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Embracing Complexity
Time to think differently

Does where families live influence access to early years support?

Embracing Complexity webinar

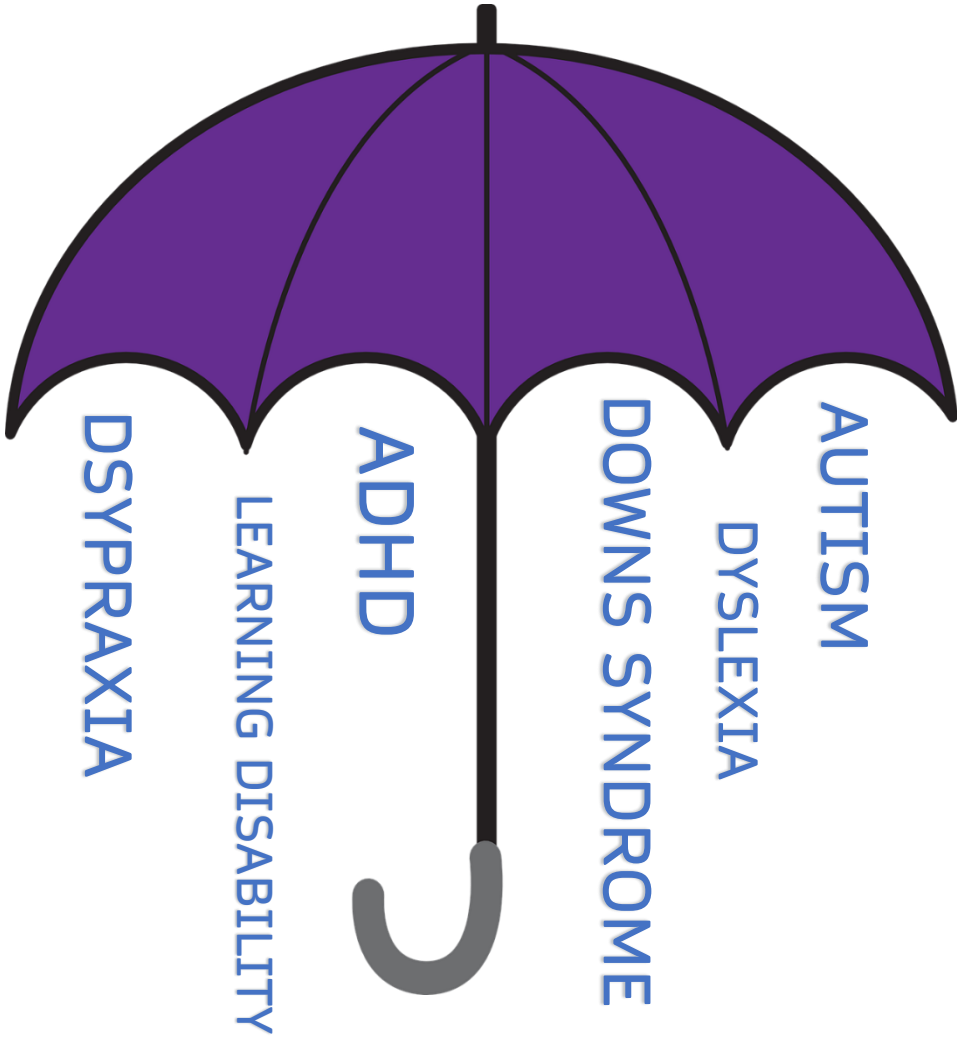
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@TizardCentre @EmbraceComplex #EmbraceComplexity

What are neurodevelopmental conditions?

- Neurodevelopmental conditions is an 'umbrella' term used to describe life-long conditions that influence the way a person thinks, feels and experiences the world



What is early years support?

- Early years support describes ***any formal support*** children with neurodevelopmental conditions and their families receive
- This support can be targeted to the child's and family's specific needs, with the aim of helping them have a higher quality of life



Research into early years support

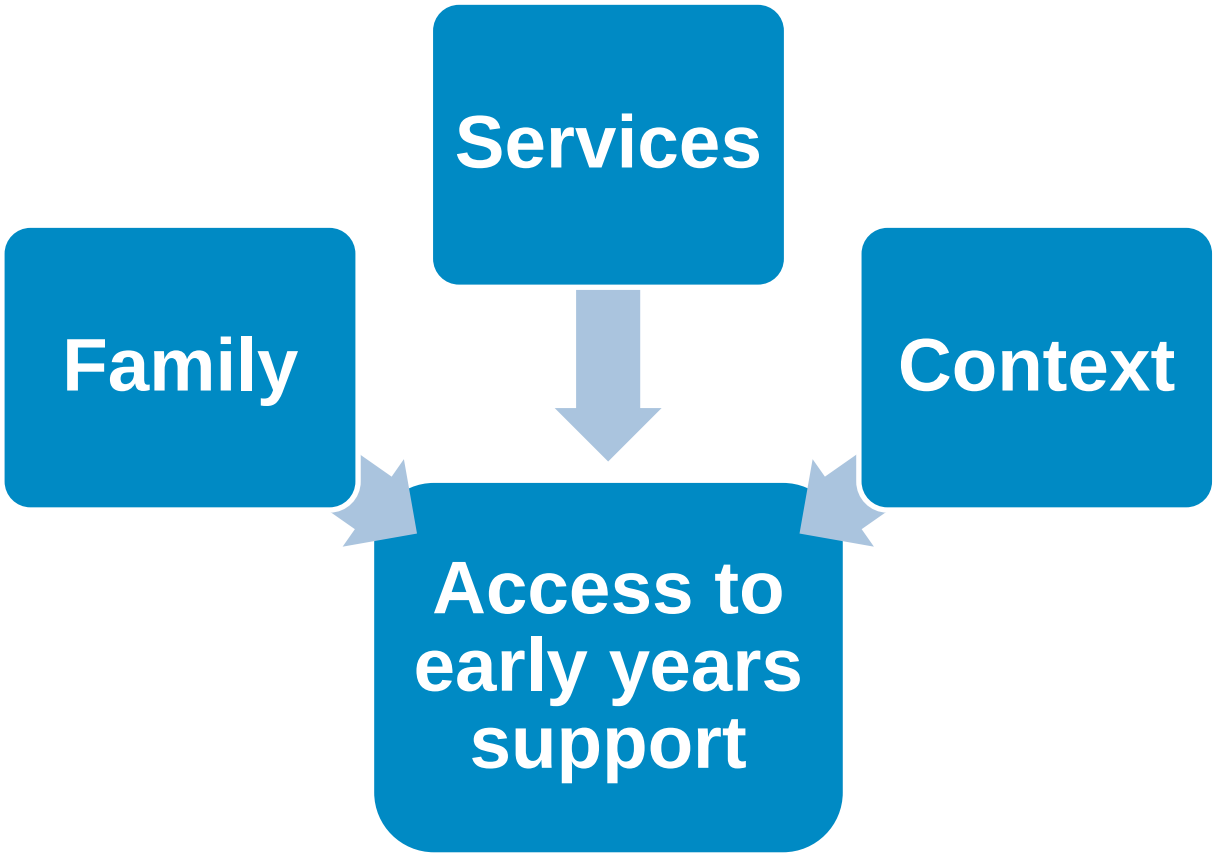
- Research shows early years support can improve many outcomes for children with neurodevelopmental conditions:
  - Improve children's developmental skills (e.g., communication)
  - Prevent or reduce behaviour described as challenging (e.g., self injury)
  - Improve children's performance in school

- Early years support also benefits parents:
  - Increase understanding of their child's needs
  - Reduce stress
  - Improve well-being



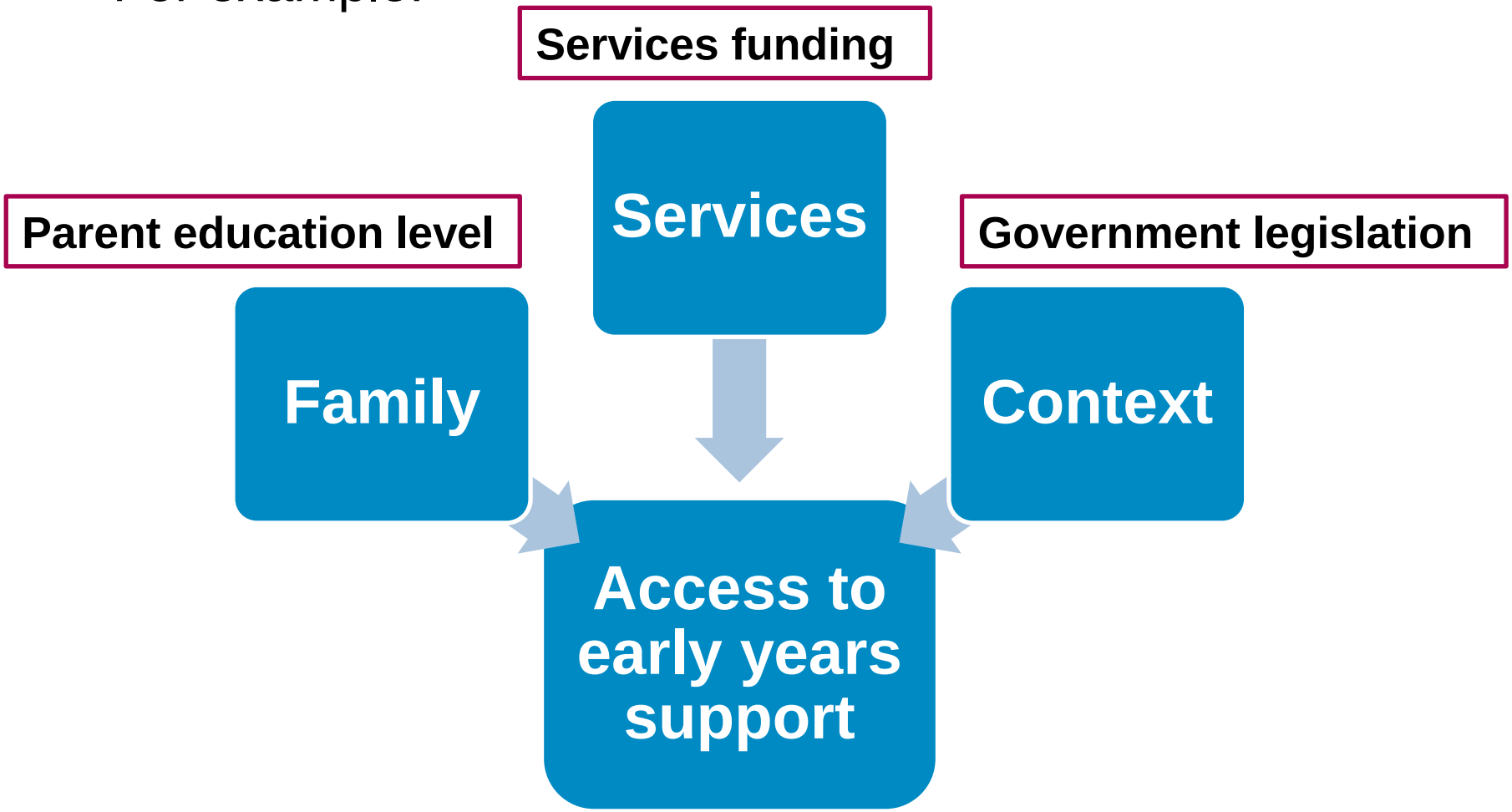
What influences access to support?

- Multiple factors influence access to support for families who have children with neurodevelopmental conditions



What influences access to support?

- For example:



Why explore area deprivation?

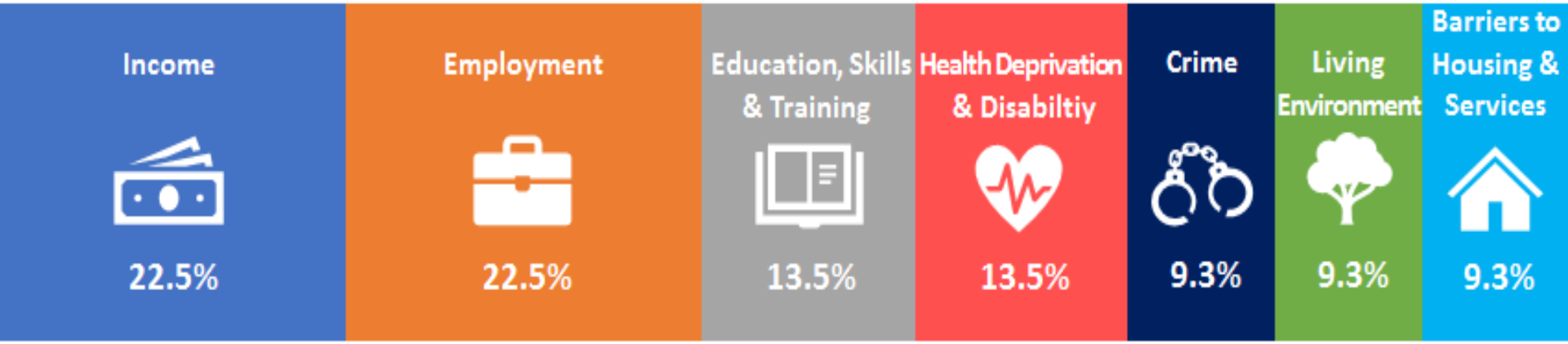
- Research has found ***families' economic deprivation*** (e.g., income poverty, unemployment) predicts ***decreased access to support*** for children with neurodevelopmental conditions and their families
- Current research has focused on family-level economic factors
- Research has not explored the relationship between ***area deprivation*** and access to early years support





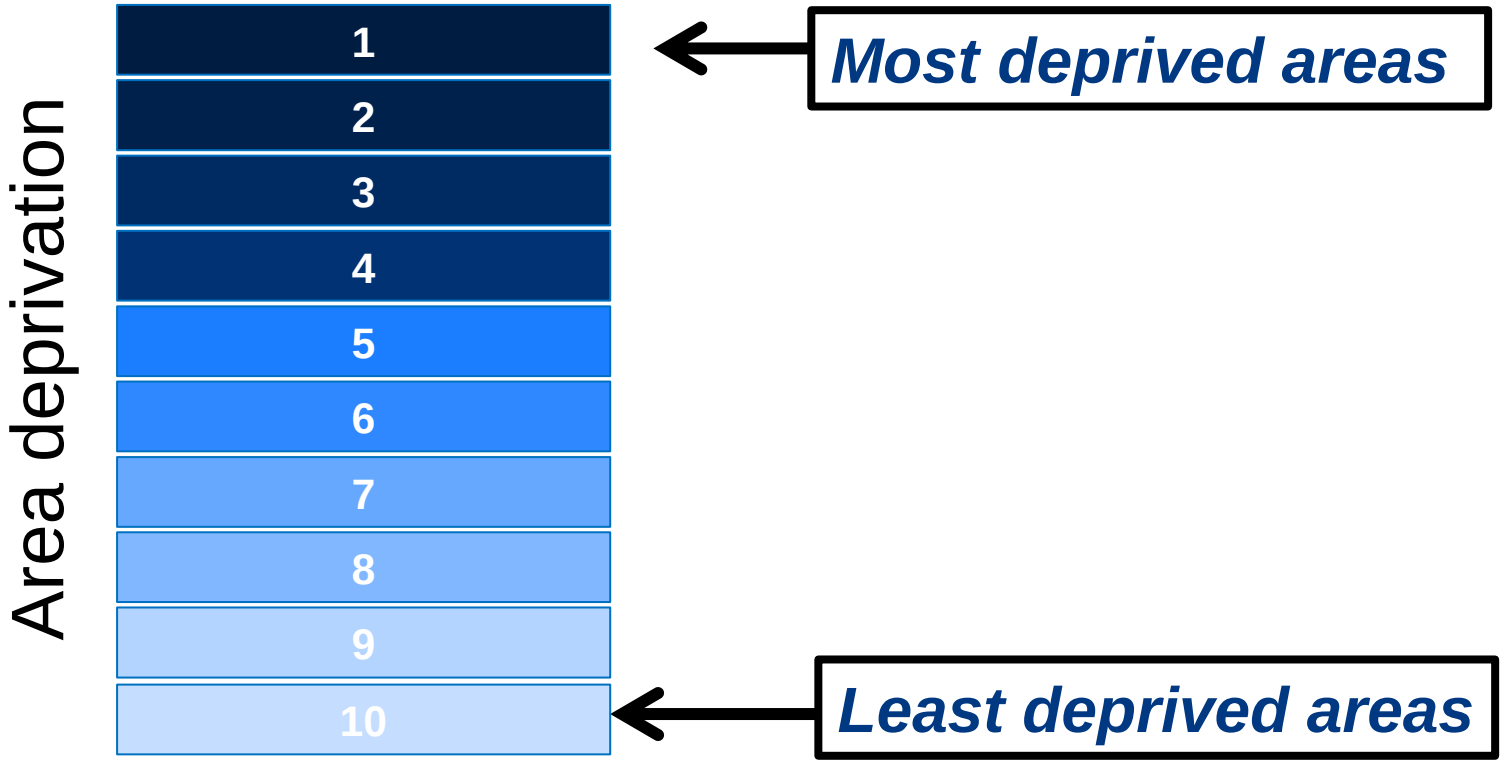
What is area deprivation?

- Area deprivation refers to deprivation for small areas (i.e., neighbourhoods) across the UK
- The UK government measures area-level deprivation across ***7 deprivation domains***:



What is area deprivation?

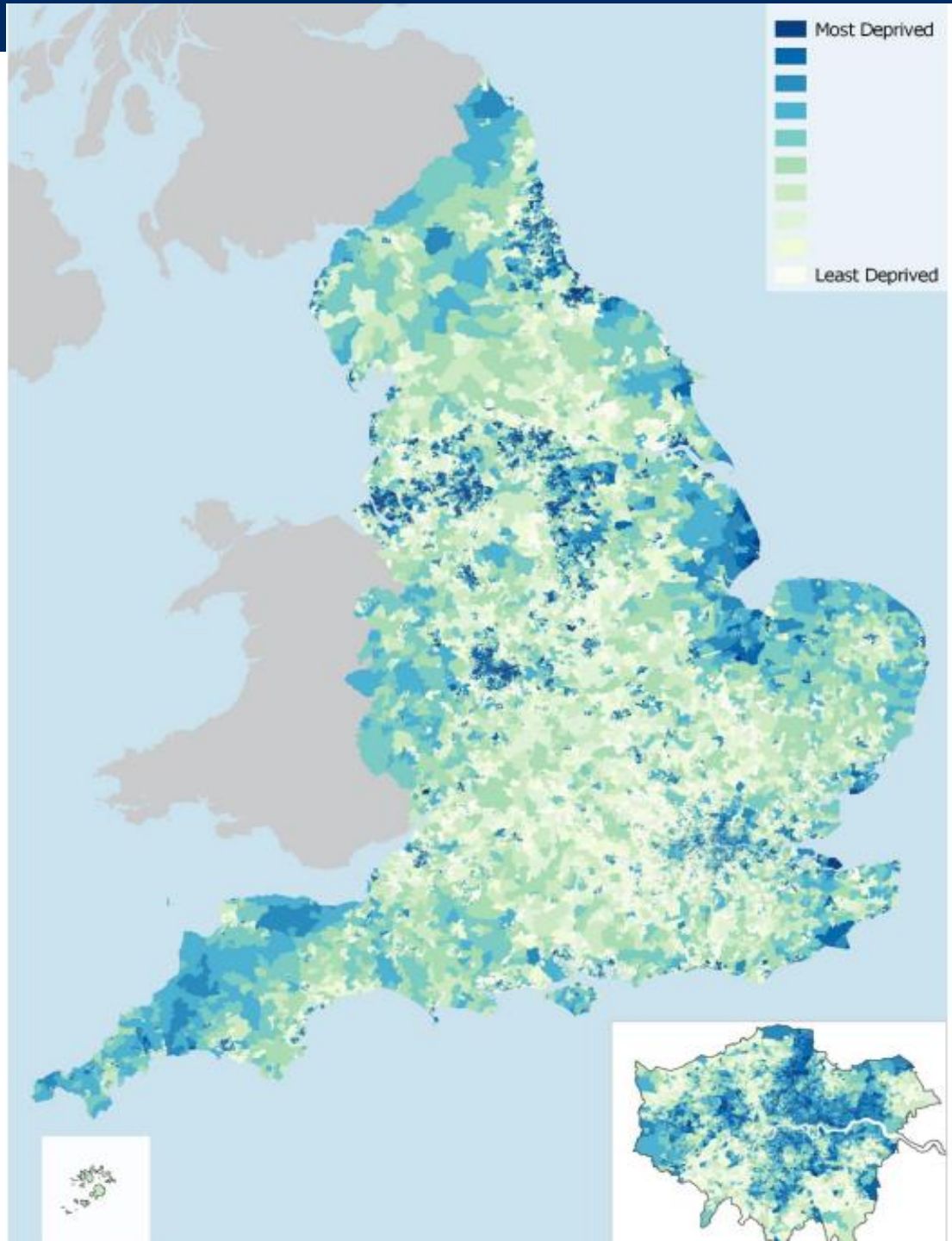
- Based on comparisons across the 7 domains, every small area is ranked on a scale of 1 to 10 for deprivation



What is area deprivation?

- There are 32,844 small areas in England

- Each is rated 1-10 for area deprivation



Research questions

- Is there a relationship between ***area deprivation*** and ***access to support*** for families who have young children with neurodevelopmental conditions?
- Are there differences in ***access to support*** between families living in the ***most deprived areas*** compared to families living in ***other less deprived areas***?



Support in the Early Years study

- UK-wide survey of parents with a child aged 0-6 with diagnosed or suspected neurodevelopmental conditions
- Between September 2018 and May 2019
- Topics:
  - ***Access to early years support***
  - ***Parent and family well-being***
  - ***Child and family characteristics*** (e.g., child age, diagnosis, where the family live, income)



How did we measure access to early years support?

- By measuring families':

1. **Intervention access**

2. **Access to formal support sources**

3. **Unmet need for formal support**

Intervention access

- **What do we mean by ‘intervention access’?**

- Whether families had accessed interventions or support approaches to ***support their child’s development*** or to ***support them as caregiver*** in the last year

- For example: Early Bird, Sure Start, Early Intensive Behavioural Intervention, Therapy, Counselling



Access to formal support sources

- **What do we mean by ‘access to formal support sources’?**

- The ***number of formal support sources*** families had accessed including key professionals across education, health, and social care, health specialists, and other formal support sources for families of children with neurodevelopmental conditions



Examples of formal support sources

- GP or nurse
- Health visitor
- Paediatrician
- Staff at pre-school/school
- Educational psychologist
- Speech and language therapist
- Occupational therapist
- Family support worker
- Respite or short breaks
- Child minder or nanny
- Social worker
- Local authority or health team that assesses special educational needs
- Neurologist
- Neurologist
- Geneticist
- Audiologist
- Dietician
- Cardiologist
- Sleep practitioner
- School transport
- Parent or self-help groups
- Local Authority housing department
- Specialist services to meet the child's needs (specialist teachers, behavioural support teams)



Unmet need for formal support

- **What do we mean by ‘unmet need for formal support’?**

- The number of formal support sources (key professionals across education, health, and social care) that families ***did not access, but wanted to access***



How was area deprivation measured?

- We used the ***Index of Multiple Deprivation (IMD)*** as a measure of the level of area deprivation

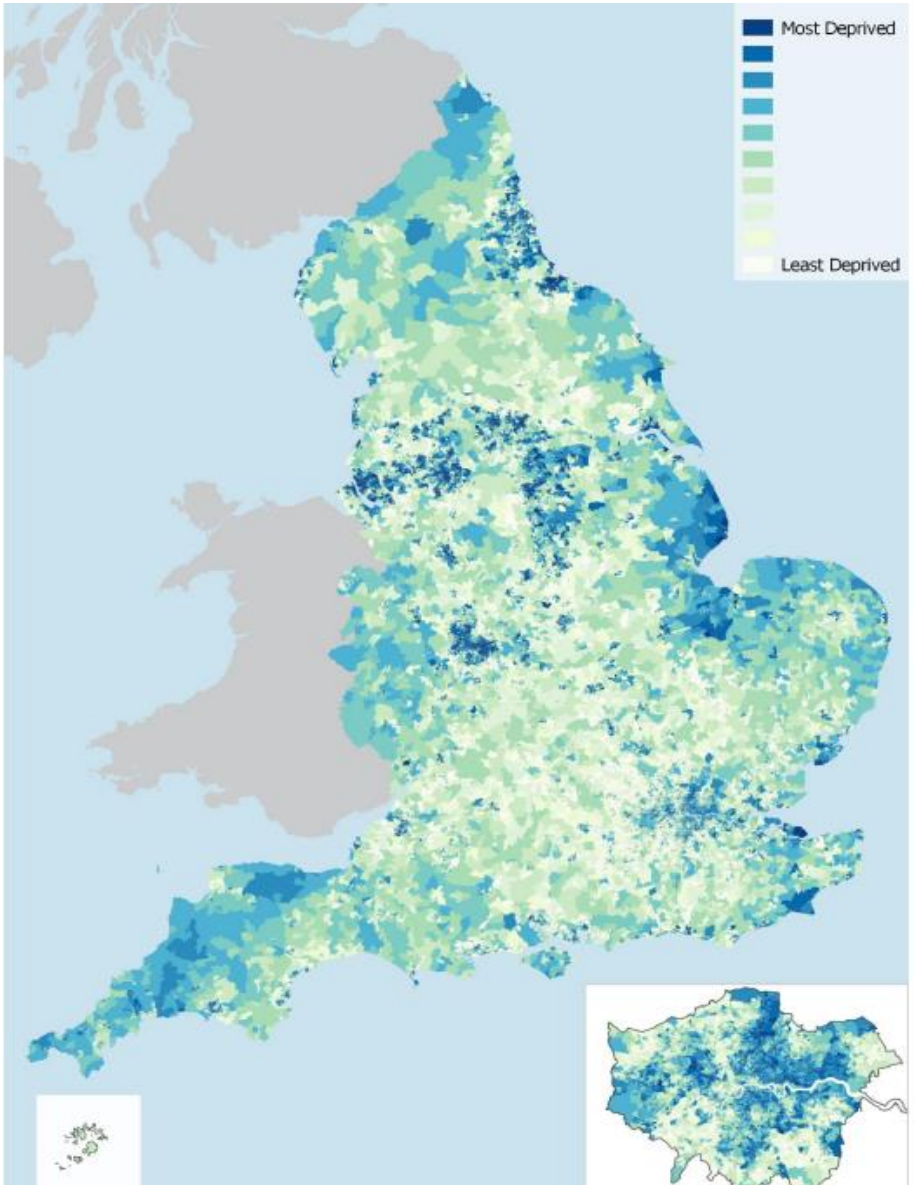
- IMD data was linked to families' postcodes to identify area deprivation for where they lived



What is the Index of Multiple Deprivation (IMD)?

- The IMD is a government measure that relatively ranks local areas across the UK to indicate their level of deprivation (**deciles 1-10**)

- These are based on 7 deprivation domains:
  - ***Income***
  - ***Employment***
  - ***Education***
  - ***Health***
  - ***Crime***
  - ***Housing***
  - ***Living environment***



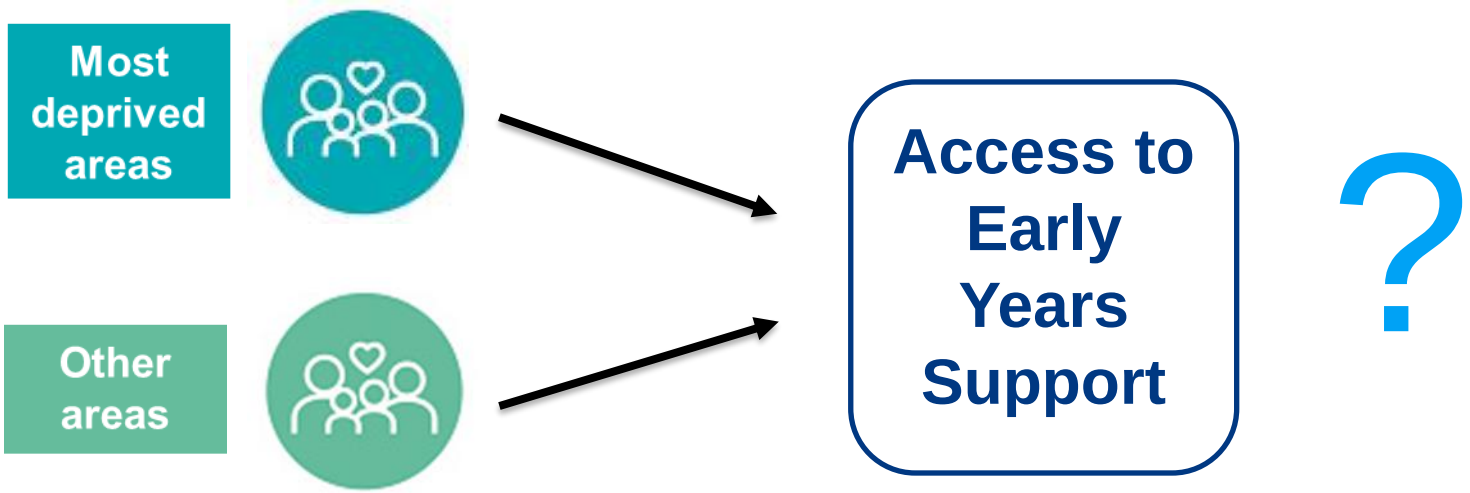
How did we use the Index of Multiple Deprivation?

- Firstly, we explored if there was a relationship between the ***ranking of area deprivation*** (deciles 1-10) where families live and their access to early years support



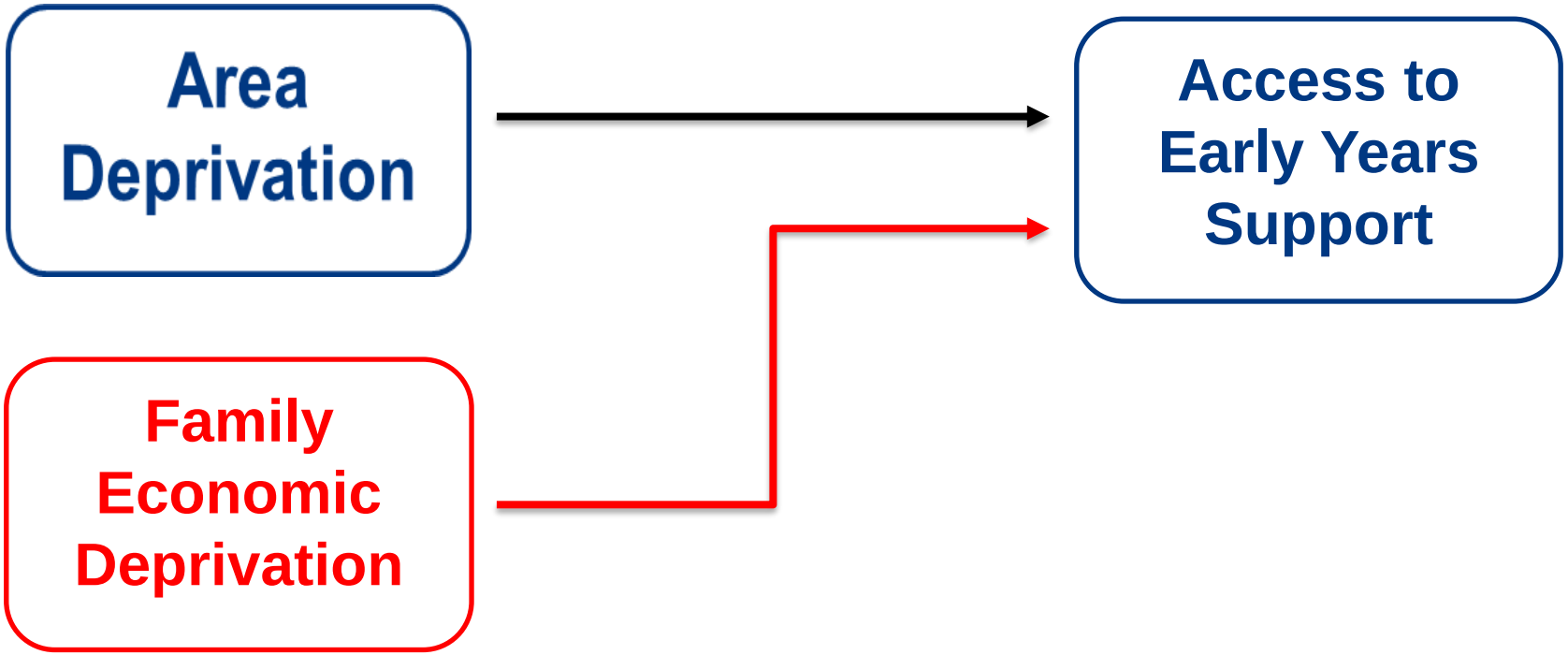
How did we use the Index of Multiple Deprivation?

- Secondly, we split the 1-10 deciles into ***the most deprived areas*** (deciles 1-2) and ***other less deprived areas*** (deciles 3-10) to explore if there were differences in access between these groups



Family economic deprivation

- We also accounted for ***family economic deprivation***



How did we measure family economic deprivation?

- Our family economic deprivation measure was made up of 4 variables:

  - **Income poverty**
  - **Subjective poverty**
  - **Ability to raise money**
  - **Household employment**

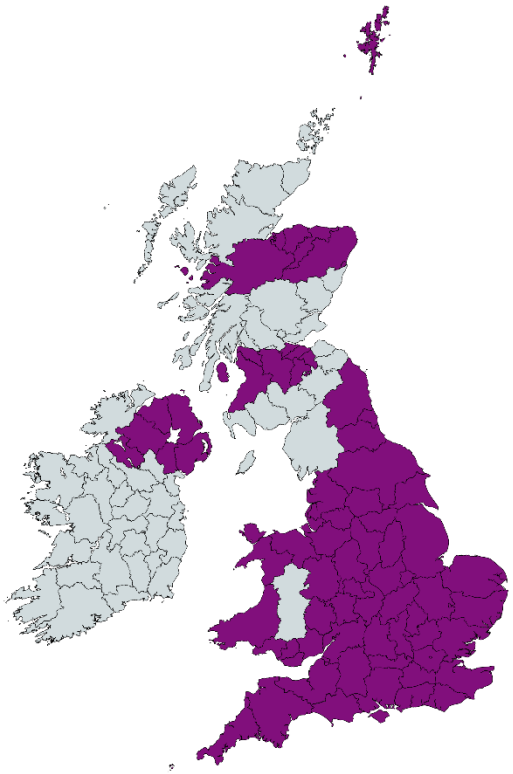
To Recap

- Our goal was to explore the relationship between area deprivation where families live and access to support
- To measure families' access to early years support we looked at: their ***intervention access***, their ***access to formal support sources***, and their level of ***unmet need for formal support sources***
- Area deprivation was examined as ranks (*1-10*) and groups (*most deprived vs other less deprived areas*)
- Family economic deprivation was included to ensure an independent relationship was being assessed

Who took part?

- Overall, 673 parental caregivers completed the survey

Characteristic	Participant Details
Child age	Mean 4.8 years (SD 1.5)
Child gender	481 (71.5%) male
Child neurodevelopmental conditions:	
Autism	524 (77.9%)
Learning disability	328 (48.7%)
Developmental delay	317 (47.1%)
Social communication	214 (31.8%)
ADHD	123 (18.3%)
Dyspraxia	121 (18.0%)
Respondent caregiver	613 (91.1%) biological mother
Caregiver age	Mean 36.5 years (SD 6.7)



Area deprivation

- Area deprivation data (IMD) was found for 544 participants

Most deprived areas →

Least deprived areas →

Area Rank	Participants
1	65 (9.7%)
2	72 (10.7%)
3	34 (5.1%)
4	62 (9.2%)
5	48 (7.1%)
6	50 (7.4%)
7	48 (7.1%)
8	55 (8.2%)
9	52 (7.7%)
10	58 (8.6%)
Mean rank 5.4 (SD 3.0)	

Group	Participants
Most deprived areas	137 (20.4%)
Other areas	407 (60.5%)

Family economic deprivation

- Many families who took part experienced economic deprivation

Deprivation	Participant Details
Income poverty	393 (58.4%) in poverty
Employment	124 (18.4%) no caregiver in employment
Subjective poverty	105 (15.6%) not managing financially
Ability to raise money	405 (60.2%) would struggle to raise money
Family economic deprivation total	***Mean 1.5 (SD 1.1), range 0-4***

Intervention access

- Less than one fifth of participants had ***accessed an intervention***, either to support the child or the parent

Intervention Access	Participants
Yes	126 (18.7%)
No	547 (81.1%)

Access to formal support sources

- Of the 49 ***formal support sources***, these were accessed by the ***most*** participants

Formal Support Source	Total Accessed
Paediatrician	569 (84.5%)
Speech and language therapist	567 (84.2%)
General practitioner	530 (78.8%)
Dentist	511 (75.9%)
Staff at school	482 (71.6%)
Interactive website	453 (67.3%)
Staff from the local authority or health team assessing special educational needs	451 (67.0%)
Staff at nursery, preschool or crèche	442 (65.7%)
Health visitor	413 (61.4%)
Educational psychologist	361 (53.6%)



Access to formal support sources

- Of the 49 ***formal support sources***, these were accessed by the ***least*** participants

Support	Total Accessed
Foster carer	7 (1.0%)
Endocrinologist	26 (3.9%)
Podiatrist	26 (3.9%)
Support to manage direct payments, independent from the local authority	38 (5.6%)
Independent support advisor	40 (5.9%)
Gastroenterologist	43 (6.4%)
Carer's centre	44 (6.5%)
Respiratory consultant	49 (7.3%)
Advocate	56 (8.3%)
Local authority housing department	56 (8.3%)



Unmet need for formal support

- 75.5% participants reported an unmet need for support
- These were reported as an ***unmet need for support*** by the most participants who had not accessed their support

Support	Unmet Need*
Occupational therapist	136 (52.9%)
Educational psychologist	131 (52.8%)
Staff from the local authority or health team assessing special educational needs	83 (52.2%)
Behaviour specialist	232 (43.0%)
Paediatrician	28 (40.0%)
Speech and language therapist	29 (39.7%)
Sleep practitioner	181 (34.8%)
Dentist	44 (33.3%)
Respite carer	156 (27.9%)
Family support worker	133 (26.6%)



*Percentage of participants who had not accessed support from the professional

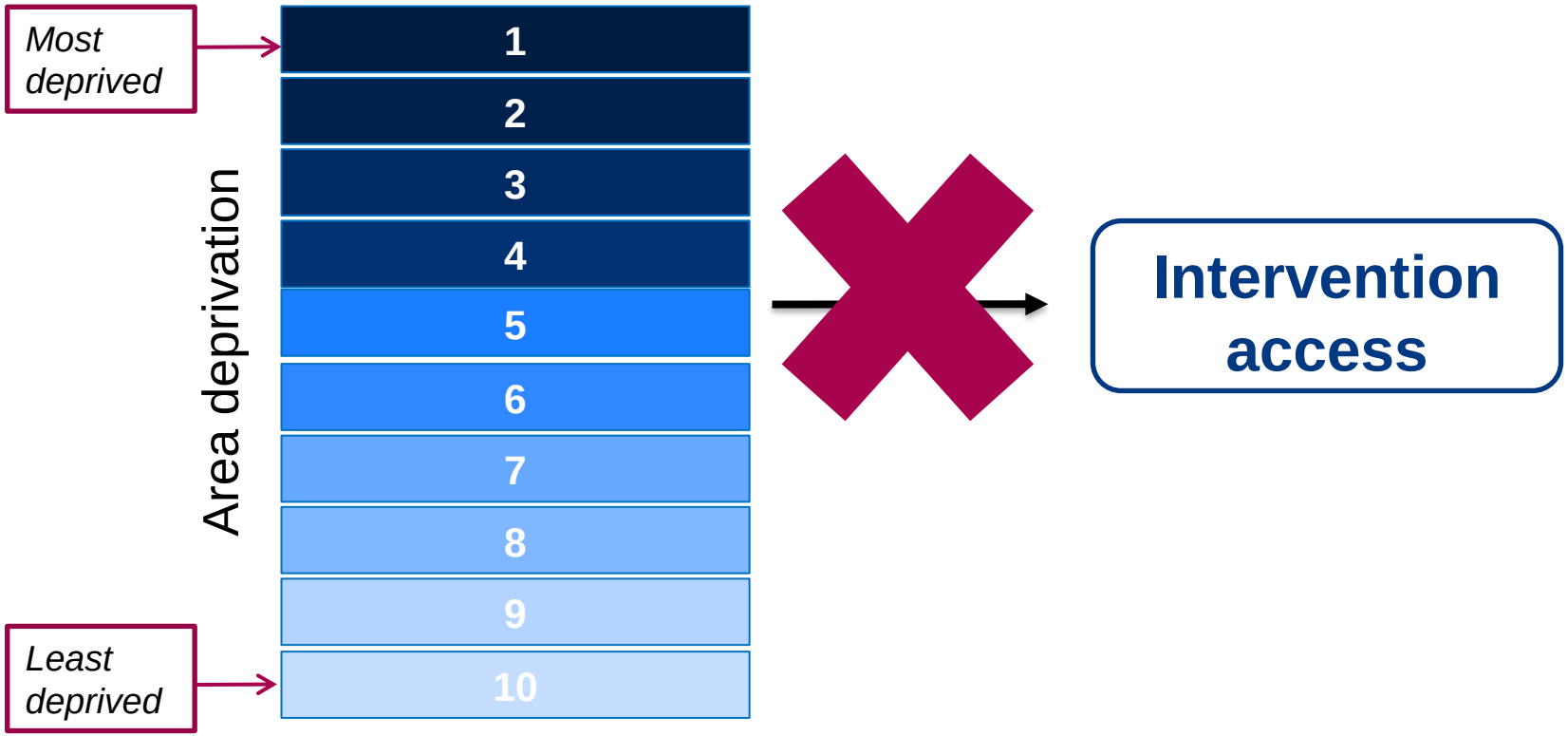
Access to support – overall

- Most families had not ***accessed an intervention***
- There was considerable variation in ***access to formal support*** and ***unmet need for formal support***

Outcomes	Participants
Intervention access	547 (81.1%) not accessed intervention
Formal support sources accessed	Mean 14.6 (SD 5.7), range 0-32
Unmet need for formal supports	Mean 3.2 (SD 3.2), range 0-17

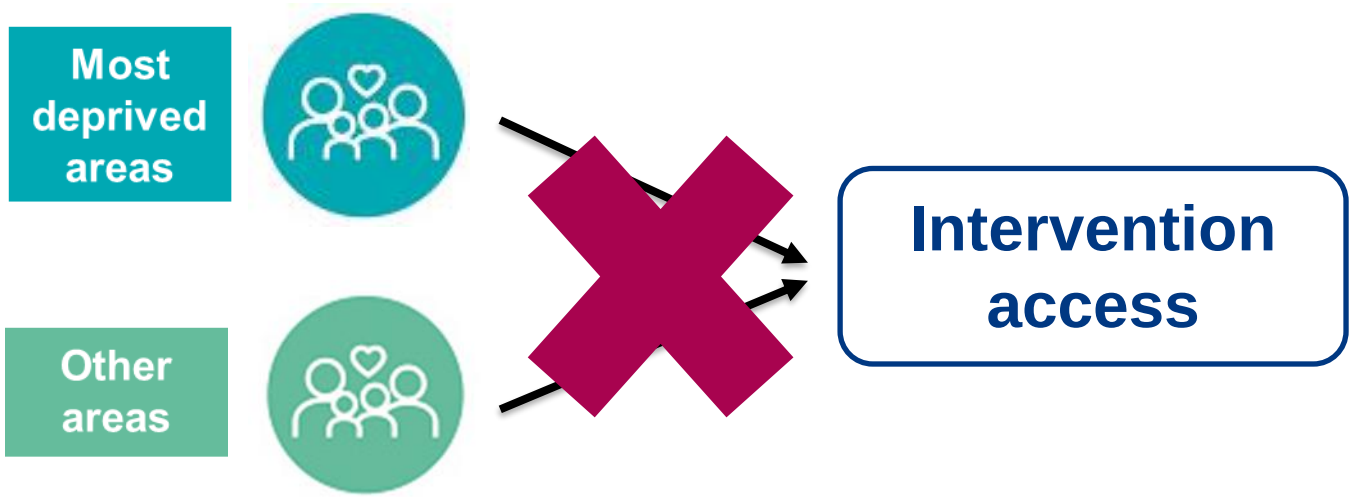
Area deprivation and intervention access

- There was **no significant relationship** between the ranking of area-level deprivation (decile 1-10) and ***intervention access***



Area deprivation and intervention access

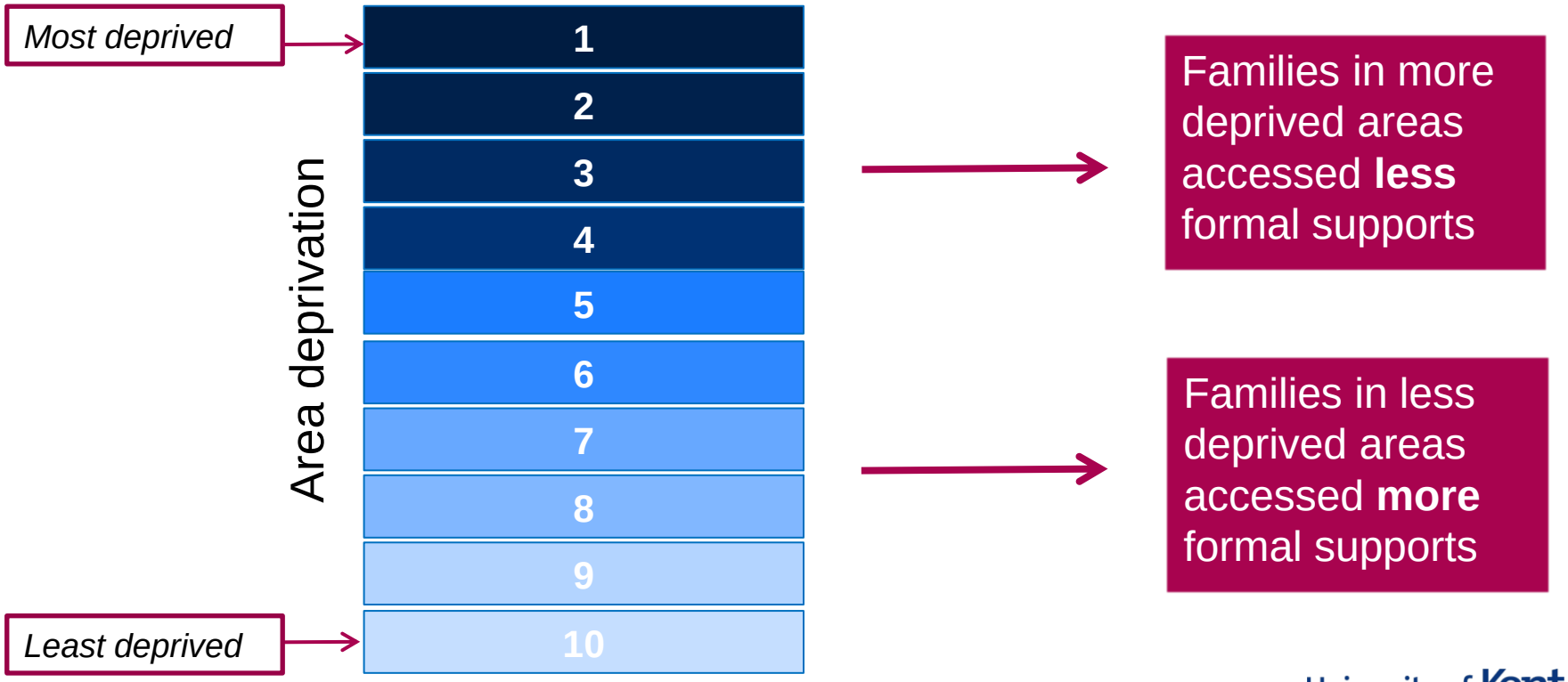
- There was **no significant difference** in ***intervention access*** between families living in the most deprived areas compared to those living in other deprived areas



- There was also **no significant relationship** between family economic deprivation and ***intervention access***

Area deprivation and access to formal support sources

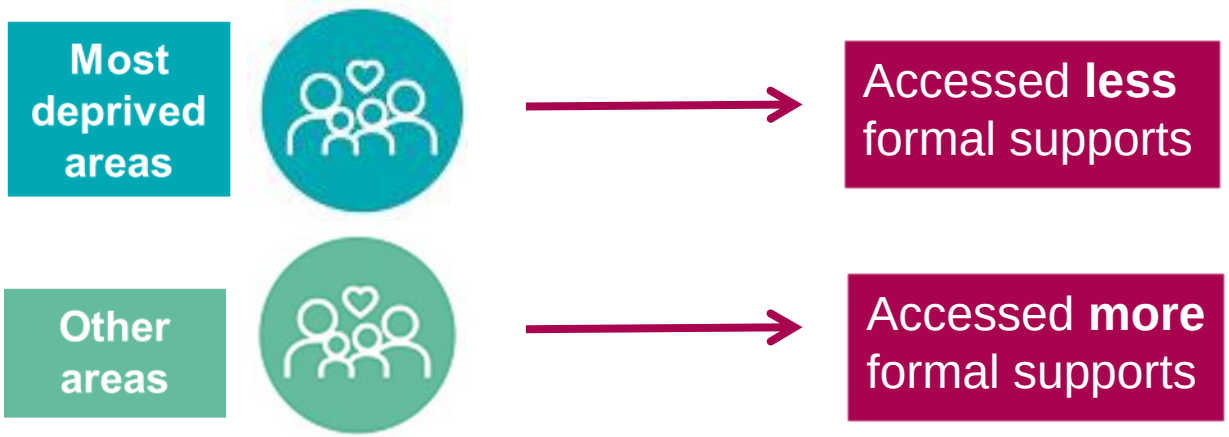
- Area deprivation rank was **a significant independent predictor** of ***access to formal support*** – *families in **less deprived** areas accessed **more formal support***



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Area deprivation and access to formal support sources

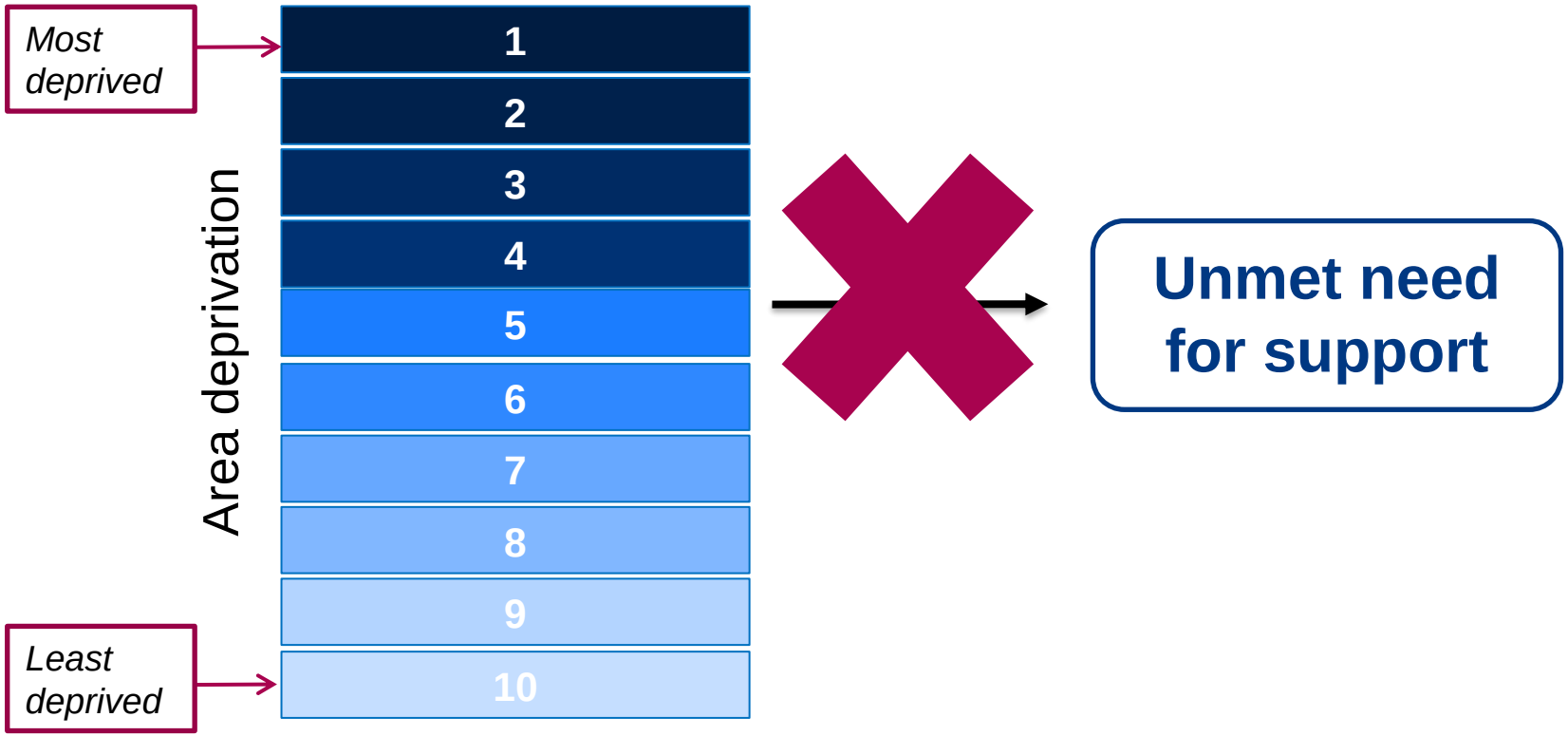
- There was **a significant difference** in ***access to formal support*** between families living in the most deprived areas compared to those living in other areas – *those in the **most deprived** areas accessed **less formal support***



- **No significant relationship** was found for family economic deprivation and ***access to formal support***

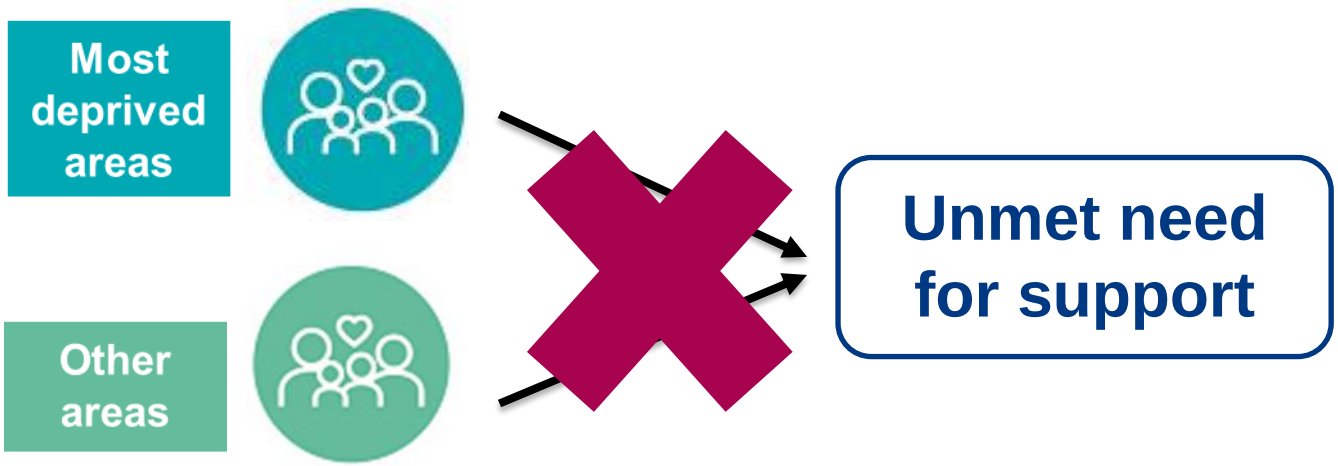
Area deprivation and unmet need for formal support

- Area deprivation rank was not **a significant predictor** of ***unmet need for support***



Area deprivation and unmet need for formal support

- There was **no significant difference** in ***unmet need for support*** between families living in the most deprived areas compared to those living in other areas



Area deprivation and unmet need for formal support

- Family economic deprivation was **a significant independent predictor** of ***unmet need for support***

- *Families with **higher economic deprivation** reported **increased unmet need** for formal support sources*

To Recap

- **Area deprivation** was related to ***access to formal support sources*** – *families living in less deprived areas accessed more formal support*

- **Area deprivation** was not related to ***intervention access*** or ***unmet need for formal support***

- **Family economic deprivation** was not related to ***intervention access*** or access to ***formal support sources***, but was related to ***unmet need for support*** – *families with higher economic deprivation reported increased unmet need for formal support*

What do our findings mean?

- Our findings show disparities of access to early years support based on ***area deprivation*** and ***family economic deprivation***

- This highlights potential ***variations in service provision*** (availability, capacity) based on area deprivation and potential ***limitations of the UK's universally free service system***

- This may be related to ***government funding cuts*** for services (austerity)

Implications and next steps

- Further action is needed to address disparities in access to early years support based on area and family deprivation.
- For example:
  - **Policies and government investment** to reduce area deprivation and family poverty – or to reduce their impact on access to early years support
  - **Actions by services and professionals** to improve access for families living in deprived areas and/or those experiencing economic deprivation
  - **Future research** to develop understanding, such as to examine differences via specific support types and using longitudinal methods to ascertain causal relationships

Questions and comments

- Thank you for listening!
- Any questions, comments, or reflections?
- Email: S.Sapiets@kent.ac.uk or @suzijsapiets

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