

“There isn’t really anything around here...”: autism, education and the experience of families living in rural coastal England

- DAVID PREECE (UNIVERSITY OF NORTHAMPTON)
- IVANA LESSNER LIŠTIAKOVÁ (UNIVERSITY OF SUFFOLK)

Content of presentation

- Background to the study
- Methodology
- Key findings – intersecting impacts of
 - Rurality
 - Coastality
 - Autism

The study

- Living with Autism in Rural Coastal Areas of England (LARCAE)
- Funded by British Academy/Leverhulme Trust (SRG\170268)
- 2018-2020
- Research undertaken by
 - Dr David Preece, Associate Professor in Centre for Education and Research, Faculty of Health, Education and Society
 - Dr Ivana Lessner Lištiaková, Senior Lecturer in Childhood Studies, School of Social Sciences and Humanities, University of Suffolk



Context of the study – a decade of austerity (1)

- Financial crisis (2008) and election of coalition government in UK (2010) led to lengthy period of austerity measures from central government
 - Wages fell in real terms (worst decade since Napoleonic Wars in early 19th century)
 - Welfare benefits and public spending cuts (local and central government)
 - Council funding on services fallen by 21% between 2009-10 and 2017-18 (IFS, 2019)
 - Local authorities had core funding cut by almost £16 billion in a decade (GMB, 2019)
 - Statutory services under pressure
 - Third sector organisations – particularly those working with vulnerable individuals – funding reductions leading to staff/service cuts (NCB, 2016)

Context of the study – a decade of austerity (2)

- British Academy of Childhood Disability (2015) 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 and rural disadvantage

- 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
- *“The areas where the most disadvantaged children are being let down by the education system...are no longer deprived inner city areas, instead the focus has shifted to deprived coastal towns and rural, less populous regions of the country.” (Ofsted, 2013)*



Autism and the family

- Autism – lifelong developmental condition with a UK prevalence of about 1.1% (Brugha *et al.*, 2016)
- 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 impacted by a range of factors including
 - Housing (Langworthy-Lam *et al.*, 2002)
 - Finances (Stoner & Stoner, 2014)
 - Relationships with schools and professionals (Whitaker, 2007)
 - Access to informal and formal support (Preece & Jordan, 2007)

Gaps in knowledge

- UK coastal community research – focused on towns (e.g. Blackpool, CLES, 2014) and South East where there are high numbers of EU migrants (Smith, 2012) – 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 anywhere
- Successful application for funding from British Academy/Leverhulme Small Grant – research began May 2018

Focus of overall project

- 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 68/326 on Index of Multiple Deprivation (2015), 83/317 (2019)
 - Norfolk: West Norfolk – ranked 89/326 (2015), 94/317 (2019) and North Norfolk – ranked 93/326 (2015), 127/317 (2019)
- Access to families obtained via local National Autistic Society groups, autumn 2018
 - NAS Cornwall
 - NAS West Norfolk



Who did we interview?

- Twenty-two families from Cornwall (n=9, 24 individuals) and Norfolk (n=13, 25 individuals) were recruited to the study in autumn 2018
- Spoke to families living in range of settings, rural hamlets (pop <100) to market/seaside towns
- Sample (n=49) comprised:
 - young people on the spectrum, aged 9-22 (n=11)
 - their neurotypical siblings, aged 5-15 (n=5)
 - Mothers, aged 25 and up (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 David and Ivana, 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
- A set of codes – derived from research questions – served as initial template
- Additional codes emerged through process of analysis (iterative process)
- Coding was undertaken by both researchers, who also audited samples of each others' coding for completeness and appropriateness
- Codes were reviewed for overlap and redundancy, and reduced into matrices to develop final themes

Presentation of findings

- Data were collected about family life and interaction with a range of sources of support – informal and formal (e.g. churches, charities, health professionals, social care)
- In this presentation – focus on family life and experience of education
- Present our findings viewed through three intersecting perspectives
 - Rurality
 - Coastality
 - Autism

The “rural idyll”

- Rural living mythologised as offering a slower-paced, higher-quality lifestyle, set in a pastoral landscape and experienced within close-knit, supportive communities

I have access to those spaces and when I lived in the Midlands I never, ever... I used to feel so stressed. I never, ever felt I had anywhere to breathe. You feel like wherever you go, even the woods in the Midlands still didn't feel enough because you could still hear all the background noises... and the traffic to get to it, stressing you out to get there. Here we don't have that.

The location generally, it's picturesque, it's pretty, we don't have loads of gangs around. There's not crime or graffiti; it's just nice!



Benefits of rural location for autism

Everyone knows everyone, which isn't always a good thing, but I know if he got out and walked down to the farm one of the tractor drivers or the farmer would bring him back.

Being rural it's quite quiet so we can go to places that are quiet and so he can just do his thing - there's no lots of people getting in his way or distracting him or whatever, and I know where the safe places are. That's beneficial.

- Families reported many autism-specific benefits associated with rural living
- Open physical space is especially important for individuals with autism who have specific sensory needs and might feel anxious or overwhelmed in crowded urban environments
- Living in small communities led to greater feelings of safety, and opportunities for social learning
- Rural areas that were not popular holiday or second home destinations provided access to affordable housing with gardens/inside space

Negatives associated with rural living

- However, downsides also associated with rural living
- More limited availability of services per capita, as well as lower socio-economic and educational levels (Hartley, 2004)
- UK ‘attainment gap’ – the gap between disadvantaged pupils and their peers – is greatest in rural areas (DfE, 2019)
- Families with autism facing multiple challenges associated with rurality (Antezena *et al.*, 2017):
 - Delays regarding diagnosis
 - Low autism awareness
 - Lack of appropriate services

Delays regarding diagnosis

It took six years – from four to ten. Including going down the Autism Pathway in Cornwall three times and being told no. One of them, they said they had to say no to autism because he wouldn't engage in the tests. But as Great Ormond Street said, that alone should have red-flagged for them.

I arranged to go private. We were seen in four or five weeks, and I was presented with a report...which said he has ASD/Pathological Demand Avoidance Syndrome. And they refused to agree that he had a diagnosis. They said, "We don't recognise PDA, so he can't have that diagnosis."

- Families in both areas identified problems with the diagnostic process
- Parents reported staffing shortages, staff leaving not being replaced, and a lack of consistency and continuity
- Many families ended up paying privately and seeking a diagnosis outside the area
- Things were exacerbated by local authorities' reluctance to accept e.g. diagnosis of PDA
- Diagnostic delay was resulting in children not accessing support services and/or being out of school

Low autism awareness

- Families reported low autism awareness within the community and also within service providers
- Knowledge about autism within service providers (such as schools) was limited
- Despite this many professionals were resistant to acknowledging parental expertise and perspectives – even when parents were themselves autistic

There is a lot of blame on parents for children's behaviour, whatever their issues are, particularly with autism. They're not really up to speed.

The education consultant hadn't ever read anything about autism. He actually said, "I've never read anything about autism!" So you think to yourself, "Oh, bugger!"

Her teacher in reception was very combative of everything we said. If I said, "I think she is having a hard time because of X, Y, Z, she would say, "Oh, I don't think it's because of that!"

Lack of appropriate services

- Services were identified as reactive and understaffed, with high turnover and a significant resource shortfall
- This resulted in services failing to meet children and families' needs, often leading to conflict and relationship breakdown between providers and families
- Families whose children who did not fit into existing models of service provision (e.g. more able children on the autism spectrum, or those with multiple difficulties) faced most significant access difficulties and exclusion

In London you could have 30 special needs' kids in a 1 mile radius. Here, you might have 1 kid 40 miles away from the next and it's the co-ordination and the costs involved.

They're offering things because that's all they've got. They are not offering that because they necessarily think that's right, there's just no alternative.

Impact of lack of infrastructure

- Infrastructural shortfall – particularly with regard to transport networks – made life particularly difficult
- This was exacerbated by the fact that services (formal and informal) had shrunk back to major towns, which in some cases made them effectively inaccessible

He's always in trouble for being late...because there's only one bus an hour and by the time it gets to King's Lynn for his college, it normally gets there for 8.45. His classes start at 8.45 and he's just getting off a bus. So, then the college always do the register bang on 8.45, and by the time he's got in the classroom it's gone 8.45. Therefore, he's classed as absent, when he's not. It can't be helped. He's on his final warning for attendance.

There is very, very little public transport and what is there only connects certain places. From Launceston you have to catch 4 or 5 buses to get to Bodmin. It's actually easier for me to go to Plymouth and take an hour and a half journey that way on one bus, than it is to go somewhere else in my county.

Coastality: 'blue space'



- Literature identifies positive associations between 'outdoor blue spaces' and mental health/wellbeing and levels of physical activity

I think the natural... 'healing' is the wrong word, but the natural therapeutic element of this place, I think, is the big difference.

Benefits of coastal location for autism

- As before, families reported autism-specific benefits associated with coastal living
- Many of these were associated with sensory aspects of the environment – wind, sand, water – and opportunities for outdoor living

The boys like the wind. We took them down to Porth beach... you drive onto the beach, so it's good. So they are out the bus and they just run, so it's fine. And we do puddle suits, wellies – C just throws himself in puddles, he loves water.

When things are a bit stressed, he can go and have a walk down to the beach and he does that lot, just to go and let off some steam. He'll go and take a long walk down to the beach. He always comes back feeling ten times better.

When the weather's nice we go to Blakeney and he can go in the harbour. The water goes out and you can go a swim in there and he can make mud slides.

I love the surfing, the fresh air... When I go up country, sometimes I can hardly breathe.

Seasonal nature of life

- Seasonal nature of life has both positives and drawbacks
- Opportunities to enjoy some activities and attractions during quieter months
- But many shops and services closed during the autumn and winter months
- Summer crowds at the seaside cause delays due to traffic and limit access to preferred activities
- All of this can cause confusion to autistic individuals who have a need for sameness and consistency

Another nice thing about Cornwall is in the winter, like we've got lots of memberships, Heligan Gardens, the Eden Project. They're very, very good for disabled families. We buy reduced passes and then two carers go free with them. So, it's actually quite cheap for us in the winter.

It restricts them. Like if the beach is too busy, we can't go to the beach. Soft play... can't do soft play, it's too busy. Too much noise he doesn't like. So yes, it does become difficult. And I think it's hard for the boys because they go to these places when they're quiet and then they're full of people and it's like, 'Why are all these people here?' They don't understand it's a different season...

Living by the sea: drawbacks

From May to September appointments are impossible. You won't get a parking space because you've got everyone using the A&E so parking becomes really difficult. And even Pen Rhys, our local hospital, you just can't park.

People's attitudes are different. Up country there is a lot of ethnic diversity and there is a lot of acceptance. Down here, there isn't as much. So, if you stand out in any way, they are very good at making you feel like you stand out.

Future-wise for employment, I really don't know how that is going to pan out for either of them. It's probably more challenging for them because we have got fewer resources in a rural, coastal County.

- Impact of seasonal visitors on services, as populations treble due to holidaymakers
- Lack of diversity within population can impact on acceptance within community
- Lack of social housing and seasonal nature of many jobs means that young adults with autism have limited opportunities for independent living
- High staff turnover in school impacts on consistency, relationships and achievement
- Exacerbates impact of coastal education attainment gap – more successful students 'out-migrate' (Corbett, 2005)

Currently he's on his 5th Head Master and 9th Deputy Head.

Marginality

- For families living on county borders, remote from population centres in the county, situation was particularly difficult
- The lack of local support services, coupled with infrastructural issues, made accessing appointments and services even harder

Our biggest issue being in Saltash 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 benefit from accessing are 50 miles away down in Truro. There's just nothing up here... They just completely say no, you have to use the Cornwall service so for nearly everything I'm going to have to take him all the way down there. That's already something he'll find quite stressful and Plymouth is just across the bridge so that's not being done in the best interest of the child.

The border is literally the road that runs behind here. Because we're in West Norfolk, there is support but it is Norwich, Great Yarmouth and that way (55 to 70 miles away). We are out on a limb here. We are at the edge of the county. We are as far as you can get from Norwich. A lot of the services that we could go to are not in this county; they are in Lincolnshire or Cambridgeshire, so we are ineligible. So, anything we do have to travel to, is a catch 22, because we can't really travel without support. And all the services there are in King's Lynn are part-time ones, because everything is based in Norwich.

Underpinning impact of autism

- Regardless of the positives and negatives associated with living in a rural coastal area, the presence of autism in the family has a profound impact
- Many families rarely ventured beyond the confines of their home, and had little interaction with others or the environment
- Families spoke of the dissonance of living in areas of beauty but being unable to take advantage of their surroundings
- Family experience is impacted by systemic factors (e.g. family structure, interaction, function, adaptation) (see Preece, 2014)

There are a lot of things we would like to do really. Cornwall is stunning and it would be nice to explore, but D can't really manage that. You can plan events and you find that D doesn't want to do it and you can't make him; he's a big lad.

A is too stressed out to go out of the house, so he won't leave the house. F is pretty much the same; he doesn't like leaving the house, but A really refuses to. He won't go for a walk with the dog or a bike ride or any fun things. He just won't leave the house.

We can't go out. We don't do things as a family. The twins have never been to a soft play centre to anything. We can't travel in the car. We can't be a normal family.

Overall experience of education

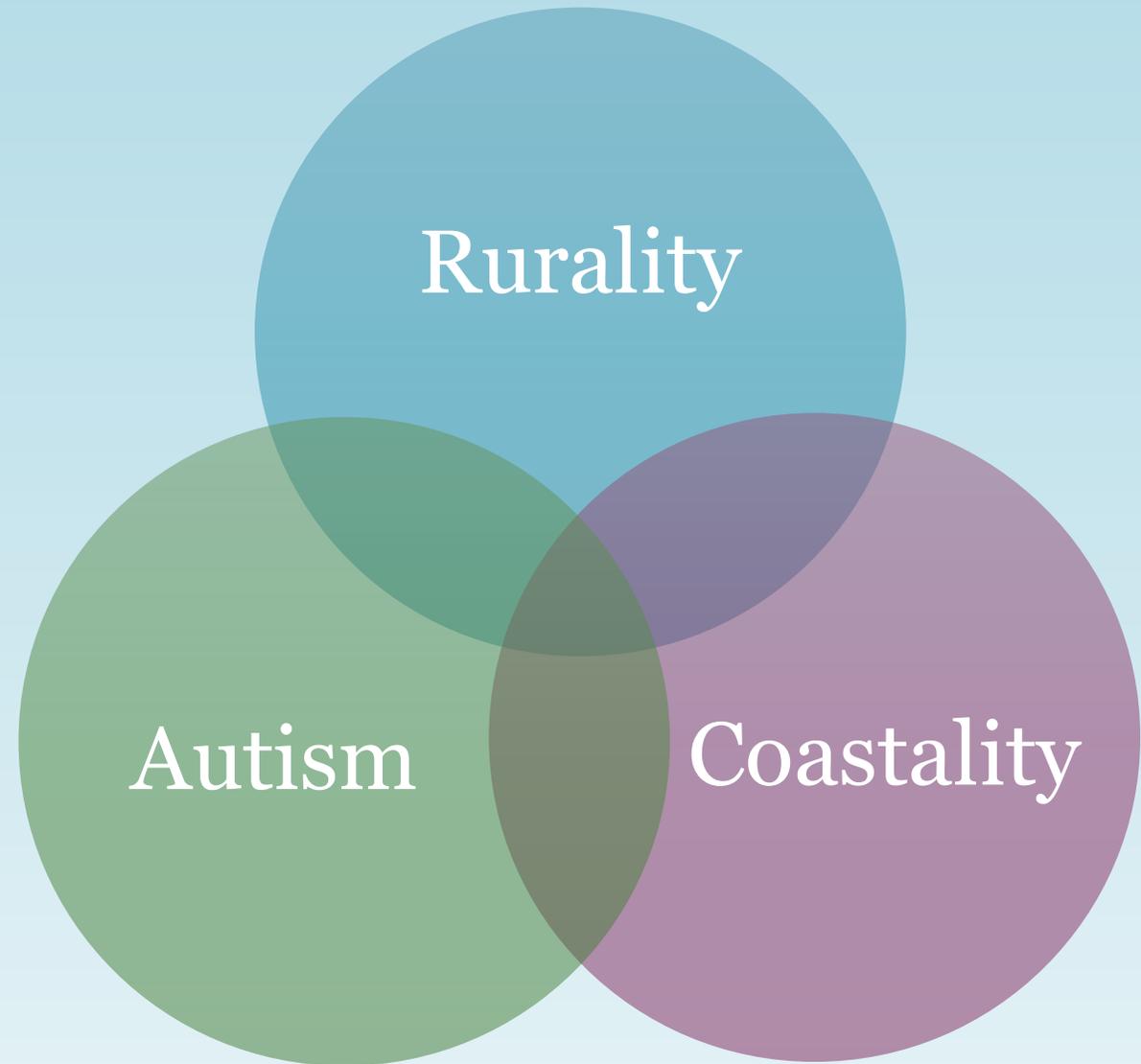
- Positives often related to individual teachers rather than systemic.
- Positive experiences often reported only after initial conflicts/changing schools.
- All families interviewed reported negative experiences with education – narratives of conflict, lack of understanding and exclusion

The teacher was really good and worked on our strengths and accepted our differences and made sure everything was really fun for us and that we got plenty of breaks when we needed them. She was really supportive of us and really believed in us. I did really well at that school.

It has been a case all along of me shouting very, very loudly and being constantly on the phone and complaining at every stage.

Intersecting impacts

- Families' experiences can be conceptualised as being shaped by:
- the intersecting impacts of the positives and negatives associated with rurality and coastality
- the underpinning impacts of autism on the family
- Access to/experience of education for children with autism in rural coastal areas of England could be improved by acknowledging and addressing the intersecting factors intensifying their marginalisation.



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