

Article

“There Isn’t Really Anything around Here . . . ”: Autism, Education and the Experience of Families Living in Rural Coastal England

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Abstract: Autism affects over 2% of the school population in England. Education has proven to be an effective intervention strategy that improves the quality of life of children with autism and their families. However, governmental austerity policies have increased disadvantage in coastal areas of England with a detrimental impact on people with disabilities. This qualitative study explored the lives of families living with autism in rural coastal England. Mothers, fathers, grandparents and young people from 21 families living with autism in West Norfolk and Cornwall shared their experience through semi-structured interviews that were conducted in early 2019. Families identified positive and negative aspects of living in these areas, including barriers preventing access to and inclusion in education. Barriers were related to poor infrastructure, sparse specialised services (resulting in diagnostic delay and difficulties), limited autism awareness, lack of trained professionals, and the impact of austerity across health, social care and education. Families’ struggles are amplified by the intersectionality of (a) autism-specific needs, (b) physical distance and small-community life related to rurality and (c) the seasonal and peripheral nature of coastal life. Access to education for children with autism in rural coastal areas of England could be improved by acknowledging and addressing the intersecting factors intensifying their marginalisation.

Keywords: autism; marginalisation; rural coastal areas; inclusion

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1. Introduction

Autism is a lifelong developmental disorder with a prevalence of 2.25% within the school population in England [1]. Research has identified that living with autism can place all family members under significant levels of stress [2–4]. The characteristic difficulties of autism can present families with many challenges and stressors. These may affect all aspects of family life, education, work and social inclusion and can lead to experience of stigma and social isolation [5,6]. Families’ experiences are subject to a range of variables that can variously act as mediators and moderators. These include housing [7], family finances/employment status [8,9], relationships with schools [10] and the availability of formal and/or informal support [11].

The financial crash of 2008 and the election of the UK coalition government in 2010 led to a period of austerity which continues to this day. Wages have fallen in real terms, while welfare benefits and public spending at central and local governmental levels have been cut. Statutory services are under increasing pressure, while third-sector organisations, particularly those working with vulnerable children such as those with autism, have experienced significant funding reductions which have led to staffing and service cuts [12]. Cuts and raised thresholds have resulted in reduced access to health, educational and social care support; diagnostic assessments failing to be carried out within required timescales and one-third of families with disabled children (including autism) reporting that they are worse off as a result of benefit changes, with 90% experiencing anxiety and stress [13].

Austerity has not impacted equally across the UK, and disparities exist regarding access to services and support. It is usual to think of the 'North–South' divide [14] or to contrast leafy suburbs with disadvantaged inner-city communities [15]. Less consideration, however, has historically been given to coastal disadvantage. Nonetheless, coastal communities (local authorities with coastal borders) face greater hardships than inland areas, with higher economic and social deprivation, low pay, elevated unemployment and health issues [16]. Moreover, the gap between coastal and non-coastal areas is widening. Problems of achievement, educational outcomes and isolation have been identified within coastal schools [17,18], while large populations of older people in coastal areas place pressure on social care and health services [19].

Research in the UK regarding coastal communities has focused mainly on struggling towns experiencing high deprivation [20,21] or the south east, where EU migrant numbers are high [22]. Although indicators of child health are more positive in less urbanized coastal areas [23] and research has identified the positive impact of coastal environments on health and wellbeing [24], the experience of those living with disability in such communities has not been identified. Furthermore, while research from Australia, Canada and the USA has explored the experiences of families living with autism in rural areas, identifying significant challenges regarding the availability of diagnostic, educational and support services [25–27], information about families living in rural communities in England—defined as those with fewer than 10,000 inhabitants [28]—is extremely limited.

2. Methods

This study was undertaken to begin to address this identified shortfall in research by seeking to give voice to the experiences of families living with autism in predominantly rural coastal England. A qualitative methodology was utilised to explore what life was like for families living with autism in rural coastal areas of England; what the challenges, barriers and benefits of these locations were; and what was their experience of informal and formal support. In this paper, we focus particularly upon the experiences of families with respect to their daily lives and their interaction with education services.

Using the Social Market Foundation [16] and Government Statistical Service [28] definitions of coastal and rural communities and taking account of the scope of the extant literature, two comparable and predominantly 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: participants were recruited from across the county. Within Norfolk, participants were recruited from two coastal local authorities: King's Lynn/West Norfolk and North Norfolk.

2.1. Research Tools

Three semi-structured interview schedules (for parents/carers, siblings and children/young people with autism) were developed. Questions were open-ended and interviewers used appropriate prompts/probes. All tools were trialled and piloted within a different local authority before use within the research population.

2.2. Sample

Interviews were carried out by the authors with mothers, fathers, siblings (as appropriate within the individual family context), and, where possible, the child/young person(s) with autism themselves. Access to families was negotiated via local National Autistic Society groups: NAS Cornwall and NAS West Norfolk. Twenty-one families were recruited to the study in autumn 2018: eight from Cornwall (23 individuals) and thirteen from Norfolk (25 individuals). In total, 34 semi-structured interviews were carried out with 48 participants. One father in Norfolk identified as White Gypsy; the remainder identified as White British. Further information is shown in Table 1. Participants comprised the following:

- Eleven young people on the spectrum—aged 9–22 years;
- Five typically developing siblings—aged 5–15 years;
- Twenty-one mothers—four of whom were on the autism spectrum;
- Nine fathers—two of whom were on the autism spectrum;
- Two grandparents with carer responsibilities.

Table 1. Demographic information regarding families.

Family ID	Settlement	Family Composition	Family Members Interviewed
Cornwall			
C1	Coastal, pop. c. 16,000	Mother, father, 12-year-old brother, 9-year-old male with Autism Spectrum Disorder (ASD)/Pathological Demand Avoidance Syndrome (PDA)	Mother (telephone interview)
C2	Inland, pop. c. 350	Mother, father, 19-year-old male twins with ASD	All family members (telephone interview)
C3	Inland, pop. <100	Mother with Asperger Syndrome (AS), 12-year-old male with ASD/Tourette's Syndrome, 8-year-old brother	Mother
C4	Inland, pop. <4000	Mother, father, 5-year-old male and 2-year-old male (both undergoing assessment for ASD), 7-month-old female	Mother and father
C5	Coastal, pop. >20,000	Mother, father, 9-year-old female with ASD, 8-year-old brother, 5-year-old sister	All family members
C6	Coastal, pop. <8500	Mother, father, 14-year-old male twins with ASD, 12-year-old brother	All family members
C7	Coastal, pop. <2500	Mother, mother's partner, maternal grandmother and grandfather, 7-year-old male with ASD	All adults
C8	Coastal, pop. >20,000	Mother with AS, 15-year-old male on diagnostic pathway	All family members
Norfolk			
N1	Coastal, pop. <800	Mother, father, 14-year-old brother, 11-year-old male on diagnostic pathway	Mother, brother
N2	Inland, pop. <700	Mother, father with AS and Attention Deficit/Hyperactivity Disorder (ADHD), 12-year-old male with ASD/ADHD, 10-year-old male with ASD/PDA	Mother
N3	Inland, pop. 1500	Mother, 10-year-old sister, 8-year-old male with ASD, 5-year-old twin sisters with physical disabilities	Mother, 10-year-old sister
N4	Inland, pop. <1500	Mother, father, 8-year-old male with ASD, 4-year-old male with ASD	Father (telephone interview)
N5	Coastal, pop. c. 100	Mother with AS, father with AS, 19-year-old male with PDA, 16-year-old female with ASD, 15-year-old male with ASD/ADHD	Mother, father, 16-year-old and 15-year-old; + 19-year-old (written response)
N6	Inland, pop. <2500	Mother, 22-year-old male with ASD, 20-year-old male with ASD/Severe Learning Disabilities (SLD)	Mother, 22-year-old
N7	Inland, pop. <10,000	Mother with ASD, father with ASD, 5-year-old girl with ASD, 2-year-old sister	Mother, father
N8	Inland, pop. <10,000	Mother, father with AS, 10-year-old female with ASD/ADHD, 8-year-old male with ASD/Global Developmental Delay (GDD)	Mother
N9	Inland, pop. <2000	Mother, father, 19-year-old male with AS/ADHD, 15-year-old female with undiagnosed AS, 8-year-old male with GDD	Mother, father, 19-year-old and 15-year-old
N10	Inland, pop. >20,000	Mother, 10-yr-old male with ASD/SLD, 7-year-old brother	Mother
N11	Inland, pop. >20,000	Mother, father, 8-year-old female with ASD/SLD, 6-year-old brother	Mother
N12	Inland, pop. <5000	Mother, father, 9-year-old male with ASD/ADHD/SLD/physical disabilities, 5-year-old sister	Mother and father
N13	Coastal, pop. <100	Mother, 9-year-old male with ASD	Mother

More than three-quarters of families participating in the study lived in rural communities as defined by the UK government, i.e., settlements with a population below 10,000 [29]. Six families (29%) lived in settlements with a population of 1000 or fewer; seven (33%)

in settlements between 1001 and 5000; and three (14%) in settlements between 5001 and 10,000. The remaining five families lived in small seaside or market towns: one (5%) in a settlement between 10,001 and 20,000 and four (19%) in settlements of more than 20,000.

Where children on the autism spectrum were interviewed, preliminary contact was made with families to identify any adaptations or supports required to facilitate participation. One young man chose to provide written answers to interview questions rather than participate in a verbal interview. Seven Cornish families were interviewed during a six-day field trip undertaken at the end of January 2019. As a result of severe snowstorms on the final day of the field trip, it was impossible to reach the homes of the two families due to be interviewed that day. These final five interviews were carried out via telephone in February 2019. Twelve of the thirteen interviews with 12 Norfolk families were undertaken face-to-face during February and March 2019. The final interview—with a parent who had recently moved out of the area—was undertaken via telephone due to the distance involved.

2.3. Ethics

Ethical approval for the research was granted by the Research Ethics Committee of the University of Northampton—where both authors were employed at the time of the fieldwork—and the research was carried out in accordance with the British Educational Research Association's Ethical Guidelines for Education Research [30]. Informed consent was obtained from all adults and young people who participated in the study; parents of all young people also gave permission for their children's participation. Participants were aware that they could withdraw from the process at any time. All participants have been anonymised in this article, and direct quotes are selected to ensure that sources are not identifiable.

2.4. Analysis

Qualitative data were subjected to thematic content analysis [31], supported using NVivo software. Provisional codes, which were drawn from the aims and objectives, served as an initial template. Coding was iterative as further codes emerged during analysis. Segmentation and coding were undertaken by both researchers, with initial coding undertaken together and a sample of further transcripts multiply coded. Researchers audited samples of each other's coding for completeness and appropriateness. Codes were reviewed for overlap and redundancy and reduced into matrices to develop final themes.

2.5. Validation

Workshops were held in Cornwall and Norfolk in January 2020, at which the authors fed these findings back to audiences of families, professionals and local politicians in both locations. These workshops served both to validate the data and findings and to provide local stakeholders with the opportunity to discuss the research and its key messages.

3. Results and Discussion

Data analysis identified that families' experiences were shaped by the intersecting impacts of geographical factors—relating to living in rural areas and to coastality—and to the underpinning impact of autism upon family life. In this section, these factors are first presented separately before considering how their intersectionality amplifies the marginalisation experienced by these families. Direct quotes from family members are identified by the family identification number as in Table 1.

3.1. Benefits of Rural and Coastal Living

3.1.1. Rural Benefits

The belief that living in the countryside can provide a 'rural idyll' is both longstanding and pervasive [32]. Rural living is typically contrasted to the fast-paced 'urban jungle' and mythologised as offering a slower-paced and higher-quality lifestyle, set in a pastoral landscape and experienced within close-knit, supportive communities [33–35].

Such narratives regarding rural living were voiced by many interviewees, including both individuals who had chosen to move to rural coastal areas and those who had lived their whole lives there.

It's a more relaxed attitude down here, whereas up country it's always very busy and you are always working really hard. There is always something you want to be doing or somewhere you have to be. Down here, everything seems to be at a very slow pace. (C2: young autistic adult)

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. (C3: mother with AS)

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. (N2: mother)

Families identified aspects of rural living, which they felt were particularly beneficial regarding autism. The closeness of community life meant that the needs of their child with autism were acknowledged and accepted, providing a sense of security, while the low population density allowed physical space and opportunities for seclusion. The openness of the physical space is especially important for individuals with autism who might have specific sensory needs and might feel anxious or overwhelmed in crowded urban environments [36].

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. (C4: mother)

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 not lots of people getting in his way or distracting him or whatever, and I know where the safe places are. That's beneficial. (N4: mother)

3.1.2. Coastal Benefits

As with rural spaces, coastal areas are idealised in similar—though different—ways, with the idyll of the fields replaced by that of the beach and sea [37]. Research has identified positive associations between 'outdoor blue spaces' and mental health and wellbeing [38,39]. Wheeler et al. [40], by analysing English census data, suggest that good health is more prevalent closer to the coast and noted important opportunities for stress reduction and physical exercise. Coastal spaces can be conceptualised as 'therapeutic landscapes', providing benefits at physical and social—as well as at more abstract and symbolic—levels [24]. The positive impacts of living by the sea, particularly regarding addressing sensory sensitivities and anxiety in autism, and thus the need for physical and social space, were strongly identified in many interviews.

I like the open space; I know the boys do too. It's just nice that if they are close to meltdown you can just pile them in the car and chuck them down on a beach or go out to some woods and it's all easy access. So that's what we like here, that's why we live near the coast and then we have the access - we've got woods literally a mile one way and less than a mile I've got the sea. So if they're struggling it's great, or if I'm struggling, I'll just go for a walk, clear my head. (C3: mother with AS)

When things are getting 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. (N5: mother)

It's very quiet, there's not a lot of traffic. When I go into a city now, I can't handle the noise and all the people. I'm like, 'How do people live like this?' I'm so used to it being really quiet. (N8: mother)

There's surfing, fresh air . . . when I go up country, sometimes I can hardly breathe. (C8: 15-yr-old)

Similarly to rural spaces, the strong sense of community inherent in coastal settlements is also noted both in the literature [41] and by interviewees. Reduced anonymity provided them with feelings of safety and support regarding the child with autism.

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 . . . (N13: mother)

People say when you come to Cornwall it's like stepping back in time. It is. And it's more of a community feel here, which is a lot more beneficial. But I think the natural . . . 'healing' is the wrong word, but the natural therapeutic element of this place I think is the big difference. (C5: mother)

They all know I'm living with an autistic brother and they're quite supportive of that. At nights he'll go and play outside, shouting loudly even though I tell him not to. And they'll be angry, but they won't be that angry with him because they know he can't help it. (N1: brother)

3.2. Negative Factors Associated with Rural and Coastal Living Rural and Coastal Disadvantage in the Literature

Research regarding living in rural areas also identifies several characteristic disadvantages. Rural areas have more limited availability of services per capita, as well as generally lower socio-economic and educational levels [42]: regarding education in the UK, the attainment gap—the gap between disadvantaged pupils and their peers—is greatest in rural areas [43]. Antezena et al.'s 2017 review of studies from around the world identifies that families living with autism in rural areas face multiple challenges that can lead to more unfavourable outcomes for children and families alike. These include delays in screening and diagnosis, low autism awareness in the community in general and service providers and fewer services providing interventions and support [27].

Characteristic examples of coastal disadvantage are also discussed in the literature. The economies of many UK coastal areas were significantly impacted by the advent of cheap foreign travel and holidays in the 1970s. Many towns that had developed as holiday destinations lost much of their purpose and already highly seasonal local economies were affected by a permanent loss of business and jobs [20]. Coastal communities are among the lowest-ranked areas of the country with regard to health, education, employment and earnings, and the economic gap between coastal and non-coastal communities has grown in recent decades. Local job opportunities are limited and often low-skilled and poorly paid, making it difficult for school-leavers to 'get on' without moving away [16]. At the same time, house prices are often high in areas that attract second homeowners, retirees and holiday lettings. As well as being problematic for local people seeking accommodation, this can also cause problems regarding recruitment and retention in professions such as education, as housing may be priced beyond what, e.g., a newly qualified teacher moving into the area could afford [44]. Ovenden-Hope and Passy [44] further identify that challenges resulting from geographical remoteness, socioeconomic disadvantage and a lack of cultural diversity (as well as the lack of local cultural and higher education opportunities) can negatively impact such communities. Again, the impacts of these factors are to be found in the narratives of the families interviewed in this project.

3.3. Barriers to Educational and Social Inclusion

Interviewees' responses identified multiple barriers impacting everyday life and preventing access to and inclusion in education. These included the characteristic issues outlined above regarding rural and coastal disadvantage. Barriers existed at systemic and individual levels: analysis led to their being grouped within the following themes.

3.3.1. Infrastructural Issues

The physical isolation that is part of the appeal of rural and coastal areas can also mean that settlements are far away from services [45]. While this may be an issue for families in general, this can impact even more greatly upon families with children with autism, who may both need access to specialised services and also find accessing general services difficult because of the needs of their children. Infrastructural difficulties compound the problems faced by families in both regions. Public transport is limited and often inadequate.

Public transport is an issue. The entire system is very bizarre. There is very, very little and the public transport that is there only connects certain places: it takes you places you don't need to go. It's actually easier for me to go to Plymouth (in the neighbouring county) than to go somewhere else in my county. (C2: mother)

There are things I'd like to do, but because of where we live and difficulties with transport, like getting there . . . There's absolutely no youth groups in this village at all. The nearest one's about seven miles that way, or eleven miles that way, or fifteen miles that way. So it's just the transport. If we can't get the transport, we can't get anywhere. (N1: brother)

Difficulties resulting from poor public transport services were intensified by the characteristic sensitivities and intolerances of autism.

Transport is a huge issue for me, because public transport is literally hellish, but I have to rely on it. You can get a bus to King's Lynn or a train. If I need to go to Norwich, I have to get a train to Ely and then another to Norwich, which is a lot of stress for me. Am I going to get a seat or space for a pushchair? Will someone argue with me about putting the pushchair there? Will I get off at the right stop? It's very nerve-racking and very noisy. A lot of the time I will get on the train and there will be stuff on the floor, and someone eating a sandwich that smells really bad. It's too much, really, but I have no other choice. One time, me and the two girls were trying to go to Cambridge, but the train stopped at Ely and kicked us all off. There were no trains going to Cambridge and the time was passing and the platform was really crowded. I ended up having a meltdown on the platform. (N7: mother with AS)

Dependence upon inadequate public transport negatively impacted upon children's experience of education, while a lack of flexibility and understanding from service providers regarding these infrastructural issues could lead to increased anxiety and problems.

When he catches the bus, it means he's late for college, because there's only one bus an hour and the first bus to King's Lynn normally gets there for 8.45. His classes start at 8.45 and he's just getting off a bus. The college always do the register bang on 8.45, and by the time he's got in the classroom it's gone that. Therefore, he's classed as absent when he's not. He's late, but it can't be helped. He's now on his final warning for attendance. (N5: mother)

In addition to poor public transport, respondents spoke of the problems of small, slow roads that, in addition to being used by local farm traffic, became flooded by traffic during the holiday season between Easter and September. Travelling even a short distance at this time could become extremely time-consuming, presenting significant difficulties for individuals on the autism spectrum who had low tolerance for such delay.

If you get stuck behind a caravan and then a tractor, you don't get a lot done. (C2: mother)

In Cornwall, it might not be a great deal of miles between places, but the road network isn't the best. So ten miles could take you forty-five minutes, depending on the time of year. You'll double your travel time if not more, depending on where you are going. A nice sunny day, you'll sit in traffic. (C4: father)

3.3.2. Marginality

Part of the appeal of rural coastal areas is the romantic idea of 'living at the edge' [37]. The impact of this idea upon access to services for residents in such areas is identified above.

However, the experience of marginalisation is intensified for families who live not only in rural coastal areas but also in areas that are at the margins in terms of county boundaries and local authority areas. For many of these families, services within their own authorities were far distant. However, formal services located in their nearest towns—which they used for shopping and social activities—were mostly inaccessible to them because they were in different local authorities. This systemic inflexibility increased the pressures and stresses experienced by such families.

Our biggest issue being up here near Plymouth 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 down in Truro (50 miles away). There's just nothing up here. We are occasionally allowed to use Plymouth services . . . but there are some services that 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. (C1: mother)

We are out on a limb here. We are as far as you can get from Norwich. Because we're in West Norfolk, there is support but it is Norwich, Great Yarmouth and that way (55 to 70 miles away). 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. The border is literally the road that runs behind here. So, anything we do, we have to travel to . . . and that is a catch 22, because we can't really travel without support. There is very little in King's Lynn . . . and because my son has high-functioning autism, that precludes us from about 90% of what's there. Everything appropriate is based in Norwich. It is quite frustrating in that respect. (N3: mother)

3.3.3. Low Autism Awareness

A lack of diversity, regarding, e.g., race, sexuality and disability has been noted in research regarding rural and coastal communities in the UK [46,47]. Limited awareness of autism was reported consistently by parents, grandparents, siblings and individuals with autism alike. The general public was felt to have a narrow and often stereotypical attitude towards issues relating to disability and neurodiversity.

There's a definite lack of understanding of autism and other special needs. It's very much a case of unless it's visible, like a wheelchair, you don't have a problem, according to a lot of them. (C2: young autistic adult)

The 'invisible' nature of autism also led to the difficulties that individuals and families faced being misunderstood and misinterpreted and some families being stigmatised and made to feel unwelcome within their local communities.

Our old neighbours used to bang on the wall. If she was having one of her tempers, they used to bang on the wall at us. One of them even came charging round once and was like, 'We are going to report you to Social Services . . . ' because they thought we were abusing her. (C5: mother)

We had problems with a neighbour across the road. He said he was going to get me out. He made my life a living hell, like he'd sit in his car and he'd record what we were doing. (N13: mother)

The limited understanding of autism noted within the general public was also shared by many of the teachers and education specialists with whom children with autism and their families came into contact. Professionals' failure to understand the condition impacted parental confidence in the education system and services.

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!' (C2: mother)

Particular difficulties regarding professional understanding were reported when autism was not accompanied by an intellectual or language impairment, as the inconsistent cognitive profile typical of autism [48] seemed particularly problematic for professionals.

They thought she was very clever, and they didn't think that autistic people were clever. They were thinking if she was autistic, she wouldn't be talking and would be rocking in the corner and wouldn't be playing. (N7: mother with ASD)

Situations resulting from the characteristic autistic difficulties with social communication and interaction and the need for predictability were often misinterpreted, and this often resulted in parents being labelled as poor parents and blamed for their child's 'poor behaviour'. Even when parents who were themselves on the autism spectrum sought to explain the underlying reasons for their child's behaviour, professionals sometimes rejected their perspective.

I got into a lot of trouble with teachers because of a lack of understanding and me not understanding them, which was quite irritating. I spent a lot of time in internal exclusion because a teacher would make a rule for someone and then they would change it for me and I would argue, because I didn't see why it was changing. I got in a lot of trouble from not understanding situations to not reading people properly, so not realising when I was annoying someone. But rather than help me fix the problem, they just continued to punish you and think that will sort itself, which is not really helpful if you don't know what you are in trouble for. (C2: young autistic adult)

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.' (N7: mother with AS)

3.3.4. Delays and Difficulties Regarding Diagnosis

Accessing autism-specialist services or having the right to 'reasonable adjustments' [49] within mainstream educational and work settings are often dependent upon a confirmed diagnosis. However, the difficulties in accessing diagnostic services and in obtaining a diagnosis of autism are consistently identified in research regarding families living in rural areas worldwide [50,51], and lengthy delays and dead ends were commonly reported by interviewees.

It took six years—from age 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. (C3: mother)

He was on the pathway to being assessed, but still fifteen or eighteen months down the line, nobody had seen him; there was nothing happening, and things were becoming really bad at home. He was on full school refusal at this point; it was just dreadful. (N2: mother)

In order to expedite matters, some families sought to get their child assessed privately. However, this too could be problematic. Parents spoke of travelling to London or even further afield for the assessment. However, even when a diagnosis was made, this did not guarantee the provision of services. Parents in both areas spoke of their frustration in the cases where children were diagnosed with Pathological Demand Avoidance Syndrome (PDA) [52] as this diagnosis was not recognised in either area.

I brought up the idea of PDA very early on because I had done a huge amount of research myself and felt that it kind of fit the bill and it was very much, 'PDA doesn't exist; it's not a real thing.' (C1: mother)

I arranged to go private. We were seen in four or five weeks, and I was presented with a report a week or so later which said he has ASD/Pathological Demand Avoidance Syndrome. I took that back to the NHS to the paediatrician and said, 'Look, I've saved you money. You can take him off your pathway now; you don't need to put him through

it; I know things are so completely backlogged and he has a diagnosis now'. And they refused to agree that he had a diagnosis. They said, 'We don't recognise PDA, so he can't have that diagnosis.' (N2: mother)

Until a diagnosis was obtained and accepted, gaining access to appropriate support and services was identified as extremely difficult. This caused particular frustration for families given the importance and associated benefits attributed to early intervention in autism [53].

It does take many years . . . So, all those years of early intervention, you just couldn't get it. And that links into the fact that under this new Education, Health and Care Plan system, and the new funding system for schools, they wouldn't give children support unless they had a diagnosis. So, you've got this double whammy of nothing for several years of their lives . . . (N6: mother)

3.3.5. Lack of Appropriate Services

Even where an autism diagnosis had been obtained, families continued to face barriers to and problems regarding education. As identified above, funding for local councils had been reduced over the last decade, and these funding cuts have impacted upon the availability of services.

They've got no money and that's what you are told every time you go to a meeting with county. The first thing you are told is that there is no money. You feel guilty. You get this instant reaction of 'If we are going to end up spending this much on your son, then we don't have money available for other children'. It may sound awful but that's just not our problem. (C2: mother)

Specialist services were limited and located in population centres. For those living in rural areas, simply getting to and from school could be time-consuming and difficult. Moreover, these services were generally targeted at children who had a learning disability alongside their autism, and many parents of more able children on the spectrum were concerned about their suitability.

The special needs school they wanted to put him in wasn't very stimulating . . . They just group the children together and I don't think that now they can meet all the individual needs. It's really quite sad. And a lot of the children weren't mobile may be good for some children but not for our sons. But I was told there were no places at any other special school or unit in our area. The next nearest one would have been Redruth, which is nearly an hour drive away. (C4: mother)

Often these children had to cope as best they could within mainstream settings where there was limited support and limited understanding of their needs. This often led to fraught relationships between school and family, and the words 'fight' and 'struggle' were used by the majority of respondents to describe their experiences.

So it has been a case all along of me shouting very, very loudly and being constantly on the phone and complaining at every stage. And luckily having the level of knowledge to be able to make myself heard. But I equally know of a huge number of parents who don't have that. (C1: mother)

Difficulties regarding recruitment and retention of staff in rural coastal areas have been identified in the literature [44]. These issues were noted by families within both Cornwall and Norfolk, leading to increased waiting times and communication problems as well as negatively impacting the consistency needed by individuals on the autism spectrum.

Turnover here is quite ridiculous. And for someone like our son . . . he doesn't trust us, let alone anyone else, he has big issues with paranoia because his mental health difficulties are quite complex. So, he has huge issues with trust. And then when you walk into an appointment, it's a different person every time. (C2: mother)

CAMHS (Child and Adolescent Mental Health Services) sent a letter saying, 'We've spoken to the school and done the initial bit of his diagnosis'. So I thought we were getting

somewhere regarding diagnosis. But when I spoke to the school, they said they hadn't heard from them; CAMHS had got in contact with his old school. So I rang to speak to his caseworker before Christmas, but she never got back to me. In January they said she would ring me back. I called again last week, and they said, 'She's on annual leave and not returning to this post'. So I can't find out anything until he gets assigned a new case worker, which could be whenever . . . So, the timescale is just extending. But I can't really ring up and kick up because it's not really going to do anything is it? I'm just resigned to the fact that we have to wait now. (C7: mother)

Currently he's on his fifth headmaster and ninth deputy head . . . and every headmaster that comes in makes big changes. (N5: mother)

Specialist support—from educational psychologists or autism specialists—was limited and was based around population centres. Caseloads and waiting lists were large, as were the sizes of the professionals' 'patches', and again, problems regarding recruitment and retention meant that many children and families received only limited support.

Psychologists will go in if the schools request it, but there's a very long waiting list. They did try to bring somebody in to give her anger management support. They put her on a waiting list, and she was on the waiting list ten months and then left school. So they sent a letter—six months after she'd left school—to say that as she had now left school, they had taken her off the list. (N5: mother)

Exclusion from school was common, as was school refusal on the part of young people with autism; consequently, many children within families interviewed had spent significant periods of time out of education.

We've had trouble at school from where he was excluded from the age of four, after a day and a half in a mainstream school. He was out of school until he went to the special unit: he was there for about a year, and they reintegrated him back into school just before the summer. He went back in September and was there for a day and a half. Some kids threw his hat over the fence and everything went downhill. They called for us to pick him up; and so when he was aged 7, he was permanently excluded. (C7: mother)

When he was in Year 2 (7 years old) he went into full school refusal. They wouldn't put any support in place for him because they felt he didn't need any. I had to de-register him from school because they were saying they were going to take us to court and fine us if he didn't attend. We couldn't physically get him in; there was no way he would agree to going in. It was the way they were handling things; it was just so bad for him, he couldn't cope. That was three years ago. (N2: mother)

The impact of austerity policies upon services was clearly identified, particularly by older autistic individuals or those with older children, who could contrast what was currently and previously available.

The Council cut the funding . . . they cut all the short breaks, they closed down short break homes, cut all of our access to respite, cut everyone's packages . . .

There are all sorts of services that have been closed that people have been relying on and that have been going for years. (C4: mother and father)

There used to be different services, like there used to be outreach for children with behaviour and any learning difficulties, they've all gone. They've all been dissolved . . . And the school budgets are shrinking all the time. (N1: mother)

3.3.6. Underpinning Impacts of Autism

The characteristic differences and difficulties of autism—both in the core domains of social interaction/communication and restricted/repetitive behaviours and regarding sensory sensitivities [54]—underpinned the lived experiences of all the families within the study. These placed restrictions upon all aspects of social and educational inclusion, and negotiating daily life required adapting to accommodate these characteristics. Adaptations

existed on a continuum and ranged from the relatively minor—such as doing all shopping while the child with autism was at school—to the acceptance of much greater constraints.

If it's dark, we are not allowed the main light on. We have that light up there, which is a blue light; and she wants the candle lit, which is a red candle. No other lights are allowed on. That's nice in the winter! We bathe her at night-time, but I have to get in the bath with her. She will not get in the bath without me . . . And then my husband has to dry her with the lights off. We now have to turn the bathroom lights off, so I'm left in the dark in the bath while my husband dries her. Then she has to walk up and down the stairs several times and go back in and out of the rooms that she needs to. (N11: mother)

Families' ability to engage and interact within the rural coastal environment also existed within a continuum. As identified above, families identified many ways in which rural coastal spaces were beneficial to those with autism. For many, a significant challenge lay in the autistic need for sameness and predictability. Seasonal differences within popular holiday areas meant, for example, that access to beaches, or ecological factors such as noise, crowding and heat, changed throughout the year. As a result, families' abilities to engage with the environment could be limited.

It restricts a lot of the things. 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 they don'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 . . . (C4: mother)

If you just wrap him up and take him to the beach, he is happy to go in the winter. But it can be tricky in the summer because he doesn't deal well with sitting in traffic jams and crowds. You couldn't go to Hunstanton on a busy summer's day. I would just avoid things like that; I wouldn't take him on a hot day in the summer holidays. I would just stay in the garden. (N10: mother)

Some families were able to engage successfully with the rural coastal environment whilst adapting their expectations to the constraints imposed by autism.

It would be nice to go exploring more. Cornwall is stunning and it would be nice to explore the West, but it's just a little bit too far because he can't really manage that. You can plan events and you find that you get there, and he doesn't want to do it . . . and you can't make him. (C2: father)

However, for others, the impact of autism profoundly restricted their interaction with their surroundings. Families living within idyllic villages a few miles from the sea spoke of being effectively housebound due to factors such as their child's extreme social anxiety or the severity of their behavioural challenges.

He is too stressed out to go out of the house. He really refuses to. He won't even go for a walk with the dog or a bike ride or any fun things. He won't go out and play in the garden. He just won't leave the house. It's just so sad. He will sit on his X-Box, PC or iPad solidly for fifteen hours and get very, very cross and angry at it most of the time. So, it's not a nice place to be. It's not a quiet place to be. (N2: mother)

There are two workers who provide a few hours' support, but they refuse to take him out into the community. I have to be present in the house, and I have had to intervene a few times; so it's not a true break really. We can't go out. We don't do things as a family. The twins have never been to a soft play centre or anything. We can't travel in the car. There is no way that he will stay in the car: he doesn't mind travelling up the A47 at 70 miles an hour and opening the door to get out. (N3: mother)

4. Conclusions

This study has identified that families living with autism often seek to live—or choose to remain—in rural coastal areas in order to experience the benefits typically associated with such spaces and that many such families and autistic individuals are indeed able to en-

joy the characteristic advantages of rural and coastal living. However, equally characteristic disadvantages have been identified with regard to these areas, and these have impacted heavily upon the families in this study. Whilst the barriers and problems associated with rural living and coastal living are in many ways similar, the experience of families living in areas that are both rural and coastal is one of amplification and compounded difficulties. The problems facing families living with autism in rural areas relating to physical distance, infrastructure and small community living are increased by virtue of the seasonal, peripheral and often expensive nature of coastal living. The pressures resulting from a paucity of service provision are compounded when high housing costs restrict the recruitment of much-needed professionals.

Furthermore, the barriers facing families are further amplified and compounded by the intersectionality of these factors with the characteristic challenges associated with autism. For some, their experience of daily living and social and educational inclusion was a balance in which they acknowledged the trade-offs made and the need to tolerate the negatives in order to experience the associated positives.

We're equally blessed and cursed, because it's a nice way of life, but then when you want things to happen . . . (C4: father)

For others, however, the severity of the impact of a specific factor—the severity of the individual's autism, diagnostic delay and the inadequacy of services—could push families into a situation in which the impact of negative factors was so overwhelming that any positives associated with living in a rural coastal location were lost.

The experiences of these families stand in stark contrast to the typical narratives regarding such areas as rural idylls or of coastal beauty; conflicting and contrasting narratives run side by side in these spaces. The impact of intersecting marginalities, such as those discussed here, is an issue that requires acknowledgement and further activity from both service providers and researchers. It is vital that service providers—not only within education but also across health, social care and more other areas—acknowledge and seek to address the intersecting factors that serve to intensify the social and educational marginalisation experienced by families and young people with autism in rural coastal areas. Further research is also urgently required within this under-researched area and the knowledge base would benefit from the perspectives offered by implementing interdisciplinary collaboration, for example, by involving researchers from geographical as well as education and social science backgrounds. Such collaboration would provide opportunities to better understand and address the needs of those living with intersecting marginalities.

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