



THE CAPACITY TO

ACT ?

**OPENING THE DOOR FOR PEOPLE WITH HIDDEN
DISABILITIES AND DIFFERENCES.**

“What does research and expert practice tell us, about the relevance of executive functioning assessments, to work with people who are homeless or rough sleeping and who have complex needs.”

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Executive summary:

Aims	<ol style="list-style-type: none"> 1. To raise awareness and understanding of hidden disabilities and differences reflective of executive dysfunction. 2. To evidence the necessity of including executive functioning needs in Care Act (2014) assessments to optimise the 'Capacity to Act.' 3. To evidence the importance of including executive functioning needs in support plans to optimise the 'Capacity to Act.' 4. To evidence the need for social, emotional, and environmental scaffolding to optimise the 'Capacity to Act.' 5. To evidence the need for behavioural research approaches, to support longitudinal chronologies, of executive dysfunction, in Mental Capacity Act (2005) assessments.
Methodology:	<p>Boolean search strings Thematic reviews Grey literature</p>
Findings:	A wide range of conditions and contexts can affect executive functioning.
Conclusion:	When executive functioning is disorganised or underdeveloped, it can inhibit appropriate decision making, reducing peoples problem-solving abilities and poses difficulties in having the capacity and or ability to act out their wishes and decisions.
Recommendations:	<ol style="list-style-type: none"> 1. Include the executive functioning wheel as part of Care Act (2014) assessments to identify hidden disabilities and differences. 2. Promote the understanding of executive functioning with social workers and citizens to co-produce self-awareness, self-management, and self-development of their executive functioning. 3. Design, commission and deliver contexts that optimise peoples executive function needs to meet unmet care and support needs. 4. Implement executive functioning in Mental Capacity Act (2005) assessments. 5. Consider further research into areas of executive functioning that are risk markers for people with behavioural addictions and that repeatedly neglect self.

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Introduction:

I am a social worker, in practice for 20 years, in Adult Social Care complex needs service in Manchester. I work with adults who sleep rough, often in addiction, who share with me their lived experiences of childhood trauma, and that they feel excluded by closed doors to services, a metaphor for 'you are not worthy'.

The people I work with, often don't have their basic hierarchy of needs met. Maslow (1954). They live moment to moment, on the streets, for all to see. They live high risk, chaotic lives, in a whirlwind of deterioration and usually neglecting everything other than what people describe to me as their survival need of using substances to cope.

This report seeks to explore and understand the human ability and capacity to execute our wishes, decisions, and goals, in context. It focuses on the concept of executive function, the part of the brain that is responsible for the cognitive process of controlling and monitoring our behaviour, that are necessary for humans to be able to have the capacity to act and execute their decisions.

The report aims to unveil and illuminate, "what research and expert practice can tell us, about the relevance of executive functioning assessments to work with people who are homeless or rough sleeping and who have complex needs."



Expert by practice hypothesis:

In 2019, the COVID pandemic hit Britain.

For people sleeping on the streets of Manchester, this provided a unique opportunity, the first of its kind. It showed, that when political will, financial investment and legal frameworks come together, under the Governments drive to get 'everybody in' off the streets, people sleeping rough was at an all-time low.

With 'stay at home' Covid legislation, the streets of Manchester were empty, except for a minority of people that either refused to come indoors or presented with high-risk behaviours that resulted in them not being able to stay indoors.

This report aims to evidence, through research, an expert by practice hypothesis of why 'the everybody in initiative' did not end rough sleeping in its entirety during this time.

The evidence from research strives to influence, how we use legislation, implement policy, develop practice and service provisions, as an early intervention and prevention model. This will reduce people developing complex needs and rough sleeping. It will achieve this by unveiling what is beyond an individual struggling, and what is the larger context, in which that struggle appears.

I am a safeguarding lead for adults with complex needs. I advocate for multi-disciplinary, 'team around the person' safeguarding approaches that are strength based, by galvanising on all the knowledge, resources, and skills available. I promote a behavioural research methodology to understand 'why' a

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person may be presenting as they are, using safeguarding as a framework. With this engaged, we were able to identify themes of people that remained on the streets during the pandemic.

What we saw:	The context of what we saw:
People had difficulties with emotional control & regulation.	People reacted and behaved in flight, fight, freeze, and flop dysregulated nervous states.
People had difficulties with controlling their impulses.	People would act without thinking of the consequences.
People had problems with their self-monitoring & self-awareness.	People were disconnected from their sense of self.
People had difficulties with their working memory, the processing of information.	People would struggle using and weighing up information to make decisions.
People had difficulties in planning & prioritising goals they wanted to achieve.	People needed co-production models to achieve what it was they were asking for.
People had difficulties in starting tasks they wanted to achieve.	People needed support to instigate what it was they wanted to achieve.
People had challenges in organising oneself to be able to receive care and support they were asking for.	People needed services to go to them to receive the care and support they wanted.
People found it difficult in adjusting to changes.	People said that they did not trust.

These themes are reflective of the executive functions, of the human brains' frontal lobes.



Executive function, what does that even mean?

Executive function is a set of cognitive processes that are essential for the cognitive control of human behaviours. They are the skills that help us 'get things done', the mental process that enables us to set goals, make plans and see them through. They are controlled by the frontal lobe of the brain. Sira, and Mateer (2014) When these processes are compromised, this is called executive dysfunction.

In cognitive science and neuropsychology, certain disorganisations of the mind or brain are widely recognised to be associated with executive dysfunction, and include acquired brain injury, dementia, delirium, learning disability, attention deficit and hyperactivity disorder (ADHD) and Autism.

However, many other mental disorders can be associated with executive dysfunction including, schizophrenia, depression, anxiety, stress, general emotional and mental overwhelm.

As a social worker who uses behavioural research approaches to understand 'the why', we began to implement an executive functioning wheel to support professional curiosity.

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Executive functioning wheel, a social work tool to understanding behaviours:

This is an executive functioning wheel.



It breaks down the core elements of our executive functions, into 8 parts.

Over a period, it is possible to gather longitudinal evidence of behaviours, that can explain why a person may present and behave as they do.

Below is a fictitious case study, to demonstrate what this looks like in practice. Berg, (2009)



Case example of executive function wheel in practice:

58 years old, gay, white, Welsh, man. Developmental trauma from childhood, neglect, and sexual abuse from a family member. Further trauma experienced witnessing the murder of his partner. Large scar on his head, indicating a historic head injury. Dependent methamphetamine use, no desire to change or stop use.

We observed these behaviours:

The gentleman would obsessively make 80+ calls a day across services accounting for how he was spending his time. He had fixed delusions, persecutory beliefs, paranoia and consistently communicated maliciously. He had a history of exposing himself in public, made threats to set places on fire, to hold people hostage, damage vehicles and threats of violence to staff. He lived in a disorganised way, for example, his kettle would be boiling in amongst clothes and bin bags. There were repeated obsessive behaviours with faeces and the 'spoiling of facilities, all making it difficult to house him.

As a result of these behaviours, he has had 28 different temporary accommodation placements across Greater Manchester in one year during the pandemic.

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Behaviour analysis, using the executive function wheel:

1/ Working memory: It was extremely difficult to understand and communicate with him. He would not hold onto a topic long enough to register the content and communicate about it, his brain seemed to be working so fast he was not able to retain, recall, weigh up or communicate around any decisions.

2/ Self-awareness and monitoring: He had no insight into how he was presenting, he was a proud man, with no awareness of faeces on his hands or that his trousers had fallen.

3/ Flexible thinking: He was fixated on topics and would struggle to adjust to any attempts to change topic.

4/ Task initiation: He would say he wanted to organise and clean his living area, that this was very important to him, but he never did.

5/ Planning and prioritising: He was unable to manage self-care and maintain relationships.

6/ Organisation: He could be highly organised in some areas of his life, but this was limited to topics he was fixated on.

7/ Impulse control: He would act impulsively; his behaviour was unpredictable and caused fear and apprehension from others.

8/ Emotional Control: He presented in hypervigilant dysregulated aroused states, that fluctuated between panic and grandiose.

He was later diagnosed with post-traumatic stress disorder (PTSD), attention deficit hyperactivity disorder (ADHD), acquired brain injury from years of methamphetamine toxins and traumatic brain injury related to the significant scar on his head.

He had lived with, limited quality of life, for at least 20 years, with undiagnosed disabilities and differences. It had been assumed by every professional he had contact with, that his behaviour was drug use related. When the drugs were ceased, the behaviours continued.



Expert by practice hypothesis methodology:

We robustly applied the executive function wheel as a method to the people that the 'everybody in initiative' did not work for.

Themes emerged of hidden disabilities and differences. These were often undiagnosed but loosely referred to in the person's story.

What we learnt was that understanding people's life stories was critical to developing a deeper understanding of how people present. These conditions can impact on executive functioning

<ul style="list-style-type: none">• Childhood trauma, complex trauma,• Post-traumatic stress disorder.• Neurogenetic conditions. (Fragile x,)• Neurodevelopmental conditions.• Foetal alcohol spectrum conditions.• Neurodivergence.	<ul style="list-style-type: none">• Acquired brain injury.• Traumatic brain injury.• Epilepsy.• Stroke.• Alcohol related brain damage.• Mental health conditions.
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What the pandemic revealed was, where there is professional curiosity and safeguarding frameworks, when we seek to find the reasons for behaviours in others that we can't make sense of, we can start to 'make sense of the why'. Preston-Shoot, M (2021)

This was the basis on which the research internship and research question was founded.



Formal research methodology:

ID	Field	Content
1	Research title	The capacity to act....? Opening the doors for people with hidden disabilities and differences.
2	Research question	"What does research tell us about the relevance of executive functioning assessments to work with people who are homeless or rough sleeping and who have complex needs?"
3	Research objective	Explore the relevance of executive functioning, in the capacity and ability to act out decisions.
4	Searches of databases	<ul style="list-style-type: none"> National academic databases were searched as a primary resource through Salford Library University access portal. A Boolean search string was implemented, using key words. Three-phrase search string which included the terms "addiction-executive-functioning-". Academic and grey literature were ascertained through targeted website searches and independent, free text internet searches were also conducted and accessed, comprising of Government and third sector publications, policies, guidance, quantitative and qualitative research data.
5	Domain being studied	Executive functioning
6	Research of domain in context:	<ul style="list-style-type: none"> Hidden disabilities and differences reflective of executive function, with people that have needs for care and support experiencing multiple exclusion homelessness, rough sleeping, and addiction.
7	Inclusion/exclusion criteria	<p>Exclusion:</p> <ul style="list-style-type: none"> Non-English language articles. <p>Inclusion:</p> <ul style="list-style-type: none"> Executive function
8	Primary outcomes demonstrating an awareness of differing arguments, theories, and approaches.	<ul style="list-style-type: none"> The evidential link between executive dysfunction and the capacity and or ability to act on one's own wishes and decisions. Emotional, social, and environmental contexts of executive functioning as a continuum. Differences in literature under the executive functioning umbrella term. Addiction as an umbrella term, rather than substance misuse.
9	Collation of potential themes	<ul style="list-style-type: none"> Ascertaining what causes executive dysfunction. Narrowing of themes-focus on how executive functioning relates to the 'capacity to act'. How this transpires into multiple exclusion homelessness, rough sleeping, substance misuse, self-neglect, and complex needs.
10	Language	<ul style="list-style-type: none"> English
11	Anticipated start date	<ul style="list-style-type: none"> May 2022
12	Anticipated completion date	<ul style="list-style-type: none"> March 2023
14	Collaborators	<ul style="list-style-type: none"> Appendix 2: Acknowledgements

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Research findings:

The results are 'messy'. From a critical stance, the research on executive functioning as an umbrella term was too broad.

The results evidenced a gap in literature, the research string evidenced only 102 articles.

The term addiction was also broad and evidenced unexpected results. This wide umbrella term removed unconscious bias around substance misuse. It evidenced a need for further research in neurodiversity, repeated behavioural addictions as a risk marker compromised by executive function of dysregulated emotional control, impulse control, and self-monitoring.



Research themes:

1. **Executive functioning and addiction**, any addiction, were clearly evidenced. One study evidenced executive functioning and psychological symptoms in food addiction in obese women. This is pertinent information in reflection of Manchester's SAR GAYLE case (2022)
2. **Alcohol foetal syndrome** can result in alcohol related **neurodevelopmental disorders**, that can impact on executive functioning, which is an important consideration of generational patterns of addiction.
3. **Alcohol use disorder**, alcohol related brain damage is well evidenced to impact on executive functioning, particularly **working memory**. It has similarities to dementia, however, is on a continuum and can improve, unlike dementia.
4. **Neuropsychological consequences** of drug and alcohol use is noted as a risk marker on **executive functioning**.
5. **Autism** is well researched in terms of **executive functioning** and can impact all areas. However, the diagnosis also correlated with **co-occurring behavioural addictions**, any addiction, internet, social media, food, substance misuse.
6. **ADHD** diagnosis can impact all areas **executive dysfunction and reward dysregulation, a risk marker for behavioural addictions**.
7. Several studies evidenced the use of **executive functioning** as a new **neuropsychological tool for people in addiction**.
8. Several studies evidenced the use of **testing the frontal lobe battery (FAB)**. This is a cognitive test usually used for front temporal lobe dementia. However, although designed for this purpose, is being increasingly used to assess for executive dysfunction in **substance dependence**.
9. The research results identified '**co-occurrence**' of **neurodevelopmental needs, as a consistent theme in executive functioning**.
10. **Brain injuries** are clearly and robustly evidenced to impact **executive functioning**. Research carried out in Leeds and Glasgow, ascertained that 48% of the homeless participants reported a history of traumatic brain injury, 90% indicated that they had sustained their first traumatic brain injury before they became homeless.

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11. There were **variations in the literature around what ‘falls under the executive functioning umbrella’**. In literature reflective of neurodevelopmental conditions, for example, ADHD and Autism, executive functions of ‘attention and working memory’ are consistently referred to as executive functions. However, in adult neuropsychology, such as brain injury or acquired brain injury, less so.
12. Evidence that **emotional, social, and environmental contexts impact on executive functioning**. Wright, (2021) This is particularly relevant in people with **post-traumatic stress disorder or complex trauma**. These two conditions are evidenced to cause remarkable dysfunction in areas of fear processing and dysregulated nervous system. This is evidenced to significantly impact on executive functioning, particularly in the areas of **emotional and impulse control and self-awareness and monitoring**.
13. Research indicates that it is **difficult to identify which executive functions** are impaired and can be several functions or all functions, as the case study identified earlier in the report.
14. **Executive dysfunction can be slippery, subtle, and hard to spot**. It requires a longitudinal observation of behaviours from a consistent observer, for this reason a lead professional and ‘think family’ is critical in assessments.
15. What the grey literature evidenced is that our executive functioning is our ‘human brain’. **When it is ‘full’, for whatever reason, it is no longer able to organise information effectively to support us to have the capacity to act out our decisions.**



What does research and expert practice tell us about the relevance of executive functioning assessments:

Greater use of ‘ No refusals ’ of section 11 (2b) of The Care Act (2014) to increase assessment potential in the first instance, for hard-to-reach people, to start understanding their lived experiences and find the meaning of ‘why’.
Robust use of the executive functioning tool in ALL Care Act assessments, including Section 42 Safeguarding enquiries, with a team around the person approach, including think family.
Co-produced support plans that include executive functioning needs within an emotional, social, and environmental context.
Review the importance of key support workers , based on models of co-production, co-regulation, and connection, as a critical consideration in optimising executive functioning.
Review the need for integrated care models . The necessity of knowledge, skills and resources of occupational therapists and the use of cognitive and functional screening tools, such as the frontal lobe battery test evidenced in the research, as part of assessment and support planning. The need for access to clinical neuropsychologists and speech and language therapists as a holistic model of working with executive dysfunction.
Utilise what resources are already out there . Brain Injury specialists are experts on how executive functioning impacts on day-to-day living.
Review the need for trauma informed and psychologically informed environments that focus on the regulation of the nervous system that impacts on the emotional and impulse control of executive function.
Develop ways of working with ‘windows of tolerance’ and ‘spikey’ profiles. Methods of distraction, diversionary and desensitisation techniques. Rhythmic and creative activities -polyvagal techniques, to truly provide strength-based outcomes reflective of executive functioning growth models.
Review the Penumbra and the Glasgow out of hospital care models for the people in Manchester with complex needs recovering from addiction with executive dysfunction.
Review of The Liverpool Partnership and Care Model (LPaC) for people with complex needs in Manchester. What are the barriers for implementation?
Propose the need to commission research for Manchester’s rough sleeping and homeless population, as a comparable to the Leeds and Glasgow research to understand the Manchester context.
Executive functioning considerations in Safeguarding Adults Reviews . Review the impact of executive dysfunction in preventable deaths.

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Research implications:

Legislation:

In conclusion there is an emotional, social, and environmental context to executive functioning and potential for further research in this area. This is touched up on by Melanie Georges publication, The frontal lobe paradox. Whereby a person says one thing and does another repeatedly. This can be hard to evidence, because a person's ability to execute their decisions and wishes can change depending on the context. For example, in a clinical setting, such as hospital, a person may perform well. However, out of that setting, with an increase in social, emotional, and environmental stressors, they may not be able to execute the same decisions and wishes. George and Gilbert (2018)

The research title, "The capacity to act" prompts us to think of the Mental Capacity Act (2005)

The five principles of the Mental Capacity Act (2005) ask us to assume capacity and ensure steps are in place to optimise a person's ability to make and carry out their decisions.

By including executive functioning in Care Act assessments and support plans, moves the power dynamic on us as social workers, to be curious about behaviours that may reflect challenges in executive functioning. We need to co-produce assessments, support plans, with a shared understanding of the emotional, social, and environmental context of executive functioning as part of an early intervention agenda and strength-based model.

This paradigm shift would place the emphasis on us, as organisations, to design, commission and implement a different approach, to optimise a person's cognitive and functional abilities in the first instance. This model is evidenced in the NHS Penumbra and the Liverpool Partnership and care model (LPaC). This would be truly strength based in the real world.

Practice:

Currently in the UK, social work is focused on strength-based practice, emphasising people's own self-determination. The critical stance presented here, is that by placing the emphasis on the person's ability to self-determine and grow, requires a solid evidence base that the person has that current rationality and that their environment and basic hierarchy of needs supports this, which is often not the case reflective of the population cohort this research has focused on.

By overestimating people's strengths at circumstantial trajectory, where they find themselves 'surviving', without the social, emotional, and environmental scaffolding needed to function, supports the 'doors to remain closed and the equity gap to widen and language used of, 'they did not engage in support', rather than they do not have 'the capacity to act, what do they need?'

The research suggests, there is clear evidence to consider the 'underground of executive functioning', the assessing and support planning for it, as part of our Care Act duties, as an early intervention and preventative model, to improve the health and well-being of the people we serve, to have better outcomes and better lives (BOBL).

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Research conclusion with final recommendations:

In conclusion, 'The Capacity to Act', requires a tiered approach.

Firstly, the ownership is on us to optimise people's ability to do so. That we co-identify and understand executive dysfunction, assess, and support plan for these needs of hidden disabilities and differences by ensuring the emotional and environmental context is provided to do so.

Secondly, when we are assessing capacity specific decisions, it is essential that we consider the person's ability to execute their decision. Considering longitudinal evidence of executive dysfunction, in what areas and how this repeatedly impacts on their ability to have the capacity to act on their wishes and decisions.

Finally, we must see what is beyond an individual struggling and what is the larger context in which that struggle appears.

"There comes a point where we need to stop just pulling people out of the river. We need to go upstream and find out why they're falling in." — Desmond Tutu

By using this mentalising approach, we can begin to shift the power dynamic to "not what's wrong with you but what's happened to you, what do you need?"

Executive functioning assessments can support us to understand the persons 'underground' of behaviours in context. For example, research evidence states that **85%** of people homeless, sleeping rough and using substances will have experienced childhood trauma. Sundin and Baguley (2015)

Furthermore, research evidence states that the likelihood of further trauma from violence, abuse, sexual assaults whilst being homeless is around **95%**. Irving and Harding (2022)

Dr Stephen Porges (2011) states that "When we are well regulated and feeling safe, our reasoning and logic becomes at it's optimum". Ensuring people feel safe in the first instance is the priority.

When the nervous system is regulated, and we live in safe environments, and are connected to others in a safe way, this supports our executive functioning to be at its optimum, to have the capacity to act out our decisions and wishes.

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Research context Summary:

"If the outcome of your brain injury or neurodevelopmental/cognitive need is that you struggle to plan, to organise, to carry out actions that you know are in your best interests,

If you struggle to remember what it was that you planned to do, if you struggle to stay on track and prioritise tasks that will help you secure or maintain accommodation,

If you are impulsive, if you lack the ability to see how actions/inactions have consequences

Then homelessness is an obvious outcome.

It takes skills to maintain tenure and self-care, those skills are cognitive, executive, and behavioural in nature.

Those are the very skills that executive dysfunction takes away from people, and some aspects for adults with neurodivergence struggle with.

Some people of whom may have not been functioning brilliantly because of social deprivation, societal inequality, and developmental trauma.

It will be statistically very likely that 50% of the people that cannot control their behaviour have experienced at least one brain injury."

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Appendix 1:



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OPENING THE DOOR FOR PEOPLE WITH HIDDEN DISABILITIES AND DIFFERENCES

Appendix 2:



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OPENING THE DOOR FOR PEOPLE WITH HIDDEN DISABILITIES AND DIFFERENCES

Appendix 3:



Research poster:

OPENING THE DOOR FOR PEOPLE WITH HIDDEN DISABILITIES & DIFFERENCES

Author Ellie Atkins

ABSTRACT

Aims: To raise awareness of hidden disabilities and differences reflective of executive functioning. To highlight the necessity to include executive functioning in Care Act assessments. Assessing and understanding needs to ensure strength-based scaffolding to support people to have the 'capacity/ability to act out their wishes and decisions.'

Methods: Literature review

Results: A wide range of conditions can affect executive functioning.

Conclusions: When executive function is disorganised or underdeveloped, it can inhibit appropriate decision-making and reduce a person's problem-solving abilities.

EXECUTIVE FUNCTIONING SKILLS

- Emotional Control
- Impulse Control
- Flexible Thinking
- Working Memory
- Self-monitoring
- Planning & Prioritising
- Task Initiation
- Organisation

HIDDEN DISABILITIES AND DIFFERENCES

- Acquired Brain Injury
- Traumatic Brain Injury
- Developmental Trauma
- PTSD
- Alcohol Related Brain Damage
- Alcohol Foetal Syndrome
- Autism & ADHD
- Epilepsy

THE UNDERGROUND OF EXECUTIVE FUNCTION

RESULTS

'All kind of minds' can experience executive dysfunction, on a continuum, affected by emotional and environmental factors.

Brain Injury, ADHD and Autism are robustly evidenced to impact on executive function requiring executive function scaffolding.

PTSD is driven by remarkable dysfunction in brain areas vital to fear processing and response, which impacts on executive functioning.

Voices of lived experience share significant life narratives of repeated traumas and share that using substances helps them feel 'different to function'. Homelessness is recognised as a significant trauma.

INTRODUCTION

The capacity to act ... Opening the door for people with hidden disabilities and differences.

What does research and expert practice tell us about the relevance of executive functioning assessments to work with people who are homeless or rough sleeping and who have complex needs.

COVID-19 PANDEMIC

In 2019, the COVID 19 pandemic hit Britain. This was the first time in our history where political will, financial investment and legal frameworks resulted in the Government drive to get 'everybody in' off the streets. In Manchester, what emerged during this time, was a group of people that either refused to come indoors or presented with behaviours that resulted in them not being able to stay indoors. The pandemic provided a unique opportunity to reveal a hypothesis of why.

Professional curiosity and safeguarding frameworks supported longitudinal observations of behaviours that reflected hidden disabilities and differences.

CONCLUSION

We need to include the executive functioning wheel as part of Care Act assessments to capture hidden disabilities and differences.

We need to design, commission and deliver contexts that optimise peoples executive function needs to meet unmet care and support needs.

We need to implement executive functioning in Mental Capacity Assessments.

We need to consider further research into areas of executive functioning that are risk markers for people that repeatedly neglect self.

RECOMMENDATIONS

'Opening the doors for people with hidden disabilities and differences' by including executive functioning assessment wheels in Care Act assessments, including greater use of 'No refusals' (section 11.2b) and think family to gather longitudinal information.

'levelling up the equity gap' requires assessment of executive functioning needs. This is vital to understanding the needs and co-produced care and executive function support plans.

Capturing and understanding needs are vital to inform the design and deliver of provisions and ways of working that are truly strength based in the 'real world'.

'Back to basics approach', care and support that promotes the Care acts well-being principle first and foremost, by providing a framework reflecting Maslow's hierarchy of needs.

'Early intervention and prevention' models of interdependence and co-regulation that support the emotional and environmental factors that affect executive function.

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