New Script
FOR MENTAL HEALTH

Choice, Connection, & Community

Initial Results of a Community Consultation on a New Script for Mental Health

Parliament Buildings, Stormont. Tuesday 10th October 2023

Welcome by MLAs

Mark H. Durkan & Órlaithí Flynn

New Script
FOR MENTAL HEALTH

Introduction

Maria Perkins
Event Chair

New Script
FOR MENTAL HEALTH

‘There comes a point when we need to stop just pulling people out of the river. We need to go upstream and find out why they are falling in’.

Bishop Desmond Tutu

New Script
FOR MENTAL HEALTH

Contextual Overview

Sara Boyce

New Script
FOR MENTAL HEALTH

Conall's Story

Background

- Conall was born on 13th April 1995
- Our first born, an only son and a big brother to 5 younger sisters.
- When he was 3 years old we moved our then small family to Northern Ireland, a better life beckoned.

I will always be grateful that I knew

Conall and had the pleasure of

Sharing so many fun times with him

Throughout our school and Uni years,

As said on the day of his funeral, I

Will always smile because Conall lived

And will forever cherish every memory I have of him.

Cara

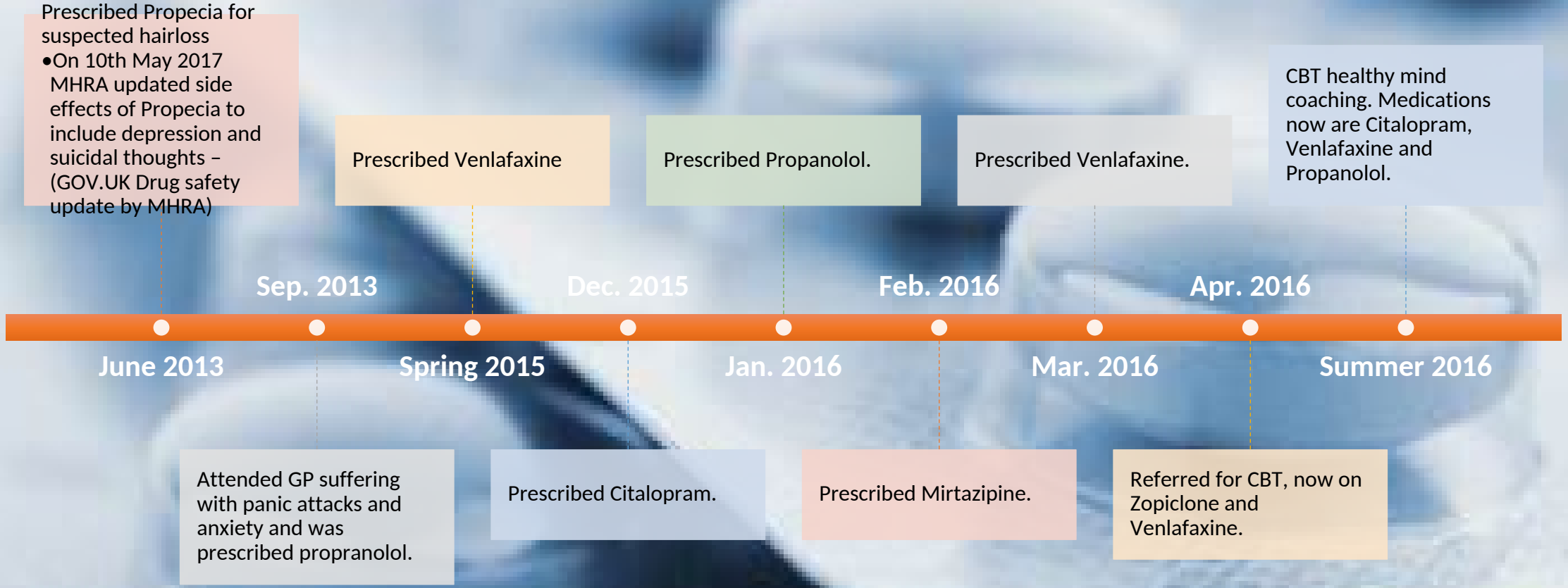
- At age 10 diagnosed with ADHD prescribed Ritalin, experienced an adverse reaction to the drug so we made the decision to stop giving him this medication.
- Conall attended a local Grammar school, he was an integral part of the local community, played Gaelic football, had many friends, was very sociable and full of life, summer holidays spent on the campsites of Europe where testimony to his character had him making multiple friends from all corners of the continent.
- Conall achieved 3 Grade B's at A level, 2013 went to QUB to study Physics however Maths was his first love and so in the Spring of 2014 he repeated his Maths A level and gained a grade A thus allowing him to commence a degree in Mathematics.

- That same year he joined his Uncle who was a Director in a Mental health Trust in England for work experience, he navigated the busy Motorways with ease and made a positive impression on all those he came into contact with.

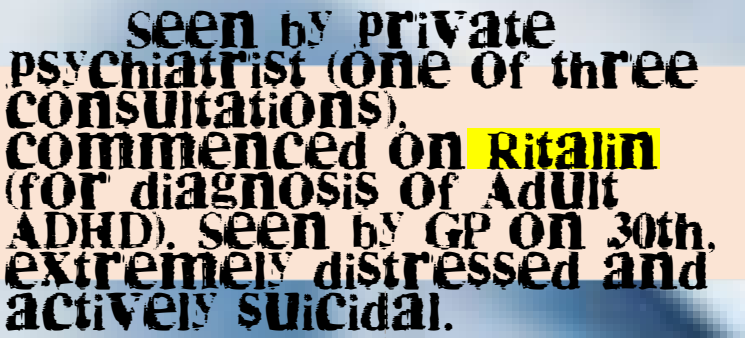
- Spring of 2016 he dropped out of University, he had not been attending his lectures, had only passed one of several exams and was suffering with severe depression and anxiety and even though he came home every weekend there were no signs of the difficulties he was experiencing.

- His mental health deteriorated rapidly, seeking out a private Psychiatrist, many visits to his GP, one course of CBT, it all culminated on 23rd December 2016 with him making an attempt on his life in the family home, on 13th February 2017 he would be dead, he was 21 years of age.

Timeline


Prescribed Propecia for suspected hairloss
•On 10th May 2017 MHRA updated side effects of Propecia to include depression and suicidal thoughts – (GOV.UK Drug safety update by MHRA)
June 2013
Attended GP suffering with panic attacks and anxiety and was prescribed propranolol.
Sep. 2013
Prescribed Venlafaxine
Spring 2015
Prescribed Citalopram.
Dec. 2015
Prescribed Propanolol.
Jan. 2016
Prescribed Mirtazipine.
Feb. 2016
Prescribed Venlafaxine.
Mar. 2016
Referred for CBT, now on Zopiclone and Venlafaxine.
Apr. 2016
CBT healthy mind coaching. Medications now are Citalopram, Venlafaxine and Propanolol.
Summer 2016

Timeline



September 2016

November 2016

Seen by specialist psychiatrist, commenced fluoxetine, diazepam, olanzapine. Possibly prodromal.

22nd December 2016

Parents call lifeline following attempt on life and discovery of 'Goodbye' notes. Admitted to a MH unit in the Belfast Trust.
Commenced on quetiepine, changed back to Olanzapine And dose increased.
Also prescribed Diazepam and Zopidem

January 2017

Discharged to the home treatment team of our local trust.

- Taken to accident and emergency on 19th January after taking an overdose. Discharged in the early hours of the morning. Under the care of the CRHTT in the run up to this crisis, daily visits in order to complete the perfunctory box ticking with no substance to the service provided, no actual support to the family more akin to an invasion of privacy.

- Attended scheduled appointment that morning with Consultant of home treatment team but following discharge from A&E in the early hours of the morning an additional overdose had taken place, in total 72 Xanax (A Benzodiazepine) had been taken.

- Admitted “voluntarily” without a capacity assessment and without assessment under the Mental Health Order NI, discharged a week later.

- Mental health care pathway not followed.
- Hospital policies not followed.
- NICE guidelines not followed.
- No risk assessment.
- No care plan.
- No discharge planning meeting.
- No liaison with Home treatment team.
- GP unaware of increase in medication.
- No follow up
- Death occurred 14 days later (In England at his Grandmother's)

- Lack of Candour

  In house SAI investigation full of factual inaccuracies and failed to learn from the events that led to Conall's death. We were excluded from investigation.

  "Amended" medical records

  Withheld crucial records from the Coroner

- Adversarial and defensive reaction towards family following the event

  Family excluded from the investigation.

  Withheld records from the family.

- Duty of care terminated.

  No acknowledgement of the failings in care, sought to blame the family rather than support them through this trauma.

  Failed to acknowledge a breach in trust in the weeks before our son's death that drove him away when he was at his most vulnerable.

- Reputational damage limitation.

- Regulation 28 prevention of future deaths issued to the Trust by the Birmingham Coroner.

- “Have the Trust learned anything from Conall’s tragic death?” Independent expert 2019

  To date the answer to this is no.

- Victims of a “Legacy” of poor standards in Mental healthcare
  - Concerns for other families who will be failed by the system, how many more Conall’s are there?
  - Parity of standards unequal to other areas of healthcare.
  - Strategy after strategy but outcomes are worse.
  - Lack of data in order to build a better service.
  - Legal failure of RQIA to regulate Community MH care for 14 years following a Judicial review (May 2023)
  - Lack of accountability or access to justice for families.
  - “Reach out” “It’s ok to not be ok” meaningless straplines


THE TRUE MEASURE OF ANY SOCIETY CAN BE
OUND IN HOW IT TREATS ITS MOST
ULNERABLE MEMBERS”

New Script

FOR MENTAL HEALTH

Consultation Results

Ger McParland

New Script
FOR MENTAL HEALTH

Purpose

- It’s time to have **an open conversation** about mental health.
- We are **creating opportunities** to have this conversation.
- We **all have ideas** from our own experiences and wisdom.
- This consultation is about **sharing those ideas.**
- **Collectively creating** a New Script for Mental Health.

Methodology

Invitation to :

'think about what would really address the causes of emotional pain and distress and then write your New Script for Mental Health'

- Mix of consultation methods – online, video, workshops, stall at health & well-being event for young people
- 127 New Scripts completed
- Responses anonymised
- Thematic analysis

Key Themes

1. Reform mental health services
2. Give people wider options
3. Individual and collective empowerment
4. Address underlying causes of emotional pain and distress
5. Underpinning values

Theme 1:

Reform Mental Health Services

New Script
FOR MENTAL HEALTH

1

‘Put talking therapy at the heart of the mental health framework. This means huge investment in making it acceptable to everyone, not just small increases in funding. A total refocusing is needed. There is a de-facto two-tier system of mental healthcare, where those who can pay £50-£60 per session of counselling have more options’.

(a) Talking Therapies

End the post-code lottery

End the de facto 6 week cap on number of sessions

Invest in community-based counselling services

Provide counselling in schools

Make it affordable for new counsellors to practice

2

‘Counselling and psychiatric support available in a timely manner through GPs, including for children and young people’.

3

‘Immediate access to counselling and for as long as needed’

(b) Timely Access

☞Not **just** during crises /but absolutely during crises

☞to support for children and young people

☞to the appropriate professional

4

‘Trauma informed practise by all healthcare professionals and awareness of the impact of trauma.’

5

‘Warm boundaries in place. When people are being transferred to other services, there should be person to person contact and handover to the new service, not just a letter or a phone call.’

(c) Trauma-informed process

- Remove targets and focus on caring relationships
- Warm handover
- Whole systems approach
- Improved record keeping and communication between services
- Greater respect for mental health staff

6

‘Additional funding for the community and voluntary sector and long-term funding for community based peer support.’

7

‘Lobby for changes to our funding model so the Health Department can do multi-year funding.’

(d) Funding

- More funding

- Change the funding model to multi-year budgets

- Funding should follow the patient

8

‘Fully informed consent around prescribing of psychoactive drugs to include risks of long term use and difficulties of coming off’

9

‘Provide early intervention, timely support for children and young people’

(e) Services for particular groups that address specific issues

- Investigate physical health when requested
- Bespoke mental health services for people with Asperger's Syndrome
- Resolve the dual diagnosis issue
- Regular review of medication
- Provision for people without family support

Theme 2:

Give people wider options

New Script
FOR MENTAL HEALTH

10

‘Recognise the role that nature, creativity and the arts have, and support this’

11

‘Greater availability of social prescribing for social, creative and active pursuits. People may have a one hour appointment with a mental health professional once a fortnight, but what support do they have in between these appointments?’.

12

‘More community based initiatives like The Rest of the Story storytelling programme, to empower people to frame their own experience, enabling them to support each other in the community’.

- Access to arts and creativity
- Access to nature
- Non-drug based approaches e.g. The Rest of the Story & social prescribing
- Alternatives to ED for emotional distress
- Rehab services
- Community networks & support

Theme 3:

Individual & Collective Empowerment

New Script
FOR MENTAL HEALTH

13

‘Give people the tools to create ‘good’ mental health instead of fighting ‘bad’ mental health’

14

‘My new script for mental health involves power at the community level, redistribution of power downwards from those at the top to those at the bottom. This is crucial because too often those at the top want those at the bottom to blame themselves. For hunger, for illness, for substandard housing. In this way, redistribution of power promotes wellness’.

Individual level

- A person, not a diagnosis
- Connect with others with similar experiences
- Empowered to tell your story

Collective level

- Value lived experience
- Listen to activists & their solutions
- Communities empower themselves, collective agency

Theme 4:
Address underlying causes of emotional pain & distress

New Script
FOR MENTAL HEALTH

15

‘Shelter, food, clothing, love and proper income to provide…..are essential to human existence’

16

‘More social housing. Waiting lists are a joke. Affordable housing. Rental market is so stressful’.

17

‘Asylum seekers come from countries torn by war and poverty. We come traumatised and we face more trauma here. Asylum seekers need to be able to work and have access to services so we can live in dignity’

Address the structural context of people's lives, with an explicit focus on human rights

- More social and affordable housing
- Allow asylum seekers to work
- Universal Basic Income
- Address transport barriers
- Stop privatisation of NHS

New Script
FOR MENTAL HEALTH

Theme 5:
Underpinning Values

Choice, Connection and Community. Parliament Buildings, Stormont. Tuesday 10th October 2023

‘ a love ethic’

‘treat people as human beings’

New Script
FOR MENTAL HEALTH

Choice, Connection and Community. Parliament Buildings,
Stormont. Tuesday 10th October 2023

Response from MLAs

New Script
FOR MENTAL HEALTH

Next Steps

New Script
FOR MENTAL HEALTH

Thank you for being with us ??

www.nlb.ie/campaigns/mental-health

sara@pprproject.org

Tel : 90-313315 / 07864074235

Twitter / FB/Instagram #WMHD23 #NewScript

New Script
FOR MENTAL HEALTH

Choice, Connection and Community. Parliament Buildings, Stormont. Tuesday 10th October 2023