Systemic influences on parent carer mental health and co-creation of resources to inform service improvement

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Background

- The SPaCE Project aimed to understand:
  - the prevalence of mental health conditions in parent carers of children and young people with special educational needs and disabilities (SEND)
  - parent carers’ experiences of seeking and accessing mental health support and treatment
- 11% of children in the UK have been identified as disabled, and that number is increasing, with most living at home and being cared for by their parents
- Health, social care and education services are struggling to meet families’ needs. Despite government attempts to improve this, parents must often advocate for their child and fill in service gaps.
- Their caring role and the associated burden places parent carers at increased risk of mental health problems.

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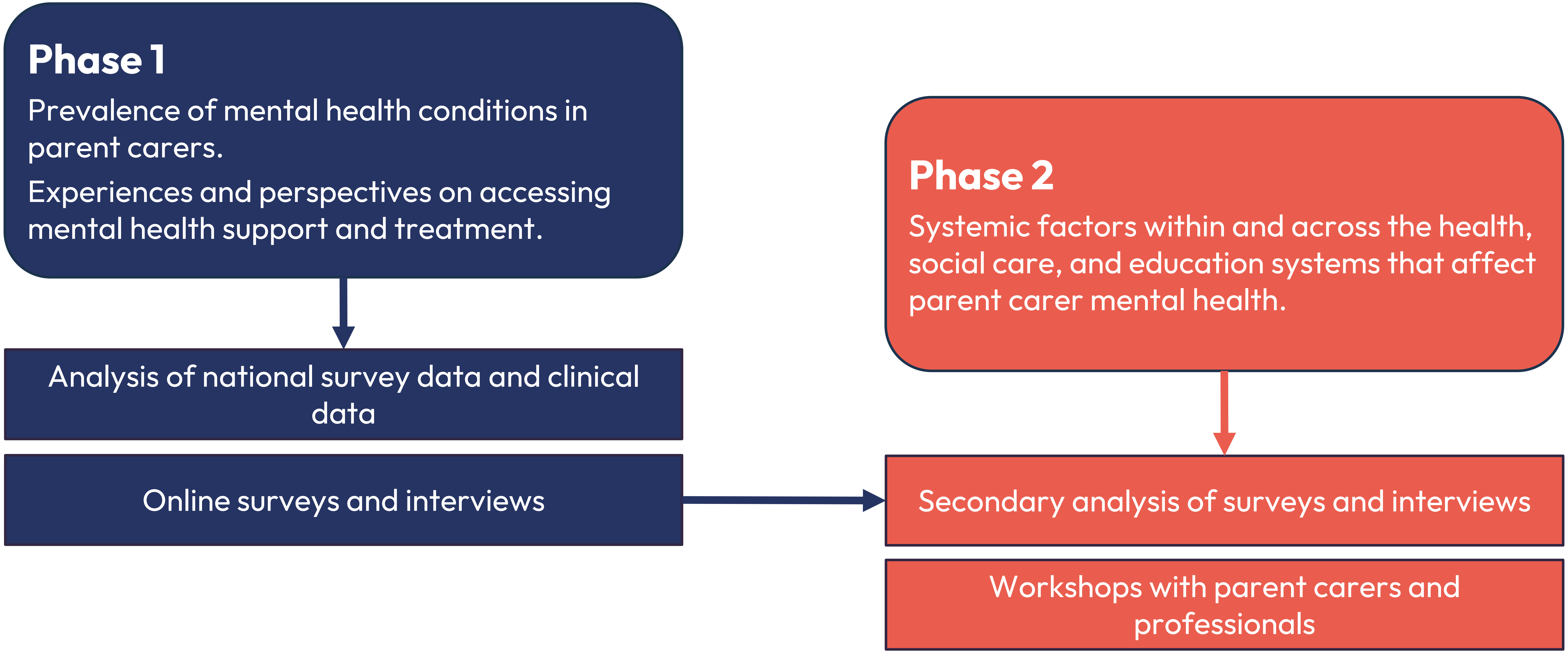


Phase 1

Prevalence of mental health conditions in parent carers.

Experiences and perspectives on accessing mental health support and treatment.

Analysis of national survey data and clinical data

Online surveys and interviews

Phase 2

Systemic factors within and across the health, social care, and education systems that affect parent carer mental health.

Secondary analysis of surveys and interviews

Workshops with parent carers and professionals

Clinical Practice Research Datalink

- Clinical Practice Research Datalink (CPRD “Aurum”) provides primary care data collected from GP practices: coverage of at least 24% of population of England and growing
- The Mother-Baby Link for CPRD Aurum was released in 2023
- It also links to:
  - the Indices of Multiple Deprivation (IMD 2019) for each patient, which allows us to report on levels of deprivation
  - linkage to Hospital Episode Statistics to help identify maternal mental health conditions treated in secondary care (hospital)

Clinical code lists

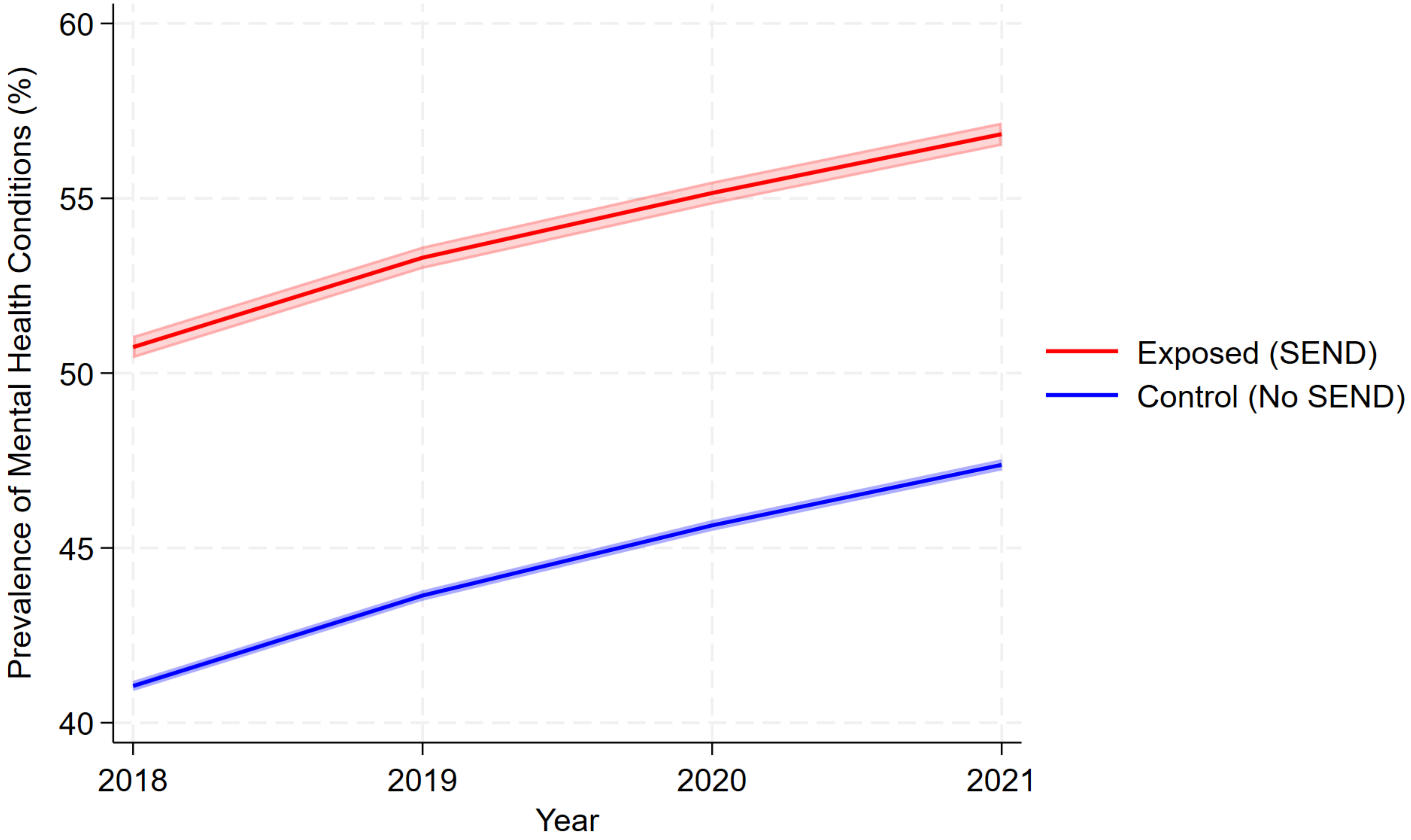
- Clinical code lists are used here for identifying:
  - – SEND conditions in children using CPRD code lists developed by our team
  - – Mental health conditions in mothers, using linked:
    - CPRD coded data for anxiety disorders, depressive disorders, psychosis, eating disorders, and substance/alcohol dependence
    - Prescription data
    - Hospital Episode Statistics from Admitted Patient Care and Outpatient data

- Development of our clinical code lists was strongly driven by our Patient and Public Involvement (PPI) group and clinical reviewers
  - – Frequently identified SEND conditions such as autism and ADHD
  - – Identify rare conditions
    - collectively children with rare conditions can make a fair-sized group together

Selecting children & link to mothers

- All children in the study were aged 0-21 on the study start date of 1st May 2018, meaning that by the end of the study they were up to 25, in line with UK legislation.
- Children were identified as having SEND if they had 1 or more of the SEND codes before the study end date of 1st May 2022.
- Mothers of children of at least one child with any of the SEND codes, were matched to controls based on child's age, child's gender at birth, and GP practice.

Prevalence of maternal mental health conditions 2018-2021



National survey data analysis

- Analysis of data from the Mental Health of Children and Young People datasets 2017 – 2020.
- In 2017, 32% of parent carers of children or young people (CYP) with SEND (aged 5-16) reported psychological distress (GHQ-12), compared with 18% of parents of CYP without SEND (p<0.000).
- This increased to 56% in 2020 (CYP aged 8-19 with SEND), compared to 37% of parents of CYP without SEND (p<0.001).

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Online Surveys

498 Parent Carers

Survey Questions

- Do you work with Parents/carers of a child or young person with SEND?
- Have any health or social care professionals assessed/asked you about your mental health?
- Do you consider it part of your role to identify or recognise potential mental health problems in parent carers?
- Have you ever had /do you conduct formal mental health assessments or diagnoses?
- Have you been referred /do you refer or signposted to any support or treatment for your mental health?

295 Professionals

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Demographics

Children's Diagnoses

Diagnosis	Frequency (%)
Autism Spectrum Disorder	333 (66.9%)
Learning Disability	163 (32.7%)
Attention-Deficit Hyperactivity Disorder	155 (31.1%)
Global Development Delay	68 (13.7%)
Mental Health Disorder	62 (12.4%)
Genetic or Rare Disorder	54 (10.8%)
Epilepsy	47 (9.4%)
Visual Impairment	45 (9.0%)
Hearing Impairment	43 (8.6%)
Sensory Processing or Sensory Integration Disorder	42 (8.4%)
Cerebral Palsy	23 (4.6%)
Profound and Multiple Learning Disability	22 (4.4%)
Pathological Demand Avoidance	21 (4.2%)
Down's Syndrome	16 (3.2%)
Anorexia Nervosa, Eating Disorder, Avoidant Restrictive Food Intake Disorder	15 (3.0%)
Syndrome Without a Name	13 (2.6%)
Foetal Alcohol Spectrum Disorders	10 (2.0%)
Speech and Language, Social or Communication Disorder	10 (2.0%)
Tourette Syndrome or Tics	7 (1.4%)
Other	180 (36.1%)

Limitations

Over representation

- White British (92.4%)
- Mothers (92.8%)
- Autism (66.9%)
- GP's (12%)

Underrepresentation

- Most deprived (9.0%)

Professionals' Roles

Role	Frequency (%)
GP	36 (12.2%)
Paediatrician	27 (9.2%)
MHPractitioner	21 (7.1%)
SENCO	20 (6.7%)
Health Visitor (Nurse)	16 (5.4%)
Physiotherapist	15 (5.1%)
Educational Psychologist	14 (4.7%)
Community Nurse	13 (4.4%)
Teacher	13 (4.4%)
Local Authority	11 (3.7%)
Mental Health Nurse	11 (3.7%)
Occupational Therapist	10 (3.4%)
Other Nurse	10 (3.4%)
School Nurse	9 (3.1%)
Speech and Language Therapist	9 (3.1%)
Charity	8 (2.7%)
Specialist Nurse	8 (2.7%)
Child and Adolescent Psychiatrist	5 (1.7%)
Head Teacher	5 (1.7%)
Practice Nurse	5 (1.7%)
School Support Worker	5 (1.7%)
Social Worker	5 (1.7%)
Other (psychologist, researcher, etc.)	15 (5.1%)
No response	4 (1.4%)

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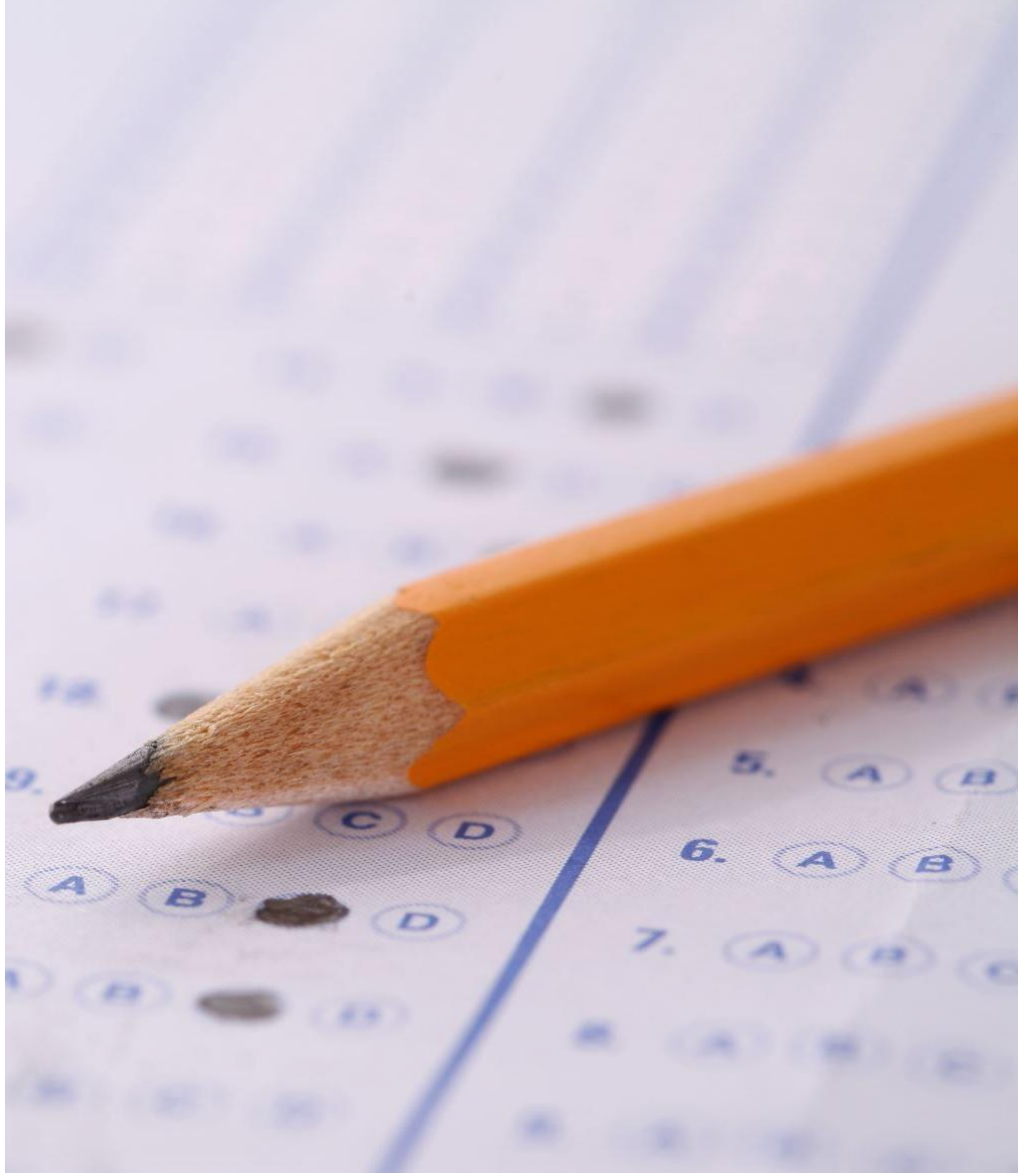
Survey key findings

- Only 38% of parent carers in our survey said that they had ever been asked about their mental health by a professional.
- 78% of parent carers had not received a statutory Carer's Assessment.
- Over half (52%) had resorted to paying for private mental health services.
- Most professionals (90%) considered it their role to recognise mental health problems in parent carers, but 2/3 did not conduct assessments.



Survey qualitative findings

- Parent carers reported barriers such as limited appointment times, negative past experiences, and a lack of tailored care.
- Fears of disclosure of mental health issues due to impact on their ability to advocate for their child, fears of being perceived as inadequate parents, or safeguarding procedures.
- Professionals recognised the importance of addressing parent carers' mental health but reported a lack of knowledge about referral pathways and appropriate services.

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Interviews

Online interviews: 12 parent carers – 9 female, 3 male

- Varied by geographical region, child condition, mental health support received, and referral route
- Topics covered: discussing mental health with professionals, access to mental health care, and what support parent carers need

Analysis: Thematic analysis of interview transcripts and open-ended survey responses.

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Interview findings

- Parent carers are frequently in contact with a range of professionals.
- The need for trust is key.
- Professionals with longer-term relationships may be in the best position to identify need.
- An awareness of parent carer concerns and need for reassurance is required.
- Peer support or peer-led services may also be a promising source of support.
- Bespoke, tailored mental health interventions for parent carers are needed.

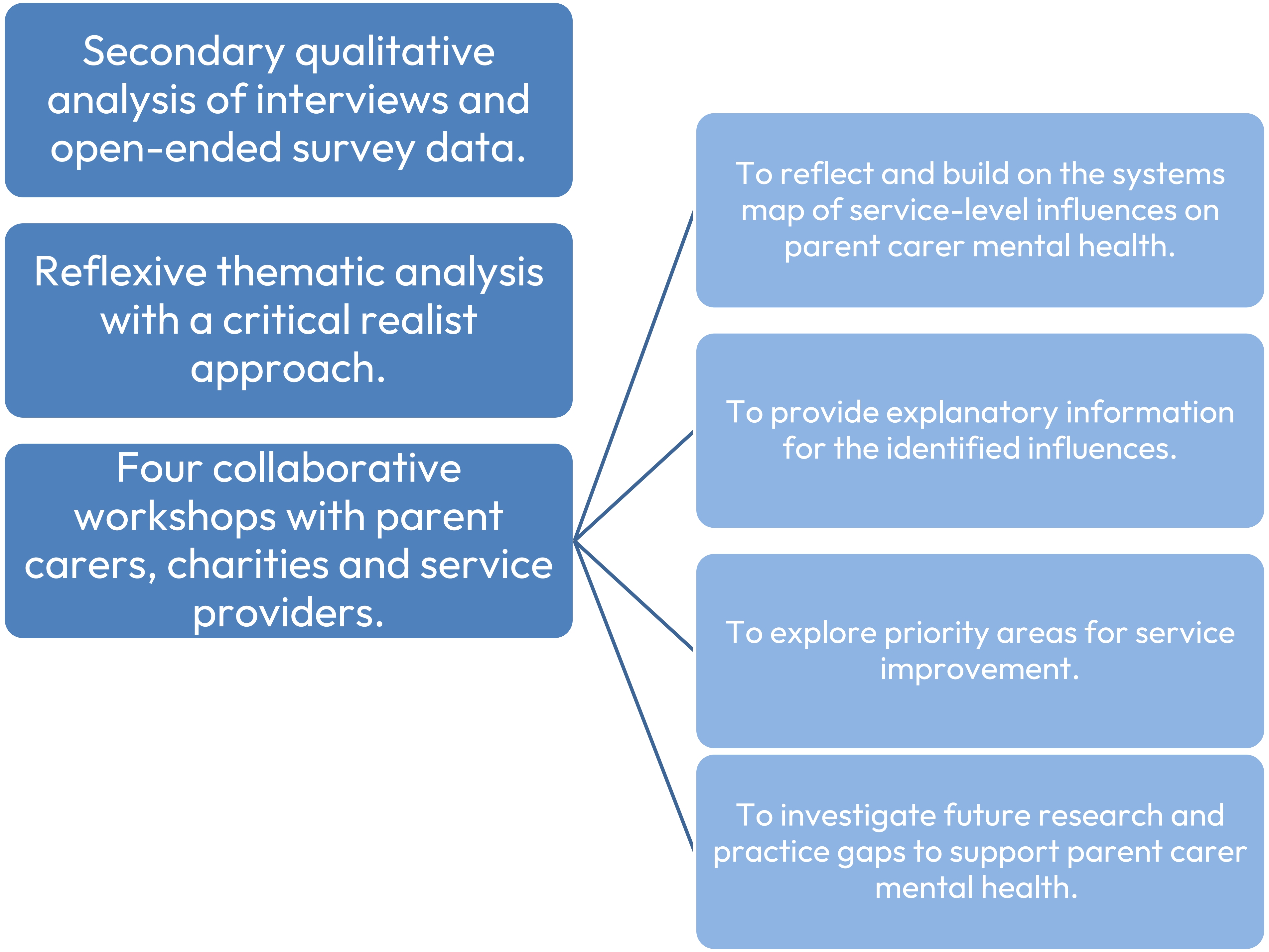
Phase 2: A systems perspective on parent carers' mental health and access to support

How service systems shape:
- Parent carers' mental health
- Access to support

Focus on interactions between:
- Family resources
- Parents' ability to navigate systems
- Service system functioning

Aims:
- Identify practical ways to improve coordination
- Reduce navigation and administrative burden on families

Phase 2: The study



Secondary qualitative analysis of interviews and open-ended survey data.

Reflexive thematic analysis with a critical realist approach.

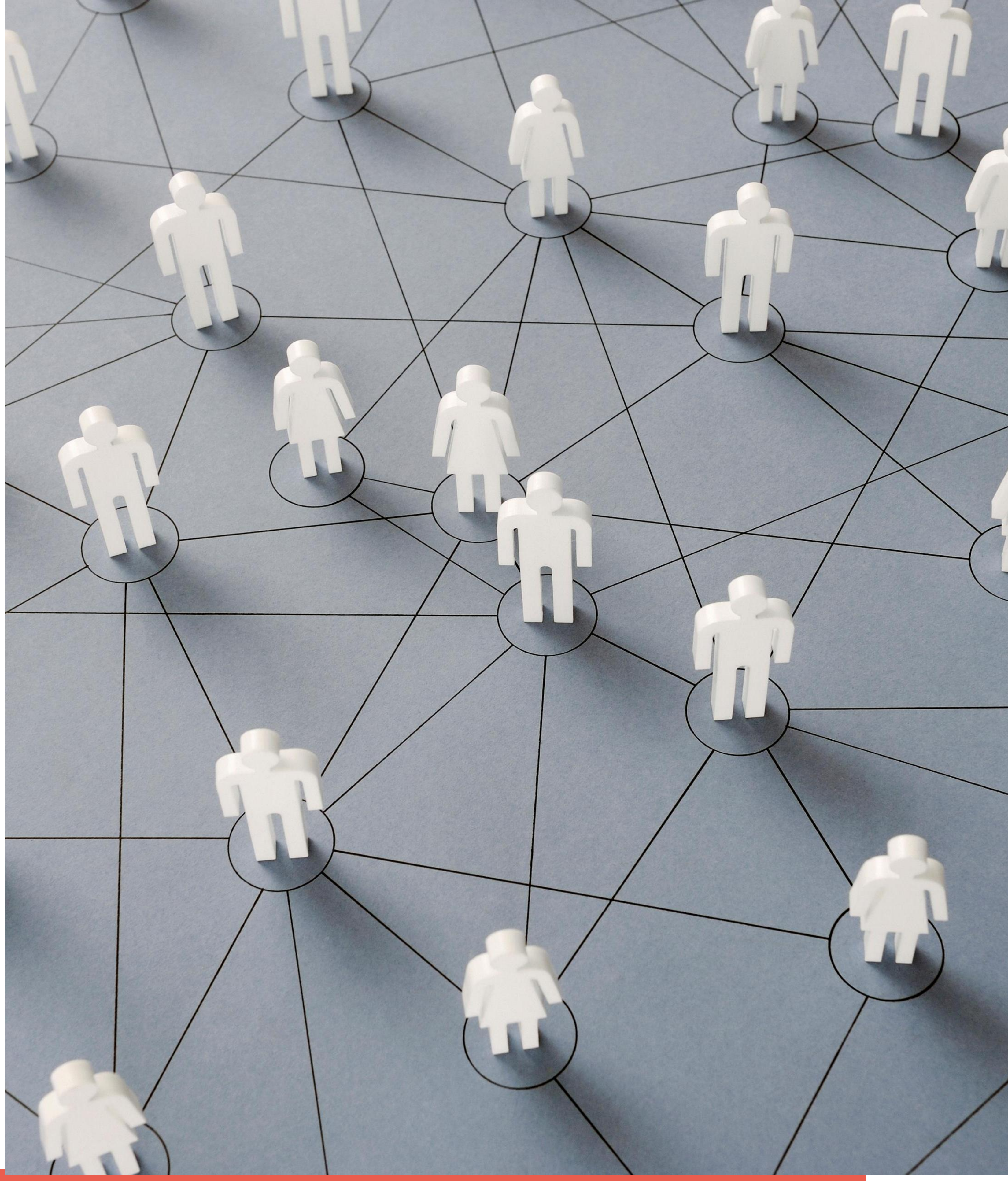
Four collaborative workshops with parent carers, charities and service providers.

To reflect and build on the systems map of service-level influences on parent carer mental health.

To provide explanatory information for the identified influences.

To explore priority areas for service improvement.

To investigate future research and practice gaps to support parent carer mental health.



Phase 2: Findings

Four interacting domains:

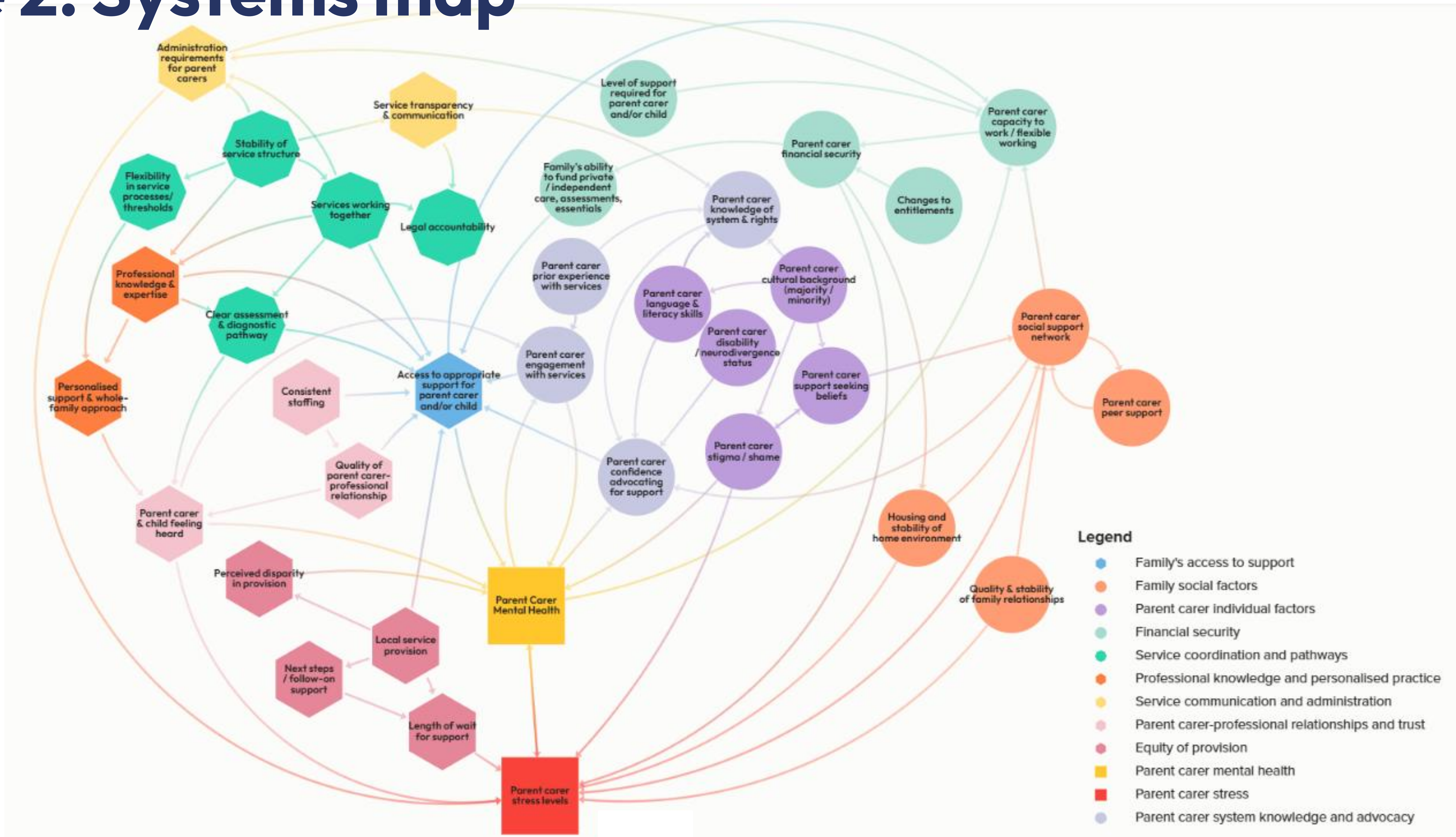
Family resources and social context
-Social support
-Individual factors
-Financial resources

Capacity to navigate systems
-Systems are complex and difficult to understand
-Access depends on advocacy, knowledge of services
-Hidden expectation of parents as coordinators and advocates

Service system functioning
-Fragmented pathways
-Poor coordination and communication
-Heavy administrative demands
-Variable professional knowledge
-‘Postcode lottery’ in provision

Outcomes for families
-Access to support for child directly impacts parent mental health
-High levels of stress, exhaustion, emotional burden

Phase 2: Systems map



Legend

- ● Family's access to support
- ● Family social factors
- ● Parent carer individual factors
- ● Financial security
- ● Service coordination and pathways
- ● Professional knowledge and personalised practice
- ● Service communication and administration
- ● Parent carer-professional relationships and trust
- ● Equity of provision
- ■ Parent carer mental health
- ■ Parent carer stress
- ● Parent carer system knowledge and advocacy

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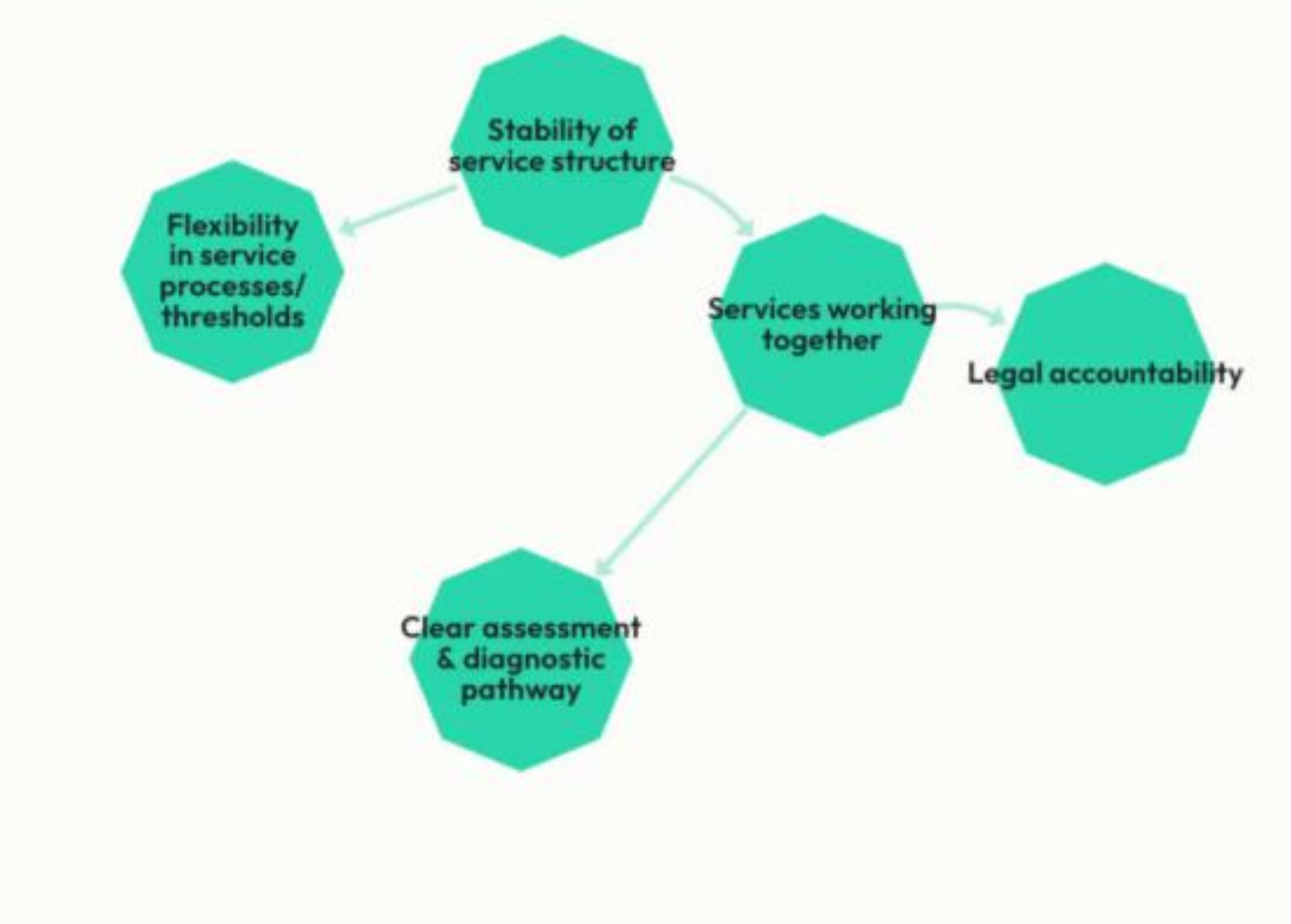
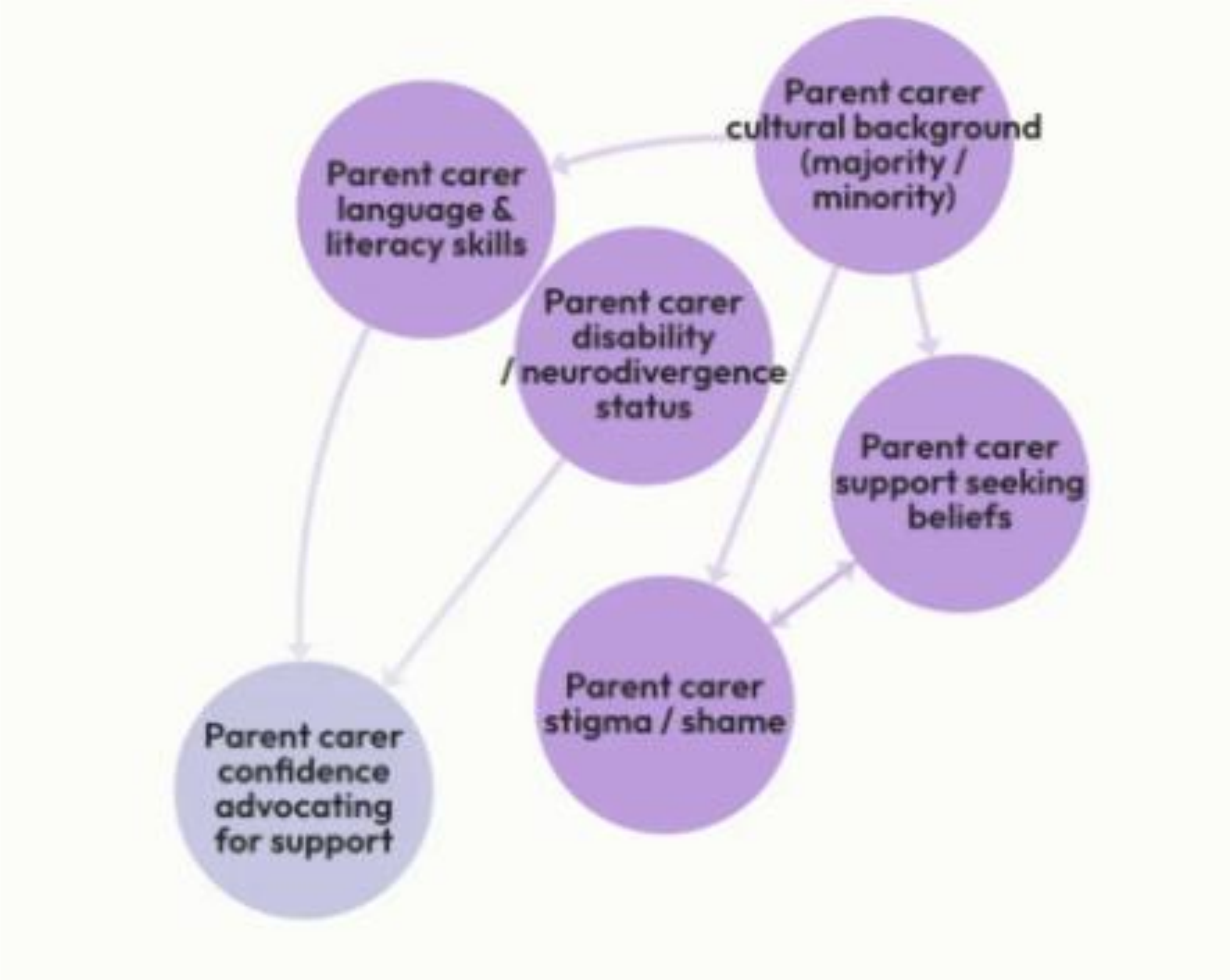
Service coordination and pathways



- “But I think the whole way the system works, and the lack of joined up approach between health, education and social care, adds to the mental health pressures of parent carers. And something as simple as sorting out coordination between the three of them, and understanding of the pressures that it causes, that would help the mental health of parent carers.”
- “You have 15 different departments and agencies in your phone book, and it’s your responsibility to make sure that they’re all in place and you can’t get them around the table together, ever.”

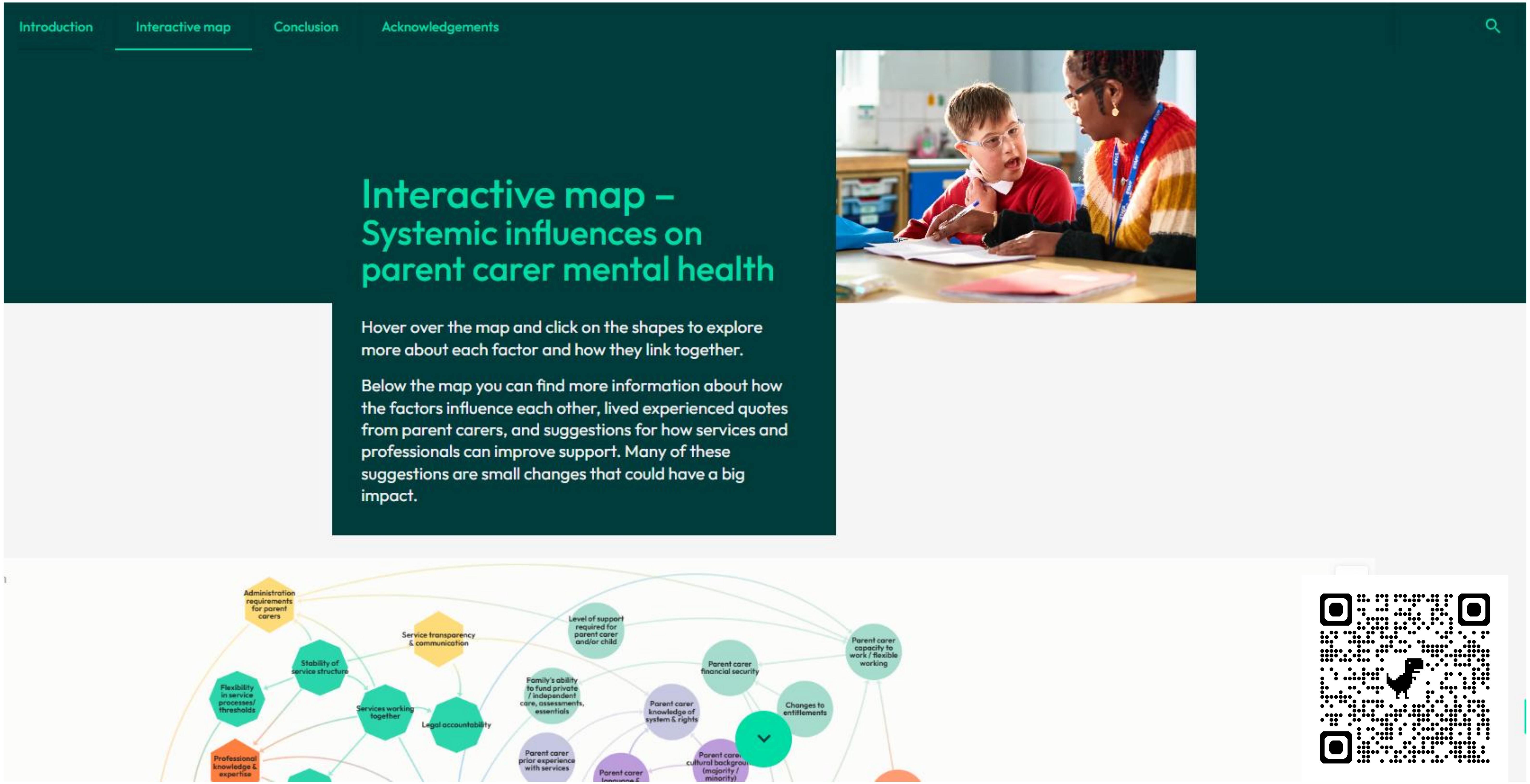
Parent carer individual factors



- “So we got seen a lot quicker and things got turned around a lot quicker because I was squirrelling away in the background working out. And I can only do that because I’m an English speaker, because I have a family with medical backgrounds… and I think if you don’t have access to those things and English is your second language or third language, you're screwed, absolutely screwed.”
- “Support networks / groups are limited to certain areas… there is limited access for parents like me with disabilities and energy limiting conditions… I don’t drive.”

Interactive website

https://digital.exeter.ac.uk/parent-carers-mental-health/



Interactive map – Systemic influences on parent carer mental health

Hover over the map and click on the shapes to explore more about each factor and how they link together.

Below the map you can find more information about how the factors influence each other, lived experienced quotes from parent carers, and suggestions for how services and professionals can improve support. Many of these suggestions are small changes that could have a big impact.

Phase 2: Findings

Three, core, cross-cutting mechanisms:

Hidden labour of care coordination
Parents organise and connect services

Inequalities in navigation capacity
Resources shape ability to access support

Mental health is system-dependent
Linked to service responsiveness

Phase 2: Opportunities for change

Increase awareness & understanding:
- Public awareness
- Knowledge of available services
- Professional training
- Link parents together

Improve service coordination:
- Key worker / care coordinator
- Clearer pathways

Reduce administrative burden:
- Service communication
- Less duplication

Address inequalities in navigation:
- Accessible information
- Advocacy support

Phase 3 : Impact

- We are working together to create outputs to share our findings, including:
  - An interactive website to share our system map
  - An animation
  - Training for professionals
  - Engagement with third sector partners, colleagues, professionals, and policymakers

Importance of Impact

Impact refers to the difference a project makes beyond academia, the tangible change it creates in the real world

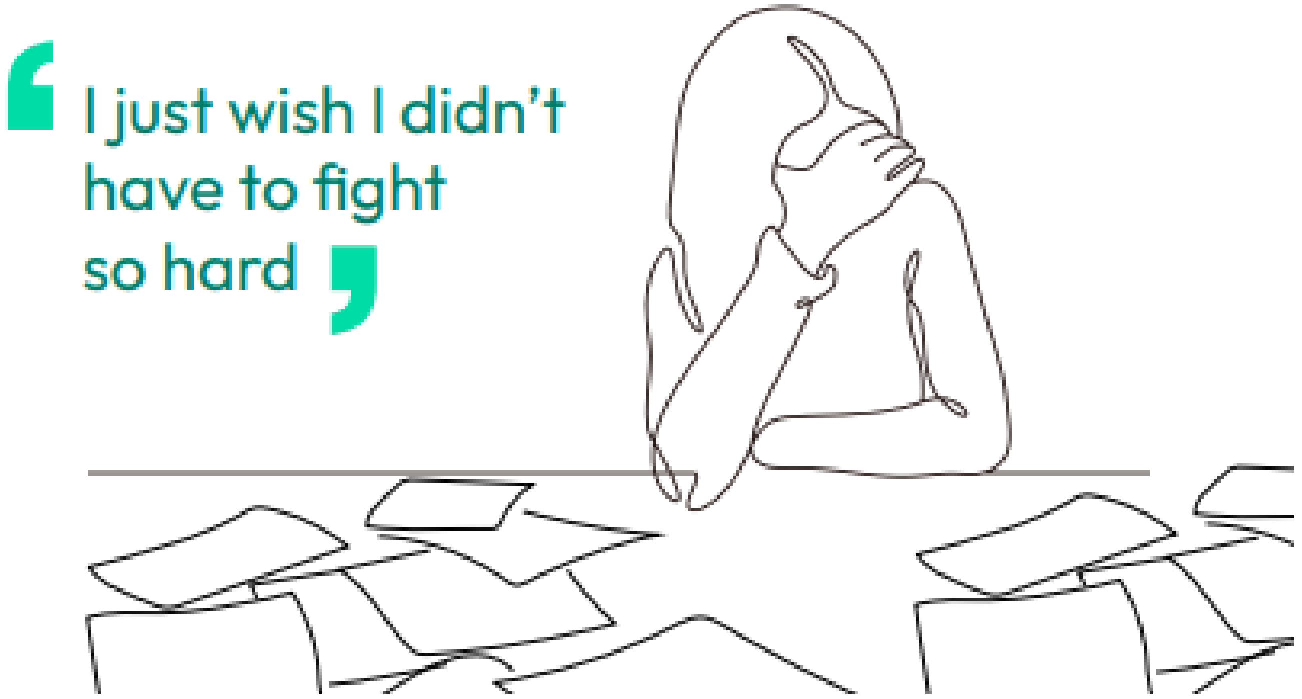
The animation communicates research findings in an accessible, shareable format

The training is designed for professionals in health and social care who may never read academic papers

The interactive map displays academic findings in a digestible format

Research findings only create change if they reach the people who need them

Animation



SCENE 7

RECORDED VOICE OVER
"I'd walk over hot coals for my kids I just wish I didn't have to fight so hard to get them what they need."
"nobody thought to ask if I was okay. I felt completely invisible."

HIGHLIGHTED TEXT
I just wish I didn't have to fight so hard

SCENE 10

RECORDED VOICE OVER
"There's a safety in talking to another parent who just nods and says, 'Yes, me too.' It's the first time ... you don't feel like you're failing."

HIGHLIGHTED TEXT
There's a safety in talking to another parent
You don't feel like you're failing

Animation

Training

1. **Lived experience and reflection**
   Understanding the realities of parenting a child with SEND and how these experiences can shape mental health and engagement with services.
2. **Evidence and systems**
   Exploring research findings on parent carer mental health, the impact of service navigation, and how systems can inadvertently contribute to distress.
3. **Implications for practice**
   Translating understanding into action, with practical strategies for compassionate, trauma-aware, and relational practice.

Training

Online delivery

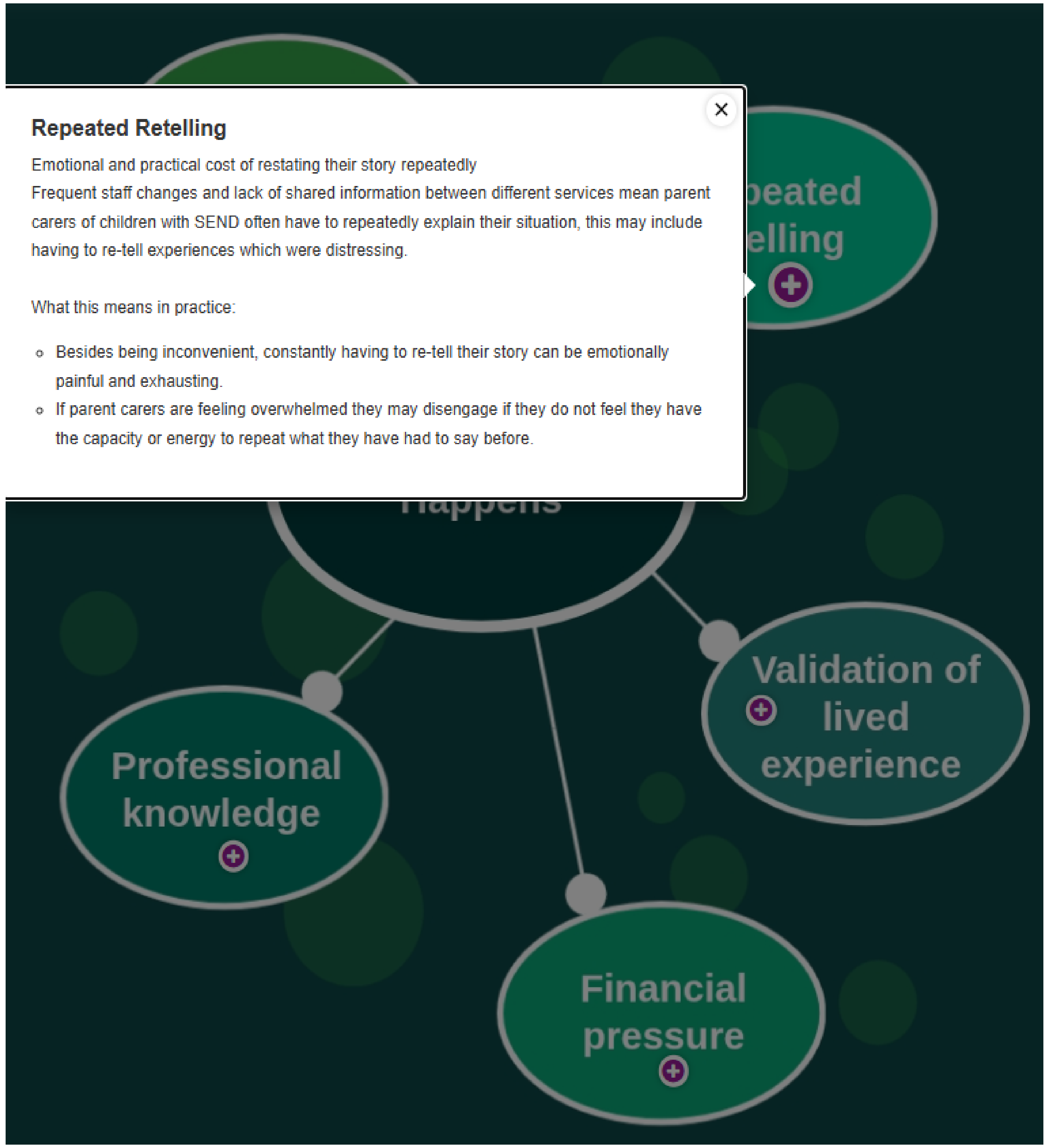
- Free open course

Collaboration

- Medical Students
- Devon County Council SEND teams
- Other professionals/LAs

Training

- Videos
- Interactive elements
- Activities
- Downloadable worksheets
- Signposting links



Repeated Retelling

Emotional and practical cost of restating their story repeatedly

Frequent staff changes and lack of shared information between different services mean parent carers of children with SEND often have to repeatedly explain their situation, this may include having to re-tell experiences which were distressing.

What this means in practice:

- Besides being inconvenient, constantly having to re-tell their story can be emotionally painful and exhausting.
- If parent carers are feeling overwhelmed they may disengage if they do not feel they have the capacity or energy to repeat what they have had to say before.

Co-production

- This project has involved parent carers from the start and throughout each phase.
- Three parent carers are co-investigators
- 12 parent carers sit on our 'working group'
- Parent carers have shaped the evolution of the SPaCE project at every stage.
- Findings and outputs are being developed as part of an active co-production process between researchers and the wider project group.

Co-Investigator Perspective

- Three unique perspectives and sets of experience:
  - Anna – parent carer of adult with complex needs and decades of experience of various systems. Experienced independent training consultant and advocate
  - Bel – parent carer of adult with a learning disability. Experienced public collaborator, trainer, facilitator and advocate
  - Sharon – parent carer of 11-year-old with PMLD. Advocacy experience and professional comms experience.
- Collaborative and equal
- Involved from project inception: Almost 4 years of full involvement-essential for a solid knowledge base on all aspects of the project

PPI in practice: Co-Investigator Input

Phase 1

- Involved in design and direction of the project from the very beginning.
- Helped plan what was taken to the working group for their input
- Analysing the interview responses with research team to bring in lived experience expertise in how we interpreted what people had said
- Writing a section of the main survey results academic paper

Phase 2

- Discussions in management meetings to help create the map
- Linked with networks for stakeholder workshops

PPI in practice: Co-Investigator Input

Phase 3- Animation and Training

- Joined the working group to help with the animation design
- Writing retreat – 3 Co-I's worked together to enhance training bringing in lived experience
- Drawing on training and facilitation experience from Bel and Anna
- Added in voice overs to bring to life the parent carer experience and add 'heart'
- Case studies of two different children to permeate throughout the training
- Developed and added an activity on emotional impact of being a parent carer which was missing

PPI in practice: Working Group Input

Phase 1

- The conditions included to identify SEND in the CPRD code list.
- The mental health conditions included in the CPRD analysis
- Shaping the survey questions and testing the survey functions
- Sharing the survey through parent carer networks.

Phase 2

- Development of the system map of factors influencing parent carer mental health - we started with linear pathways and PPI helped us to develop it into the complex map.
- Development of recommendations/implications for service improvements to include on the map website.
- Amended language in map and influenced selection of quotes.

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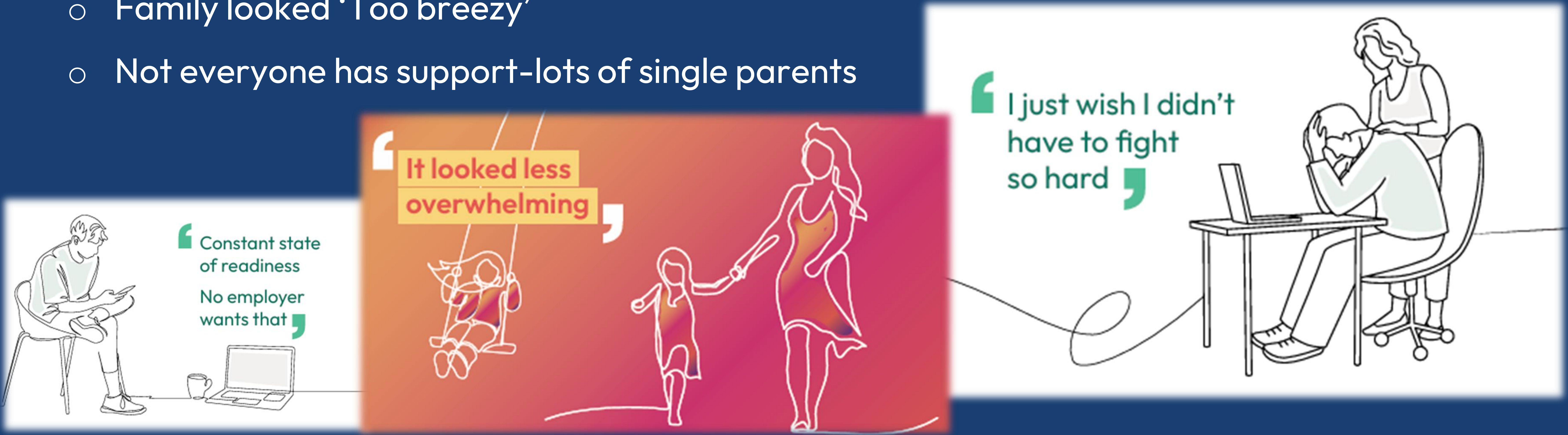
PPI in practice: Working Group Input

Animation:

- Drawings didn't express the stress experienced by parent carers
- Picked up on subtleties
  - The man looked more like a bored teenager than a parent carer
  - Family looked 'Too breezy'
  - Not everyone has support-lots of single parents



PPI in practice: Working Group Input

Animation continued:

- Concerns over animation looking like it was just an 'easy fix'
- Diversity needed
- Male dominated – carer and child not representative of the reality
- Recorded voice overs

PPI in practice: Working Group Input

Training:

- Input on Iceberg activity scenarios and what is ‘under the surface’.
    - e.g., Parent getting an unexpected phone call from school/ service etc where they are put on the spot and expected to drop everything and turn up for an appointment/ meeting
- Providing responses for activities for trainees to check against their own reflections.
- Reviewing implications for practice – actions practitioners can take, such as asking the parent what they think would help.

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“It was a lovely team to work with; they really lived and breathed being inclusive and welcoming. Parent contributions were valued and welcomed. We were equal partners guiding the development of the research and outputs.

This has meant that the research addressed issues that matter, the outputs are meaningful and the research will have an impact, not just sit on a shelf. I'm looking forward to sharing the resources with my networks.”

> "Great to see how you've taken on the feedback and improved as a result of the team working together. Well done everybody, it was lovely to hear everyone's familiar voices. It doesn't feel tokenistic, it feels real."

Did you have enough opportunity to contribute and say what you wanted to say?

Yes, it was very inclusive

Yes lots of opportunity

Yes, I always felt heard and acknowledged.

Absolutely, feel valued and welcomed

Yes

Yes, always encouraged to open up.

Yes. contributions were welcomed and respected.

Yes- and our contributions were listened to acted on and feedback was intergral to steering the project

Always! The team were always so helpful to ensure our voices were heard acknowledged

driving change an antidote

respected meaningful inspired therapeutic

collaborative no hierarchy

co-produced insightful brilliant

included cared for

positive

teamwork

supported valued heard

network

self-esteem equality hopeful seen in awe

united inclusive human strong together

support network optimistic listened to worthwhile

connected

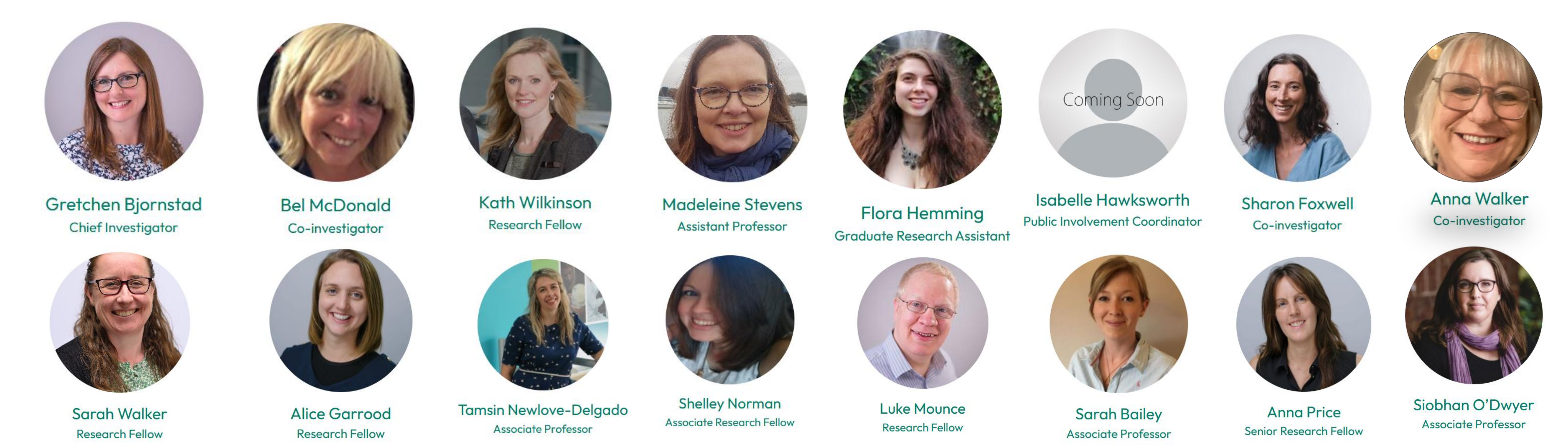
sense of purpose understood

empowered

Thank you

To the parent carers who shared their experiences with us through our survey and interviews, and those involved in this work as co-investigators and through our working group, as well as the professionals who responded to our survey and the partner organisations who have supported this work.

The SPaCE team:



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