JCPPP Advances First Year Anniversary

Thursday 9 June 2022

Twitter - @TheJCPPPAdvances JCPPAdvances
Will the neurodiversity concept change child psychology and psychiatry research?

ADHD as an example

JCPP Advances Anniversary Celebration

Edmund Sonuga-Barke

King’s College London
Aarhus University
Neuro-diversity as a rights-based concept

• Originating within the autism community.

• New way of thinking about people with neuro-developmental conditions....

• .... motivated by the pursuit of justice....

• ... valuing & accommodating to different ways of thinking/being ....

• ...promotes their personal dignity/societal acceptance..
Neuro-diversity as a rights-based concept

• **Accepts** - The neuro-biological reality of “ADHD”.

• **Rejects** – “ADHD” as disorder.

• **Emphasizes** - Positive “ADHD” aspects.

• **Looks to** - Accommodate to “ADHD”.

• **Privileges** - Personal experience of ADHD.

• **Promotes** - Self determination & solidarity.
These radically different assumptions about the nature of ADHD also have the potential to transform our scientific paradigm.
• Incremental gains within stable framework - a **paradigm** (DSM/ICD).

• Facilitates and constrains science through assumptions, scientific & non-scientific, about disorder’s nature.

• Step change occurs when meta-theory is overturned and paradigm shifts.

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**The Kuhn Cycle**

- Pre-science
- Normal Science
- Model Drift
- Model Revolution
- Model Crisis
- Paradigm Change
Key science question – what brain dysfunction causes disorder?

ORIGINATING CAUSES GXE

TRANSLATIONAL SCIENCE ORIGINATING CAUSES GXE DYSFUNCTIONAL BRAIN

PROBLEM: IMPAIRMENT TO CREATE DISORDER

STIGMA & REJECTION INHERENT
IMPAIRMENT

LOW SELF WORTH

LONG TERM RISK FOR MENTAL ILL HEALTH

IMPROVED BRAIN FUNCTION

RESOLVED IMPAIRMENT

ACCEPTANCE

SELF Esteem

LONG TERM WELL-BEING

ADHD

Tx^1

Tx^2
Reframes “ADHD” as divergent attention/activity caused by natural brain variations.

Breaks the link impairment and disorder – presents it as contingent, situated & socially constructed.

Focuses research on how cultural norms impose environmental constraints to impair, stigmatize & stifle potential.
Key science question: What defines “ADHD” positive environments?

ORIGINATING CAUSES
GXE

ATYPICAL BRAIN

CENTRAL CONTINGENT IMPAIRMENT

ADHD'

STIGMA
WASTED TALENT

FROM REJECTING TO UNDERMINING

FROM ACCEPTING TO EMPOWERING

FEELING WORTHLESS
REMAINING PASSIVE

FAILING BECOMING VULNERABLE

FEELING VALUED
GAINING AGENCY

DEVELOPING RESILIENCE
THRIVING

ACCOMODATING INCLUSIVE?
AFFIRMING NURTURING?
GUAGED CHALLENGE STRUCTURE – SCAFOOLDING?

DISCOVERING HIDDEN TALENT
FEELING ACCEPTED

FEELING ACCEPTED

GAINING

ACCEPTED

HIDDEN TALENT

DEVELOPING

RESILIENCE

THRONING

ACCOMODATING

INCLUSIVE?

AFFIRMING

NURTURING?

GUAGED CHALLENGE

STRUCTURE – SCAFOOLDING?

FEELING

VALUED

GAINING

AGENCY

DISCOVERING

HIDDEN TALENT

FEELING

ACCEPTED

KEY SCIENCE QUESTION: WHAT DEFINES “ADHD” POSITIVE ENVIRONMENTS?
Reframes “ADHD” as divergent attention/activity caused by natural brain variations.

Redefines impairment as contingent, situated & socially constructed.

Places the personal experience of neuro-divergent people at the heart of these attempts.

Focuses research on how cultural norms impose environmental constraints to impair, stigmatize & stifle potential.

Neurodiversity paradigm changes what’s studied and how!
Regulating Emotion – Strengthening Adolescent Resilience

An experiment in co-intentional translational science

Part of UKRI’s Adolescent Mental Health & the Developing Mind initiative.
Integrated care to improve 21st Century child and adolescent health

Mina Fazel

Professor of Adolescent Psychiatry, University of Oxford
Consultant in Child & Adolescent Psychiatry, Children’s Psychological Medicine, Oxford University Hospitals
The Changing Face of Medicine

- Infancy, childhood and adolescence
  - Physical growth
  - Cognitive capacities
  - Social relationships
  - Communication
- Children with chronic and increasingly complex health problems
  - Medical and technical advances
  - Improved survival
  - Heavy burden of health care
- Legacy of separation
Models of care: how and by whom

- Complex needs mainly treated in tertiary hospitals
- Previous model: single specialist
- Contemporary paediatrics
  - Specialisation
  - Sophistication of technical tools
  - Multidisciplinary teams
- Can be easy to neglect non-biological aspects of care
Mental health

- Increasing awareness of mental health difficulties
- Especially for those children with chronic health difficulties
- Affects treatment adherence, health outcomes, quality of life
- Social and environmental determinants of health
Areas of need for psychiatry services in children’s hospitals

- Poor diagnosis of emotional distress and mental disorders
- Service challenges: Lack of psychiatric capacity, Inconsistent models of care
- Specific management issues
- Recognition + Diagnosis
  - Multidisciplinary Teams: Can promote clarity of referral pathways, Efficient use of limited psychiatric expertise
- Psychiatric approach:
  - Psychiatric medications
  - Psychological therapies – CBT
  - Behavioural therapies – distraction, relaxation, problem solving
  - Consideration of family, school, peers

Education (Patients, Families, Clinicians)
Main areas

- Life limiting illnesses
  - High burden of care
- Disorders involving the brain
  - Epilepsy; TBI
- Common chronic conditions
  - Diabetes, Asthma
- Psychiatric emergencies
- Disorders where psych and paeds intertwined
  - Gender dysphoria
  - Severe eating disorders
Coordinated Care needs communication

Co-located Care needs physical proximity

- Minimal collaboration
- Basic collaboration at a distance (e.g., telepsychiatry)
- Basic collaboration on site
- Close collaboration with some system integration

Integrated Care needs practice change

- Close collaboration approaching an integrated practice
- Full collaboration in a transformed/merged practice
Young Person’s account

Disorders involving the brain

When I first came to the hospital I thought my problems were physical. When I was told I didn’t have epilepsy I had a mixed bunch of emotions. Initially I was very confused because I had been taking antiepileptic medication for 5 years….

Now I really understand what epilepsy is, and that I don’t have it, but I needed help to understand it. If at that point I had been told I needed to go somewhere else to get mental health support, I would have felt that they were brushing me off. I would have been angry and annoyed towards the health care system. I probably would have become depressed.

I don’t think I would have been able to trust medical professionals again.”

[15 year old presenting with seizure].
A defining moment that still brings tears to my eyes is when I recall the meeting that we had with our neurologist and psychiatrist. This was the meeting where as a team, the neurologist and psychiatrist told us that they were 95% sure that our son did not have epilepsy. That was a very scary (and also a very hopeful) time for us. Before we left the meeting the doctor locked eyes with our son and said 'on behalf of the medical profession, I apologise'.

That statement was a turning point for our whole family. It took courage to say it and it helped us move on to the next step of getting care. We felt that we could do that because the psychiatrist was part of that process and that conversation. We were turned over to their care, quite literally, on that day with the neurologist in the room.
Models of integration

- Bring biological, psychodynamic, pharmacological, developmental, family, and systems perspectives into the consultation
- 1930 John Hopkins: first example of collaborative care paediatric psychology unit
- In North America
  - Triple Board training
  - Paediatric portal training
Conclusions

Increasing numbers

Psych comorbidity affects
• Treatment adherence, health outcomes, quality of life

Current configuration erode opportunities to better integrate
• Inertia of institutions to change
• Need to incorporate adolescent voice to shape services

LMICs
• Focus on acute care
• Low mental health literacy
• Mental illness highly stigmatised
Do we need integrated care for children and adolescents?

oxchildpsych Our team recently researched whether there was a need for integrative care for children and adolescents. This post contains a little more... more

dredge02 Yes we do! Is the simple answer, from day one. It should be a health system and not a sickness system. Active healthcare instead of...
Our researchers recently published a paper on how new types of hospital 'integrated care' teams are needed for young people with the most complex health problems - with paediatricians, psychiatrists and surgeons all working together in larger teams with families, schools and allied health professionals.

Here's what the patients thought.....
Paediatricians don’t understand mental health and sometimes say things that are inappropriate, and make you feel worse about yourself. Mental health people are not confident with physical stuff and often panic and send you to hospital. Maybe if physical and mental health were more together they could learn from each other and provide what is best for the patient.
-14 year old female with an eating disorder

It has been invaluable to have mental health as part of my treatment in the hospital. I am anxious and I know anxiety makes my symptoms worse. I was referred to Mental Health services in the community, but they didn’t understand IBD [inflammatory bowel disease], and they didn’t work out the connection. They thought that I had an eating disorder because I was under-weight. I need somebody that understands both and the impact on each other.
-13 year old with IBD
Definitely having mental health support is very important for children with cancer. It is a massive thing and it affects you in every way, physically, emotionally and socially. You need someone there and then, you can’t wait.

-18 year old with acute leukemia

*Professor Michael Sharpe*

*Oxford University Hospitals*

*Young people who shared their experiences*

*Josie- insta and tiktok assistance*
How small is a *small* effect size?
Reflections on the pandemic

Argyris Stringaris
Professor of Child & Adolescent Psychiatry
University College London
04/06/2022
Research findings in plain English.

Scientists are asked to communicate in plain English in order to explain their findings to non-specialists, including politicians and journalists.

This became an urgent need during the pandemic when scientists found themselves at the epicentre of public debates.

For the sake of communication scientists often resort to translations of numerical findings into plain language.

How well does this translation work?
Research findings in plain English.

For example, some scientists have reassuringly told us that the negative effects of the pandemic on young people are “small”.

How reassured should we be? Haven’t CAMHS presentations increased (¹) since the pandemic?

I will take this “small” as my point of departure and try to simulate the problem.

Ford TJ, John A, Gunnell D (2021) Mental health of children and young people during pandemic BMJ 2021;372,
Standard take on effect sizes.

The most common interpretation of effect sizes comes from Jacob Cohen. He declared (and apparently later regretted having done so), that for an effect size $d$, defined thus:

$$d = \frac{\text{difference in the average between two conditions}}{\text{standard deviation of these two conditions pooled together}}$$

the following holds:

- A value of 0.2 represents a small effect size.
- A value of 0.5 represents a medium effect size.
- A value of 0.8 represents a large effect size.

A good study to estimate effect size.

Assume you have done the ultimate study:

- Is longitudinal with two periods (pre- and during)
- Accounts for regression to the mean
- Does careful statistical inference

and have arrived at an effect size about the difference in depression scores in children before and during the pandemic.

You find an effect size of $d = 0.14$.

I will try to put this small effect in context

Simulating the pandemic: data.

Consider the Mood and Feelings Questionnaire, a common depression measurement tool, as your outcome.

Let the mean pre-pandemic\(^1\) in adolescents be:

\[
\text{MFQ\_mean\_pre} = 4.90 \text{ with an SD of } \text{MFQ\_sd\_pre} = 4.49
\]

For an effect size close to \(d = 0.14\) as per Mansfield\(^2\), the mean post-pandemic would have to be:

\[
\text{MFQ\_mean\_post} = 5.53 \text{ (let's keep the standard deviation the same)}
\]

and let the threshold for caseness be the standard

\[
\text{MFQ\_threshold} = 12
\]

---


Simulating the pandemic: two distributions.
Simulating the pandemic: two distributions.

I used a scaled beta distribution to simulate the data.

Shifts in depression **mean** during a pandemic affecting 1M YP at Cohen's $d \sim 0.14$

![Graph showing distribution before and after a pandemic](image-url)
Simulating the pandemic: two distributions.

Here you see the two distributions with the threshold. It looks fairly innocuous.

Shifts in depression **means** during a pandemic affecting 1M YP at Cohen's $d \sim 0.14$
Simulating the pandemic: what happens to the cases.

But is it that innocuous?
Simulating the pandemic: excess cases due to the pandemic.

Here you see what the shift in mean values does to the tails.

Increase in Depression **cases** during a Pandemic at Cohen's \( d \sim 0.14 \) by Number of Youth Affected
Simulating the pandemic: a reality check.

According to Mansfield et al\(^1\), the empirical excess prevalence, is about 1.6%.

This number corresponds to our simulation results:

e.g. for 1M people, we get about 16K excess cases of depression.

Simulating the pandemic: small effects

## Warning: Removed 12 row(s) containing missing values (geom_path).
Simulating the pandemic: small effects

I have now varied the small effects to give you an idea of the range.

![Graph showing increase in depression cases during a pandemic by number of youth affected and effect sizes.](image)
Small effects at large scales

Small effects are irrelevant (mostly) in a clinic.

- That’s why the label makes sense in clinical medicine.

Small effects are very relevant when they scale.

- That’s why the label makes no sense in public health.

Other factors, such as effects for what are important too.

The approach presented here emphasises the value of simulation.

Useful Readings:

Matthay EC (2019) Powering population health research: Considerations for plausible and actionable effect sizes. SSM Population Health, 19, 100789

Funder DC, Ozer DJ (2019) Evaluating Effect Size In Psychological Research: Sense and Nonsense,
Small effects and reality

The findings here have implications about how we perceive reality and how we communicate about it.

Conventions (e.g. small effects) and summary statistics (e.g. Cohen’s d) are useful and necessary.

But they can also be highly misleading.

We propose that presentations of raw data, absolute numbers and simulations become the norm in scientific abstracts.

Last but not least: think how important small effects may be for interventions.

Pre-registering child mental health research using existing data: Challenges and potential solutions

Jessie Baldwin
Sir Henry Wellcome Postdoctoral Fellow

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@jessiebaldwin
Researcher bias
Researcher bias

Apophenia
Researcher bias
Researcher bias

- Confirmation
- Apophenia
- Hindsight
Researcher bias

Confirmation
Apophenia
Hindsight

p-hacking
Selective reporting
HARKing
Researcher bias

Confirmation
Apophenia
Hindsight

p-hacking
Selective reporting
HARKing
Challenge 1: Prior access to data
Solution: Multiverse analysis
Solution: Multiverse analysis

RUN
Specification 1
Specification 2...
Specification 1000
Solution: Multiverse analysis

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Specification 1
Specification 2...
Specification 1000
Solution: Multiverse analysis

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Orben et al., 2019, *Nat Hum Behav*
Challenge 2: Pre-registered analyses not appropriate for the data
Solution: Trial analyses on blinded data
Solution: Trial analyses on blinded data

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Data distribution = same
Solution: Trial analyses on blinded data

Data distribution = same
Missingness = same
**Solution: Trial analyses on blinded data**

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Data distribution = same  
Missingness = same  
Associations = different
Solution: Trial analyses on data missing outcome
Solution: Trial analyses on data missing outcome

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Multivariable distributional characteristics ✔
Solution: Trial analyses on data missing outcome

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Multivariable distributional characteristics ✔
Collinearity ✔
Solution: Trial analyses on data missing outcome

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Multivariable distributional characteristics ✔
Collinearity ✔
Predictors of missing data ✔
Challenge 3: Research may not be hypothesis-driven
Solution: Pre-register research questions & conditions for interpretation
### Solution: Pre-register research questions & conditions for interpretation

#### Research question: Is $X$ causally related to $Y$?

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<th>Interpretation</th>
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Solution: Pre-register research questions & conditions for interpretation

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- Effect size thresholds for interpretation
Solution: Pre-register research questions & conditions for interpretation

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• Effect size thresholds for interpretation
• Smallest effect size of interest
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• Initiatives to increase ease of adoption = wider uptake
Acknowledgments

Jean-Baptiste Pingault
Tabea Schoeler
Hannah Sallis
Marcus Munafò
The extent and drivers of the gender-gap in adolescent mental health

Praveetha Patalay

June 2022
Estimate double the prevalence of internalising difficulties/disorders in females

This gap seems to appear in adolescence, and persist across the lifecourse

Also seen in other key mental health outcomes such as life satisfaction and wellbeing
Still seen at age 17

Fig. 1

Male M=6.84
Female M=8.37

Patalay & Fitzsimons, 2021 BJPsych
Why is there a gender gap?

- Some literature investigating this question, no consensus and evidence base is weak

  - 'Artefactual' reasons
    - Measurement: desirability, ineffective thresholds, symptoms covered
    - Recall bias, help-seeking, course of illness

  - Potential actual reasons
    - Family environments
    - Risk of adverse experiences: sexual violence
    - Social roles and cultural norms
    - Life events
    - Coping styles
      - Social support
      - Hormones
      - Neurotransmitter systems

Note the lack of good quality and longitudinal evidence for possible causes for emergence of gender differences

Piccinelli & Wilkinson, 2000; BJPsych
Over 500,000 adolescents from over 70 countries (data: PISA 2018)
I² is the percentage of variation across nations due to heterogeneity rather than chance.

High I² >95% indicates that there is considerable and non-random variation.
Why are we not interested in the reasons for the excess common mental health difficulties experienced by females ???
Country level gender equality: Complex associations

- Suggested by other studies too (inc for depression diagnosis)

- Hypothesized explanations inc expectation-reality gap; comparison group and multiple role pressures...

- Some studies suggest ‘U’ shape associations...no countries with perfect gender equality
Environments (e.g. school): differential impacts?

Interaction between sex and school climate in predicting emotional difficulties

Patalay et al 2020, Preventive Medicine
Gendered risk factors:
e.g. sexual violence

Prevalence of mental health outcomes at ages 14 and 17 in girls

Bentivegna & Patalay, 2022, under review
Assuming this effect is causal...

- We estimated Population Attributable Fractions that could be attributed to sexual violence
  - 16-21% of mental health difficulties in females at this age may not occur in hypothetical scenario where mid-adolescent sexual violence does not occur
• Large sex/gender inequalities in internalising mental health that appear in adolescence (and then the gap persists through life)

• The gender gap in mental ill-health and wellbeing might not be inevitable

• Understanding why it varies and identifying context dependent factors that reduce it is important for reducing this disparity (prevention)
Thank you
JCPP Advances from conception to our first birthday

Sarah Oates
Senior Editorial Director, Wiley
2022

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- **World class editorial team**
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• Offer a fast and easy publishing experience for our authors
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