

PEP leadership and the development of a new neurodiversity pathway in Portsmouth

Liz Robinson
Principal Educational Psychologist
Portsmouth City Council
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Neurodiversity Assessment Pathway Project

Co-Producing a new approach

- Dr Asha Gowda Consultant Psychiatrist, CAMHS
- Natalie Abraham, Parent Voice
- Liz Robinson, Principal Educational Psychologist
- Zach Dunn, Assistant Psychologist
- Autumn term 2020





Our Theory of Change



The 'Problem'

- Long waiting times for ND diagnosis – demand outstripping supply
- Investment skewed to diagnosis rather than support and intervention
- Parental dissatisfaction... “I have a diagnosis...now what?”
- Prioritisation of assessment over meeting needs – our aspiration to be a ‘needs-led city’



Our Theory of Change



The Strategy

- Inspired by the vision of a different model by the former Clinical Director of Solent NHS – Dr Jonathan Prosser
- To enable the identification of difference and diversity without solely relying on clinical pathways
- Conceptualising an ‘early help’ response to neuro-diversity
- Enabling and empowering the child, their family and those that work with them to understand their diversity – ‘difference’ not ‘disability’
- System-wide response – NHS, local authority, education settings
- “Things that help” - enabling access to evidence-based resources to help that make life easier



Our Theory of Change



Outputs

- A Profiling Tool based on 9 dimensions (sub-profiles) that can be used by non-clinicians in a wide set of context alongside families
- A Training programme
- 100s of trained professionals across the children's system able to use the Profiling Tool alongside children and families
- A bank of resources for families to use, to try to experiment with
- A reduction in demand for formal diagnosis – but not a 'switching off' – many families will continue to benefit from formal diagnosis



Our Theory of Change



Outcomes: Our families described the following outcomes:

- “I have a better understanding of my child’s differences”
- “My child’s teachers has a better understanding of his/her differences”
- “My child’s needs are being met at school / pre-school setting ”
- “I am meeting my child’s needs at home”



4 main elements



1. The profiling tool

2. Training

A training programme to enable teachers, social workers health visitors etc. to be able to use the Portsmouth ND Profiling Tool

3. Resources: 'Things that Help'

A wide array of resources in one place for children, families and professionals to use – everything from equipment, to advice and guidance, to services (linked to the SEND Local offer)

4. Evaluation

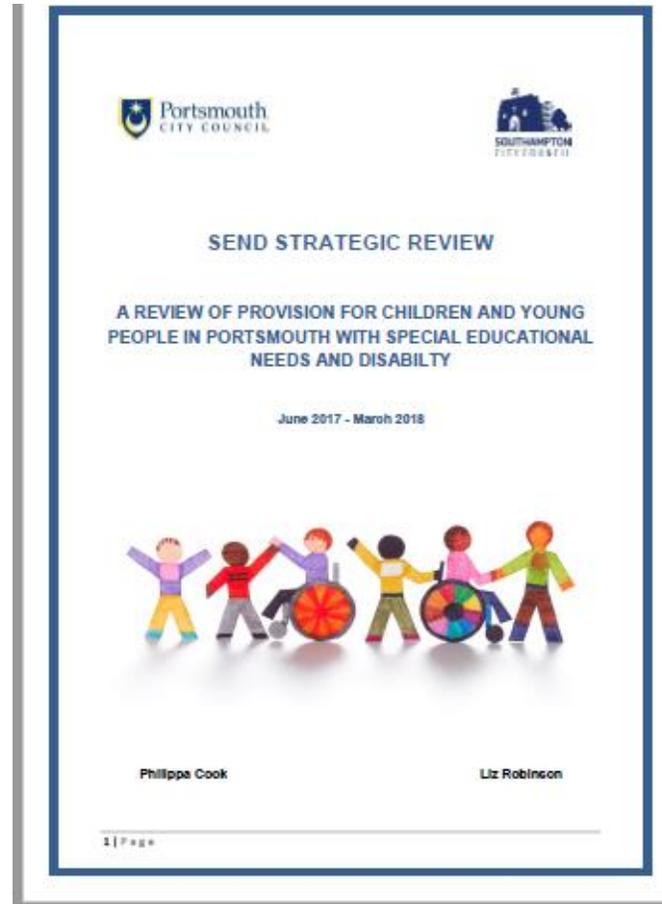
Qualitative and quantitative information to enable us to understand if this is making a difference – are we achieving the outputs and outcomes we want.



So what did the PEP bring to the party?



1. Taking the opportunity



2. Appreciative enquiry

	Known by self	Not known by self
Known by others	Open	Blind
Not known by others	Hidden	Unknown

3. A social model of disability



Profile on a page

Name and DOB of young person:

Names and roles of people completing this form & date completed:

Neurodiversity Profile

average

Speech and Language Ability	Low	----- ----- -----	High
Energy levels	Low	----- ----- -----	High
Attention skills (O) and Impulse Control (x)	Low	----- ----- -----	High
Emotion Regulation skills	Low	----- ----- -----	High
Motor skills	Low	----- ----- -----	High
Sensory levels	Low	----- ----- -----	High
Level of Flexibility and Adaptability	Low	----- ----- -----	High
Empathising and Systemising skills	Emp.	----- ----- -----	Sys.
Cognitive Abilities	Low	----- ----- -----	High

Version 1.09.10.2020 1



(name of the child) is at their best when:

It is more difficult for (name of the child) when:

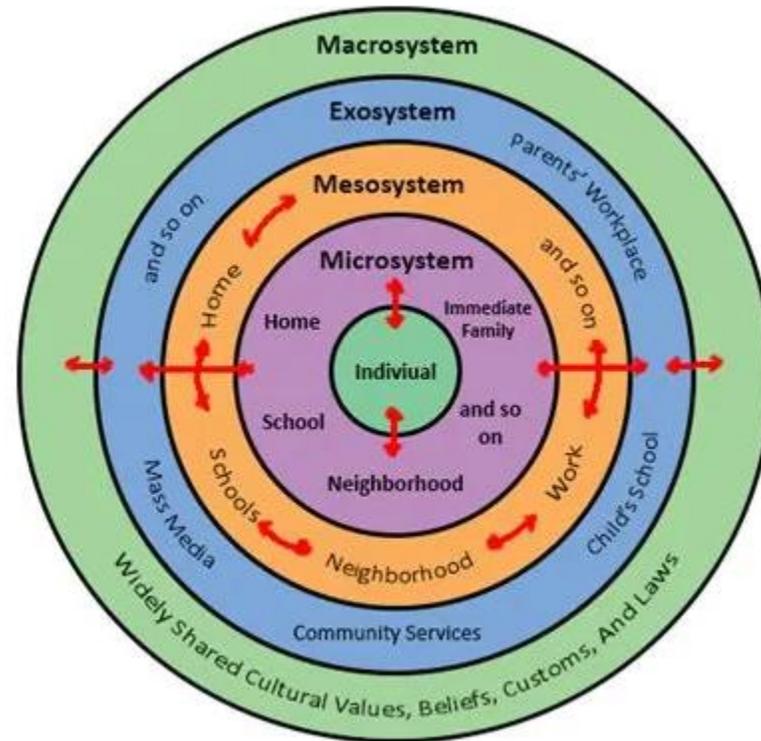
What else can explain (name of the child)'s profile:

Other comments:

Resources/ strategies and adaptations required:

This plan will be reviewed when:

Bronfenbrenner's Ecological Systems Theory



Why this Model?

- Diagnosis alone do no justice
- Culture shift from labels to needs led
- Restorative and person-centered approach



4. Language

These Neuro-Developmental differences are very likely to have been present from birth, perhaps only demonstrating as a **problem** later in life where life becomes more demanding. Common diagnoses which are related to Neuro-Development are Autism Spectrum Disorder (ASD), Attention Deficit Hyperactive Disorder (ADHD) and Learning Disability (LD).



Robinson, Liz

Not necessarily a problem. Can we find problem free language



- *“Me and my friend have the same diagnosis but we’re different people; you can have two people with the exact same diagnosis, but they go off in two completely different ways of thinking and what their interests are.” – Service User*

“I think neuro - diversity is a kinder term, because looking at two autistic people with a learning disability and saying ‘oh you have the same thing so you must be completely the same’ is just wrong” – Service User

5. Co-production



Co-production with parents:

- Regular sessions alongside professionals and parents to co-produce the Profile
- Parents helped shape the structure and the language
- Parents contributed to the resources pack

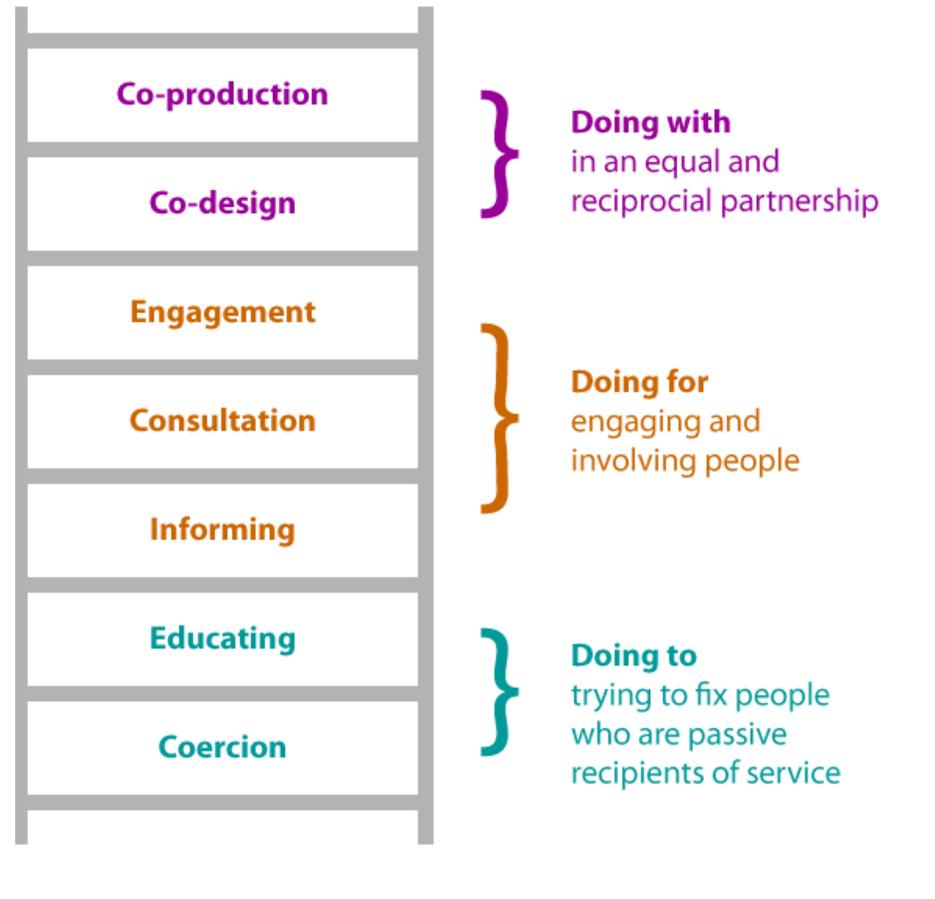
Parents said...

- The Profile must be taken seriously by all
- It has to have weight
- Accessible language used must be used
- Liked 'Profile' rather than 'diagnosis'
- Gives a view of all skills / abilities – not just academic
- Liked the fact that it is very visual.



Ladder of co-production

developed by the National Co-production Advisory Group



6. Contacts



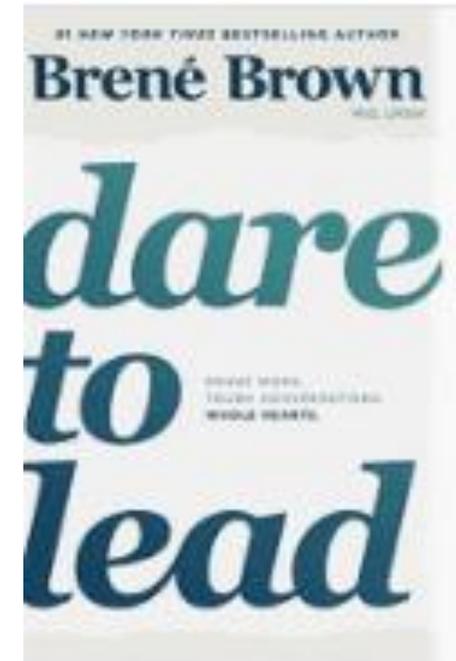
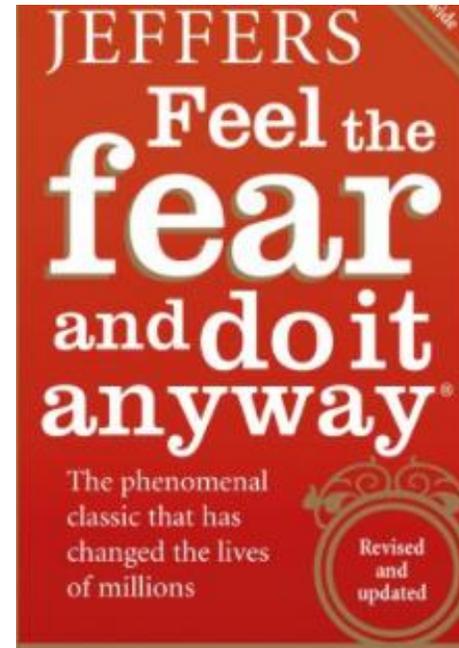
...a gateway in getting our vision across to the education sector and helping them feel that they own this piece of work and have a stake in it.

Consultant psychiatrist CAMHs

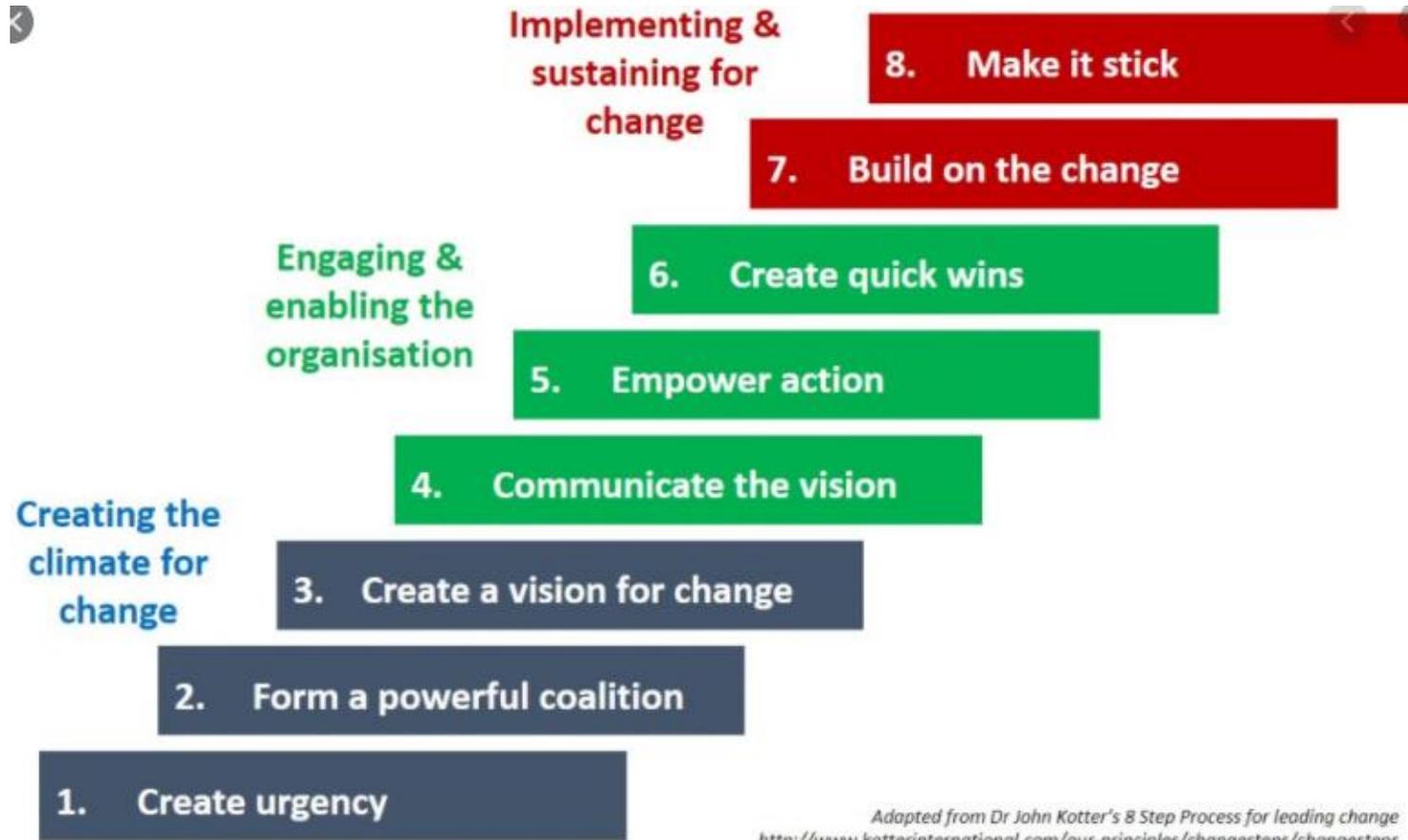
...insight/links within the education setting have had a major positive impact upon the outcome to the project – without it I truly don't feel we would have as many agencies signed up to the project as we have.

CAMHS operational manager

7. Influence



Kotter's change model



Adapted from Dr John Kotter's 8 Step Process for leading change
<http://www.kotterinternational.com/our-principles/changesteps/changesteps>

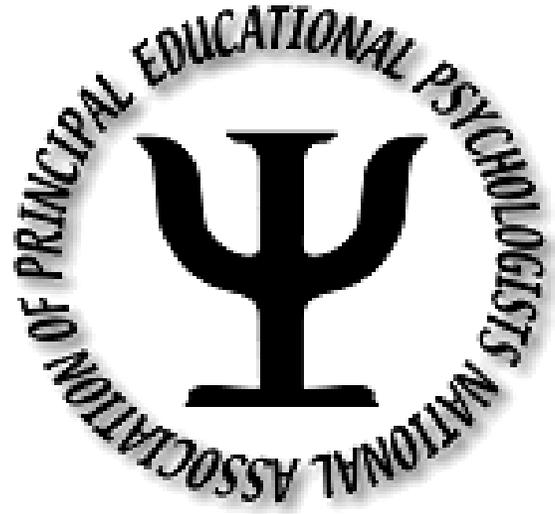
Our mini groups working on profile areas

ND Pathway Level 1 Profile 'Mini Groups'

Each group should have a minimum representation from Education, parents and Health

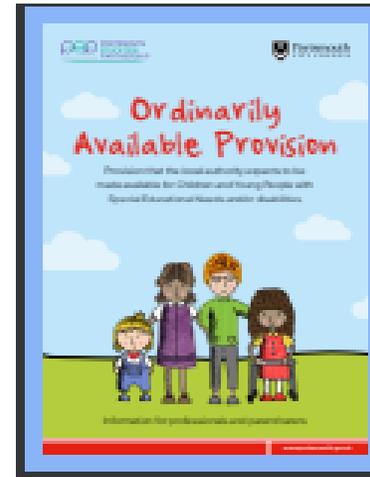
Dimension	Lead	Education Rep	Parent Rep	Health Rep	Others
Intellectual Functioning		Mike Bower	DAWN JONES	Melissa Watts, CamHS	
Energy Level		② KAMARIE MCHAMY Dorise Flynn.	Kate Bradley		
Attentional Ability / Impulse Control	ASHA GOWDA	Sally Turner	NATALIE ABRAHAM PRV MANAGER. CAT SIDWELL	ASHA GOWDA CAMHS	
Level of specific language ability		Vikki Gidney	DAWN JONES	Louise Higgins louise.higgins@slouh.nhs.uk	
Empathising Ability / Systemising Ability		Adrian Sully	CAT SIDWELL	Jonathan Prosser	
Levels of tolerance, flexibility & adaptability		Helen Mead	Mel Mealy	Jo Johnson	
Level of Emotional Regulation		Dorise Flynn. ① KAMARIE MCHAMY	Mel Mealy	(Someone if none else available)	
Motor Functioning			Michelle Treacher Kate Bradley	Jo Johnson	

8. Psychological knowledge



9. Systems knowledge and de-bunking myths

- Linking the profile and approach to
- SEN Support
- EHC assessments
- Profile of Needs
- Ordinarily Available Provision
- Avoiding unintended consequences of the profile being used as evidence for EHC assessment request or exam access arrangements



10. Supervision

- “Psychology Based Supervision – I myself have found it useful when we have our meetings as its been useful knowledge for myself and my perspective on how systems work between the NHS and the Local Government. Your role has been able to facilitate this reflection in myself, and how other psychologist practice in different environments”

Psychology Assistant based in CAMHs



As each goose flaps its wings, it creates an “uplift” for the birds that follow. By flying in a “V” formation, the whole flock has 71% greater flying range than if each bird flew alone.