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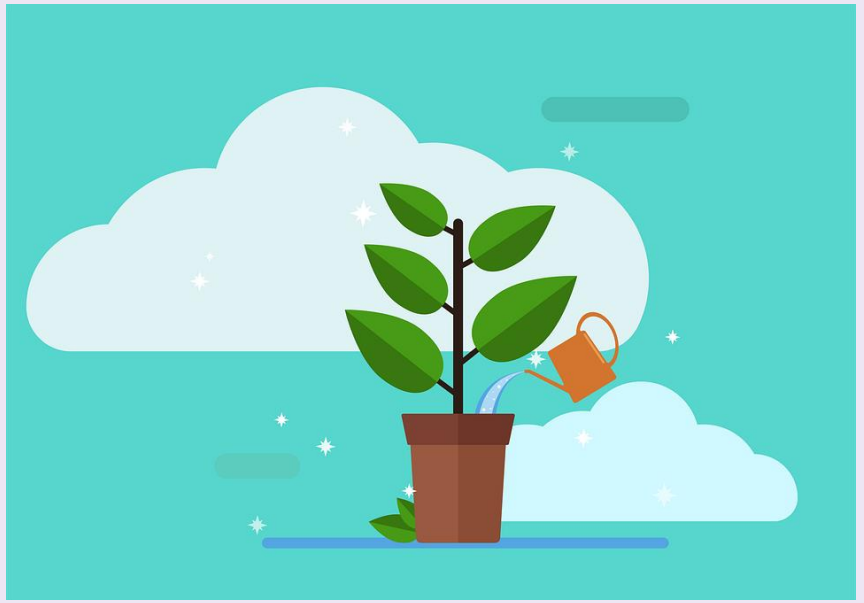
Access to support in the early years for neurodivergent children and their families

Dr Suzi Sapiets

BeyondAutism Conference 2023



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Hello and Thank You!

Who am I?

- Suzi Sapiets – Research Associate, Tizard Centre, University of Kent, working with the Sharland Foundation Developmental Disabilities Research and Impact Network

What am I presenting?

- PhD research supervised by Vaso Totsika and Richard Hastings at the Centre for Educational Development Appraisal and Research (CEDAR), University of Warwick
- Subsequent research at Tizard Centre
- Personal and family experiences of access (or non-access) to support

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Presentation Overview

Introduction

- What is early support and why is it important?
- Current context (policy, practice, research)
- Interest in topic and research aim

Overview of research:

- Review of factors influencing access to early support
- Survey examining families' access to early support in the UK
- Predictors of access to and unmet need for early support in the UK
- Location and access to support

Discussion

Introduction

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What is early support?

- Umbrella term referring to a range of different supports to ensure "optimal" child development (e.g., Akhmetzyanova, 2016; Brito and Lindsay, 2015; Lipinska-Loks & Stein-Szala, 2015; Powell et al., 2021)
- For my research, early support was conceptualised as **all formal support provided in the early years** (0-6 years) for neurodivergent children (suspected or diagnosed) and their families **across service systems** (education, health, social care, voluntary, community, etc.)

Why is early support important?

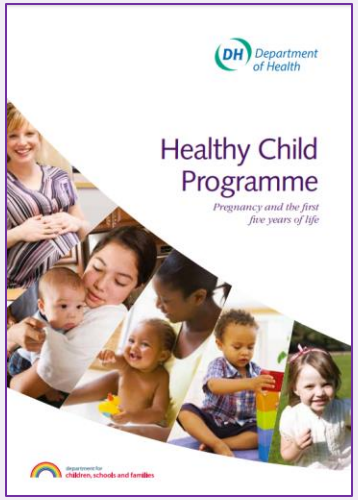
- Developmental differences (Gillberg, 2010; Odom et al., 2009; Thapar et al., 2017)
- Early emergence and lifelong (e.g., APA, 2013; WHO, 2018)
- Physical health, mental health, and social inequalities:
  - Increased risk of physical and mental health conditions, disparities of access to healthcare, unmet healthcare needs (e.g., Bitsko et al., 2009; Kinnear et al. 2019; Munir, 2016)
  - Increased parental stress, trauma related to ineffective support (e.g., Baker et al., 2003; Clements & Aiello; 2021)

Neurodiversity refers to the **diversity of human brains**, where neurological and developmental differences are recognised and respected

'Neurodivergent' refers to a person with neurological and/or developmental differences, such as developmental delay, learning disabilities, autism, dyspraxia, attention differences, etc.

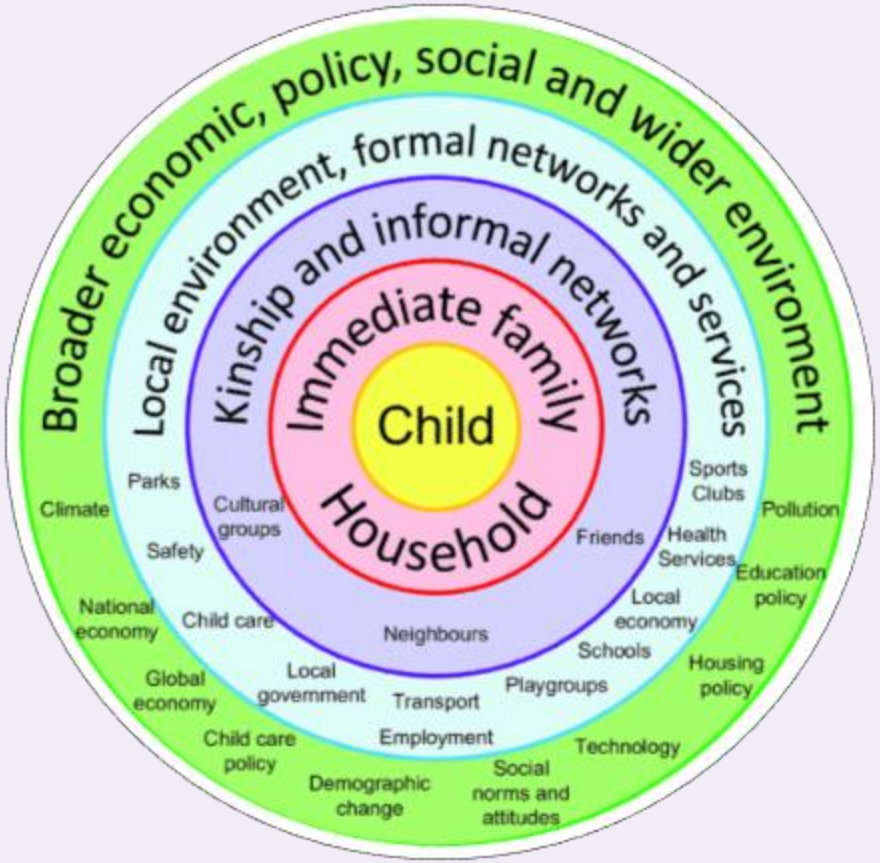
Policy and Practice Context

- Internationally, early support is advocated for in policy and practice documents, such as:
  - UN Convention on the Rights of the Child (1989)
  - UN Sustainable Development Goals (2015)
  - Individuals with Disabilities Education Act (2004)
  - National Disability Insurance Scheme Act (2013)
- Key UK-specific developments:
  - Children and Families Act (2014)
  - SEND Code of Practice (2014) and subsequent polices and practice guidance across UK nations
  - Child Health Programmes (e.g., DHSC, 2009)
  - NICE guidance (2011, 2013, 2015, 2016, 2017, 2018)



Research Context

- Early support can improve several child and family outcomes (e.g., Einfeld et al., 2013; Fuller & Kaiser, 2020; Leung et al., 2013; Sofronoff & Farbotko, 2002)
- International research indicates **relatively low levels of access** to early support – and there are disparities in access – indicating **inequitable access** and **potential unmet need** for early support (e.g., Grant & Isakson, 2013; McManus et al., 2014; Overs et al., 2017; Roberts et al., 2008; Ruble et al., 2005)
- To improve access to early support, research is needed to develop our understanding of access to early support for families
- Theoretical perspectives: ecological systems, family systems, developmental systems (Bronfenbrenner, 1979; Dunst, & Trivette, 2009; Guralnick, 2001)

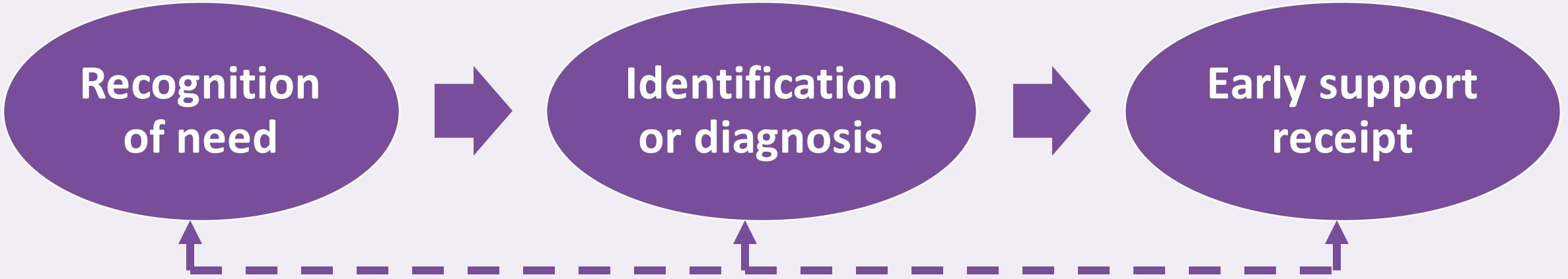


Interest and Aim

- My interest in topic
  - **Personal experience** – experiences of diagnosis and access/non-access to support of myself and my siblings (autism, attention deficit hyperactivity disorder)
  - **Professional experience** – specialist inpatient mental health hospital for children, subsequent experience in a range of educational, community, and voluntary services
- Overall aim of research
  - To examine access to early support for neurodivergent children and their families, including **current levels of access** and **factors influencing access** to early support

Study 1 – Review of Factors Influencing Access to Support

- **Aim:** To identify factors that influence the process of access to early support for families of neurodivergent children
- **Method:** Narrative review to examine potential barriers, facilitators, and modifiers of access to early support across the **pathway of access to early support**

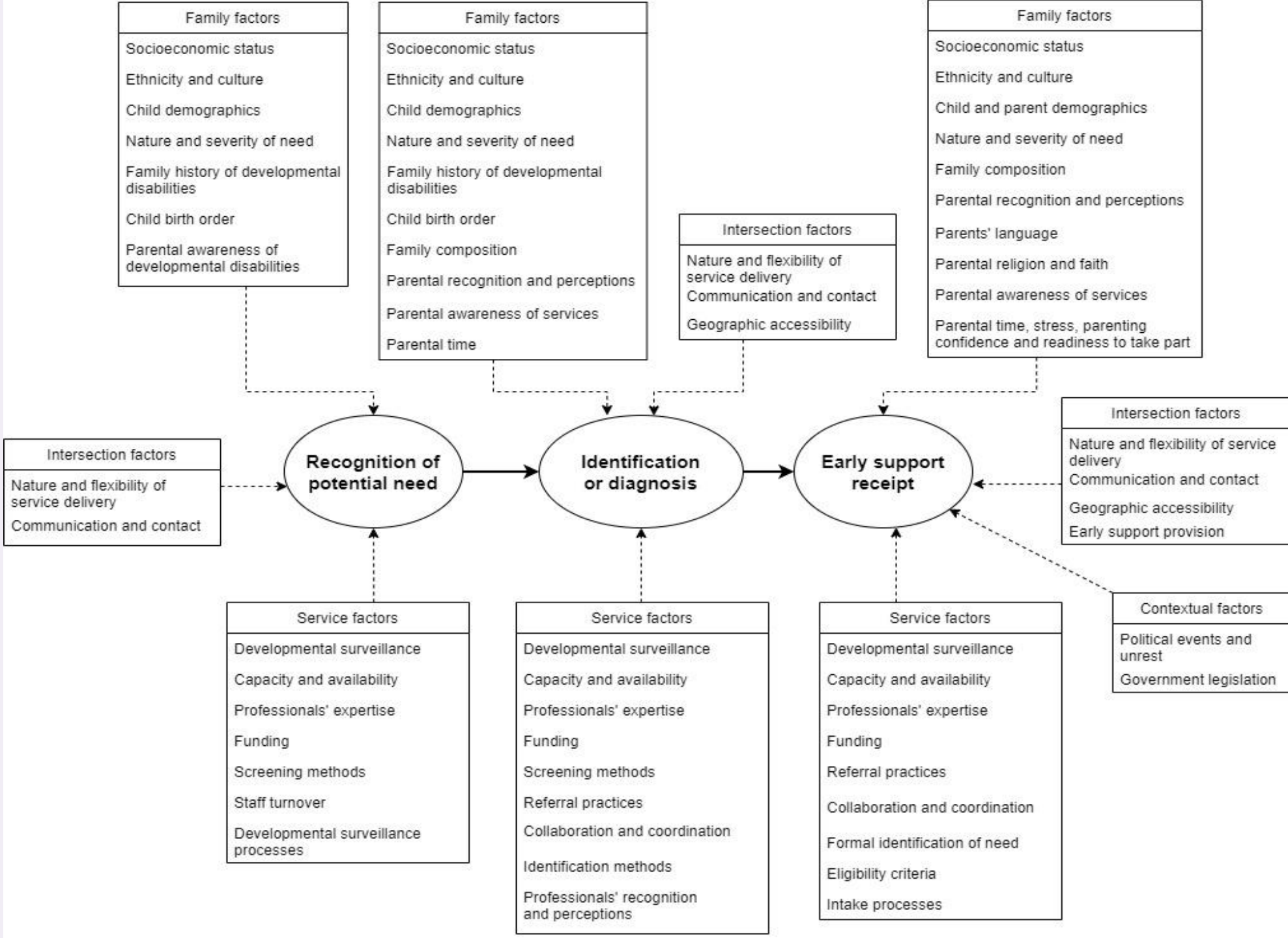


- Model influenced by existing frameworks of access, help-seeking, and referral pathways (Aday & Anderson, 1974; Arcia et al., 1993; Birkin et al., 2008; Guralnick, 2001; Pavuluri et al., 1996; Verhulst & Koot, 1992)

Study 1

Various factors influence the process of access to early support across multiple levels:

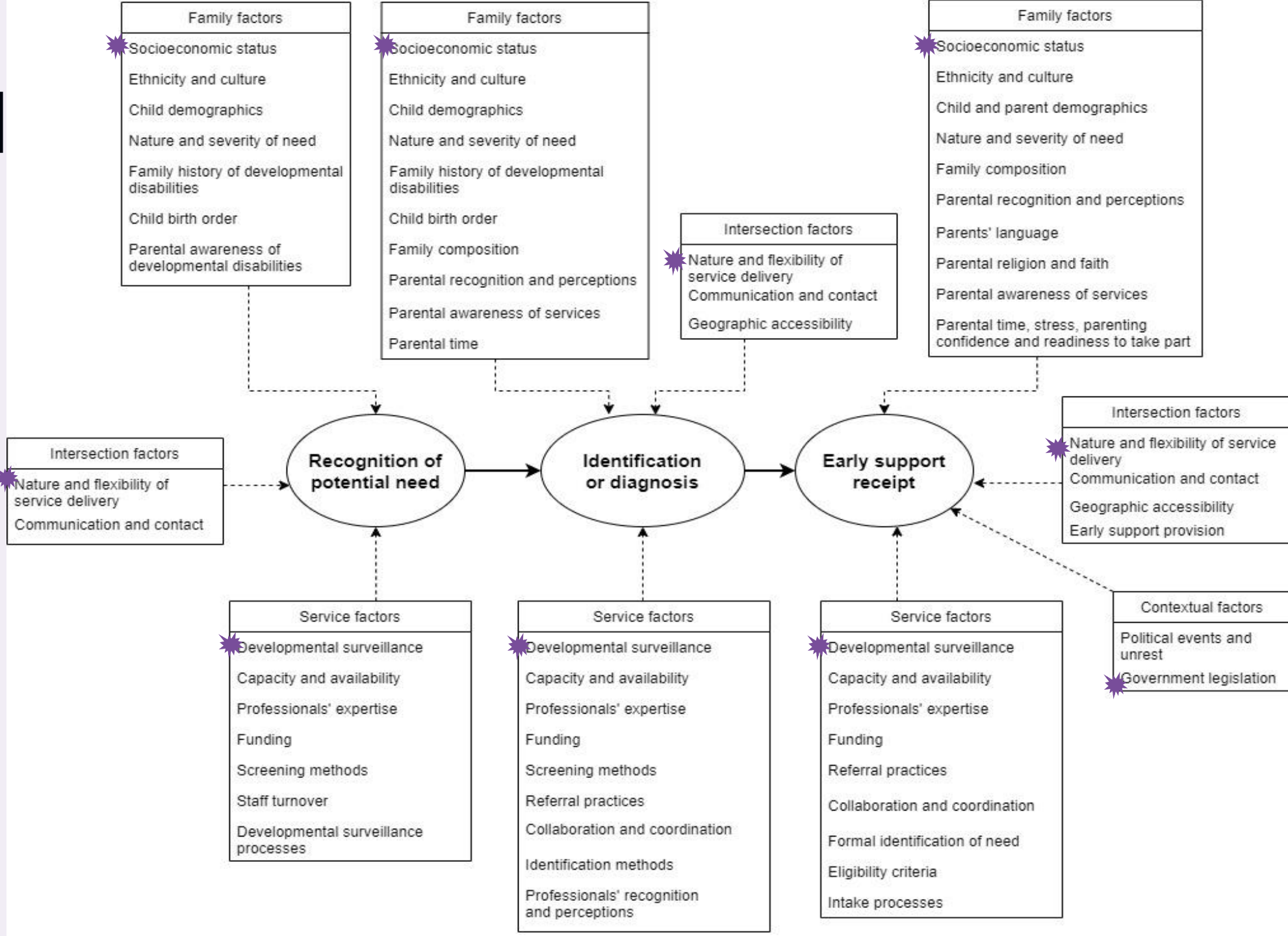
- Family
- Service
- Intersection
- Contextual



Study 1

Selected key factors:

- Family socioeconomic status
- Developmental surveillance
- Nature and flexibility of service provision
- Government legislation



Study 2 – Parental Caregiver Survey of Access to Support

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- **Aims:** To **a)** provide an overview of **current access** to early support for neurodivergent children and their families, and **b)** investigate perceived **ease of access** to, **unmet need** for, and **barriers and facilitators** of access to early support
- **Method:** UK-wide survey of parental caregivers of children aged 0-6 years with diagnosed or suspected neurodivergence
  - **Access to and experiences of early support (<12 months)**
    - Intervention programmes (open-ended)
    - Sources of support (49 items) – 27 education, health, and social care professionals, 10 health specialists, and 12 other supports
    - Perceived ease of access (27 professionals)
    - Unmet need for support (27 professionals)
    - Barriers and facilitators (open-ended)
  - **Participant characteristics**
    - Range of participant characteristics and demographics

Examples of support sources

- General practitioner (GP)
- 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
- Nurse
- 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)

Study 2 – Participants

Characteristics	Participants (N = 673)
Respondent	613 (91.1%) biological mother
Child age (years)	Mean 4.8 (SD 1.5)
Child sex	481 (71.5%) male
Child diagnosis/ label (suspected or diagnosed)	524 (77.9%) autism
	390 (57.9%) special educational needs
	328 (48.7%) learning disability
	317 (47.1%) developmental delay
	214 (31.8%) social communication disorder
	123 (18.3%) attention deficit hyperactivity disorder
	121 (18.0%) dyspraxia
Statutory statement	338 (50.2%) received statement of SEN or equivalent
Child health	446 (66.3) ≥1 physical health problem

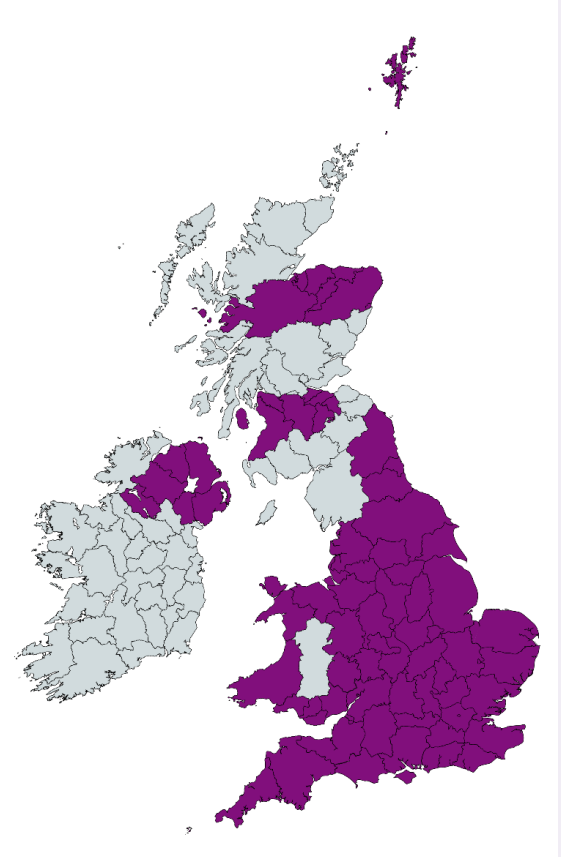


Fig 1. Illustrative depiction of the geographic spread of participants

SEN = special educational needs

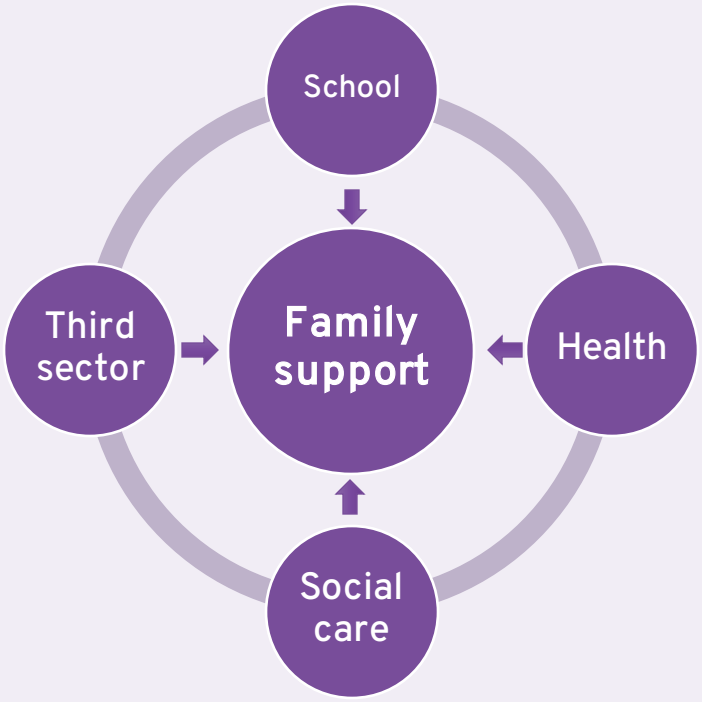
Study 2 – Results

- **Intervention Access**
  - 29.3% reported access to an intervention to support **their child's development** or to **support them as a parental caregiver**
  - Free text responses from 18.9% described an intervention programme
- **Access to Support Sources**
  - **Most accessed:** paediatrician (84.5%), speech and language therapist (84.2%), GP (78.8%), dentist (75.9%), school staff (71.6%)
  - **Least accessed:** foster carer (1.0%), podiatrist (3.9%), endocrinologist (3.9%), support to manage direct payments (5.6%), independent support advisor (5.9%)
- **Unmet Need for Support**
  - 75.5% reported at least one professional as an unmet need
  - **Most frequent:** occupational therapist (52.9%), educational psychologist (52.8%), staff from team assessing SEN (52.2%), behaviour specialist (43.0%), paediatrician (40.0%)

Early Support	Participants (N = 673)
Intervention	547 (81.1%) no access
Support sources	Mean 14.6 (SD 5.7), range 0-32
Unmet need	Mean 3.2 (SD 3.2), range 0-17

Study 2 – Results

- **Ease of Access**
  - Mean ratings between 2.3-3.8 (possible range 1-5)
  - **Highest:** foster carer (3.8), dentist (3.8), charity worker (3.7), optician (3.7), advocate (3.6)
  - **Lowest:** mental health professional (2.3), social worker (2.4), staff from team assessing SEN (2.6), home support staff (2.6), behaviour specialist (2.6)
- **Barriers of access**
  - Service-level barriers, unhelpful professionals, parental caregiver barriers, absence of services, nature and presentation of child needs
- **Facilitators of access**
  - Supportive and competent professionals, empowered parental caregivers, peer and family support, accessible services, professionals' acknowledgement of need, information and advice, service collaboration



Study 3 – Predictors of Access to Support

- **Aim:** To examine predictors of access to early support for families of young neurodivergent children (suspected or diagnosed) in the UK
- **Method:** Using data from the UK survey of parental caregivers (N = 673), regression models were fitted for three outcome variables:
  - **Intervention access** (binary logistic)
    Intervention access yes/no
  - **Access to early support sources** (multiple linear)
    Count of support sources families accessed across all supports listed in the survey (0-49)
  - **Unmet need for early support** (negative binomial)
    *Count of support sources families did not access but **wanted to access** for key professionals (0-27)*

Early Support	Participants (N = 673)
Intervention	547 (81.1%) no access
Support sources	Mean 14.6 (SD 5.7), range 0-32
Unmet need	Mean 3.2 (SD 3.2), range 0-17

- Each regression model included **14 predictor variables** spanning child, family, and service domains

Study 3 – Predictor Variables

- **Service Factors:**
  - **Developmental disability diagnosis** (none/at least one diagnosis)
  - **Statutory statement receipt** (yes/no)
- **Child Factors:**
  - **Child age** (years)
  - **Child sex** (male/female)
  - **Child adaptive skills** (GO4KIDDS adaptive behaviour total)
  - **Child physical health** (total conditions)
- **Family Factors:**
  - **Caregiver ethnicity** (ethnic minority group/non ethnic minority group)
  - **Caregiver disability** (yes/no)
  - **Caregivers in household** (one/two)
  - **Caregivers' educational level** (at least one educated to degree level or higher/none)
  - **Family economic deprivation** (composite score)
  - **Other disabled children in household** (yes/no)
  - **Informal support sources** (total)
  - **Helpfulness of informal support** (mean rating)

Study 3 – Predictor Variables

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Predictor Variables	Participants (*N* = 673)
Service	
Developmental disability diagnosis*	561 (83.4%) received at least 1 diagnosis
Statutory statement receipt	338 (50.2%) received statutory statement
Child	
Child age (years)	Mean 4.8 (SD 1.5), range 0.1-6.9
Child sex	481 (71.5%) male
Child health conditions	Mean 1.4 (SD 1.3), range 0-5
Child adaptive skills	Mean 21.4 (SD 7.6), range 8-39

*Most common diagnoses included: autism, learning disability, developmental delay, social communication disorder, dyspraxia, cerebral palsy, Down syndrome, Williams syndrome, Fragile X syndrome, attention deficit hyperactivity disorder

Study 3 – Predictor Variables

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Predictor Variables	Participants (N = 673)
Family	
Caregiver ethnicity	560 (83.2%) ethnic majority group
Caregiver disability	410 (60.9%) no disability
Household caregivers	536 (79.6%) two caregivers
Household education	338 (50.2%) ≥1 caregiver educated to at least degree level
Family economic deprivation	Mean 1.5 (SD 1.1), range 0-4
Other children with disabilities	477 (70.9%) <1 other children with disabilities
Informal support sources	Mean 3.6 (SD 2.4), range 0-12
Helpfulness of informal support	Mean 3.7 (0.8), range 1.3-5.0

Composite Variables	Participants (N = 673)
Unemployment	543 (80.7%) ≥1 caregiver in employment
Income poverty	393 (58.4%) ≤ poverty line
Subjective poverty	557 (82.8%) managing financially
Inability to raise money	405 (60.2%) would struggle to raise money

Study 3 – Significant Results

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- **Access to early support sources**
  - Developmental disability diagnosis receipt
    b = 1.306, β = 0.084, p = .019*
  - Statutory statement receipt
    b = 2.469, β = 0.218, p < .001**
  - Child health conditions
    b = 1.780, β = 0.400, p < .001**
  - Child adaptive skills
    b = -0.110, β = -0.150, p < .001**
  - Caregiver ethnicity group
    b = -1.275, β = -0.081, p = .016*
  - Caregivers' educational level
    b = -0.812, β = -0.072, p = .048*
  - Informal support sources
    b = 0.428, β = 0.170, p < .001**
- **Intervention access**
  - Developmental disability diagnosis receipt
    b = 1.027, *OR* = 2.792, *p* = .013*
  - Caregivers' educational level
    b = -0.617, *OR* = 0.539, *p* = .008*
- **Unmet need for early support**
  - Caregivers in household
    b = -0.366, *RR* = 0.693, *p* = .007*
  - Family economic deprivation
    b = 0.101, *RR* = 1.107, *p* = .033*
  - Informal support sources
    b = -0.084, *RR* = 0.920, *p* = .001**
  - Helpfulness of informal support
    b = -0.140, *RR* = 0.870, *p* = .023*

*p = < .05
**p < .001

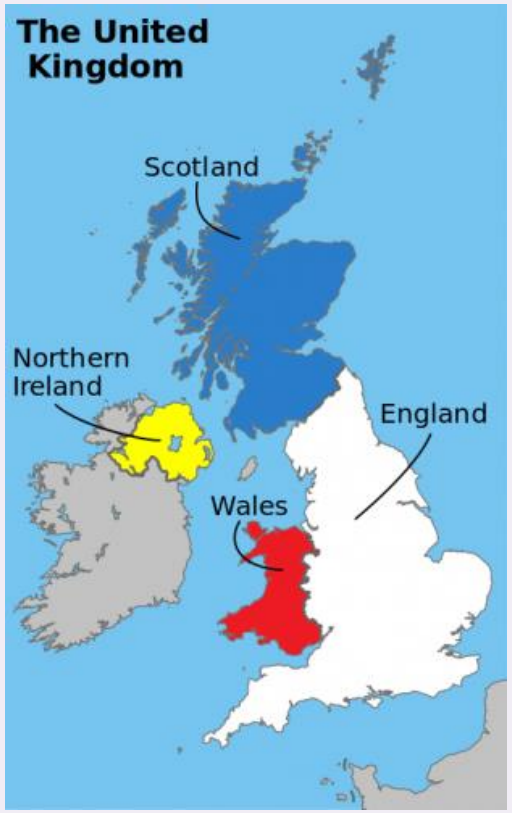
b = unstandardised beta; β = standardised beta; OR = Odds Ratio; RR = Rate Ratio

Additional Analysis – Location

- Additional regression models were fitted for the same outcomes
- These models included:
  - **Location**
    - **Country** (England/Scotland/Wales/Northern Ireland)
    - **Neighbourhood deprivation** (Index of Multiple Deprivation – IMD)
  - **Control variables from previous study:**
    - **Family economic deprivation** (composite score)
    - **Caregivers' educational level** (at least one educated to degree level or higher/none)
    - **Developmental disability diagnosis** (none/at least one diagnosis)
    - **Informal support sources** (total)

27 (4.0%) families in Scotland

62 (9.2%) families in Northern Ireland



400 (59.4%) families in England

55 (8.2%) families in Wales

Neighbourhood Deprivation

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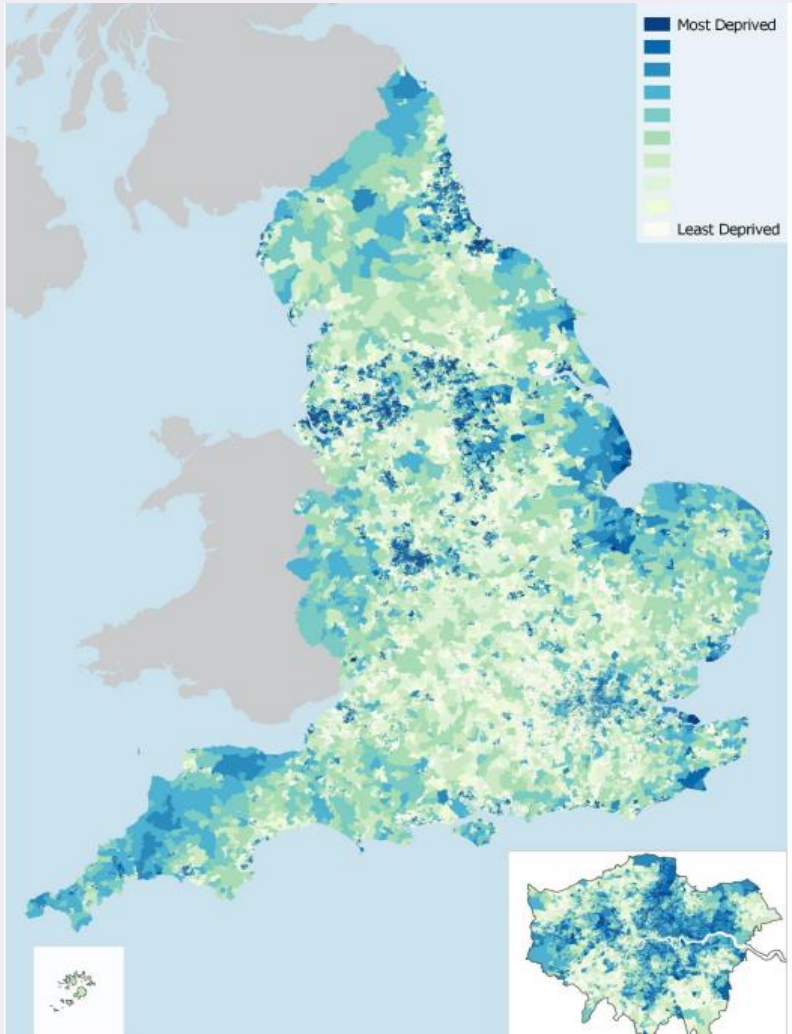
- The **Index of Multiple Deprivation (IMD)** is a government measure that relatively ranks small areas (i.e., neighbourhoods) across the UK to indicate their level of deprivation (deciles 1-10)
- The IMD is based on comparisons across 7 deprivation domains:
  - **Income**
  - **Employment**
  - **Education**
  - **Health**
  - **Crime**
  - **Housing**
  - **Living environment**
- IMD data was identified for participants who provided **a postcode** and linked to their survey responses and analysed in two ways:
  - Ranking of neighbourhood deprivation (**IMD deciles** 1-10)
  - Comparison between 2 groups (**IMD binary**): most deprived neighbourhoods (deciles 1-2) and other less deprived neighbourhoods (deciles 3-10)



Neighbourhood Deprivation

- Neighbourhood deprivation (IMD) data was found for 544 participants
- Participants lived in areas with a mean deprivation rank (IMD decile) of 5.4 (SD 3.0, range 1-10)

Most deprived areas →

IMD Decile	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%)

Least deprived areas →

IMD Binary	Participants
Most deprived areas (deciles 1-2)	137 (20.4%)
Other less deprived areas (deciles 3-10)	407 (60.5%)

Results

- **Intervention access**
  - Neighbourhood deprivation (IMD decile or binary) not significant
  - **Country (Scotland vs. others) significant**
    b = 0.994, *OR* = 2.702, p = .027*
  - Other country variables not significant

- **Access to early support sources**
  - **Neighbourhood deprivation (IMD binary) significant predictor**
    b = -1.346, β = 0.101, *p* = .022*
  - IMD decile not significant
    b = 0.162, β = 0.083, *p* = .069
  - Country variables not significant

Most deprived (decile 1-2) *vs.* less deprived (decile >3)

- **Unmet need for early support**
  - Neighbourhood deprivation (IMD decile or binary) not significant
  - Country variables not significant

*p = < .05 *b* = unstandardised beta; β = standardised beta; OR = Odds Ratio

Discussion

Summary

- Access to early support is complex and multifactorial – broad range of factors influence access across multiple levels
- Key selected factors:
  - Family socioeconomic status
  - Formal identification of need
  - Service coordination and collaboration
  - Professionals' expertise
  - Nature of service delivery in relation to family factors

Implications

- System-wide investments across multiple factors (intersectional approach) likely to be most effective, though there are also investments at individual service and professional levels

Implications based on key factors

- Reduce economic deprivation
- Increase availability and capacity of universally free services
- Improve service coordination and collaboration
- Enhance professionals' engagement styles and competence
- Provide family-centred support and adapt provision to ensure accessibility for all families (flexible systems)

Discussion

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Limitations

- Limited co-production
- Focus on English language
- Non-systematic review
- Convenience sample
- Cross-sectional data
- Focus on parental report

Future directions for research

- Further develop understanding of factors influencing access to early support
  - Systematic reviews of specific factors/phases of access
  - Studies examining the influence of (and relationships between) multiple factors
  - Prospective longitudinal and population studies
  - More accessible studies
- Develop and test ways to enhance access to early support

Thank You!

- **Thanks to everyone who took part** – for the time they took to share their experiences on early years support
- **Thanks to the funders** – Warwick Collaborative Postgraduate Research Scholarship, Cerebra, Mencap, Ambitious about Autism, SF-DDARIN, Summer Vacation Research Competition at Kent
- And **thank you for listening** today!
- Any questions, comments or reflections? ☺

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