

# nt challenges and dilemmas within learning disability research and ac



Dr Sara Ryan  
@sarasiobhan



## C.Wright Mills



### Private troubles

‘an individual’s character and with those limited areas of social life of which he is directly and personally aware’

## C.Wright Mills



### Private troubles

‘an individual’s character and with those limited areas of social life of which he is directly and personally aware’

### Public issues...

An issue is a public matter: values cherished by publics are felt to be threatened...

## Buroway 2004:

We have spent a century building professional knowledge, translating common sense into science, so that now, we are more than ready to embark on a systematic back-translation, taking knowledge back to those from whom it came, making public issues out of private troubles, and thus regenerating sociology's moral fibre.





# A very personal journey from academia to activism





Going where the air is free...







○ Foster House – LD – 2 minor impact compliance actions

A Serious Incident Requiring Investigation (SIRI) occurred in one of the Trust's Learning Disability in-patient facilities, leading to the unexpected death of a service user. The post mortem indicates the user died of natural causes and early investigations indicate all appropriate systems and processes were in place and being followed leading up to the incident, however a full investigation is underway, in line with the Trust's agreed policy. Support has been offered to the family and to staff at the Unit. The Trust has informed commissioners, CQC and Monitor.

**Public board minutes, Southern Health NHS Foundation Trust  
July 23 2013**



# mydaftlife

the funny stuff that happens

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**Home**

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Summary (read first)

The characters

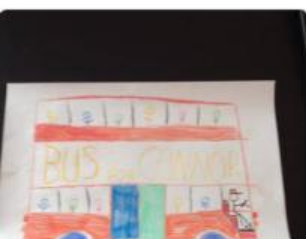
Public engagement

Academic skills



#JusticeforLB  
1. the joy and engagement





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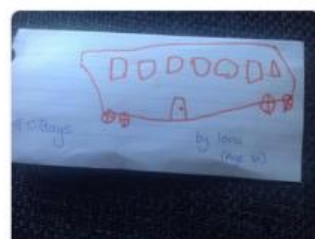
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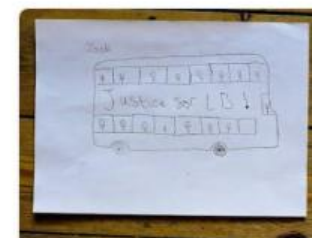
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## The making of dreams...









# IN SEARCH OF RIGHTS AND COLOUR



**An exhibition to celebrate the life of Connor Sparrowhawk**

Factoría Cultural de Avilés, Avenida de Portugal 13, Avilés, Asturias, Spain

Friday 16<sup>th</sup> December 2016- Friday 13<sup>th</sup> January 2017

Monday-Friday 09:00 - 14:00 / 16:30 - 21:00

[book now 2](#)

## A memorial to Connor Sparrowhawk

26 June 2016 at the University of Warwick Arts Centre

Connor was known to family and friends as 'Laughing Boy' or 'LB' for short. He had a way with words and was known for his quirky sense of humour. He loved fun times with his family and wide circle of friends. Connor had epilepsy, was learning disabled, and autistic. He died, aged 18, while a temporary patient in a specialist NHS treatment and assessment unit in Oxford. He drowned in a bath following an epileptic seizure.

An independent inquiry found that his death had been 'preventable' and the inquest in October 2015 concluded that neglect was a contributory factor in his death. In June 2016 the NHS Trust involved admitted full responsibility for his death.

It was difficult for Connor's family to discover the truth about what had happened to their son; a voluntary network of people grew up in the UK and elsewhere to support them and to campaign for better understanding, better rights, and better services for people with learning disabilities.

### 11am - Mead Gallery Balcony

A large community arts work, LB's Justice Quilt will be hung from the Mead Gallery balcony above the cinema foyer in Warwick Arts Centre. The quilt was made from hundreds of pieces of cloth contributed by children and adults in the UK and around seven other countries who wanted to support LB's family in their fight to find out the truth about what had happened to him. Over the past two years, it has been exhibited in a number of academic and arts venues as well as

### 6.30pm - in front of the quilt

In the cinema foyer, Paul McGrath, Director of Music, will conduct the Warwick Chamber Choir and any members of the public who would like to participate in a free, open performance of the moving spirituals from Michael Tippett's 'A Child of Our Time.' While we are gathering to remember Connor and to celebrate his life, we also want to draw attention to the widespread violation of the rights of many other people with learning disabilities in this country and elsewhere.

Everyone is very welcome to join us and sing, or listen.



#JusticeforLB  
2. The reach





Kristin Bjornsdottir @kbjorns · Sep 14



Staff in Akranes Iceland learn about  
[#humanrights](#) and [#JusticeforLB](#)



3



6





**anne townsend** @aftjae · 21 Mar 2014

@sarasiobhan just gave LB postcard to lovely bus driver on my commute. He posed 4 picture and was v. happy to help. Left camera case on bus!

3 1



**Sara** @sarasiobhan · 21 Mar 2014

@aftjae Oh no!!! Hope you get it back! What a lovely driver. I remember that lovely driver first night in Vancouver all those years ago..

1 1 2



**Tamadude** @TheWookieNutter · 21 Mar 2014

@sarasiobhan @aftjae Found it! I was said driver! Your case will be at Translink lost & found. Call 6046827887 to collect it next week :)

1 3 5



**Sara** @sarasiobhan · 21 Mar 2014

@TheWookieNutter @aftjae No way. No.way. I will laugh my socks off if you're for real. And believe change will happen.. :)))) #justiceforLB

5 2 2









#JusticeforLB  
3. the blame



**Sophie Grubb** @OxMailSophieG · Nov 12

TRIBUNAL: 'Deplorable' care failures in Connor Sparrowhawk tragedy  
[@TheOxfordMail oxfordmail.co.uk/news/15656594....](https://www.oxfordmail.co.uk/news/15656594....)



1



13



4



**Adam** @ProperEllipsis · Nov 12

Horrific scenario. But. Dreadful witchhunt against a single professional worker.

**I feel immense  
sympathy for her,  
but I believe her  
campaigning has  
actually done a lot  
of damage.**

Moffat letter, OCC  
commissioner



Opinion

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# The Guardian

Education Media **Society** Law Scotland Wales Northern Ireland

## Mother of dead teenager gets abusive message 'from NHS trust worker'

Woman claiming to work for Southern Health NHS trust calls Dr Sara Ryan 'vindictive cow' after report on son's death



Advertisement

 WCG

Think it's  
too late for  
a degree?

*Think again*

"It was quite hard to get back  
into studying but really exciting."  
- Liz, BA (Hons) Early Years and Education



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#JusticeforLB  
4. the process



NHS

# THE INQUEST

JUSTICE?

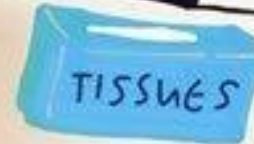
MEDICAL  
DIRECTOR

BARRISTER

SOLICITOR

NHS LEGAL  
BOD

The family





### **What should I wear to the hearing?**

You should wear clothes that you feel comfortable in but should remember that fitness to practise hearings take place in a formal environment. Most people choose to wear clothing that is neat and smart. We would ask that you do not wear denim, sportswear or trainers.

### **What if I need an adjustment because**

## **Expenses**

### **Will you organise my travel and accommodation?**

Yes. Your Scheduling Officer will contact you about travel, and if required, hotel arrangements. If you



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Sara

@sarasiobhan



10 hours until the @JusticeforLBHSE judgement. Half a decade. Five years. 10 hours. 107 days. A life time. #JusticeforLB



1:03 PM - 25 Mar 2018

3 Retweets 7 Likes



# Charities risk becoming irrelevant, warns new report

Voluntary sector must stop chasing government contracts and go back to fighting for communities in need





# Charities risk becoming irrelevant, warns new report

Voluntary sector must stop chasing government contracts and go back to fighting for communities in need



Windrush scandal. A small group of parents and activists linked by social media, not a national charity, she

says, won justice for Connor Sparrowhawk, and in doing so transformed the discussion about NHS neglect of people with learning disabilities. “The big challenge to charities is not whether they become more corporate or not, but whether they stay relevant,” Unwin says.





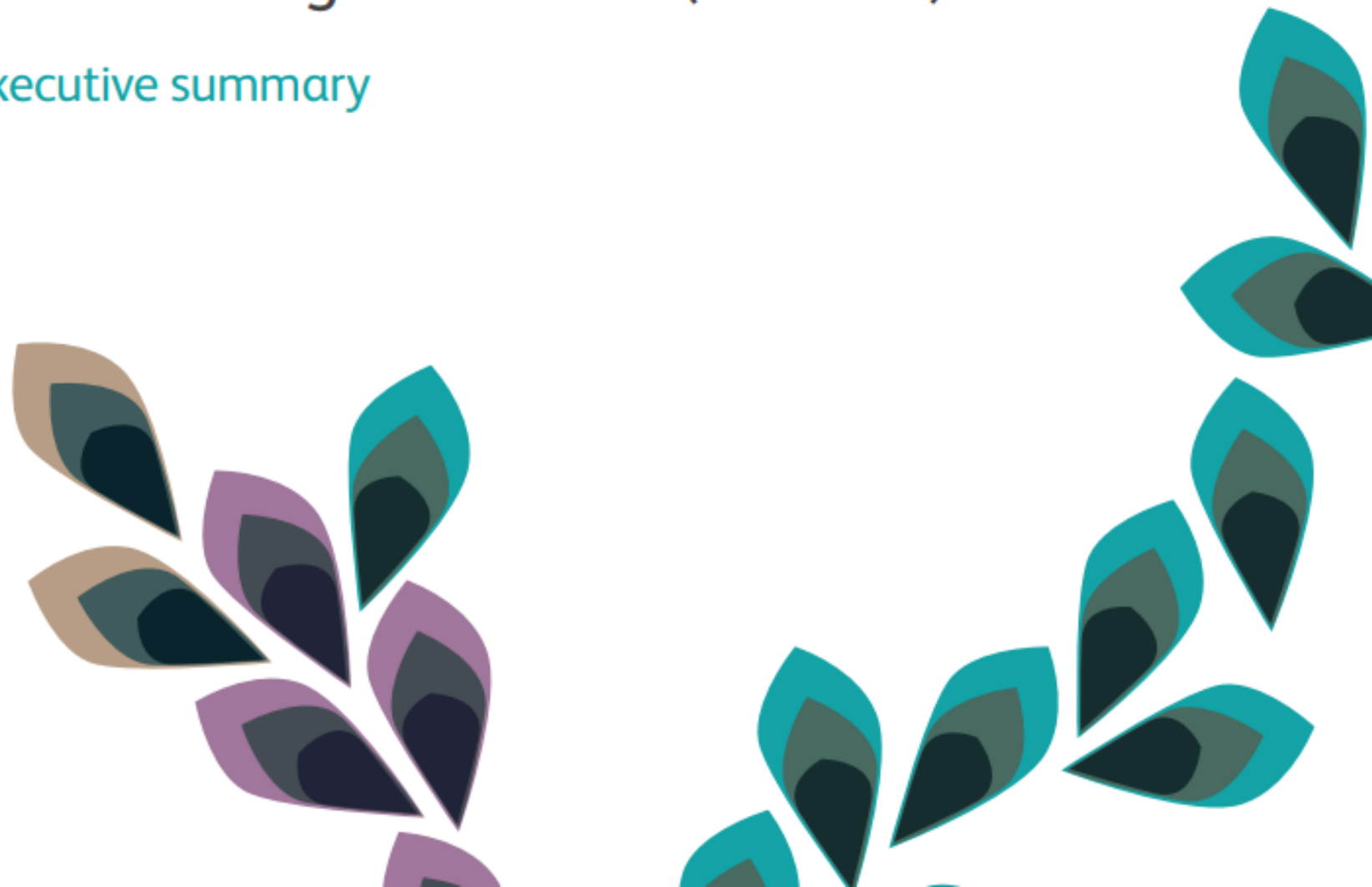
#JusticeforLB

5. The making of a scandal



# Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)

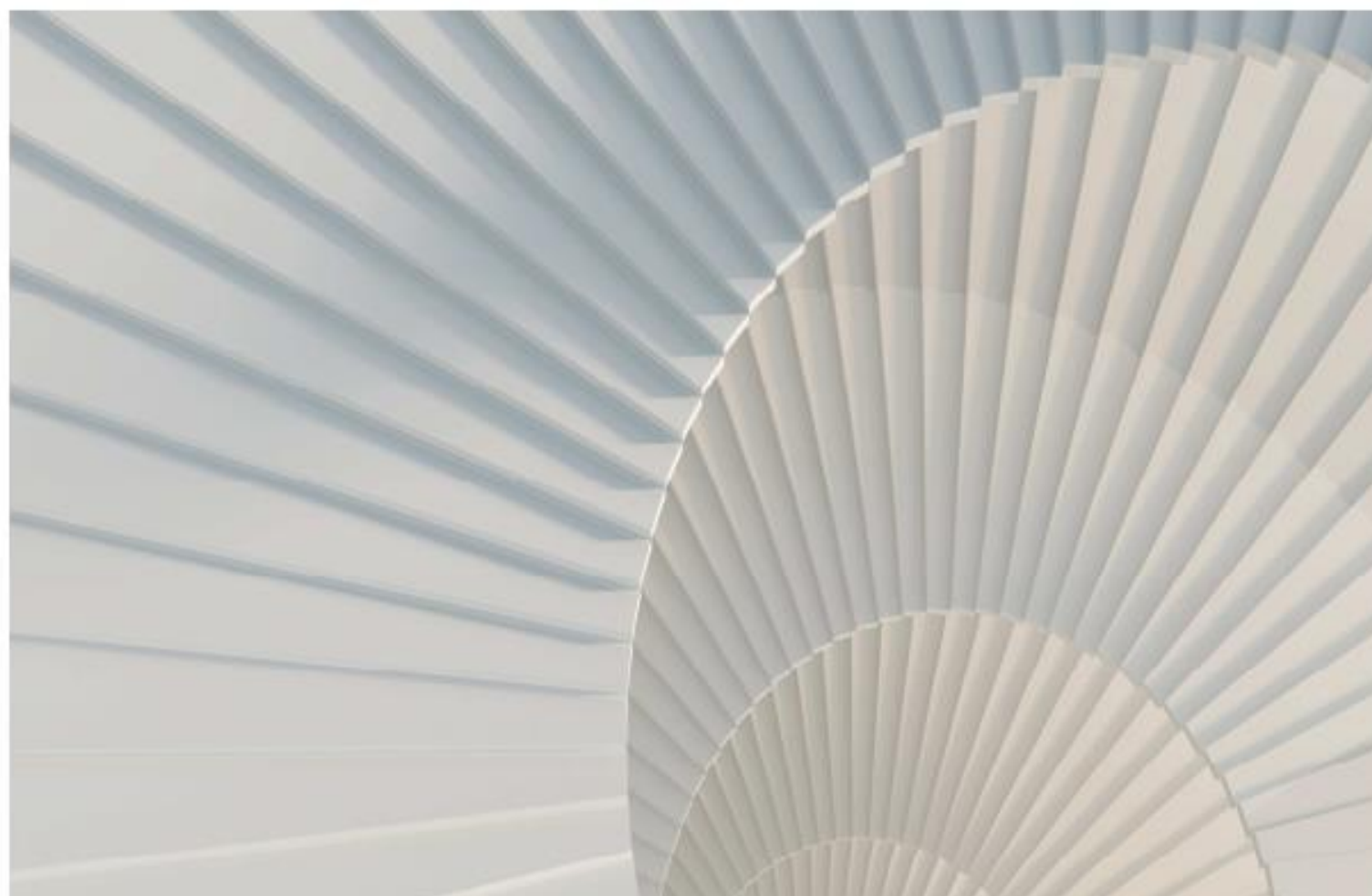
## Executive summary



**Independent review of deaths of people with a Learning Disability or  
Mental Health problem in contact with Southern Health NHS Foundation  
Trust April 2011 to March 2015**

December 2015

**FINAL VERSION FOR PUBLICATION**







## **Acknowledgements**

This report presents a lot of numbers. The team recognise that each number represents a loved one and would like to give their condolences to the families of every person referred to in the following chapters.

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#JusticeforLB  
6. The legacy





LinnetMac @LinnetMac · Apr 14  
 Thank you to all who came on our mini #CaminoLB this morning. The sun shone, we laughed, we cared and we walked to a fountain with mermaids ❤️





The Learning Disabilities Mortality Review  
(LeDeR) Programme

University of  
Bristol Norah  
Fry Centre for  
Disability Studies





**Bringing it back to learning  
disability research...**

# **Bringing it back to learning disability research...**


. challenges, dilemmas and what actually makes a difference




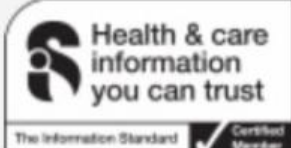

# **Marginalisation and siloing**

# Example 1

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<a href="#">About</a>	<a href="#">The research</a>	<a href="#">News &amp; Blog</a>	<a href="#">Scrapbooks</a>	<a href="#">Donate</a>	<a href="#">Register</a>	<a href="#">Login</a>



healthtalk.org  
youthhealthtalk.org



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Home

## Chip in

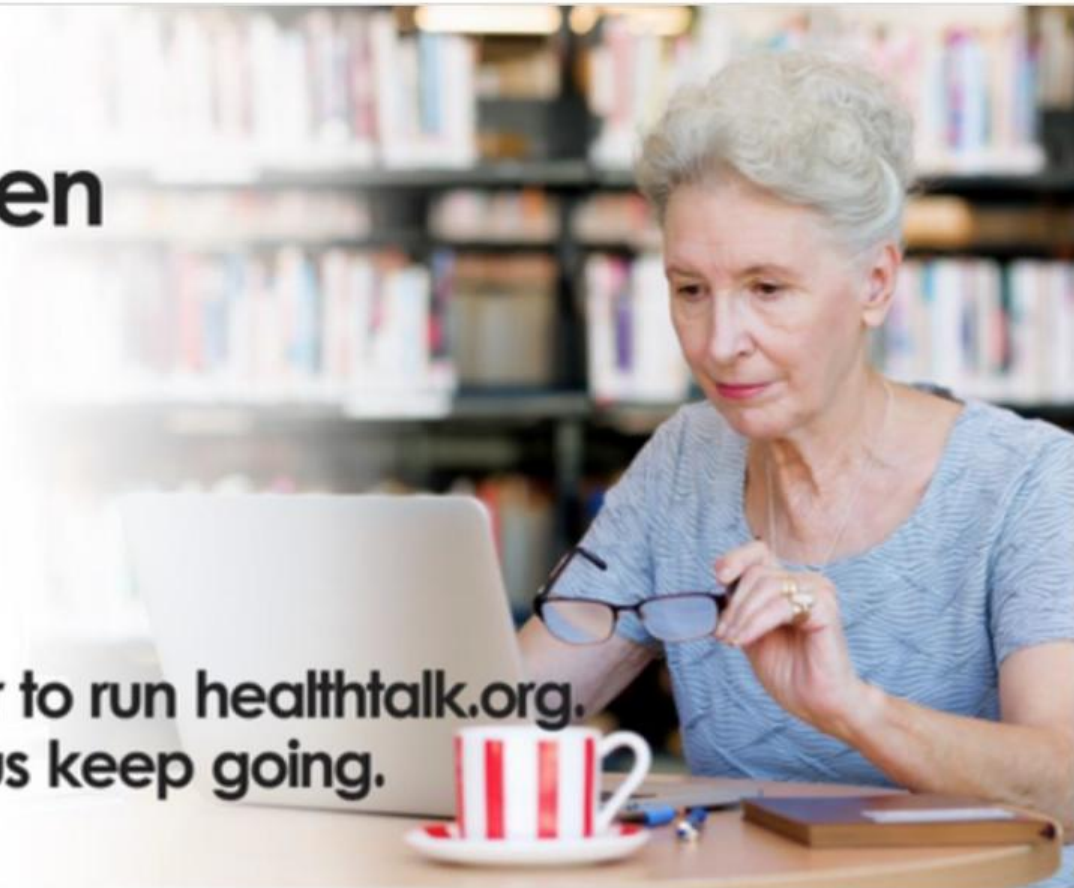
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It costs just £10 an hour to run healthtalk.org. Please chip in to help us keep going.



HEALTH INFORMATION

CHIP IN

LEARNING & TEACHING

YOUNG PEOPLE





## Example 2

# An analysis of learning disability research published in *Disability and Studies* 1994-2013

RANGE:  
2 → 30

DISABILITY AND SOCIETY \*

Year	UK	ALL	%
1994	17	28	
1995	14	16	
1996	9	16	
1997	30	30	
1998	25	28	
1999	24	33	
2000	7	13	
2001	13	22	
2002	8	10	
2003	9	15	
2004	9	13	
2005	16	22	
2006	14	30	
2007	9	16	
2008	17	25	
2009	7	20	
2010	2	7	
2011	9	17	
2012	12	16	
2013	9	23	

High: 1997 30%  
Low: 2010 2%  
Average: 10%

## Example 2

**So what is missing from this body of research across 2 decades?**

Family, love, relationships, divorce, mortality rates, health and social care staff attitudes, intersectionality, experiences of criminal justice system, mobilities, homes and housing...



# The way forward 'wish list'

Researchers/advocates to take off learning disability/autism lenses and break across silos.

Always work *with*; self advocates, family members, third sector organisations, professionals, anyone and everyone, to make research as robust as possible.

Keep working *with* (as above) when research is complete to make sure it hits the spots it needs to hit.

Move discussion beyond academia and dusty journals and bring it back to the public.

Always remember these are public issues not private troubles

# Final thoughts...

Keep asking 'why?'

(Evidenced) change and improvement things should be at the heart of our work

Be bold, fearless and never accept the unacceptable.



**Thank you**