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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

DSYPRAXIA

LEARNING DISABILITY

ADHD

DOWNS SYNDROME

DYSLEXIA

AUTISM

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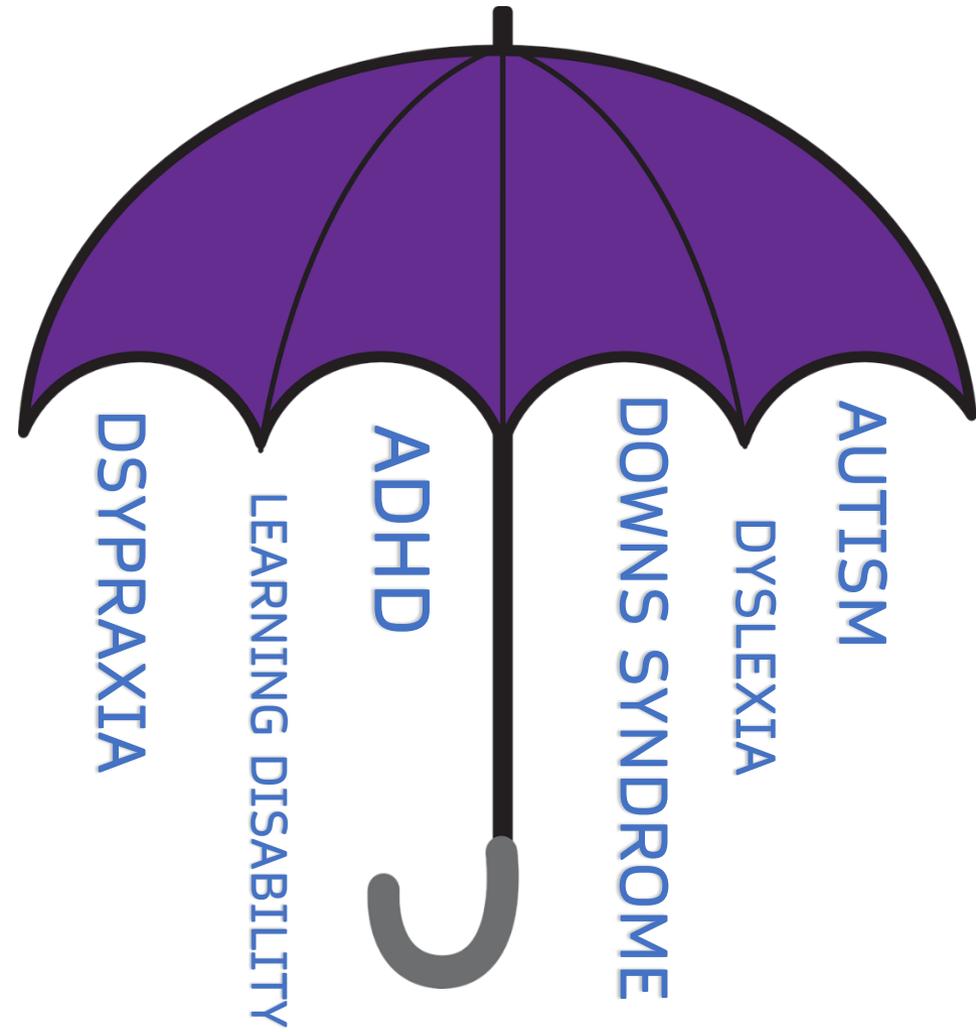
What is early years support?

- 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

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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

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What influences access to support?

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

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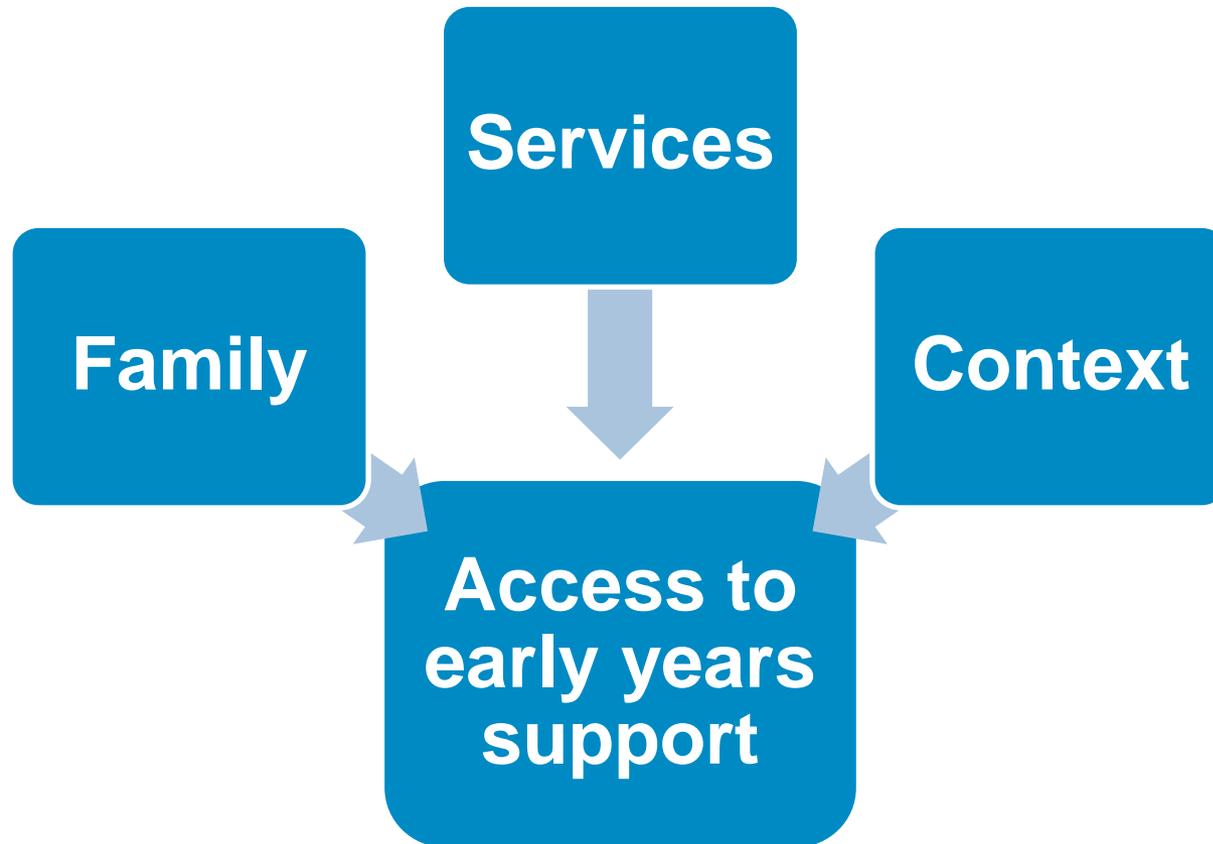
What influences access to support?

- For example:

Services funding

Parent education level

Services

Government legislation

Family

Context

Access to early years support

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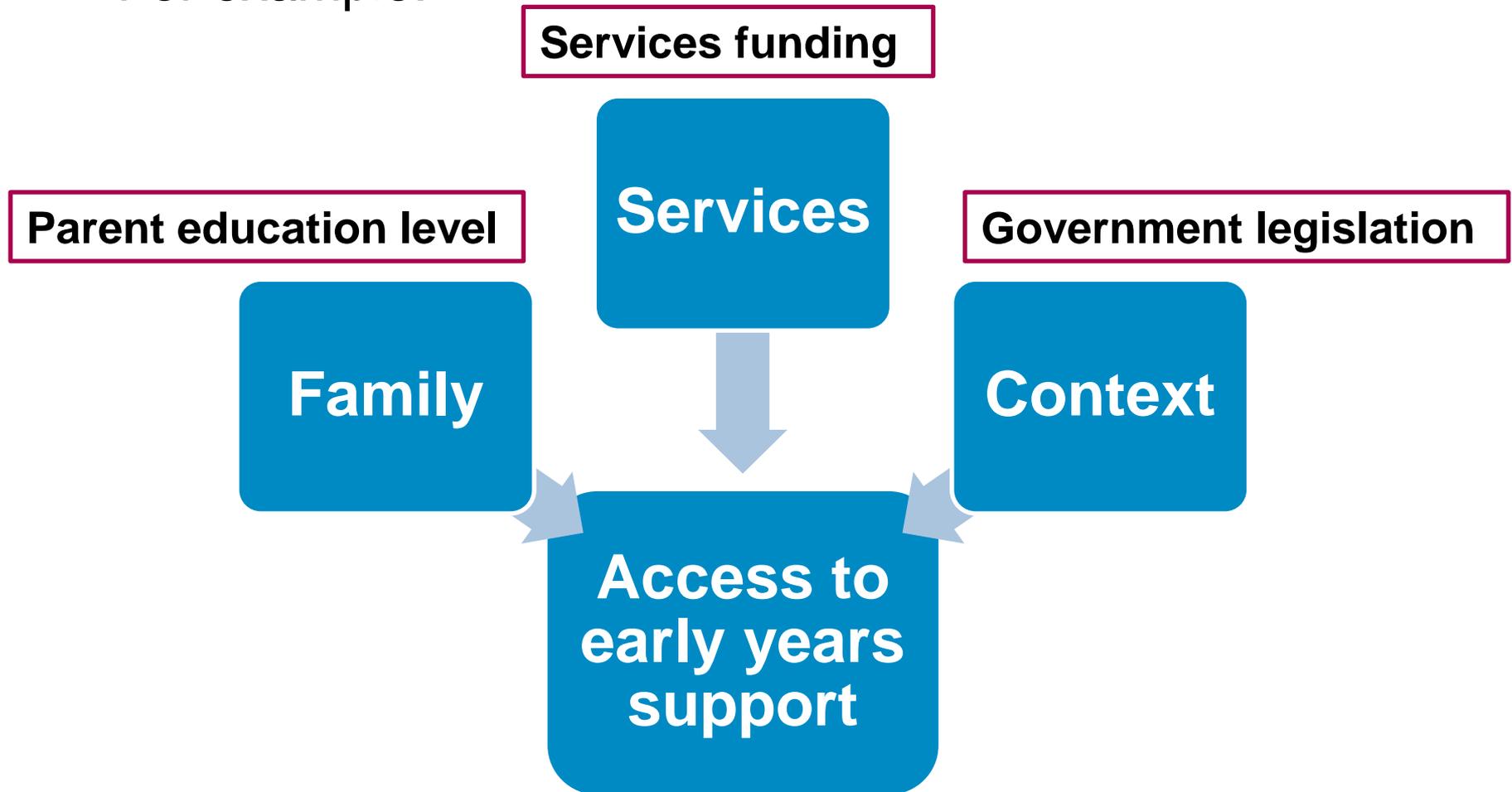
Why explore area deprivation?

- 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

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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*:

Income	Employment	Education, Skills & Training	Health Deprivation & Disabiltiy	Crime	Living Environment	Barriers to Housing & Services
22.5%	22.5%	13.5%	13.5%	9.3%	9.3%	9.3%

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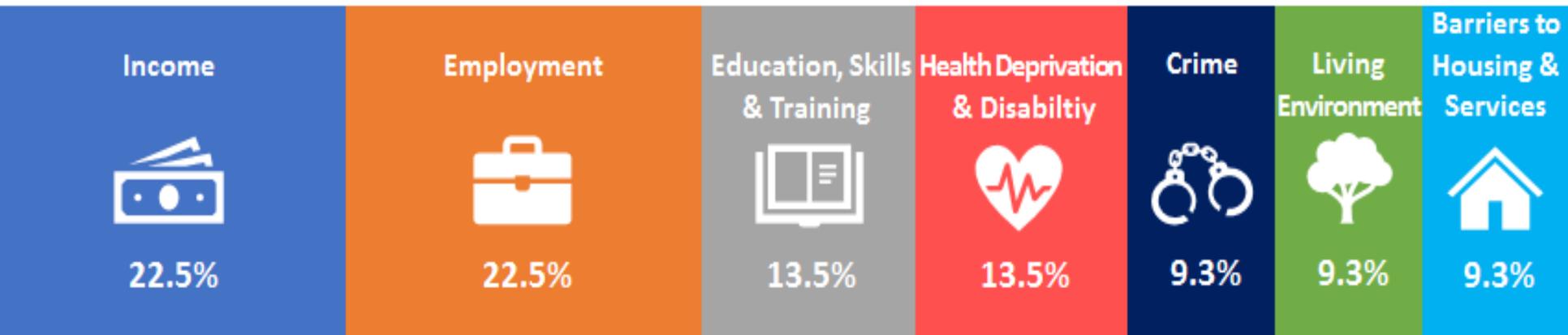
What is area deprivation?

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

Area deprivation

1
2
3
4
5
6
7
8
9
10

← *Most deprived areas*

← *Least deprived areas*

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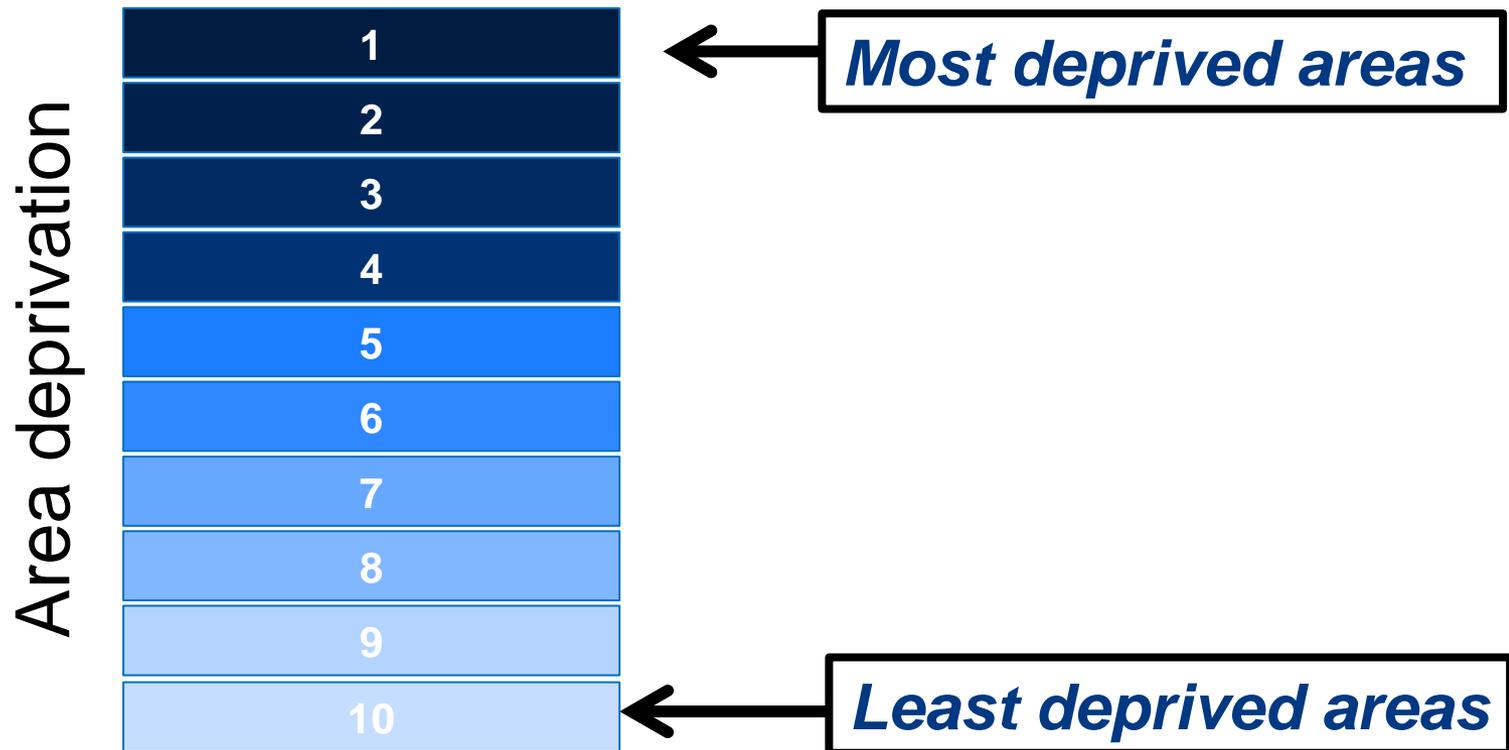
What is area deprivation?

- There are 32,844 small areas in England

- Each is rated 1-10 for area deprivation

Most Deprived

Least Deprived
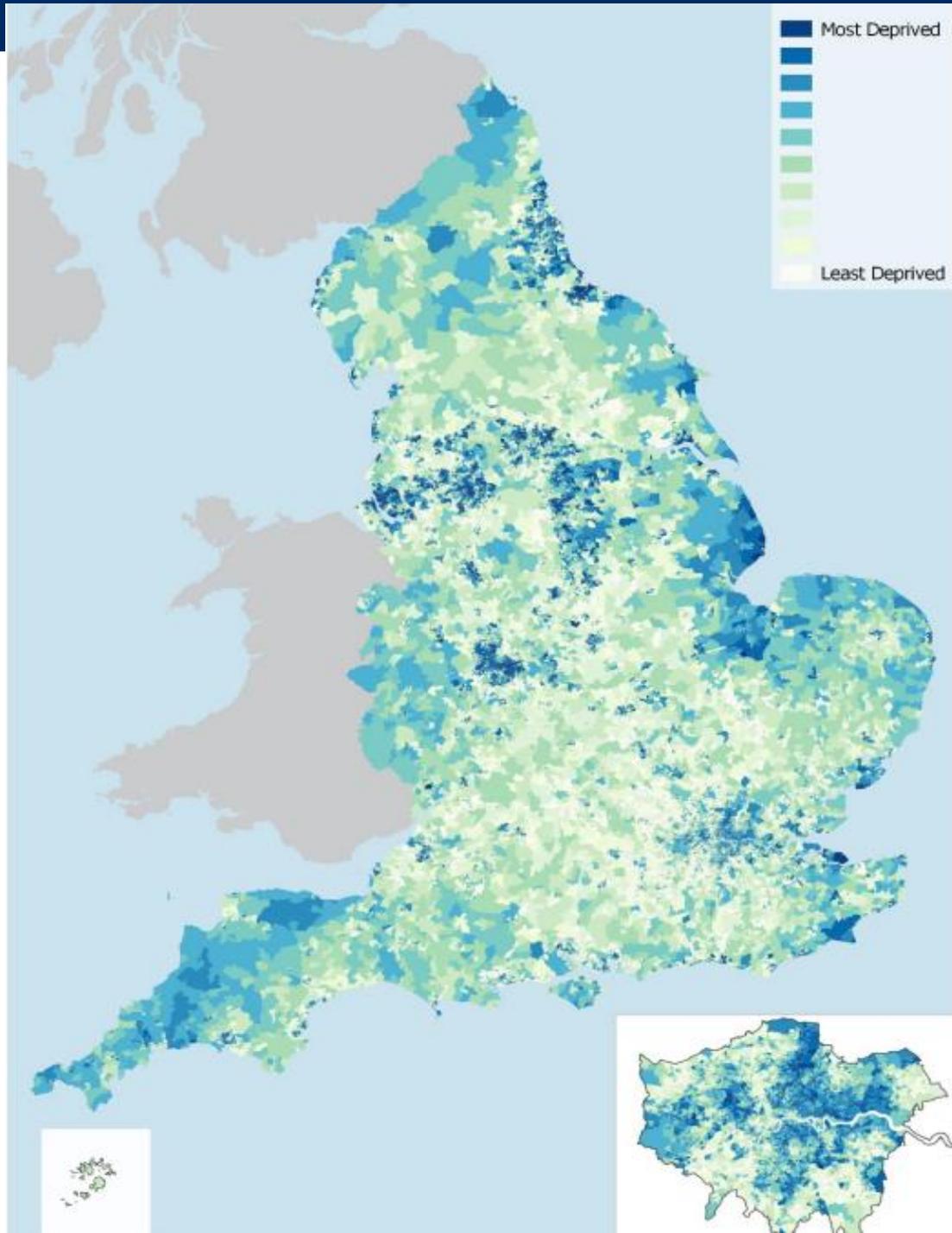
Research questions

- 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*?

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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)

WARWICK   CEREBRA   mencap   Ambitious about Autism   ENABLE Scotland

Support in the Early Years

Are you the parental caregiver of a child aged 0-6 years old with a diagnosed or suspected learning disability and/or autism?

If so, you are invited to take part in our survey exploring how families access support in the early years

Find out more: www.bit.ly/2NwSo4O

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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**

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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

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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

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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)

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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*

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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

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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*

Most Deprived

Least Deprived
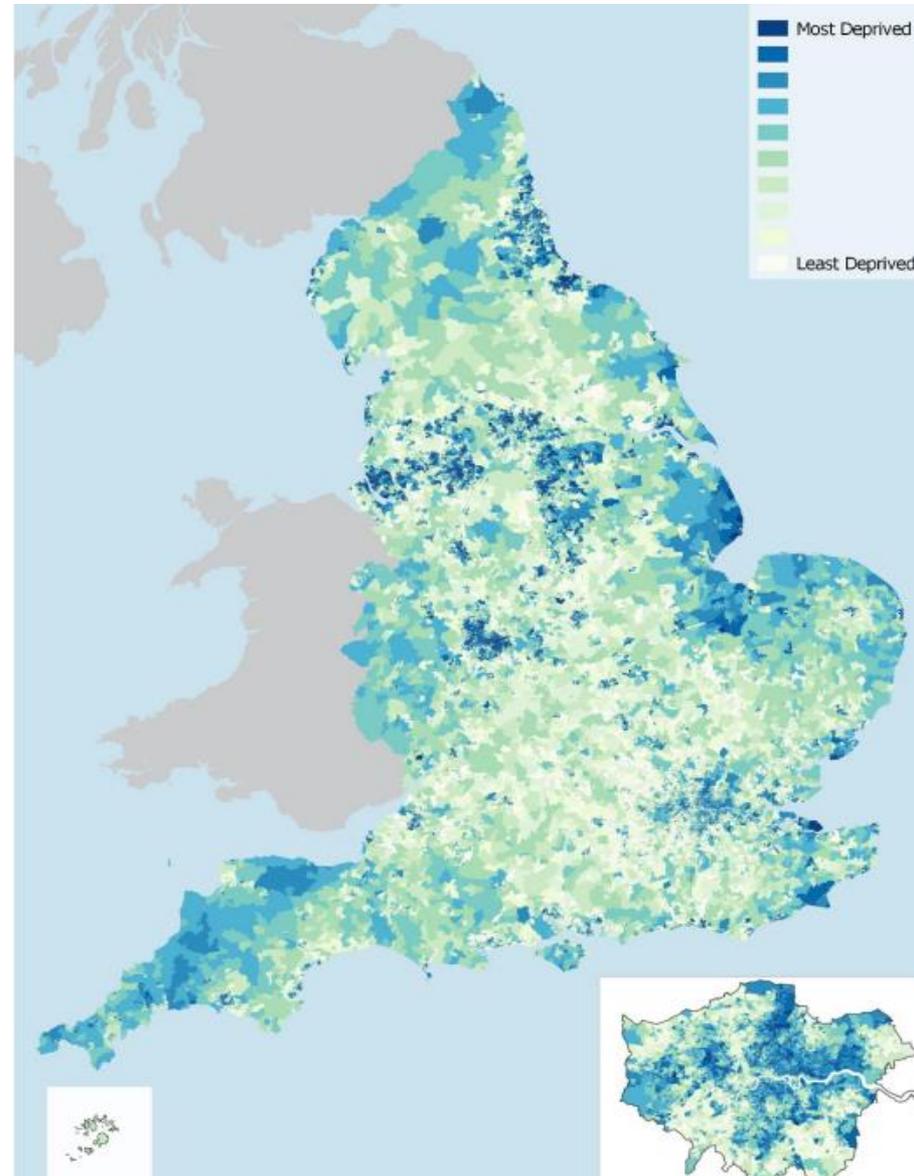
How did we use the Index of Multiple Deprivation?

- 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

Most deprived	→	1
Area deprivation		2
		3
		4
		5
		6
		7
		8
		9
Least deprived	→	10

→ **Access to Early Years Support** ?

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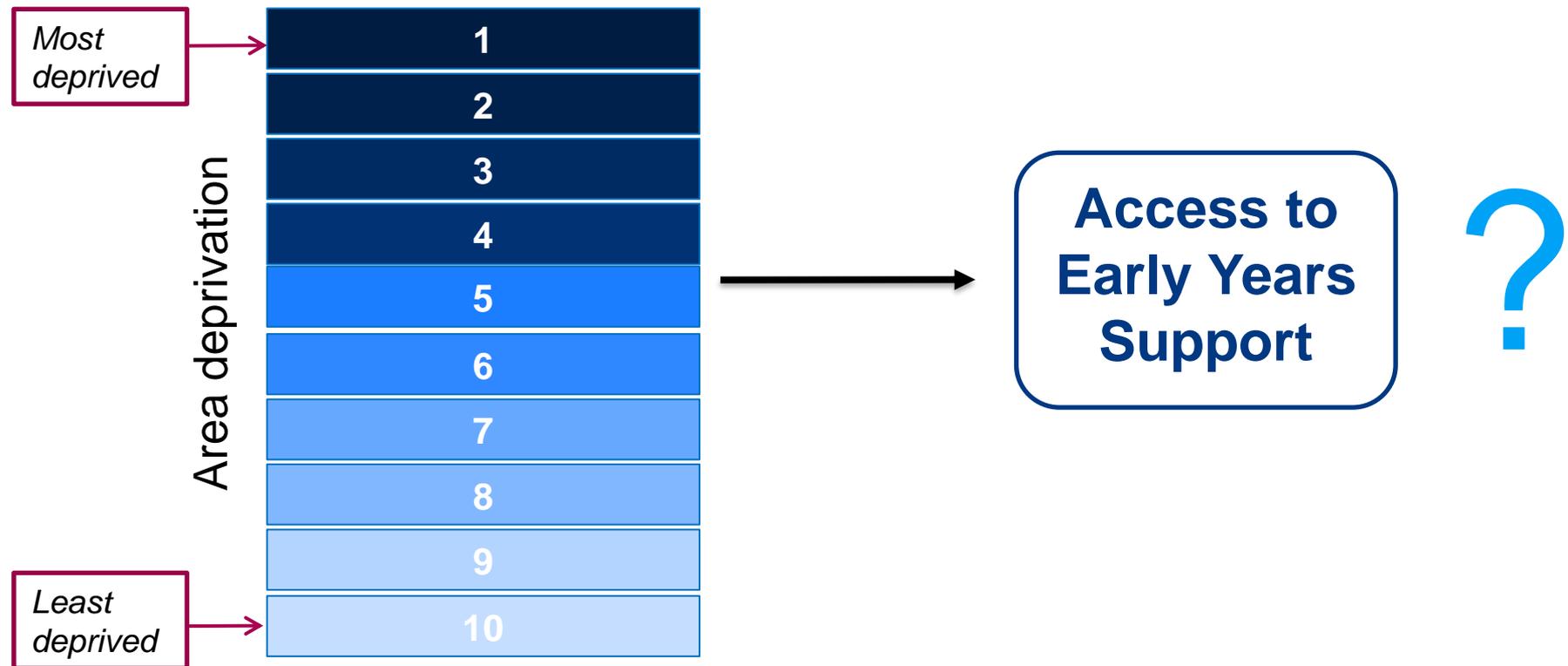
How did we use the Index of Multiple Deprivation?

- 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

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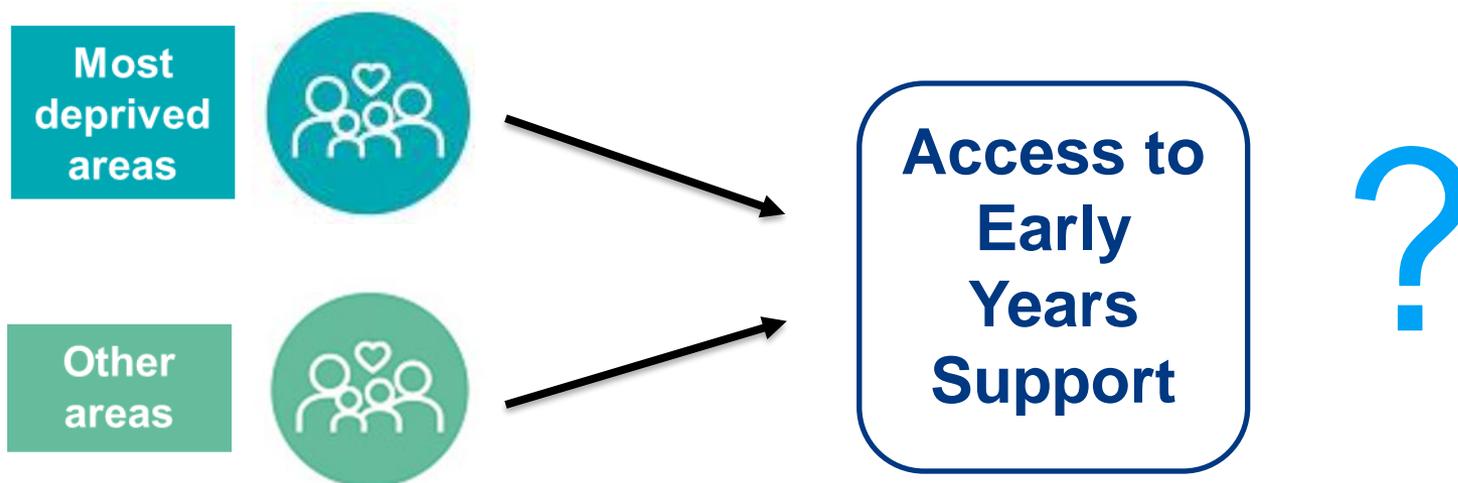
Family economic deprivation

- We also accounted for *family economic deprivation*

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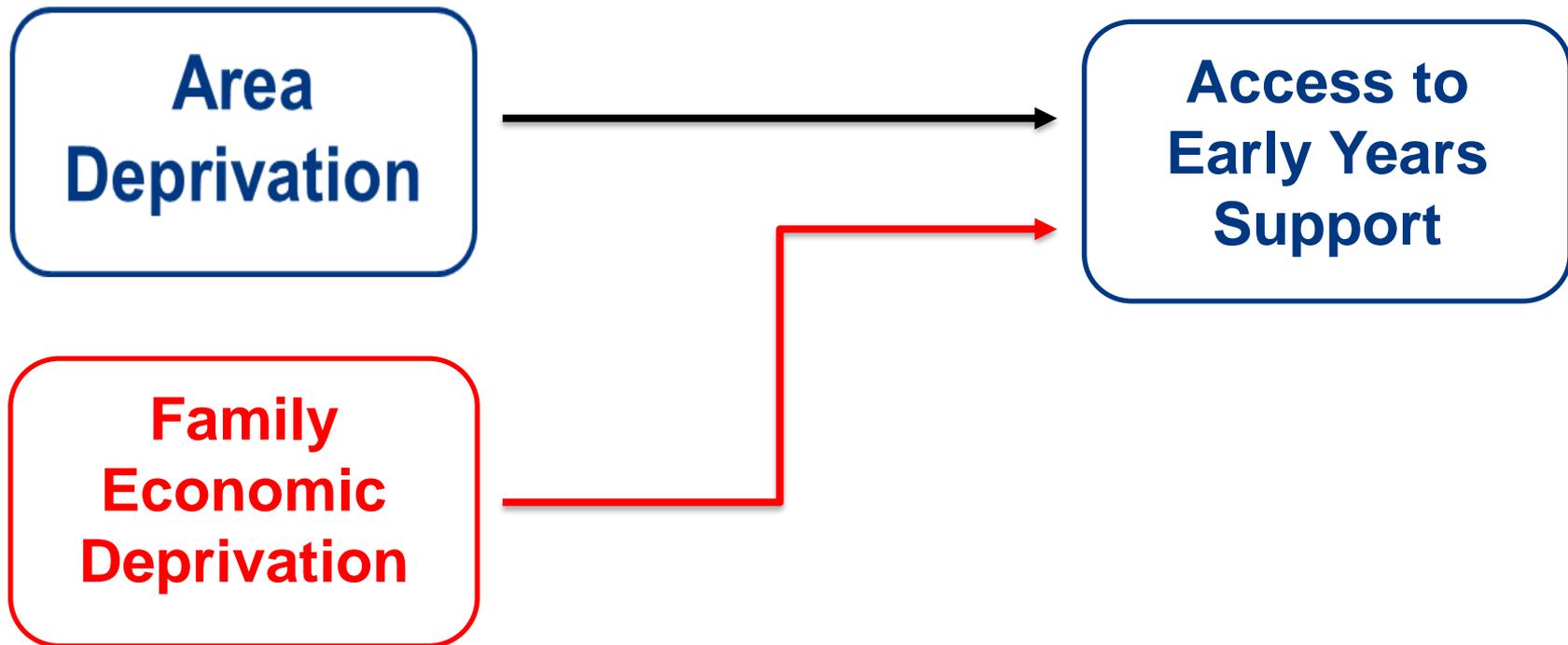
How did we measure family economic deprivation?

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

  - **Income poverty**

  - **Subjective poverty**

  - **Ability to raise money**

  - **Household employment**

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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

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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)

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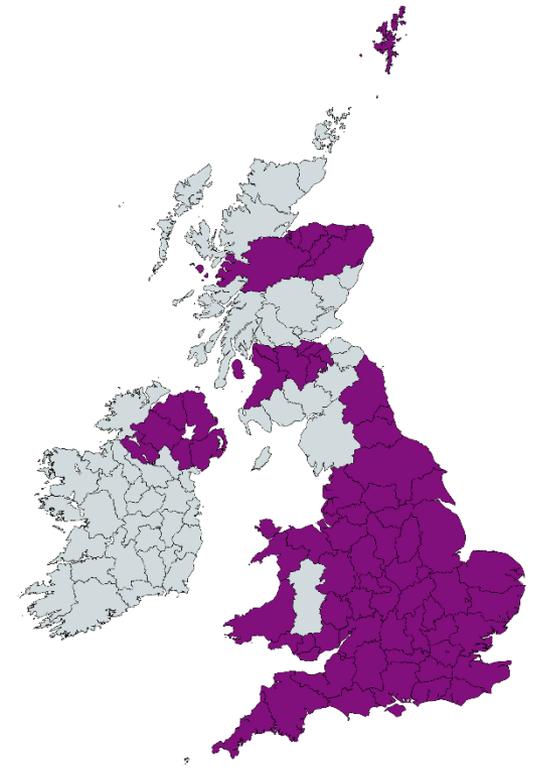
Area deprivation

- 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%)

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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*

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Intervention access

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

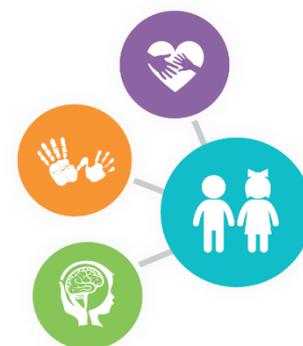| Intervention Access	Participants
Yes	126 (18.7%)
No	547 (81.1%)

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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%)

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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%)

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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
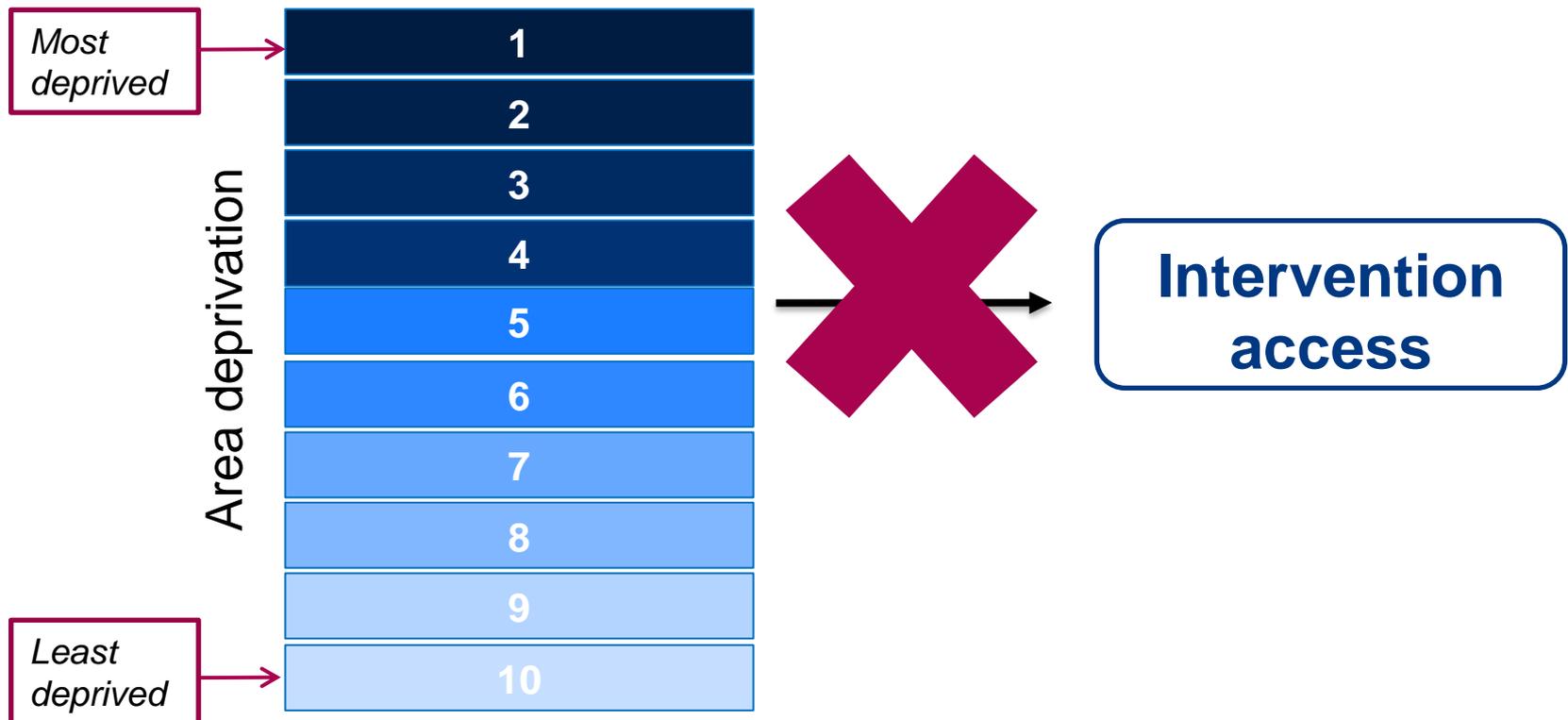
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Access to support – overall

- 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

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Area deprivation and intervention access

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

Most deprived →

Area deprivation

| 1 |
| 2 |
| 3 |
| 4 |
| 5 |
| 6 |
| 7 |
| 8 |
| 9 |
| 10 |

Least deprived →

Intervention access

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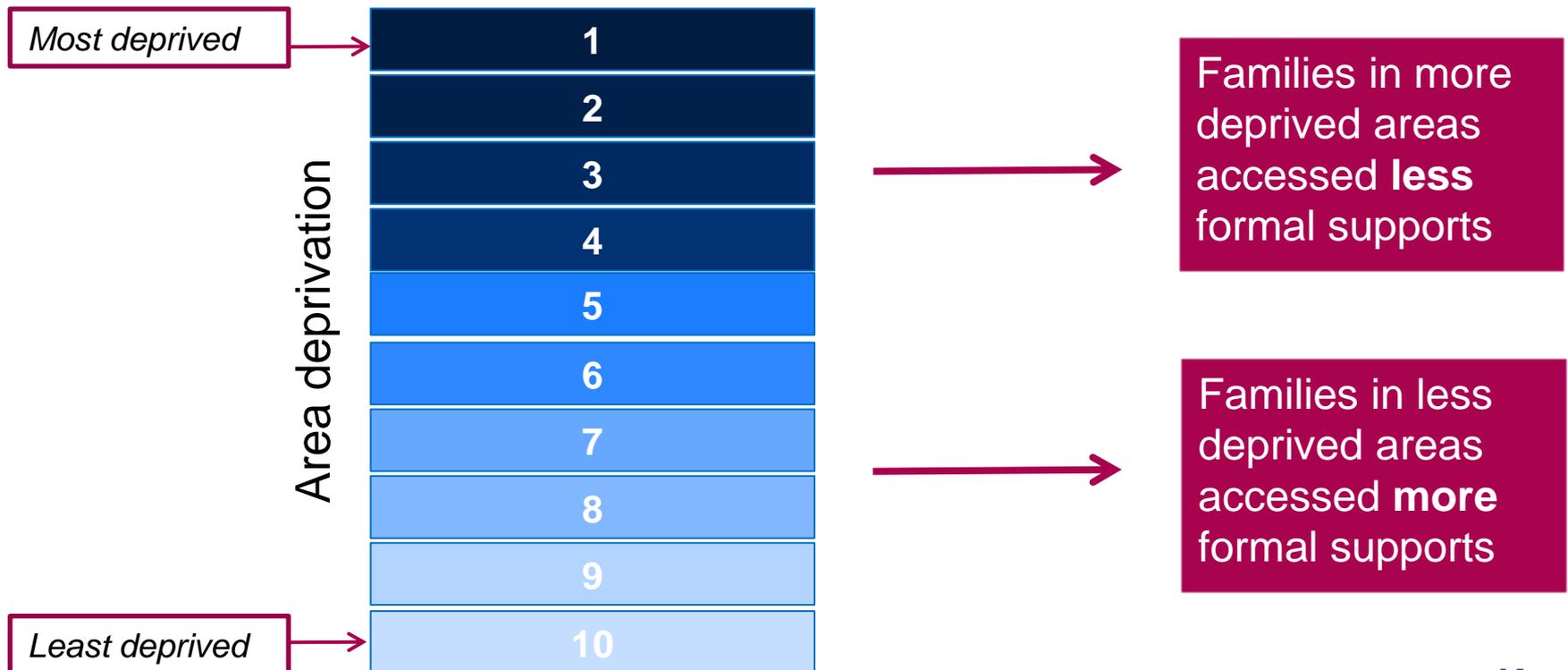
Area deprivation and intervention access

- There was **no significant difference** in *intervention access* between families living in the most deprived areas compared to those living in other deprived areas
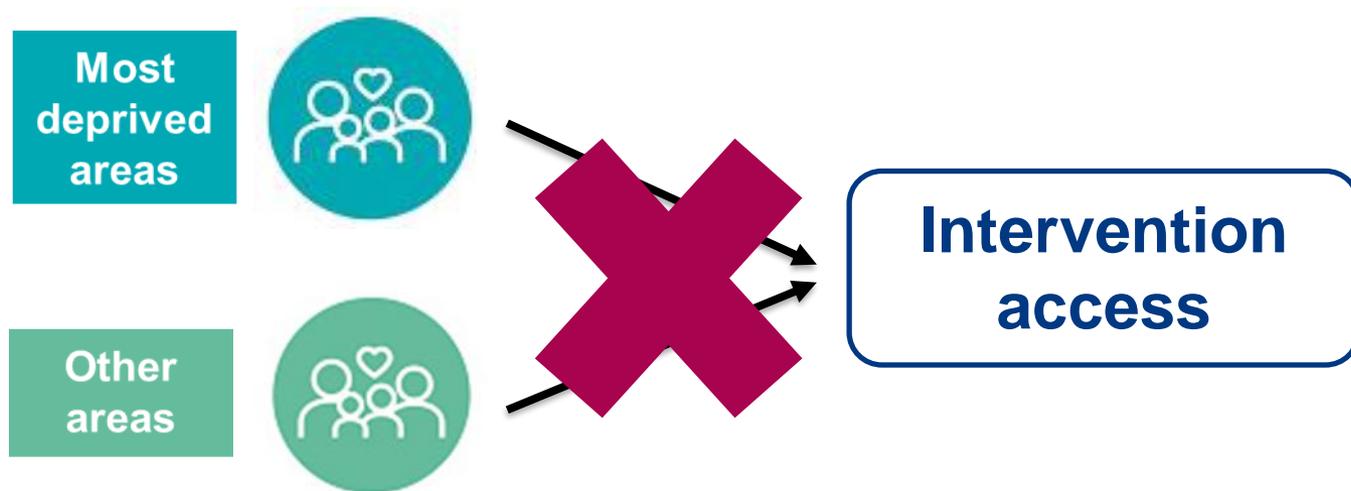
- There was also **no significant relationship** between family economic deprivation and *intervention access*
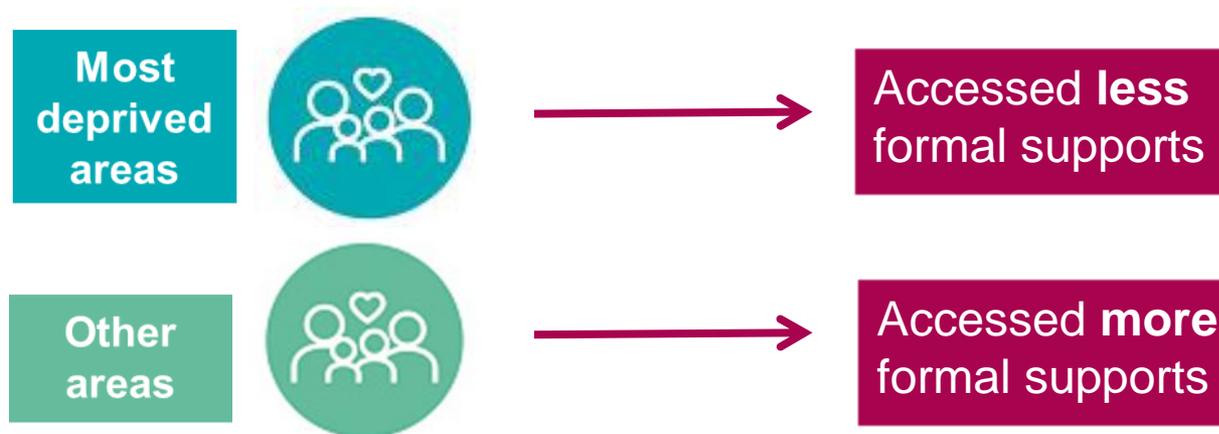
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Area deprivation and access to formal support sources

- 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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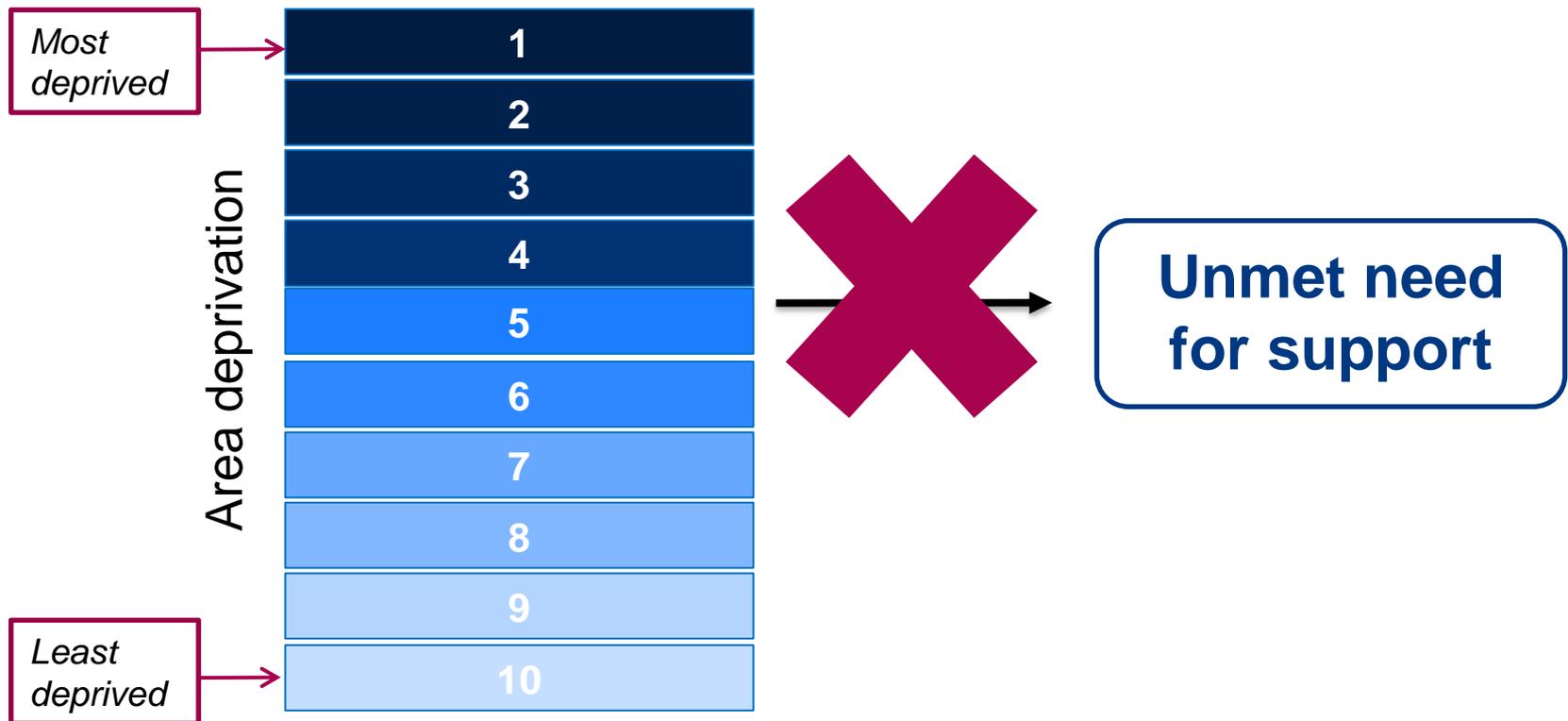
Area deprivation and access to formal support sources

- 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*

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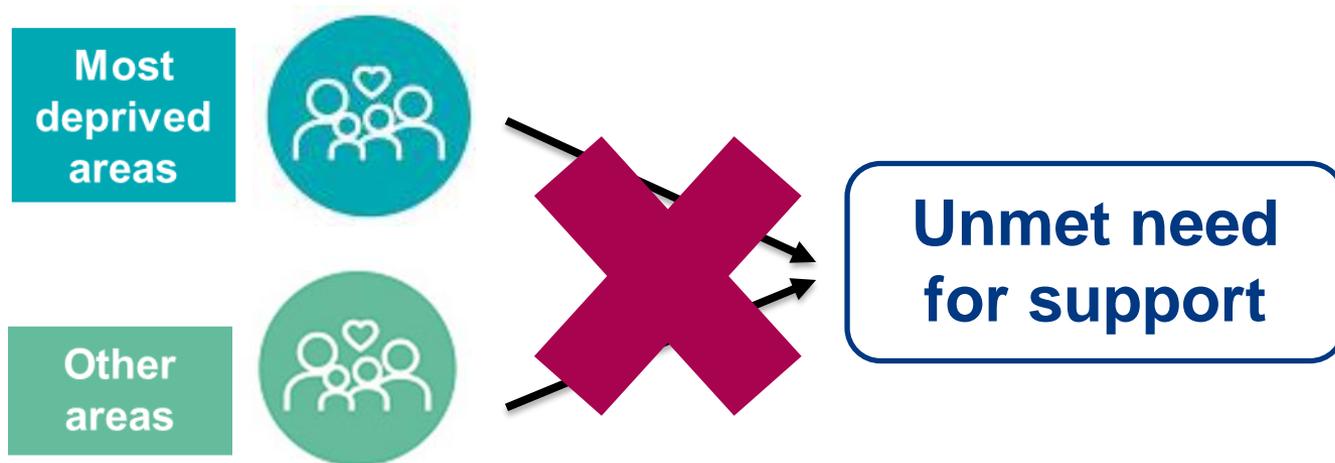# Area deprivation and unmet need for formal support

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

Most deprived	Area deprivation
1	
2	
3	
4	
5	
6	
7	
8	
9	
Least deprived — 10	

Unmet need for support

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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

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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*

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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*

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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)

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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

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Questions and comments

- Thank you for listening!

- Any questions, comments, or reflections?

- Email: S.Sapiets@kent.ac.uk or @suzijsapiets

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