# Making a case for BPD diagnosis and management before the age of 18

**Ian Gould** – Lived experience Dad

**Jane Cannon MBE** – Lived experience Mum

# THE REASON WE ARE HERE …

**SAM GOULD**

**Born 22/11/01**

**Died 02/09/18**

**Age 16**

**CHRIS GOULD**

**Born 22/11/01**

**Died 26/01/19**

**Age 17**

# We believe an earlier diagnosis of BPD (with treatment) would have saved our daughters' lives

- **We could have educated ourselves as carers and made better decisions**
- **Avoided invalidating therapies (which led later to refusing DBT)**
- **Avoided (or minimised) in-patient stays in general wards**
- **Reassured our girls they were not "mad and bad"!!**

**NHS Key Principle #1:** “The NHS provides a comprehensive service, available to all …The service is designed to improve, prevent, **diagnose and treat** both physical and mental health problems with equal regard…”

- When you have an illness you expect medical professionals to diagnose you accurately, to inform you of that diagnosis so you and your carers can educate yourselves and to recommend the most appropriate treatments to help you overcome, or at least improve, your condition.
- In the UK there is also an expectation that the NHS will provide that treatment in accordance with NICE Guidelines.
- **What other disorder is wilfully hidden from patients and carers – keeping them ignorant of the services they should expect?**

# **Inquest Findings** – Preventing Future Deaths Coroner's Concerns:

**"Diagnosis of Borderline Personality Disorder (For CPFT)**. I am concerned that the evidence in Chris' case, in particular, suggested **a degree of age-related reluctance consistently to use the terminology of Borderline Personality Disorder** (or Emerging Personality Disorder or EUPD), even when a highly specialist second opinion had supported this and appeared to have been accepted. There are risks associated with a reluctance to use a personality disorder diagnosis (c.f. Position Statement from the Royal College of Psychiatrists dated January 2020). I received evidence that there have already been some changes/improvements in the preparedness to recognise Borderline Personality Disorder and that further consideration will be given in the context of the new ICD 11."

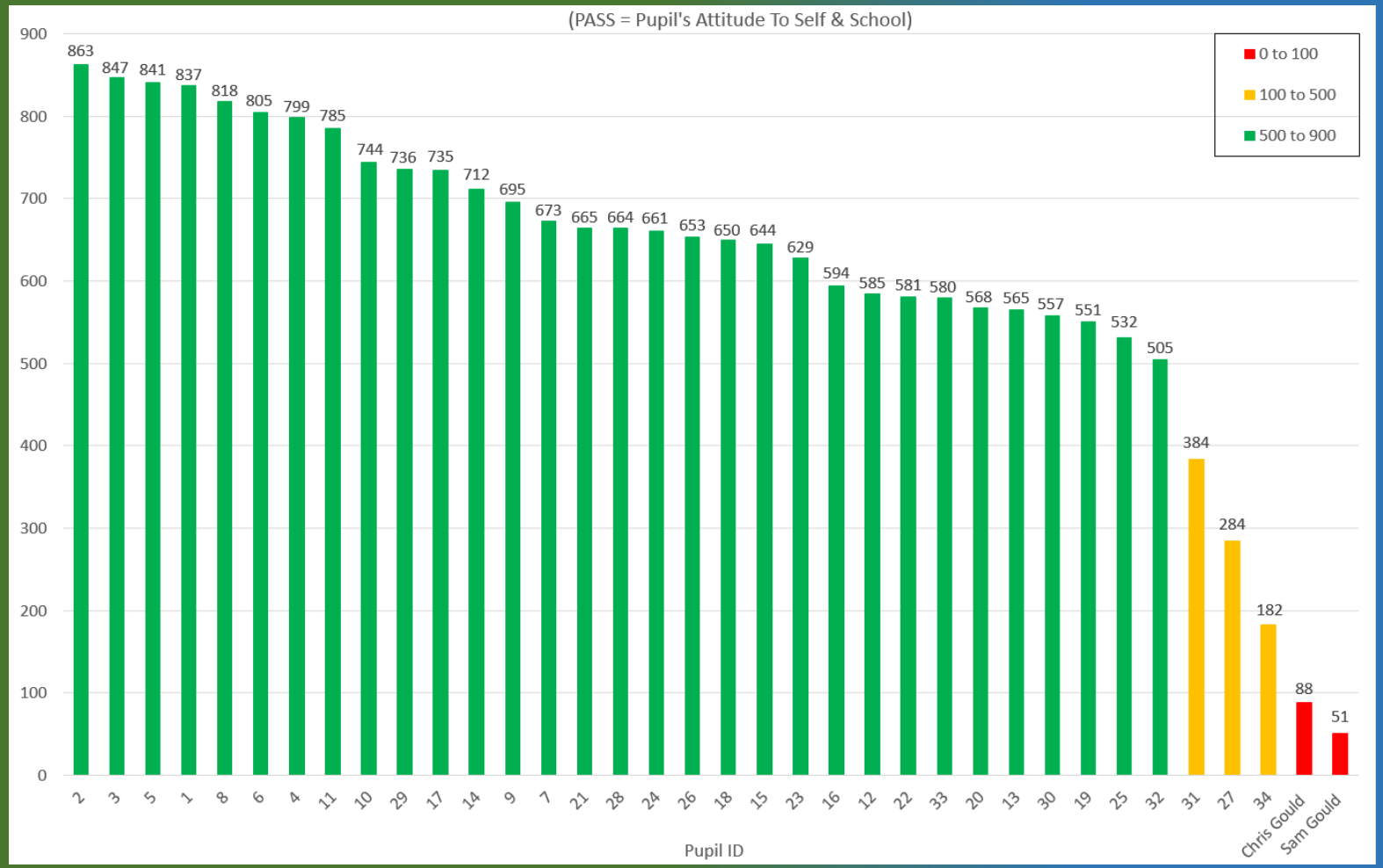
# How it all began…
(the benefit of 20:20 hindsight…)

Healthy, happy children …until….

- Age 6 – “inappropriate sexual behaviour” at school (no safe-guarding note or referral)
- Age 7 – Chris … thumbsucking
- Age 8 – Sam … trichotillomania
- Age 9 – Sam CAMHS (for trich)
- Age 10-13 – still bed wetting
- Age 10 – P.A.S.S. test….

# PASS – Pupil Attitude to Self and School – Year 6

(No social care referral!)



# Our girls had everything…
# why were they falling apart…??

- Age 12 – school work deteriorates
- Age 13
  - Self harm discovered
  - Eating disorders suspected
  - Suicidal thoughts emerge
- Age 14 – Sam to CAMHS : self harm
- Age 14 – Chris to CAMHS after first suicide attempt
- Age 14½ – DISCLOSURE…

# “ I want to know what’s wrong with me…”

**… was that too much to ask?** (*CAMHS Notes – age 14)*

## SAM – Eating Disorders Pathway

- ✓Self-harm
- ✓Thoughts of death and suicide
- ✓Previous plans for suicide
- ✓Dissociation
- ✓Binge eating
- ✓Low self-esteem/negative self-beliefs
- ✓Anxiety / social anxiety,
- ✓Low mood / Emptiness,
- ✓Anger – unable to manage emotions
- ✓Poor sleep, daily headaches,
- ✓Hair pulling as a form of self-harm

## CHRIS – Core Pathway

- ✓Self-harm
- ✓Suicidality
- ✓Eating difficulties : (fast/binge/purge)
- ✓Body image issues
- ✓Struggles to recognise own identity
- ✓Feelings of shame / disgust / anger / contempt
- ✓Challenges with emotional regulation and rapidly fluctuating moods,
- ✓“Black and white” thinking
- ✓Intense relationships

EDNOS?? DEPRESSION?? ANXIETY??

# From bad to worse… still no diagnosis…

(Girls age 15 : 2016 – 2017)

## SAM

- Jan 17 – CBT “invalidating”
- Feb 17 – Serious overdose
- Mar 17 – **Admitted inpatient**

…. ***Deteriorated*** ….

- June 17 – MHA Section 3
- **SECOND OPINION … BPD!!**

*“I knew it wasn’t depression!!”*

***“BPD is like a roadmap of me”***

## CHRIS

- Nov 16 – Mute / shut down
- Dec 16 – Suicide attempt
- Jan 17 – **Admitted inpatient**

…. ***Deteriorated*** ….

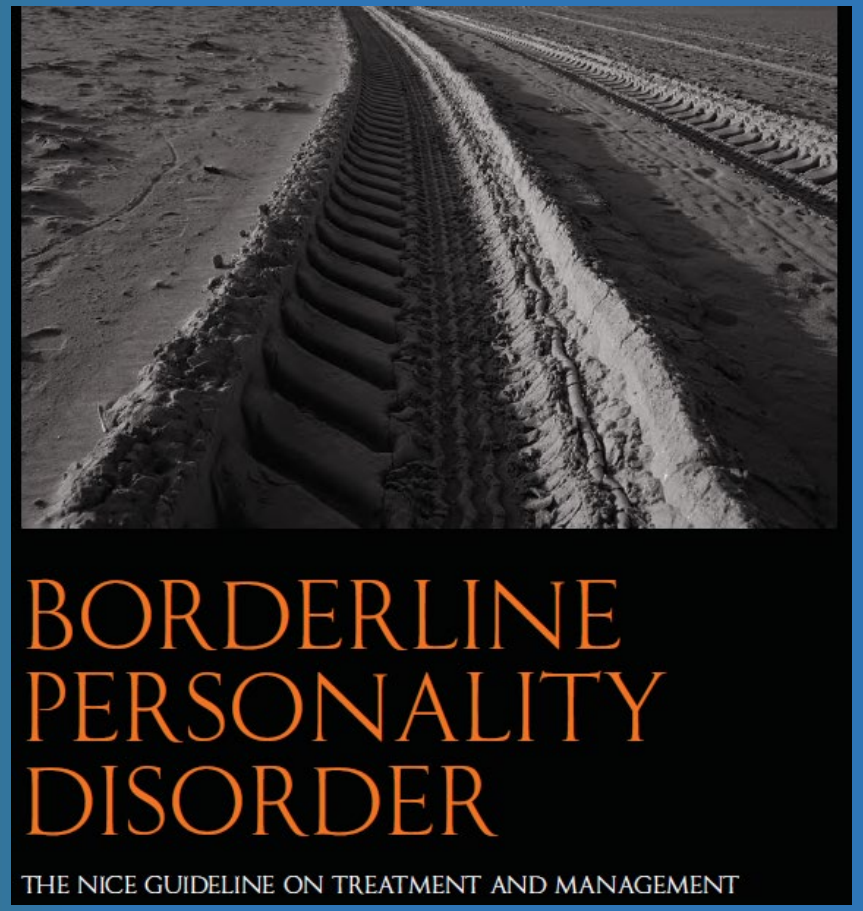
- Oct 17 – MHA Section 3
- **SECOND OPINION … BPD!!**

*“I knew it wasn’t just cPTSD!!”*

# At last we could educate ourselves …

(… but the damage was done)

- "Outcomes from RCTs of …CBT … did not show any benefit of treatment … it also reduced considerably the health-related quality of life of people receiving the intervention."
- **CBT put Sam off therapy for the rest of her life**
- "Young people with borderline personality disorder and a history of childhood trauma may also deteriorate if trauma therapy that involves repeated and/or in-depth exposure to the trauma is embarked upon before their more impulsive behaviours are stabilised."
- **Chris refused family therapy after the therapist insisted on talking about her abuse**



# If we knew then what we know now…

(...but how could we – without a diagnosis?)

- "When a person with borderline personality disorder presents during a crisis … **explore other options before considering … inpatient admission"**
- "Several experts have not only dismissed the therapeutic impact that non-specialist hospitalisation has on borderline personality disorder but **have gone as far as suggesting that inpatient admission actually has a negative outcome"**

- "Admission to a general purpose adolescent unit with a mixed client group can lead to an **escalation of risk and deterioration in symptoms** and functioning"
- "Mental health professionals working in secondary care services, including … CAMHS **should be trained to diagnose borderline personality disorder"**

*(all quotes from NICE BPD guidelines)*

# From worse to worst…
(Girls age 16/17 : 2017 – 2019)

## SAM

- Oct 17 – discharged

*Frequent A&E visits and crises*

- Feb 18 – arrested during crisis
- Feb 18 – excluded from school and writes suicide notes
- Stockpiles meds after GCSEs
- Sep 18 –**Takes her own life**

## CHRIS

- Feb 18 – transfer to Low Secure (against our wishes)
- Apr 18 – discharged home
- Summer 18 great improvement
- Readmission to Tier 4 after Sam died – persistently suicidal
- Jan 19 –**Takes her own life**

# We are trying to understand how a profession can let young people down so badly… yet believe they are doing “the right thing”

## STIGMA / DISCRIMINATION?

- Agreed - the stigma and discrimination faced by some sufferers is awful … BUT
- So is stigma for AIDS / lung cancer / obesity … Doctors don’t withold diagnosis for those.
- TACKLE THE STIGMA!!

## AWFUL NAME

- Agreed – telling someone their personality is disordered seems horrible / cruel … but …
- Name used worldwide / body of research & evidence
- Aim for Global agreement – ICD12 name change??
- Not “Voldemort diagnosis”

# Isn't complex PTSD a "nicer" diagnosis??

- Both our girls had "**cPTSD**" suggested as a diagnosis when they were inpatients. Both rejected this in the strongest terms:
- They wanted to be able to talk about their mental health without facing the inevitable question: "**so what was your trauma**?"

**SAM**

- Flatly refused to accept that the abuse caused her problems
- Rejected therapy that focused on abuse.

**CHRIS**

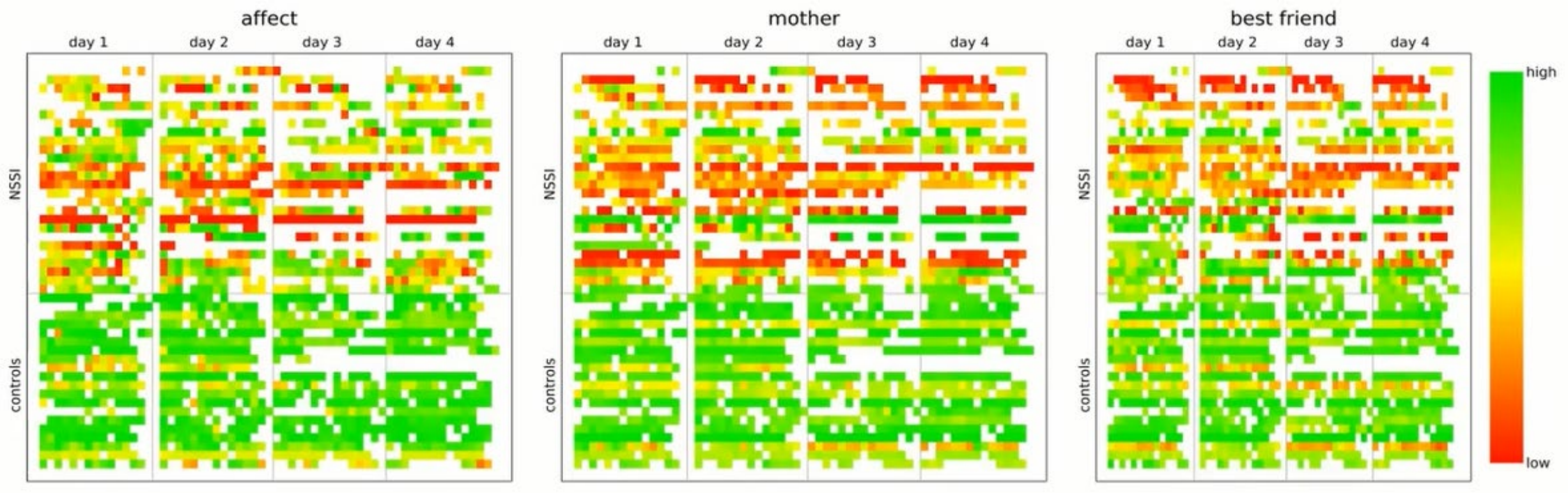
- Accepted that the abuse caused some of her problems but not all
- Did not feel cPTSD symptoms were as good a "fit" as BPD.

Also, both girls were diagnosable BEFORE the abuse was disclosed … and some people never disclose … ***"What happened to you?" doesn't work for everyone!***

*PLUS – no NICE guidelines and comprehensive evidence base for cPTSD*

# Might be mistaken for normal teenage emotions ??

...There was nothing “normal” about Chris and Sam’s emotional pain…




Heat map to visualise affective and interpersonal instability using Ecological Momentary Assessment.

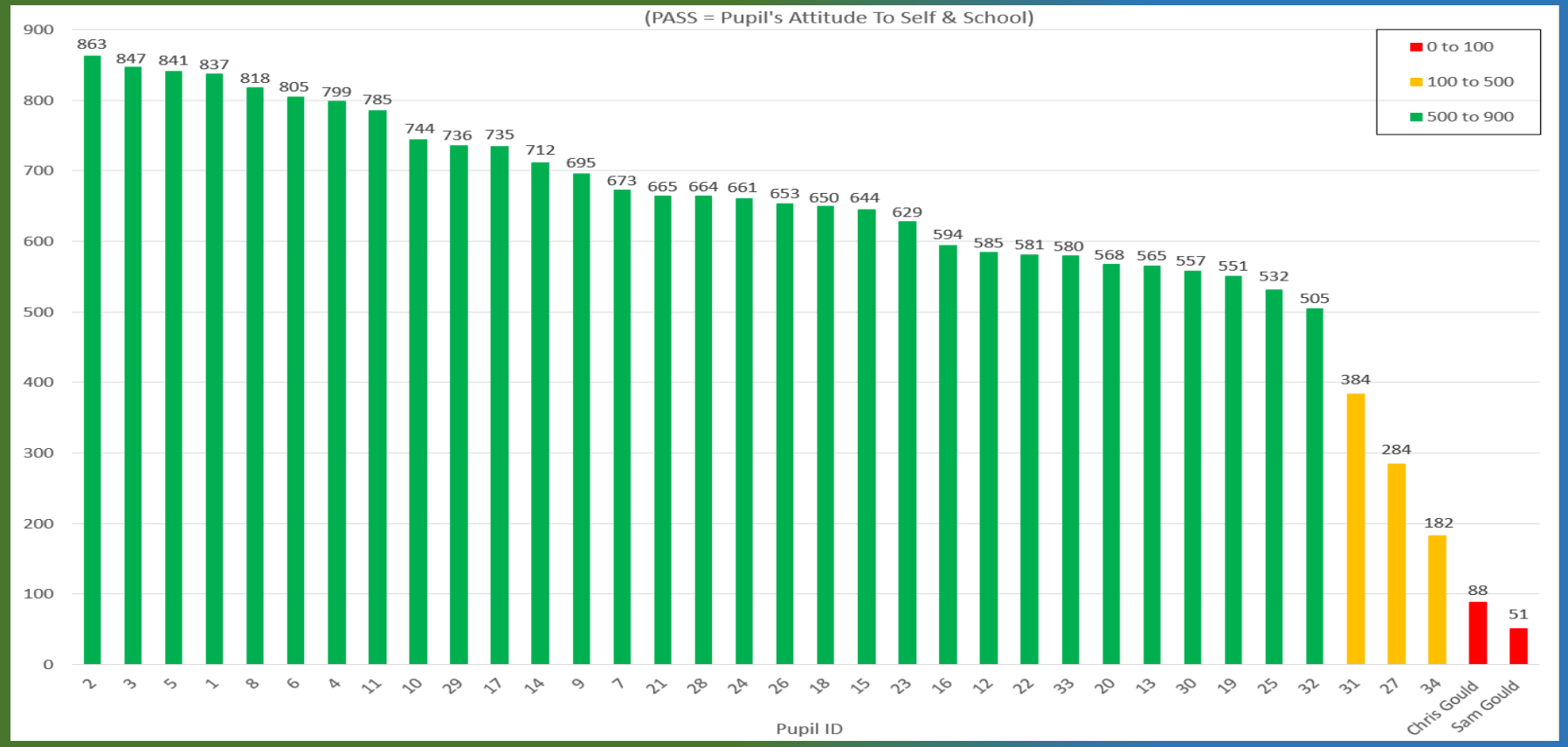
**Healthy teenagers – bottom half**

**BPD teenagers – top half**

(used with permission of Prof. Dr. med. Michael Kaess – University of Bern)

from Santangelo et al (2017)

# It is possible to identify the children with emotional problems who need your help…




# Intervene early … improve lives … save lives.

# Forensic / Criminal Justice aspects…

Sam died with a criminal record. Chris was terrified of Police.

## SAM

- Dissociate / self-harm / fight back if restrained. Safety plan "call police" because no crisis team. Kicked a policeman…
- Learned as an inpatient : threaten violence then adults leave you alone -> report to police
- *Forensic suggested but not offered*

## CHRIS

- Reported to police for throwing a phone case when a distressed inpatient.
- Several traumatic restraints led to:
- Terror of police & sirens
- Wrongfully chased and restrained (mistaken identity)

NHS Quality Improvement Taskforce (CYP Inpatient) – new project: "***Criminalisation of Young People***". Involvement from this AFPSIG community very welcome.

# BPD Campaigning …

(now Inquests complete and Serious Case Reviews written)

- **EDUCATION**
  - Exclusions = discrimination
  - No 16+ education (GCSE retakes)
  - MH education on curriculum
- **LOCAL AUTHORITIES**
  - EHCPs for all inpatients
  - Supported accommodation
  - Practical help from Social Care
- **POLICE / JUSTICE**
  - Avoid criminalising mental illness
  - Burden of proof for CSA
- **DWP** – PIP / assisted employment
- **TREASURY** – economic cost
- **EHRC** – Fight stigma + discrimination

**HEALTH / CAMHS**

- Very early identification & intervention & treatment – in schools / GPs / community
- DIAGNOSE!!!
- BPD pathway in CAMHS **0-25** "Emotional Regulation"
- DBT / MBT locally for all (incl. online)
- Home treatment & crisis team 24/7
- Peer support
- Carer support / education
- BPD specialist wards in CAMHS
- More research effort on BPD in <18s
- Fight stigma – esp. amongst professionals

# Changing the world of BPD

(in memory of Sam and Chris)