

# Living with Autism in Rural Coastal Areas of England

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# Autism and the family

- Autism – lifelong developmental condition with a UK prevalence of about 1.1% (Brugha et al., 2012)
- Can place all family members under elevated levels of stress (Petalas *et al.*, 2012; Preece & Jordan, 2010)
- Characteristic difficulties in social interaction, social communication and restricted, repetitive interests impact on all areas of family life and can lead to stigmatisation and social exclusion
- Family experience is mediated and moderated by a range of variables including
  - Housing (Langworthy-Lam *et al.*, 2004)
  - Finances (Stoner & Stoner, 2014)
  - Relationships with schools and professionals (Whitaker, 2007)
  - Access to informal and formal support (Preece & Jordan, 2007)

# Austerity

- Financial crisis (2008) and election of coalition government in UK (2010) led to decade of austerity which still continues
- Wages have fallen in real terms
- Welfare benefits and public spending (local and central governmental) cut
- Statutory services under pressure
- Third sector organisations – particularly those working with vulnerable individuals – funding reductions leading to staff/service cuts (NCB, 2016)
- British Academy of Childhood Disability (2014) identified:
  - Raised thresholds for education, health and social care support
  - Assessments delayed
  - 33% of families with disabled children (including ASD) worse off
  - 90% experiencing anxiety and stress

# Coastal impact

- Austerity does not impact UK equally – often think of North-South divide, but less consideration given to coastal disadvantage. However...
- Coastal communities (local authorities with a coastal border) face greater hardship than inland areas (SMF, 2017):
  - Higher economic and social deprivation
  - Low pay
  - Higher unemployment
  - Health issues
- Gap in educational achievement between coastal/non-coastal areas (Ofsted, 2014)
- Large populations of elderly place increased pressure on health/social care services (SMCPC, 2016)

# Research gaps

- UK coastal community research – focused on towns (e.g. Blackpool, CLES, 2014) and South East where there are high numbers of EU migrants (Smith 2011) – more rural coastal areas – under-researched
- Growing body of non-UK literature re experience of families living with autism in rural areas (Antezena *et al.*, 2017; Murphy & Ruble, 2012) – but no similar UK research
- No previous research on experience of families living with autism in rural coastal areas
- Successful application for funding from British Academy/Leverhulme Small Grant – research began May 2018

# Focus of research

- What are families' experiences of living with autism in rural coastal communities?
- What are the challenges, barriers and benefits experienced?
- What are families' experience of informal and formal support?
- What is the perceived impact (if any) of living with autism in a rural coastal community during a period of austerity

# Methods

- Qualitative methodology – semi-structured interviews
- Research settings – 2 x comparable rural coastal areas:
  - Cornwall (ranked 143/326 on Index of Multiple Deprivation)
  - Norfolk: West Norfolk (89/326) and North Norfolk (93/326)
- Access to families obtained via local National Autistic Society groups, autumn 2018.



# Sample

- Twenty-two families from Cornwall (n=9) and Norfolk (n=13) were recruited to the study in autumn 2018.
- Sample comprised:
  - young people on the spectrum (n=11)
  - their neurotypical siblings (n=5)
  - mothers (n=21, 4 of whom are on the autism spectrum)
  - fathers (n=10, 2 of whom are on the autism spectrum)
  - grandparents (n=2).

# Fieldwork

- Interviews in Cornwall were undertaken at the end of January 2019.
- Interviews in Norfolk were undertaken during February and March 2019.
- Interviews carried out by DP and ILL, either individually or together



# Interviews

- Thirty-five semi-structured interviews were carried out with 49 respondents
  - twenty-nine interviews completed in family home
  - Six interviews (with seven individuals) undertaken over phone due to adverse weather conditions (5)/distance (1)
- Over 33 hours of interview data.



# Analysis

- Thematic analysis using QSR NVivo
- An a priori set of codes – derived from research questions – served as initial template
- Additional inductive coding developing through process of analysis
- Coding undertaken by both researchers, who also audit samples of each others' coding for completeness and appropriateness
- Codes will be reviewed for overlap and redundancy, and reduced into matrices to develop final themes

# Emerging themes – from analysis so far

- Challenges
  - Length of time to get diagnosis
  - Accessing and relationships with services
  - Impact of distance & lack of infrastructure
  - Impact of austerity and cuts

“Our biggest issue being rural, and particularly being here, is that we’re Cornish in terms of our post code but everything, all the provisions and all the special schools and all the things that we could probably benefit from accessing is down Truro, well no closer than Bodmin. There’s just nothing up here.”

“There’s nothing comes here. There’s nothing happens, especially for the children. You have to drive everywhere to get anything. All the services - if I lived in Norwich - I keep hearing about all these wonderful things...it’s only based in Norwich.”

# Emerging themes – from analysis so far

- Positive experience
  - Outdoor living
  - Peace and quiet
  - Belonging to a community

“Surfing, fresh air... when I go up country sometimes I can hardly breathe.”

“Lovely, it’s absolutely lovely...It’s a lot safer here. Before, if he got out the door - he’s a runner and he’d run and round here you’ve got the odd car which comes down but he seems to be a lot calmer round here as well because it’s quiet...”

# Work to be undertaken

- Complete data analysis
- Feedback via local workshops in Cornwall and Norfolk (winter 2019-20)
- Complete final report for funder (June 2020)
- Further dissemination activity
  - Journal articles
  - Conferences

• Thank you

