

LIVING WITH AUTISM IN RURAL COASTAL AREAS OF ENGLAND

AUTISM Autism spectrum disorder (ASD), a lifelong developmental disorder affecting approximately 1 per 100, has been identified as causing significant stress to all family members. Research in the UK since the introduction of austerity measures has identified that vulnerable individuals – such as families living with autism – are facing increased difficulties, due to funding and benefit cuts. However, austerity is not impacting equally across the UK and coastal disadvantage is an emerging research area.

Grant scheme

BA/Leverhulme Small
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SPACE AND WELLBEING Rural coastal areas are generally viewed as holiday destinations or areas of natural beauty, and indeed many families seek to relate to such areas in search of improved quality of life. However, this study has identified a more complicated and nuanced experience for families living with autism in rural coastal areas.

This project investigated the lives and experiences of families living with autism in rural, coastal areas of Cornwall and Norfolk. Twenty-two families were interviewed in early 2019, including young people on the autism spectrum, their siblings, mothers and fathers (some of whom were themselves also on the spectrum) and grandparents. The study has provided insights into families' experiences – both positive and negative – of living in rural coastal spaces.

POSITIVE AND NEGATIVE FACTORS Clear benefits were identified by most families, both in general and with specific regard to the needs of the family members on the autism spectrum. At the same time, a large number of negative factors were identified, such as accessing diagnosis, accessing services, conflict with services and service shortfall. These specific problems were worsened by poor local infrastructure and the impact of a decade of **AUSTERITY**.

This study has specifically increased our knowledge and understanding of the experience of families living with autism in rural coastal areas. The experience of such families has received little or no attention from researchers globally. While there has been some previous research investigating autism and disability within rural contexts outside the UK, the potential impact of coastal factors has been neglected. As such, it contributes to our understanding of those living 'on the edge' – both with regard to physical location and with regard to **SOCIETAL MARGINALISATION**.

This study was undertaken to address an identified shortfall in research to explore the lived experiences of families living with autism in rural coastal communities in England, to gain insights into family members' perceptions and attitudes, and to identify emerging themes and trends. A qualitative methodology was utilised to address the following **RESEARCH QUESTIONS**:

- 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 of living with autism in a rural coastal community during a period of austerity?

CORNWALL AND NORFOLK Using the Social Mobility Foundation and Government Statistical Service definitions of coastal and rural communities and taking account of the scope of the extant literature, two under-researched and comparable rural coastal areas of England were identified as research sites: Cornwall in the south-west and Norfolk in the east. Cornwall comprises one local authority: all rural areas within Cornwall were included in the recruitment for the study. Within Norfolk, two local authorities were included: Kings' Lynn/West Norfolk and North Norfolk.

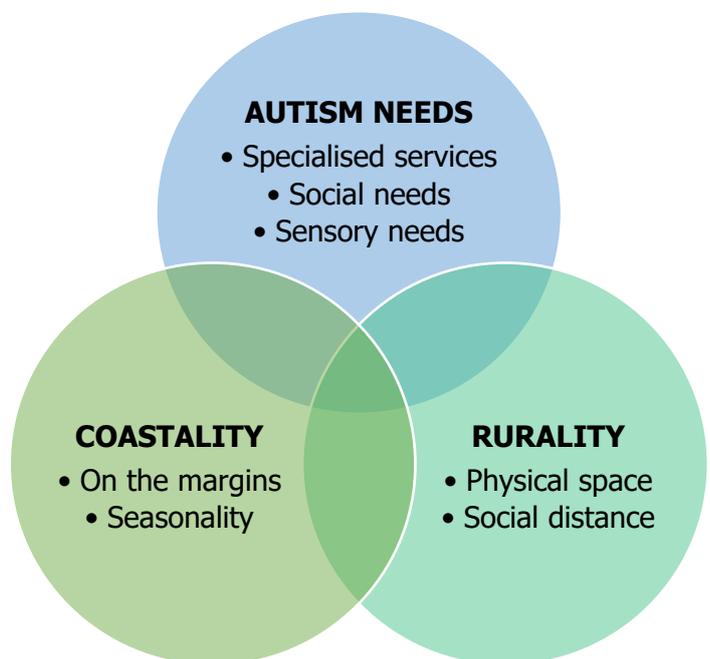
INTERVIEWS Three semi-structured interview schedules (for parents, siblings and children/young people with autism) were developed. Questions were open-ended, and interviewers used appropriate prompts/probes. Where children on the spectrum were interviewed, preliminary contact was made with families to identify any adaptations or supports required to facilitate participation. All tools were trialled and piloted with families within a different local authority before use in the field. Interviews in Cornwall were undertaken at the end of January 2019. Interviews in Norfolk were undertaken during February and March 2019.

PARTICIPANTS Interviews were carried out by the grant recipient and a co-researcher with mothers, fathers, siblings (as appropriate within the individual family context) and, where possible, the child/young person(s) with autism. Access to families was negotiated via local National Autistic Society groups: NAS Cornwall and NAS West Norfolk. Twenty-two families were recruited to the study in autumn 2018: nine from Cornwall (24 individuals) and thirteen from Norfolk (25 individuals) were recruited to the study in autumn 2018. In total, 35 semi-structured interviews were carried out with 49 participants. Participants comprised:

- young people on the spectrum, aged 9-22 (n=11)
- their neurotypical siblings, aged 5-15 (n=5)
- mothers, aged 25 and over (n=21, 4 of whom are on the autism spectrum)
- fathers (n=10, 2 of whom are on the autism spectrum)
- grandparents (n=2).

BENEFITS AND CHALLENGES A number of perceived benefits were identified as associated with living in a rural coastal space. These included the location, the sense of community and the sense of 'going back in time' as a positive experience. However, at the same time, perceived barriers and challenges were also identified: some of these were associated with negative aspects of the location, the experience of stigma and intersectionality in relation to autism and rural coastal spaces.

SPACE This research has focused on the intersecting impacts of rurality, coastality and disability to provide a novel and more nuanced understanding of such families' experiences. As such, it contributes to our understanding of those living 'on the edge' – both with regard to physical location and with regard to societal marginalisation. Families living with autism in coastal rural areas of England identified benefits such as opportunities for outdoor living, physical exercise and access to beaches and green spaces. The openness of the physical space is especially important given the sensory sensitivities associated with autism which may lead to anxiety or feelings of being overwhelmed in crowded urban environments. Many families made a conscious choice to move to a rural coastal area for these reasons. As well as the potential benefits to physical and mental health, rural coastal areas outside popular holiday/second-home destinations can offer opportunities for families to live in larger houses with gardens than they might elsewhere, which again provided them with space required due to the autism-specific needs of their family members.



“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...”

COMMUNITY Some families reported a positive sense of community in the small place where they lived. Reduced anonymity provided feelings of safety for their child with autism and where families felt accepted this reduced family stress and provided children with naturalistic opportunities for social learning. However, the rural coastal location also presented families with challenges. Physical isolation meant that families are far away from services which is particularly important in autism where there is an elevated need for professional support. Infrastructural issues, e.g. infrequent public transport and summer congestion impact significantly on characteristic autistic difficulties with transition and change. Moreover, the popularity of coastal areas as holiday destinations for UK citizens from large urban areas, as well as the agricultural activity associated with rural areas has led to an influx of British and foreign in-comers with a negative impact on the availability and affordability of housing for local residents and their young adult children. Social housing in particular was identified as an area of shortfall.

FORMAL SUPPORT SERVICES Families’ experience of formal support services – health, education and social care – were in general rather more negative than positive. Though individual teachers or doctors were often identified as supportive and as making a real difference, the main themes running through family narratives were of conflict (both to initially access services and/or with service providers), lack of understanding, stigma and exclusion. Barriers and challenges were both systemic (such as eligibility criteria) and individual (staff knowledge, skills and expertise); and again, locational factors were identified, relating to e.g. where schools were situated, high staff turnover.

“We had a letter over the weekend advising us that the psychiatrist has left the service. So this will be the sixth psychiatrist in a year to have left CAMHS.”

“We had Social Workers that they kept changing – I think I’ve had four social workers in total and only met two of them, they kept swapping.”

HEALTH CARE	EDUCATION	SOCIAL SERVICES
<ul style="list-style-type: none"> • Difficulties engaging services, accessing the diagnostic process and post-diagnostic support • Lack of professionals • Reactive services • Out-of-date knowledge, lack of autism awareness • Lack of funding • High staff turnover 	<ul style="list-style-type: none"> • Exclusion • Negative impact of school on child • Lack of provision • Lack of skills and understanding • Conflict between parents and services • High staff turnover 	<ul style="list-style-type: none"> • Fear / stigma • Reactive rather proactive (seen as punishment rather than support) • Service shortfall – respite care, adult services • Shortage of staff • Eligibility criteria – “disability”/“high needs”/labels

Access to specialist services in sparsely populated rural areas is inevitably more difficult than in more populous urban areas, and this was a major issue for families in these rural coastal locations. However, concerns did not simply have to do with waiting times or frequency of appointments,

though these issues were problematic; and accessing diagnostic services was a particular area of difficulty. Staff skill, knowledge and expertise were found wanting, with families reporting a lack of autism awareness and 'up to date' knowledge. This in turn led to services failing to meet children and families' needs, often leading to conflict and exclusion. Services were described as reactive and understaffed, with high turnover and a significant shortfall was identified in areas such as short breaks (respite care), mental health and therapy services. 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 **DIFFICULTIES AND EXCLUSION**.

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

"The experience of having the EHCP done was pretty terrible. They came and did an interview with my wife when our son was there and then the plan they wrote was barely reflective of what he was like. It was extremely negative...there was nothing in there that focused on anything that he could do."

INFORMAL SUPPORT Shortfall in formal support was to an extent mitigated by informal support. For some participants in the study, extended family, charities, support groups and churches played an important role. Other families did not or could not access such sources of support and were effectively isolated within their community, hardly ever moving beyond the confines of their house. For such families there was a stark contrast between the ideal of living in a rural coastal space and their daily lived experience.

"Granny is really good. She will come and babysit so if H has got a hospital appointment, I don't have to take G because he just causes chaos and it's just awful."

"I don't get any support off my own family...every time I try to go up they constantly rant and shout at my son and, 'Oh, he's just being naughty', and 'Stop making those noises', and then he has a meltdown."

Informal support was provided by **FAMILIES**, and to a lesser extent, by friends and neighbours. While some families received a high level of support from their wider families, others received little or no support beyond the nuclear family. The gendered nature of childcare in autism was a key theme, with many mothers being sole parents and others identifying that they received little or no support from their husbands (some of whom were themselves autistic). Charities, disability groups and churches performed an important role for families, though locational factors such as poor infrastructure and transport services impacted on accessibility.

IMPACT OF AUSTERITY Finally, the impact of austerity was perceived as marked by respondents from both research sites. Provision across both formal and informal service providers was seen as deteriorating and shrinking. Schools, specialist services, clubs and support groups were closing; eligibility criteria were becoming more exclusionary; waiting times were increasing; and professionals' caseloads and 'patch' sizes were increasing. At the same time infrastructure in terms

of roads, transport and housing was also deteriorating. Lack of funding from local and central government was identified as the key factor underpinning these changes, which were having a negative impact on the families' experience in the present as well as being a major stressor with regard to their future plans and aspirations.

“I think it's getting worse. I definitely think access to services is getting worse. They are making it harder and harder for parents to access it.”

“Services are closing. So where do you take your children? When they are teenagers, youth groups are shutting down.”

A strong message coming through the research was of **DETERIORATION** over the past decade. This was at both a general level, with reduced employment opportunities, deteriorating roads, less access to social or affordable housing, bus services reducing; and with regard to formal and informal services, groups and provision. Services had shrunk back to major towns, which in some cases made them effectively inaccessible (e.g. travelling to Norwich from rural West Norfolk can take 3 hours in each direction via public transport).

IDYLLIC SPACE AND HARDSHIP This research has highlighted the specific difficulties faced by this population, which have not been identified within previous research, and which stand in stark contrast to typical narratives regarding such areas as rural idylls or of coastal beauty. Conflicting and contrasting narratives run side by side in these spaces.

FUTURE DIRECTIONS

- Developing further projects in Cornwall and West Norfolk collaborating with the National Autistic Society.
- Collaborating with the Royal Geographical Society's Geographies of Children, Youth and Families Research Group on disseminating the research results.
- Investigating the experience of families living with autism and other disabilities within island communities.
- Evaluating potential benefits of providing online support to overcome some of the identified barriers of living with autism in rural coastal areas.
- Exploring experience of autism outside England in countries with significant rural coastal areas.

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