DATA 1: **D**igitally **A**cting **T**ogether **A**s **One**…

…for neurodivergent children

Update to the BDCT Public Board (July 2022)

Ava Green

Assistant Director for Autistic Children's Services

A definition

‘Neurodiversity describes the idea that people experience and interact with the world around them in many different ways; there is no one "right" way of thinking, learning, and behaving, and differences are not viewed as deficits.

The word neurodiversity refers to the diversity of all people, but it is often used in the context of autism spectrum disorder (ASD), as well as other neurological or developmental conditions such as ADHD or learning disabilities.’

What is neurodiversity? - Harvard Health

The Challenge

- Long waiting lists for assessment
- Parental concerns
  - Lack of awareness and understanding in schools
  - Lack of support pre and post diagnosis
- Information sharing challenges create barriers to effective multi-agency working…children and families bear the burden – a symptom of wider failings
- Proven short and long term impact; on education, health, employment and wellbeing

The Vision, part 1 – the individual

'…how do you include people who may need the benefits of inclusion, but cannot bear the physical and emotional presence of it?

The answer, from their/our point of view is that we don't want to be included, **we want mutual understanding, clear boundaries, appreciation of our gifts, based on <u>what we can do, not what we can't'</u>**

Why can't you be normal for once in your life, by Judy Singer

The vision, part 2 – the system

- A needs driven system, enabling neurodiverse children to thrive alongside their peers, characterised by:
  - informed communities, adapted, supportive environments
  - a skilled and aware 'universal' workforce, quickly and effectively:
    - identifying *most* of the support needed by *most* neuro-diverse children, and
    - meeting *most* of those needs through universal services.
    - sharing information and coordinating work with families
  - faster, efficient access to specialists, for assessment and support – as a *minimum* meeting national benchmarks on time, quality and cost
  - *…made possible by connected data and high quality, secure data tools*
  - *…and to learn from and extend this approach further, over time*

Three linked projects

Project 1: Speed up and strengthen assessment

- **Issues:** fragmented data within the health system and barriers to accessing useful information from outside the health system
- **Proposal**: Use our research platform 'Connected Bradford' to provide clinicians with all the health, education etc information they need on a child, in one pack.
- **Challenges**: Information governance (consents) and technical
- **Opportunity**: to demonstrate the value of making linked data routinely available to professionals; to develop more efficient and secure approaches to information sharing; to improve vfm of spending on technical solutions.
- **Current status:** in progress – relevant data has been identified; working through information governance; talking to clinicians about the final product.

Three linked projects

Project 2a: the 'neurodiversity profiling tool'

- **Issues:** neurodivergent children's learning and support needs are not recognised early or accurately enough in school.
- **Proposal:** Develop an online 'profiling tool' that teachers (non specialists) can use in the classroom and with parents, to identify both needs and effective solutions
- **Challenges**: Practical – usability in a busy school; validity of indicators; usefulness of the 'advice bank'. We also need to ensure our data science teams are properly resourced
- **Opportunity**: to break the link between diagnosis and support, by helping teachers adapt/introduce learning and environments that make it possible for neurodivergent children to thrive in a 'general' setting. Over time, for the profiling tool to draw from and feed into 'Connected Bradford'
- **Current status:** the generic profiling tool is being tested for usability in schools; work ongoing to quality assure the indicator set and advice bank; operational trial to commence September 2022, including whole school training – the trial will run across 19 schools in three localities: Keighley Central, Girlington & Manningham, and Holmewood

Three linked projects

Project 2b: reshaping specialist support

- **Issues:** For a minority of neurodivergent children, specialist support and advice will be essential to identifying the right support; for many neurodivergent children in disadvantaged areas, multi-agency support will be required
- **Proposal**: Design and trial new deployment models, enabling specialists to come together around the child and family - usually through the school; trial information sharing including shared access to the neurodiversity profiling tool, to allow better coordination of support
- **Challenges**: TBC, but likely to span practical (front line resources are stretched); legal, both in terms of how staff are deployed and information governance; and cultural, given the need to challenge and change working practices. We also need to ensure our data science teams are properly resourced
- **Opportunity**: to accelerate and improve coordination (and vfm) of the system around the child, reducing the risk of children 'falling through the net'; also to trial an approach to multi-agency working and information sharing that could be extended more widely.
- **Current status:** we are working with colleagues from health and specialist teaching (as well as policing and the VCS) at strategic and local level, and will begin design work with those partners in the autumn term.

Three linked projects

Project 3: creating neurodiverse friendly places

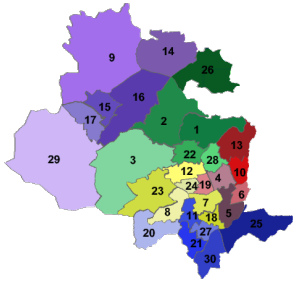
- **Issues:** neurodiverse children, and their families, do not just struggle at school – they experience barriers from dawn to dusk, navigating services, transport, shops and society in general. We know that the impact of these difficult journeys affects all aspects of neurodivergent children's lives – poor health = poor education – and that journeys look different by place, gender, community etc. But, services are usually designed independently from each other, and to a one-size-fits-all design.
- **Proposal**: Use data science (data visualisation) together with proven community co-production techniques, to help 'places' describe the lives of their neurodivergent children more accurately, and model, trial and evaluate practical changes to the way things work.
- **Challenges**: TBC – we have good examples of data-led work from Holmewood; the most likely sticking points will be when we require the authority, mandate and resources from senior leaders, to change the way services are delivered, funded or evaluated. We also need to ensure our data science teams are properly resourced.
- **Opportunity**: it is not enough to create neurodiverse friendly schools because children do not live in schools – this is an opportunity to bring together all parts of society, in places, to improve the life chances of a significant number of children (and adults)
- **Current status:** we have activated and are working with our 'Act Locally' groups in each of our three localities; we have run priority-setting workshops and are linking the groups to our data science teams, to start the modelling process.

Locality-led modelling: a 5 step design process

1.

Select an **issue – (autism)**:

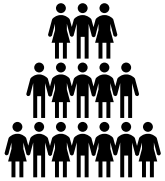
- Affecting many families
- Affecting poorest most
- Broad impact
- Inefficient systems
- Best practice understood



2.

Select a **place**(s):

- Affected by the issue
- Affected by inequality
- Connected communities
- Capacity in the system



3.

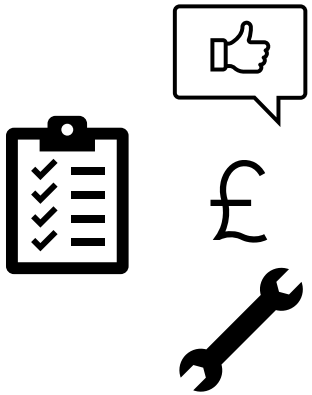
Identify **people,** from the place(s):

- Professionals who should be working together on the issue
- Community engagement partners
- Families affected

4.

Model the future system (the desired *interactions, to tackle the issue, in the place(s)*):

- *With* the people
- Using data tools
- Supported by strategic partners



5.

To **produce a 'shopping list'** of:

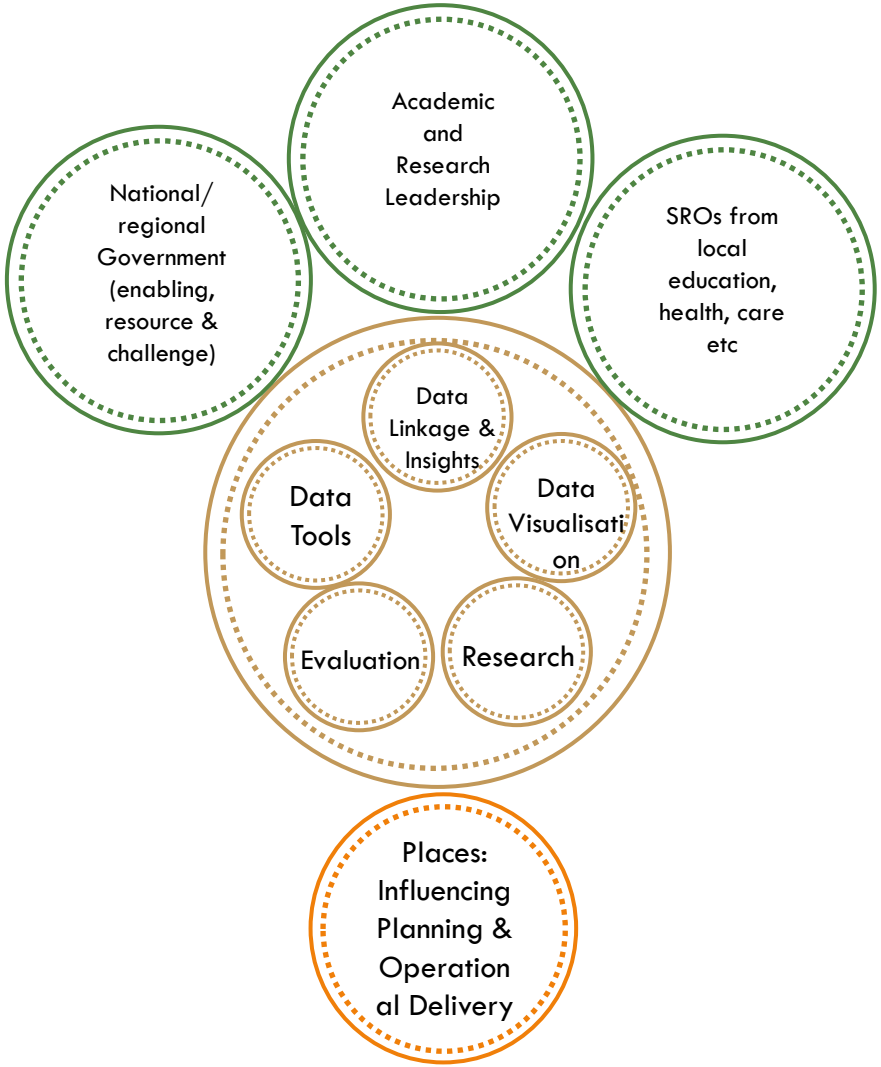
- Permissions
- Resources
- Tools

…enabling action, *by the people, in the place(s)…*

Our end goal

- Systems supporting children and families more effectively, because they routinely, and proactively deliver:
  - the information professionals require, to effectively assess and respond to needs; drawing on the best research evidence of what works
  - permissions and the means for professionals to share information on vulnerable children, including flags that make it harder (or impossible) for vulnerable children to fall through the net
  - a more accurate understanding of children's needs, as they vary by place, community, gender, culture etc; enabling more efficient joint commissioning
  - a greater awareness and understanding in society, of the challenges children and families face, with the capacity, skills and resouces to help make things better.

The IDEA Centre: the missing piece in our puzzle?



A virtual team: data scientists, researchers, analysts, service planners, staff and communities to:

- Link data and draw out insights into risk and vulnerability, as it varies by locality
- Develop data tools, delivering insights to and linking front line professionals, to allow data sharing and coordination of work with families
- Expert advice on what works, and support evaluation
- Data visualisation tools, to help families and communiites describe their lives and influence future system design

Requiring permissions, resources and a mandate to:

- bring analysts etc together with data scientists and researchers#
- overcome barriers to data sharing
- give permissions to local partners, to adapt delivery (ie deployment of staff) or release resources, to allow projects to move into delivery.