psychological treatments for borderline personality disorder (BPD) and self-harm in the context of BPD. This is reflected in the NICE guidance which recommends psychological therapies for managing and treating the disorder. It does so on the basis that, "because of the variety of symptoms and the variation in needs, flexible approaches that are responsive to the needs of each person with personality disorder are important."

She said that the evidence shows that good psychiatric management or structured clinical management is almost as good as specialist therapies. "Carefully considered, well-structured and coherent" psychological informed treatment also helps to improve outcomes.

A range of psychological treatments are offered in Northern Ireland. Each of the HSC Trusts receives one fifth of the money available to provide personality disorder services and each has picked a specific therapy to offer. She pointed out, however, that Schema Therapy and Cognitive Analytic Therapy are currently difficult to access in Northern Ireland.

The Western and South-Eastern Health and Social Care Trusts offer Dialectical Behavioural Therapy treatments. Meanwhile, the Belfast Health and Social Care Trust offers Mentalisation Based Therapy. The Southern Health and Social Care Trusts offers both treatment types, while the Northern Health and Social Care Trust is working towards offering both in the near future.

Questions and Answers / Panel Discussion

Q: Some individuals find themselves between a diagnosis of Borderline Personality Disorder and Bi-Polar Disorder – since there are many overlapping symptoms. Are there any guidelines to ensure that they are sent down the most appropriate treatment pathways?

Iain McDougall: NICE guidelines stress the need to treat the co-morbidity. It's important to ensure that the co-morbidity is under control before entering therapy – as otherwise it's going to be very difficult for the individual to successfully complete therapy. This is why it's good to have psychologists as part of PD teams, as they can help address these co-morbidities in a flexible and clinically-informed way.

Q: How can we improve links between clinicians and carers, and how can we better take account of the input of carers when providing treatment?

A mental health professional from the Western Health and Social Care Trust: We really value the input from carers. Sometimes in our interventions, we work closely with carers to improve treatment for those referred to our services. The individual cited the work of CAUSE in championing carers' rights and needs.

Breakout Session: Tackling Stigma - Changing Perceptions about Personality Disorder

Edward explained that there is still a great deal of stigma associated with mental health issues. This is especially the case among young men who struggle to come forward. However, it is possible that there is a connection between mental health issues and creativity, since both are dependent on a different perception of everyday life.

People working in the arts are three times more likely to experience mental health issues than those employed in other sectors. This could be because people with mental health issues are drawn to the arts as a form of therapy and as a creative outlet for their problems. Art and creativity form a useful way to treat mental health needs. They facilitate emotional expression and can help turn negative feelings into something positive and constructive.

It could be asked if diagnosis is always needed. Diagnosis can be helpful in identifying the treatments necessary. And it can give people comfort to have a name to apply to the source of their difficulties. However, other people may object to a diagnosis – they might not want the associated stigma or feel that they have simply been shoved into an ill-fitting pigeon hole.

Mental health is also a class-sensitive issue. Many of the problems that can contribute to poor mental health – such as poor physical health or money worries and poverty – are more prevalent among working-class individuals and people living in poverty. Additionally, middle and upper-class individuals tend to be more aware of mental health issues and hence more likely to seek treatment. Therefore, people in the working-class community may be more likely to delay treatment until the problem has become more severe.

Mental health needs are a major economic issue, leading to lower productivity and a higher number of sick days. This can be worsened by discriminatory actions within workplaces. Employees will not reveal their mental health issues to their employers if they feel it may jeopardise their job.

Q: What progress is being made regarding stigma and mental health?

A: The stigma around mental health is improving and there are a number of groups, such as Lloyds Banking Group, who are keen to support mental health charities. There is also an increase in the number of males presenting for treatment – a good sign that things are changing for the better. However, a dismissive attitude toward mental health difficulties is still too prevalent. Many people still criticise those experiencing mental health issues as simply having attitude problems.

Breakout Session: How can the Justice System Produce Better Outcomes in its Dealings with those with Personality Disorders?

Session convener: Inspector Mark Cavanagh – Police Service of Northern Ireland & Rebecca Reid – Northern Ireland Probation Board

Mark described the PSNI as being on the front line of dealing with people suffering a mental health crisis. "Whether someone arrives at a police station as a victim or a perpetrator, the police need to understand the role that mental health has played in creating the situation."

On average, the PSNI receives between 45-60 calls per day which are related to mental health issues. Of these, 20% are from people between 50-59 years old with around 10% more mental health-related calls from women. On average, the police service detains 60 people per month (roughly 2 per day) under the Mental Health (Northern Ireland) Order 1986.

As such, the PSNI sees itself as something of a "buffer zone" in dealing with mental health. It deals with people for short periods. This means it can be difficult to recognise the symptoms of personality disorder. The average time the police service spends on an individual suffering a mental health crisis is 4 hours but can be up to 20 hours – a huge use of resources.

The PSNI teaches its call-handlers to follow what it calls the 'THRIVE Model'. This stands for 'Threat, Harm, Risk, Investigation, Vulnerability and Engagement'. By following this model, call-handlers can make a flexible, individual assessment of each situation they are presented with.

Breakout Session: Specialist Intervention Showcase - Dialectical Behavioural Therapy

Session convener: Dr Nicola Gillespie, Consultant Clinical Psychologist and DBT Service Lead, SEHSCT; Fiona Barnes, Nurse Practitioner, SEHSCT; Paul Blackstock, Therapist, SEHSCT

Nicola began the session with a short practical exercise – a mindfulness demonstration. Mindfulness is a core part of Dialectical Behaviour Therapy (DBT). It was explained to participants that mindfulness is about "living in the present".

People who use personality disorder services have a baseline "emotional sensitivity" that is much higher than most people. This means that when an emotional stimulus arrives, it results in a bigger emotional response. After the emotional response, one's emotional state then takes longer to return to normal. For those with a diagnosis, being in this heightened emotional state is often described as like being "in hell".

Nicola also outlined the bio-social model – a mental health tool used to conceptualise the reasons for a person's difficulties – to help explain why those with personality disorder act in the way they do. This is a mental health tool used to conceptualise the reasons for a person's difficulties. According to the 'bio' part of this model, some people are biologically inclined to be more emotional, and to respond more strongly to emotional stimuli. The 'social' part of the model deals with trauma – at some time in an individual's life, it says, they will have had an experience that makes it harder for them to recognise the emotion they are experiencing.

Consequently, those with a personality disorder who are experiencing "emotional hell" try to get out as quickly as possible – leading to many potentially damaging behaviours. A DBT therapist will explain to his or her client that these behaviours are essentially coping strategies for their emotional dysregulation. In this way, they can help the client to accept themselves as they are – an important part of the therapy.

DBT is an evidence-based intervention, with an intensive therapeutic process. DBT tries to change the damaging behaviour that makes the client's life more difficult. It has a targeted hierarchy of behaviours to change – with suicidal behaviour being top of the list. It includes a variety of therapeutic methods to help its users "build a life worth living".

Group work is a key component of DBT. Those in the South Eastern Health and Social Care Trust's skills training group find it validating to be in a group with people who have had similar experiences. Additionally, graduates of the training programme come back for refresher days – to polish up the skills they developed from it, and to provide support to those going through the programme.

The South Eastern Health and Social Care Trust provides a range of services to people through its DBT programme, depending on the needs of the individual. The Trust has found that the therapy has helped keep people out of inpatient treatment by giving them the skills to cope better. Within the Trust, the treatment has led to a big reduction in self-harm among clients – both during and after treatment. It has been shown to be particularly successful with young people (18-25 years old), with those who are members of a young adult comprehensive DBT programme more likely to achieve 'recovered' status. And 7 out of 10 people going through the DBT programme experience a significant change in their life.

Breakout Session: The Service User Perspective

Session convener: Nicole Devlin and Terri Shaw, Harm-ed

The session was Co-facilitated by Terri Shaw: MA, BSc Hons, RGN, PGCE. Founding Director of Harm-ed and specialist trainer on self-harm, professional background of working as a staff nurse in A&E and personal experience around caring for someone who self-harms, and Nicole Devlin: a BSc Hons Psychology student at Queen's university. Nicole has had an extensive history of self-harm, borderline personality disorder, amongst long term psychiatric inpatient treatment. Nicole uses her experiences to give insight into the subject areas.

Terri Shaw give an introduction on Harm-ed, stating that while it was an England based organisation, they now deliver courses in Northern Ireland. Terri reiterated that Harm-ed training draws on a unique package of skills, knowledge, insight and direct personal experience and "we offer a wide range of courses and training packages."

Nicole spoke of the two half-day courses they delivered in Belfast last September on 'Understanding & Responding to Self-harm', and said feedback was fantastic. Nicole stated those in attendance were from a mix of backgrounds, including a psychiatrist who said the course was, 'simply excellent'. Nicole highlighted that most of the evaluations from participants that had attended stated, 'the lived experience to the course made it that more authentic', and participants left the course, more encouraged. Terri suggested the lived experience brings a real depth of meaning to the courses with the trainer's experimental knowledge.

For more information on Harm-ed; visit: http://www.harm-ed.com/

Breakout Session: The Family and Carers Perspective

Session Convener: Valerie Sullivan, Interim Chief Executive CAUSE; Rachel McMordie, Carer Advocate, CAUSE; John Doherty, Carer Advocate, CAUSE; Dr Camille Harte, Senior Healthcare Officer, Belfast Health and Social Care Trust Self-Harm and Personality Disorder team

Discussion centred on the qualitative evaluation of the impact of CAUSE NI Family Connections Workshops on carers and family members supporting a loved one with a Personality Disorder diagnosis.

The CAUSE NI Family Connections Model has been developed over the past 5 years utilising evidence based psycho-social frameworks and theories to explore behaviours. Attending a workshop provides an opportunity for carers and family members to meet and share experiences with other carers in a safe and supported environment. The workshop explores the emotional impact of supporting a loved one with Personality Disorder and is continuously developing with both participant feedback and external developments.

Dr Camille Harte shared qualitative evaluative Focus Group Feedback gathered from parent carers attending a recent CAUSE Family Connections Workshop. The session acknowledged common themes and experiences from families ranging from families expressing a sense of worry, exclusion and concerns regarding their own ability to effectively support their loved ones. Many families expressed a sense of experiencing trauma and feeling an impact on their own mental health as a result of the stress of their caring or support role.

The discussion reviewed that all of the focus group families reported that the workshop was a positive experience for them, contributing not just knowledge and skills but a sense of hope for the future. The style of facilitation, where participants can explore their own feelings and reaction that are evoked in their relationships, was noted as an effective way to enhance family coping strategies & instil hope.

CAUSE NI is a voluntary organisation providing practical and emotional support to empower carers, friends and families caring for a loved one with serious mental illness or personality disorder.

Session 3 - Resolutions and Next Steps - Q&A

Q: If you could do one thing for people diagnosed with personality disorder, what would it be?

Mark Cavanagh: A separate facility should be created outside of hospital or prison – essentially a safe space for people who are experiencing difficulties related to mental health. This would give police more options if they are called to a crime involving someone suffering from mental health problems.

Nicola Gillespie: Create a smoother pathway into care for young adults. Teaching emotional control and mindfulness in schools could help this.

Edward Gorringe: Educate GPs. They are often the first point of contact for people who receive a diagnosis of personality disorder - but many of them do not know enough about the issue.

Nicole Devlin: Use a different term to refer to personality disorder, which creates distressing associations for those with a diagnosis. The word 'disorder' is the problematic part.

Valerie Sullivan: Family and friends should be empowered to help those with a diagnosis. Bring them into the process of providing care!

Resolutions and Next Steps - Ideas Session

In this concluding session, panellists and members of the audience were invited to pitch their ideas to the conference.

It was suggested that delayed personal progression was a significant issue for those with a diagnosis of personality disorder. Those who miss school due to suffering a trauma should not be forced to go back a year. It was also suggested they should be given extra funding and support to allow them to return to their old class with their peers.

It was also suggested that the Department of Health still has work to do to improve care for those with personality disorder. One delegate said that mental health issues developed because of the work environment were under-resourced, and more funding should be allocated. Another said that more progress was required to deliver a joint Department of Health/Department of Justice policy on personality disorder identification.

Many individuals throughout the day had stressed that there should be more opportunities for people with direct experience to have their say. During the Ideas Session, suggestions on this theme included increased representation on the NI Personality Disorder Network; enhanced investment in peer-led initiatives; and a Service User Strategy Day, during which those with personal experience could consider next steps and service user recommendations to drive forward the overarching NI strategy on personality disorder.

The issue of healthcare transformation was also raised. One delegate suggested that, with community pharmacies taking on greater healthcare responsibilities, they should be given the power to refer people to personality disorder services.

In a connected vein, another delegate suggested that it was important to reduce the distance people had to travel to see their therapists by expanding regional access to services. And it was suggested that therapists could visit service users in their homes or use community venues to bring treatment to people with personality disorder – rather than the other way around.

Finally, the conference considered changes to therapeutic care. One suggestion was a greater use of 'Family Together Therapy', so that families could collectively discuss issues and emotions that were leading to problems. Involving the family so intimately in therapy, it was suggested, could lead to better understanding of the issues, more sustainable outcomes, and the service user getting stronger support from their relatives. The conference also stressed that finding ways to intervene earlier should be a key priority.

Afterword - Valerie McConnell

The 2018 Northern Ireland Personality Disorder Conference was a vital event. The turnout of over 140 mental health practitioners, civil servants, academics and service users was a testament to the huge appetite for better outcomes for those with a diagnosis in Northern Ireland.

Throughout the day there were some lively and informed discussions and some superb presentations. However, more importantly, we also heard some clear suggestions about how to improve personality disorder services in Northern Ireland. Indeed, the enthusiasm and creativity continued to flow from the first session to the last. To give just one example, a very important point about reducing the distance people have to travel to receive treatment was made in the very final stages of the day's discussions!

Looking ahead, it's important that we don't let the progress made at the conference stall. To that end, we are convennig a Service User Strategy Workshop. This will indentify a path to improving treatment and care for those with a diagnosis in Northern Ireland - and will allow service users and their families to set the agenda!.

The Northern Ireland Personality Disorder Network will continue to bring together all those with a stake in the issue of Personality Disorder. And we will continue to work to raise awareness of the issue. These are still relatively early days and there is much still to be done. But it's hugely important that we drive forward our work as quickly as we can - and ensure our friends, neighbours, family members and patients get the very best care and support possible.

Conference report
produced by

Address: 46 Newforge Lane, Belfast, BT9 5NW

Telephone: 028 9040 23223

Email: info@mindwisenv.org