

# Sensory aspects of living with autism in rural coastal areas of England

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BEYOND AUTISM CONFERENCE  
20-21 JUNE 2023  
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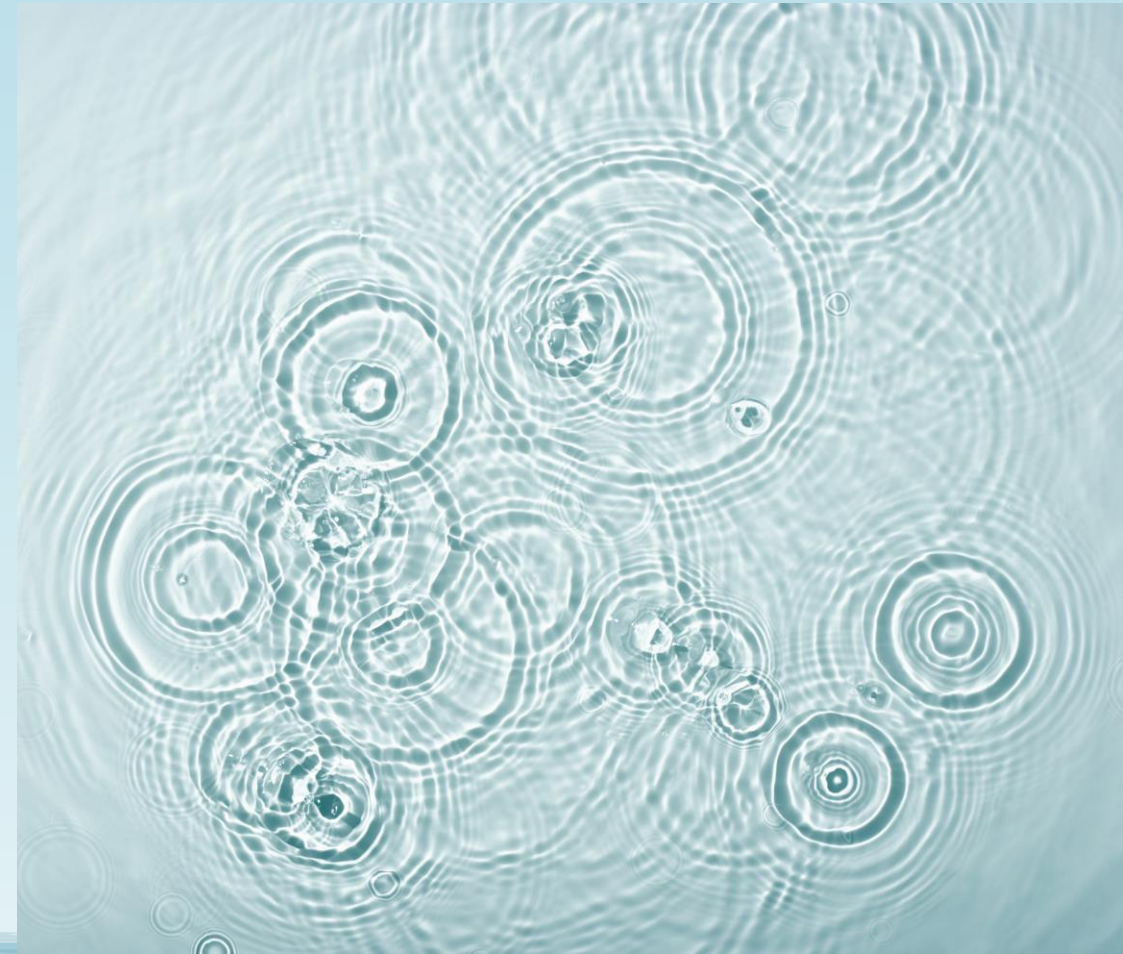
# Living with Autism in Rural Coastal Areas of England (LARCAE)

- Funded by British Academy/Leverhulme Trust (SRG\170268)
- 2018-2020
- Research undertaken by
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# Neurodiversity & bio-ecological perspective

- We are all different and we live in different ways (Walker, 2021)
- How we live might be influenced by
  - neurodivergent needs
  - physical and social environments
- Bio-psycho-social / bio-ecological perspective (Dwyer, 2022)



# How people live... with autism

- Can place all family members under **elevated levels of stress** (Tsermentseli & Kouklari, 2019; Engstrand *et al.*, 2020; Lawson *et al.*, 2020)
- Family experience is impacted by a range of factors including
  - Housing (Nagib & Williams, 2017)
  - Finances (Cidav *et al.*, 2012)
  - Relationships with schools/professionals (Preece & Howley, 2018)
  - Access to informal and formal support (Seymour *et al.*, 2020)

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**

# How people live... in coastal and rural areas

- 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
- Austerity does not impact UK equally – often think of North-South divide, but less consideration given to coastal disadvantage
- Coastal communities (local authorities with a coastal border) face **greater hardship than inland** areas (SMF, 2017): *“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)



# How people live... in a decade of austerity

- Financial crisis (2008) and election of coalition government in UK (2010) led to lengthy period of austerity measures from 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)
- 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

# 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



# 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**?





# Fieldwork

- **Range of settings**, from rural hamlets (pop <100) to market/seaside towns (over 75% from settlements with pop<1,000)
- 34 interviews (**33 hours** of recorded data) analysed via thematic analysis



# Semi-structured interviews

- **22 families (49 individuals)**
  - From Cornwall (n=9, 24 individuals)
  - From West and North Norfolk (n=13, 25 individuals)
- Young people on autism spectrum, aged 9-22 (n=11)
- Neurotypical siblings, aged 5-15 (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)



# Findings

## Rural living



Beautiful countryside,  
Slow pace, Small  
communities, Safe

Isolated, Prejudiced,  
Lack of diversity

## Coastal living



Open space

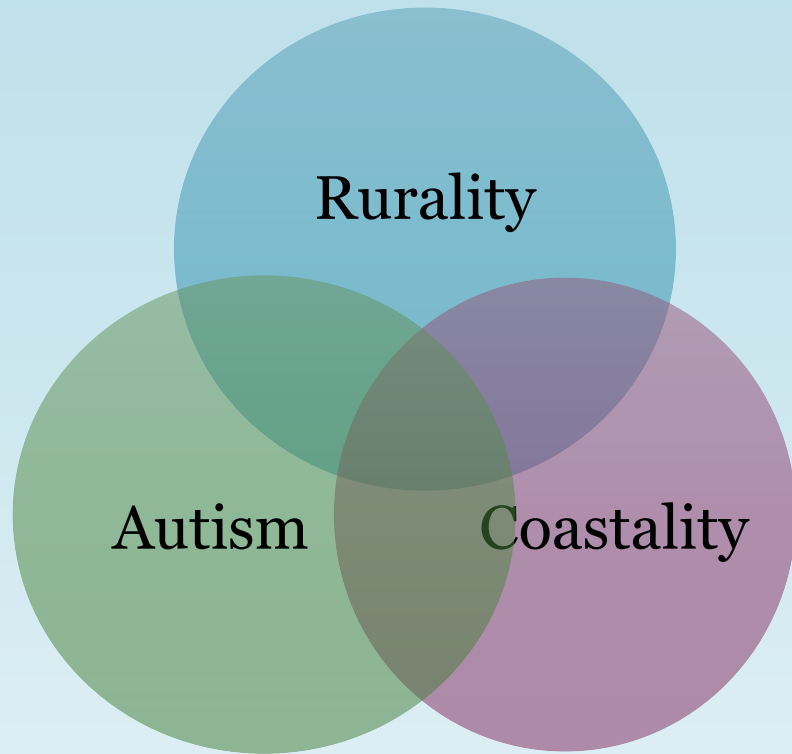
Bad traffic,  
infrastructure,  
Marginal

## Services





High turnover of staff,  
Low autism  
awareness, Specialist  
service access issues

# Intersecting factors of location and autism



Article

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

David Preece <sup>1</sup>  and Ivana Lessner Lištiaková <sup>2,\*</sup> 

Preece, D., & Lessner Lištiaková, I. (2021). “There Isn’t Really Anything around Here...”: Autism, Education and the Experience of Families Living in Rural Coastal England, *Education Sciences*, 11(8), 397. <https://doi.org/10.3390/educsci11080397>

# Sensory needs

Seeing (Visual)

Hearing (Auditory)

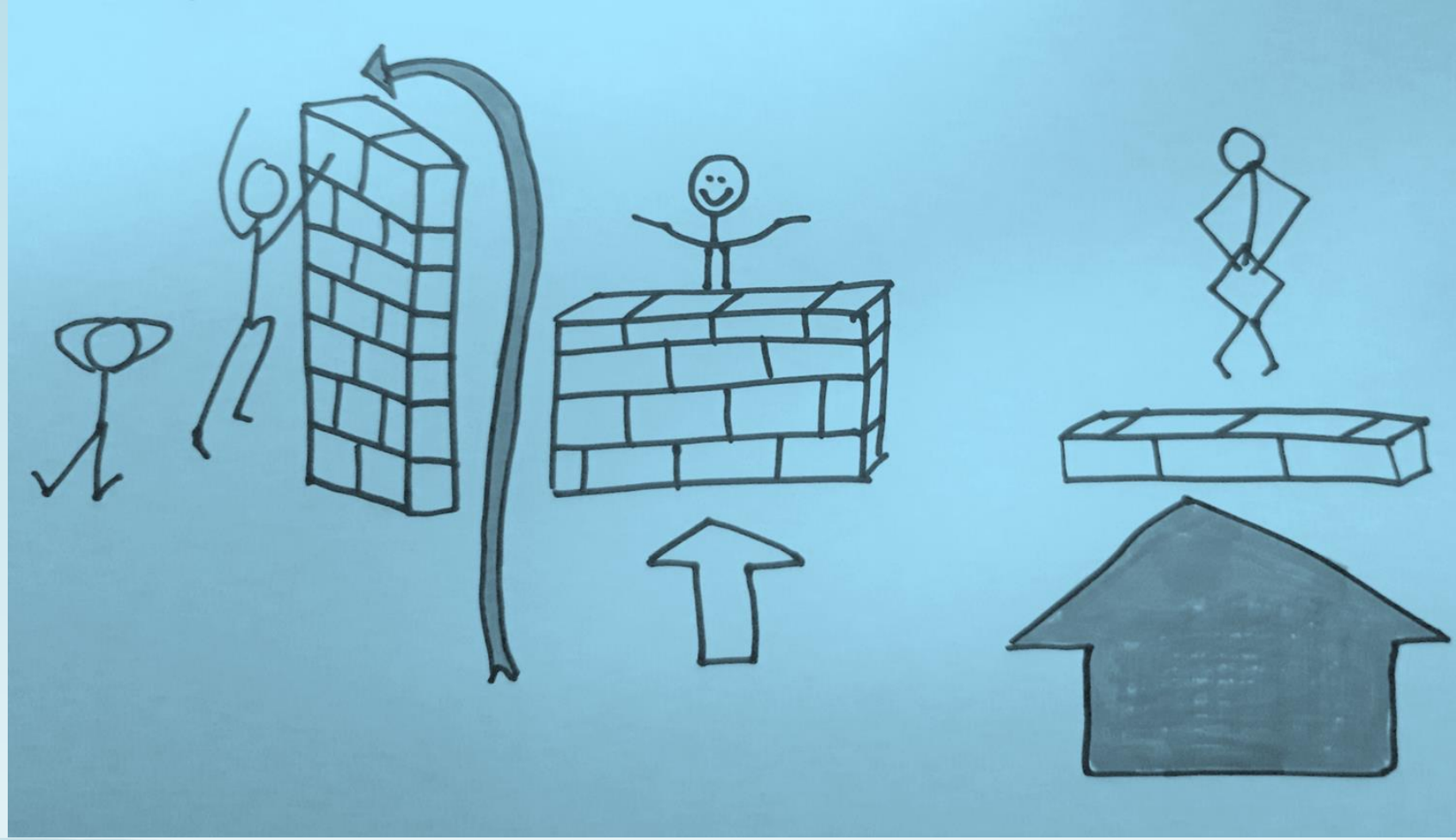
Smell (Olfactory)

Taste (Gustatory)

Touch (Tactile)

Proprioception (Body)

Vestibular (Balance)



# Responses to sensory stress

## A) Avoiding behaviour

- Vigilant at all times
- Leave the room, run away, do not want to participate
- Do not like certain people, activities or places, find excuses

## B) 'Fighting against it' behaviour

- Make your own noise
- Push others away

## C) Freeze behaviour

- Feel overwhelmed, meltdown

8% of neurotypically developing children experience sensory differences compared to 96% of children with autism (Crasta et al., 2020)



# Sensory needs affecting the everyday life of families living with autism

Families were highly aware of their (heightened) sensory needs

- sometimes able to address the needs
- sometimes left without support strategies
- Impact on levels of anxiety of parents and children
- Parents with autism => need for support as well

As soon as you say we need some specialist services, well all of a sudden the cost goes through the roof. They don't offer sensory integration as standard through the OT and for our children that's the biggest thing.

He's got sensory things. He doesn't really like wearing shoes, he doesn't like certain smells, smells make him very emotional. Actually, when he was little, he would cry at strong smells. Now he gets a bit angry. So, what happened was he just stopped getting dressed.

1) Physical location

## Benefits of rural coastal locations due to sensory qualities



3) Social geographies

2) Affordances of outdoor environments

How are sensory needs are being addressed by living in rural coastal locations?

4) Socio-economic aspects



# 1) Physical location

- Sensory aspects of geographical / physical location
- Sense of **open space, remoteness, being able to breathe, being safe**
- Addressing high sensitivity to auditory and tactile stimuli by avoiding crowded areas with a lot of traffic and human noise as well as the threat of accidental physical contact
- Providing strategies for lowering anxiety by the effects of nature

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.

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

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

- Outdoor environments suitable sensory activities
- Outdoor lifestyle
- Proprioceptive strategies through sports without needing to negotiate people

## 2) Affordances of outdoor environments

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.

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.

### 3) Social geographies

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.

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.

- Seasonal nature of coastal locations
- Not having people there in the winter provides an important 'sensory break'
- Access to facilities out of season


We're luckily got a really big garden so we spend a lot of time in the summer outside in the garden, climbing frame, trampoline, barbecues, that kind of stuff.

A bigger house, which has helped because we have got that extra space to get away.  
J can get very claustrophobic so it's nice we have lots of little rooms we can separate into.

- Socio-economic aspects supporting sensory needs
- Larger houses – more space indoors
  - Separate rooms for children
  - Sensory rooms
- Sensory materials
- Social support, understanding

#### 4) Socio-economic aspects

# Living with autism in rural coastal areas of England



Meeting  
(sensory)  
needs

Poor quality  
and access to  
services

# 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
- Continuum of experience dependent of **severity of autism, family coping style/structure**
- 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

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.

# Negatives of rural living

- More **limited availability of services** per capita, as well as lower socio-economic and educational levels (Hartley, 2004)
- Families living with autism facing **multiple challenges** associated with rurality (Antezena *et al.*, 2017):
  - Delays regarding diagnosis
  - Low autism awareness
  - Lack of appropriate services
- **Low autism awareness** within the community and also within service providers
- Despite this many professionals were **resistant to acknowledging parental expertise** and perspectives – even when parents were themselves autistic

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.

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!"

# Negatives of coastal living

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
- Seasonal living can cause **confusion and distress** to autistic individuals who have a need for sameness and consistency
- **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 turnover** of professional staff impacts on consistency, relationships and outcomes

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



# 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 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**

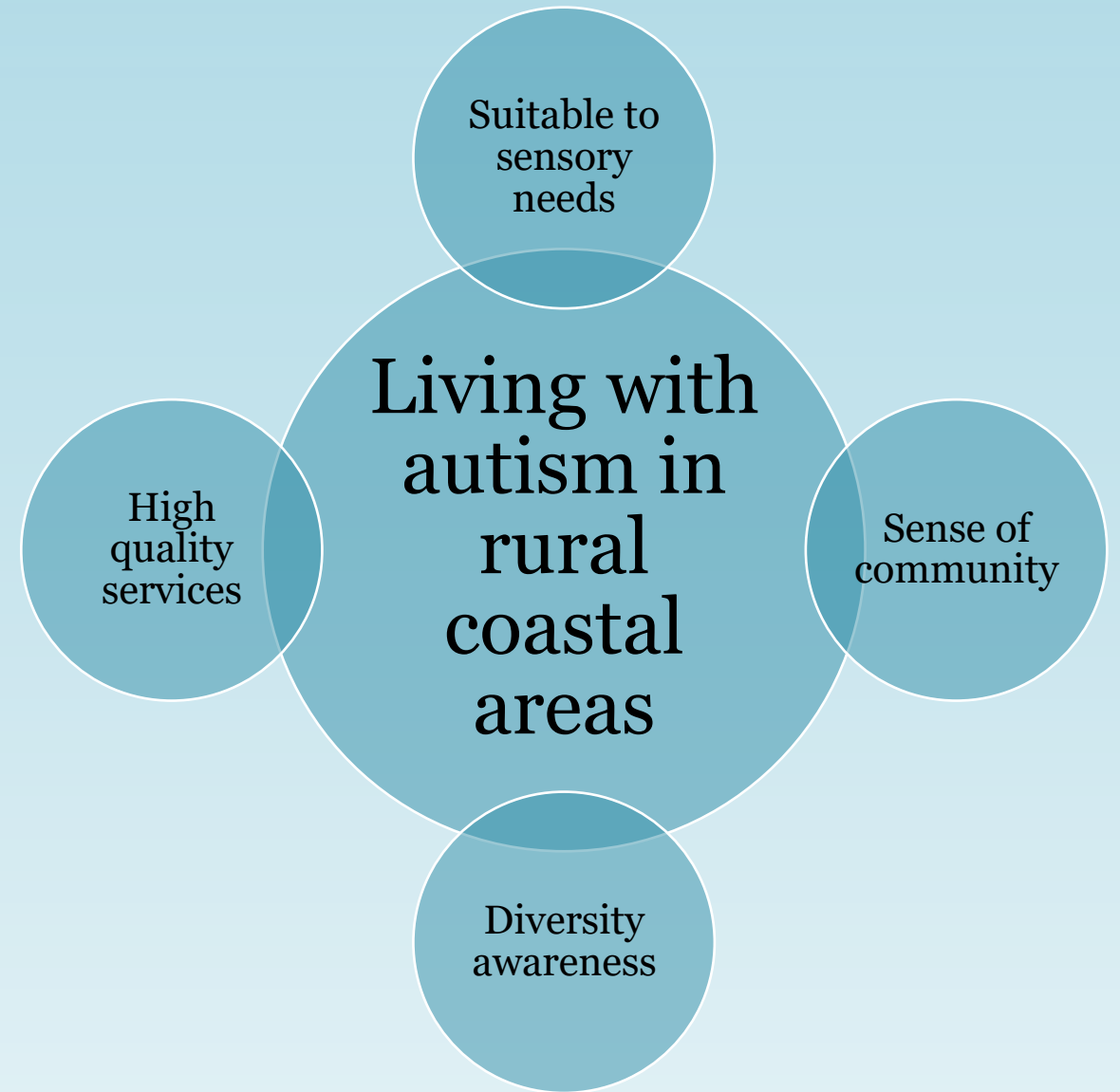
In London you could have 30 special needs' kids in a 1 mile radius. Here, you might have 1 kid 40 miles away from the next and it's the co-ordination and the costs involved.

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.

# Implications – So what?

## Implications for service provision in rural coastal communities

- Neurodiverse families make conscious decisions about moving to rural coastal areas because the lifestyle such areas offer suits their sensory needs.
- Resources and training of professionals need to be prioritised for rural coastal areas
- Services need to respond to local needs and must be co-created! Families to make decisions, it is not all about expert interventions – empowering families in strategies they apply and the ways they want to live



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# Thank you!

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