



Why Can't I Play?

A Regional Review of Leisure Inclusion for Children with Profound and Multiple Learning Disabilities across the North East and North Cumbria



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This review draws on research activity and family engagement led by Little SENDsations, whose work provided the foundation for the analysis. Inclusion North undertook the synthesis, evaluation and final report writing.

Foreword

This report explores the experiences of families of children and young people with profound and multiple learning disabilities across the North East and North Cumbria. It brings together findings from Local Offer audits, conversations with families and parent-led organisations and a systematic review of leisure and community activities across thirteen local authority areas.

The research highlights a mixed picture. There are pockets of excellent and inclusive practice that demonstrate what is possible when staff are trained, environments are accessible and activities are designed around individual needs. These examples illustrate the transformative impact that meaningful leisure can have on children and young people, as well as the value it brings to families and communities.

At the same time, the findings reveal clear and repeated barriers to leisure access. Families described challenges with travel, suitability, accessibility, information quality and the availability of activities that genuinely meet the needs of children with profound and multiple learning disabilities. The data in this report shows that only a small proportion of listed activities are appropriate for this group, and that many families rely on.

This report aims to support change. It offers a balanced and evidence-based picture, recognising the and the right of every child to enjoy ordinary and fulfilling leisure opportunities, no matter the strengths that exist while clearly identifying the areas where improvement is urgently needed. Above all, it centres the experiences of families complexity of their needs.

Hannah Tough, CEO, Inclusion North CIC

Haley Clark and Sam Ferguson, Founders, Little SENDsations

2. Executive Summary

This report examines leisure access for children and young people with a profound and multiple learning disability across the North East and Cumbria. It draws on Local Offer reviews, parent and carer interviews, and mapping of inclusive leisure activities across thirteen local authority areas.

Across the region, 324 leisure activities were listed on Local Offers. Of these, only 60 were suitable for children and young people with a profound and multiple learning disability, representing around 19% of all activities reviewed. This small proportion masks significant variation between areas: two had no suitable activities at all, while one, North Tyneside offered a higher cluster of potentially suitable provision. For most families, however, the realistic range of options locally amounted to only three to five activities.

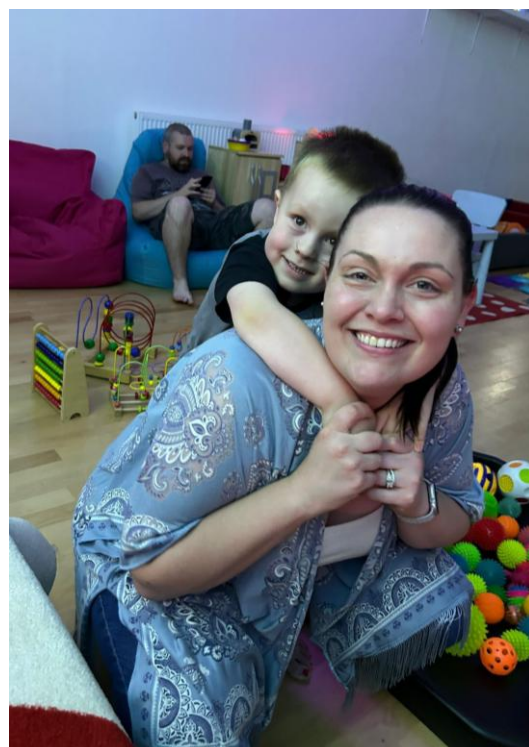
Local Offers were a consistent point of difficulty. None of the thirteen areas had a dedicated category or filter for profound and multiple learning disabilities. Instead, families had to search across multiple broad headings such as autism, learning difficulty, physical impairment, sensory impairment or mental health. Parents frequently described repeating the same searches, clicking through lengthy lists and still not knowing whether an activity would be safe or meaningful for their child.

SEND inspections across the region echo these findings, highlighting inconsistent experiences, variable coordination between agencies and a lack of explicit planning for children with profound and multiple learning disabilities. Many Local Offers also lacked clear accessibility information, age guidance or details about staff confidence and equipment, making it very difficult for families to plan outings safely and with dignity.



Parent interviews underline these challenges. Families spoke about long journeys, complex logistics and frequent disappointment when activities did not match their child's needs. Most had never used the Local Offer and described relying instead on Facebook groups, WhatsApp chats and word of mouth. In several cases, families discovered suitable activities or specialist equipment only through informal networks rather than through statutory information systems. Despite this, the research highlights strong examples of inclusive practice, particularly from specialist providers and parent-led organisations. Families spoke positively about sensory-based activities, adapted outdoor opportunities, inclusive cycling and trusted community organisations across the region. These examples demonstrate what is possible when environments are accessible, staff are trained and activities are designed with profound and multiple learning disabilities in mind.

The overall picture is one of potential combined with significant gaps. Children and young people with a profound and multiple learning disability can thrive when provision is inclusive, but too often, access depends on parental persistence, travel capacity or local knowledge rather than on a reliable and equitable system. The findings highlight clear opportunities for local authorities, Integrated Care Boards and providers to strengthen information, invest in inclusive provision and work in partnership with families to create genuinely accessible and joyful leisure experiences.



3. Why Leisure Matters for Children and Young People with Profound and Multiple Learning Disabilities

Children and young people with profound and multiple learning disabilities have the same right to leisure, play and meaningful occupation as any other child. This right is grounded in the United Nations Convention on the Rights of the Child, the Equality Act and the core principles of inclusion and participation. Leisure is not an optional extra. It is a fundamental part of what gives life structure, joy and belonging.

Families described how leisure supports their children’s development, wellbeing and identity. Even where communication is non-verbal, families spoke about how their children express enjoyment, anticipation and engagement during activities that meet their sensory and relational needs. Leisure was often described as a space where children could “just be themselves” in ways that were rarely possible in other settings.

What Leisure Means for Children with Profound and Multiple Learning Disabilities

For this group, leisure is not simply “recreation”.

It includes:



Leisure plays a developmental, therapeutic and relational role in children’s lives. Yet mainstream leisure provision is commonly underpinned by assumptions of individual choice, independence and mobility. This misalignment creates significant barriers for children with a profound and multiple learning disability, whose participation in leisure is relational, supported and highly context-specific.

3.1 Gloriously Ordinary Lives

The idea of a *gloriously ordinary life* is central to inclusive practice. Ordinary life includes exploring interests, spending time with peers, having fun, relaxing outdoors, enjoying music, experiencing nature and taking part in community life. For many families of children with profound and multiple learning disabilities, these ordinary activities require extraordinary levels of planning, adaptation and resilience.

Even so, the aspiration remains the same as for any other family. Parents told the research team that they are not asking for specialist or extraordinary experiences. They are simply asking for safe and accessible ways for their children to enjoy the world around them. "She absolutely loves being around other people. She thrives on social connection."

Where strong local practice has been identified

Parents highlighted a small number of organisations and community groups that offer inclusive or adapted leisure opportunities for children with a profound and multiple learning disability.



Organisation logos are included for descriptive purposes only, to illustrate examples of leisure provision identified through this review. Their inclusion does not imply endorsement, evaluation or partnership.

Parents spoke highly of:

- **MAIN (Tees Valley)** - consistent, sensory-aware support bridging autism and complex needs reasonably well
- **Timba Dash** - valued for physical accessibility and staff welcome
- **Wet Wheels** - praised for adapted water-based activities
- **Inclusive ice skating sessions (Tees Valley SNAPS sessions)** - one of few genuinely inclusive community sports offers
- **Alan Shearer Activity Centre** - repeatedly mentioned but not always kept up-to-date on Local Offers
- **Oasis hydrotherapy pool** - accessed by families across boundaries
- **Sunbeams Music Trust, Bendrigg Trust, Calvert Lakes** - often the only places where families felt they could "exhale"

"During Wet Wheels, he was shaking with happiness. Proper joyful."

"Everything had ramps and safety clips. Honestly, we were in tears seeing how happy he was."

"We visit one group regularly and they do great events, but without them, we wouldn't have done half the things we've done these last few years."

"Forest school has been brilliant. It's not just about nature, it's the freedom and space that makes such a difference."

"Timba Dash at Harrington Community Centre had ramps and support staff from both Timba and Lionesses, felt totally supported."

"At Roaring Rainforest, they really get it. It's not just a play space; it's a sensory environment built for children like ours. And they never judge."

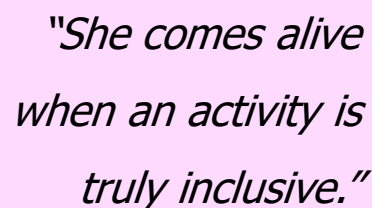
When opportunities are inclusive, families can experience the everyday joys that many take for granted. These moments reinforce the importance of ensuring that leisure provision is accessible, predictable and designed with diverse needs in mind.

3.2 Developmental and Emotional Benefits

Leisure has clear developmental benefits, even for children with highly complex needs.

Families described how good activities support:

- Sensory regulation
- Emotional expression
- Communication development
- Physical engagement
- Social connection
- Confidence and curiosity



"She comes alive when an activity is truly inclusive."

Music, water play, sensory experiences and outdoor activities were particularly valued. Parents noted improvements in mood, participation and wellbeing when their children engaged in activities that matched their sensory and communication profiles.

These benefits are not just for the child; they support family stability, reduce isolation and create opportunities for shared joy.

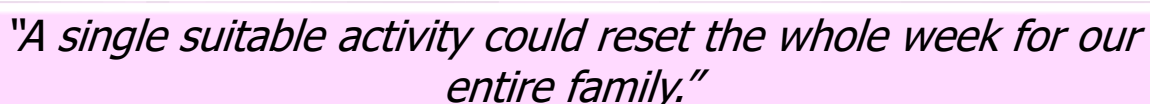
3.3 Whole Family Impact

Leisure access is a whole family issue. Outings often involve siblings, extended family members and multiple carers. When activities are not accessible, the impact is felt by the entire family.

Parents described the challenges of coordinating care, managing sensory overload and navigating environments that are not designed for children with profound and multiple learning disabilities.

Families also highlighted the emotional significance of having safe, reliable places to go:

- Opportunities for siblings to play together
- Shared experiences that strengthen relationships
- Relief from isolation during weekends and school holidays
- Time outdoors that benefits everyone's wellbeing



"A single suitable activity could reset the whole week for our entire family."

3.4 Inequalities and Exclusion

The research shows clear inequalities in who can access meaningful leisure. Families consistently described:

- Limited choice in their local area
- Long travel distances
- Lack of clear accessibility information
- Environments that are overwhelming or unsafe
- A gap between what children enjoy and what is available

Across the thirteen areas reviewed, 324 activities were listed on Local Offers, yet only 60 (19%) were suitable for children and young people with profound and multiple learning disabilities.

Several areas listed none at all. This variation creates postcode-driven inequalities where children's access to ordinary leisure depends heavily on where they live rather than what they need.

This shortfall reinforces broader patterns of exclusion. When children cannot access leisure, they miss out on opportunities that support their social and emotional development. Families are left navigating a system that does not match their needs.

3.5 The Transformational Role of Inclusive Leisure

Despite the challenges, there are clear examples of inclusive practice that families rely on and trust. Parents spoke highly of Bendrigg Trust, Calvert Lakes, Sunbeams Music Trust and a range of parent-led organisations. These providers demonstrate what is possible when staff are skilled, environments are designed around sensory and physical needs and activities are delivered with compassion and creativity.

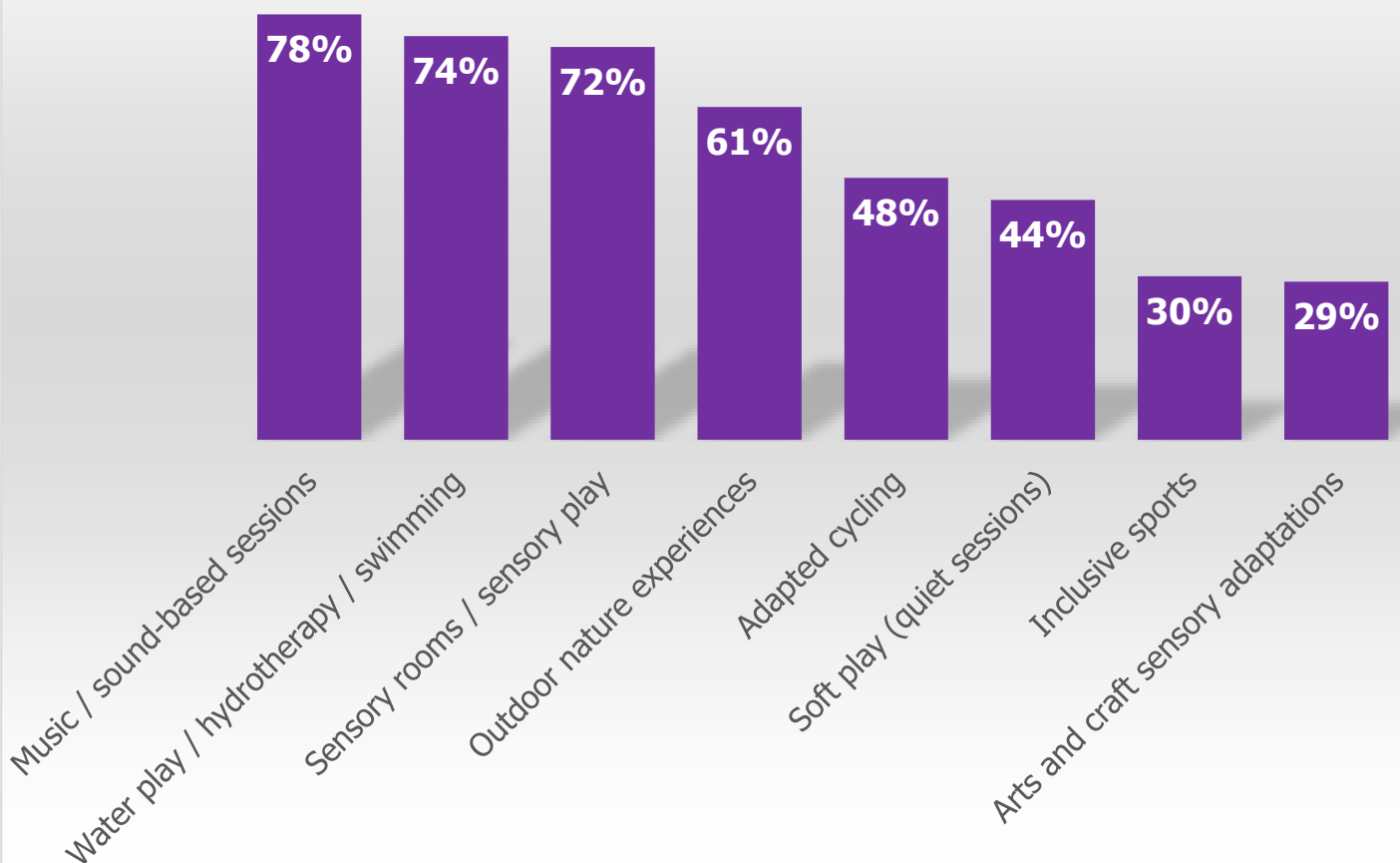


“It’s the only place she can go where we exhale.”

These examples show that inclusive leisure is achievable and can have a profound impact. They illustrate that when environments are designed for everyone, children flourish, families feel supported and communities become more welcoming.

Percentage of Parents Reporting Strong Engagement

■ Percentage of Parents Reporting Strong Engagement



Leisure is not peripheral. It is central to the right of every child to participate, explore, and enjoy life in ways that feel meaningful to them.

4. National and Regional Policy Context

Leisure access for children and young people with profound and multiple learning disabilities sits within a wider national and regional landscape of rights, guidance and policy intent. Although there is no single statutory duty that directly governs leisure access for this group, several frameworks make clear the expectation that children should be able to participate fully in community life.

4.1 National Rights and Legal Frameworks

The United Nations Convention on the Rights of the Child establishes a clear entitlement to leisure, play and participation in cultural and recreational life. Articles 23 and 31 set out the rights of children with disabilities to enjoy full and decent lives in conditions that promote dignity and social inclusion.

CQC reviews of community provision also highlight dignity in toileting, communication access and staff confidence as core components of inclusive practice.

The Equality Act requires reasonable adjustments to ensure that disabled children can access services on an equal basis with their peers. This applies to leisure centres, community venues and mainstream providers. However, adjustments vary widely in practice and are rarely tailored to the needs of children with profound and multiple learning disabilities.

The SEND Code of Practice also places responsibility on local authorities, schools and health partners to support participation and inclusion across education, health and community settings. While leisure is not a core statutory service, the Code emphasises the importance of promoting wellbeing and access to ordinary life experiences.

Despite these frameworks, the findings of this report show that families often encounter environments that are not accessible, staff who do not have confidence in supporting their child's needs and information that does not allow them to make informed choices.

4.2 National Commissioning and Provision Trends

Nationally, inclusive leisure provision is inconsistent. Research by organisations such as the Challenging Behaviour Foundation, Sense, NDTi and the PMLD Network has highlighted structural gaps in community access for people with complex needs.

These include:

- Limited sensory-friendly provision
- Gaps in adapted sports and outdoor activities
- Unclear accessibility information
- Insufficient staffing or specialist training
- Reliance on charities and parent-led groups

The lack of national guidance for inclusive leisure provision contributes to variation between areas. While some providers demonstrate excellent practice, others offer only minimal adaptations or assume that generic "disability-friendly" sessions will meet the needs of children with profoundly complex disabilities.

4.3 Regional Policy Landscape

Within the North East and Cumbria, several system leaders at local authority and Integrated Care Board level have highlighted inequalities in access to leisure and community life as part of their wider approach to prevention and wellbeing. However, **the region still lacks a coherent strategy for inclusive leisure.**

SEND inspections across the region consistently note fragmented information systems, variable confidence in mainstream settings and inconsistent experiences for families. These governance patterns mirror the findings of this research.

Findings from the Local Offer review reflect this inconsistency. Across the thirteen local authority areas:

- None had a dedicated category for profound and multiple learning disabilities
- Only four provided any accessibility information
- Fewer than half offered clear age guidance
- Several areas listed no suitable activities at all.

This reflects a wider pattern of fragmentation across leisure, voluntary sector provision and parent led initiatives.

4.4 Role of Parent-Led and Charitable Organisations

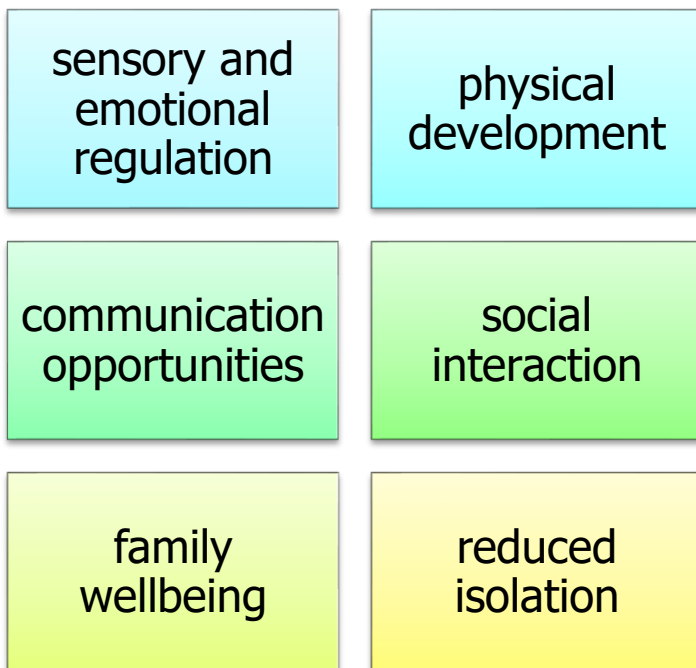
Parent led organisations play a particularly important role in ensuring that children with profound and multiple learning disabilities can access meaningful activities. Groups such as Little SENDsations provide inclusive play sessions, sensory experiences and community events that families trust.

Their work demonstrates how inclusive practice can flourish when services are designed with lived experience at the centre. The reliance on such organisations also highlights the gaps in statutory provision, particularly in areas where Local Offer listings are sparse or inaccessible.



4.5 Why Local Authorities and ICBs Should Prioritise Inclusive Leisure

Leisure is not simply a recreational issue. It intersects with health, social care, mental wellbeing and community inclusion. For children with profound and multiple learning disabilities, accessible leisure supports:



By investing in inclusive provision, local authorities and ICBs can contribute to improved outcomes in early intervention, family resilience, child development and community cohesion.

This aligns with the priorities of regional ICBs, which seek to reduce inequalities and support healthier, more connected communities.

5. Methodology

This research draws on a mixed-methods approach, combining qualitative and quantitative data to understand the landscape of leisure provision for children and young people with profound and multiple learning disabilities.

The methodology includes:

5.1 Local Offer Audit

A structured review was undertaken of the Local Offers across thirteen local authority areas in the North East and Cumbria. For each area, the research team examined:

- Usability
- Accessibility of information
- Filters and categories
- Number of activities listed
- Suitability of activities
- Age guidance
- Accessibility details
- identification of activities outside the Local Offer

In total, **324 activities were recorded.**

Only **60 were identified as suitable for children and young people with profound and multiple learning disabilities,** representing approximately **19% of all listings that had been filtered down to be potentially relevant.** No Local Authority had a dedicated category or filter for this group.

5.2 Parent and Carer Interviews

Parents and carers from across the region contributed to interviews as part of this research. Their comments represent a wide cross section of families of children with a profound and multiple learning disability. Quotes are drawn from dozens of individual parent voices across the North East and Cumbria.

These interviews followed a consistent question framework, exploring:

- Knowledge of local resources
- Activity types accessed
- What has been beneficial for their child
- Accessibility of facilities
- Suitability for profound and multiple learning disabilities
- Opportunities for social interaction
- Family involvement
- Frequency and reliability of activities
- Availability of support services
- Transport and travel issues
- The child's response to activities
- suggestions for improvement

Parents were able to speak freely, and contributions were anonymised. These narratives provide rich qualitative insight into the lived experience of accessing leisure across the region.

5.3 Review of Specialist and Inclusive Providers

The research also reviewed the work of organisations known for high levels of inclusive practice, including Bendrigg Trust, Calvert Lakes, Sunbeams Music Trust and parent led organisations across the region. This supported the identification of strengths, innovations and examples of what works well.

5.4 Data Synthesis and Thematic Analysis

Quantitative data from Local Offers was combined with qualitative thematic analysis of interview content. This allowed for the identification of: repeated patterns across local authority areas common challenges experienced by families positive examples of inclusive provision gaps and opportunities for improvement.

This mixed methods approach ensures that the report is grounded in both numerical evidence and lived experience.



6. Overview of the Region

This research covers thirteen local authority areas across the North East and Cumbria. These areas vary widely in size, geography and population, from large rural counties to small urban authorities.

Their Local Offers sit within different governance cultures, inspection histories and levels of strategic maturity. These systemic differences are reflected in the way leisure is designed, described and experienced by families of children with a profound and multiple learning disability.

This regional picture conceals substantial variation:

Two areas listed no suitable activities at all.

Ten areas had between three and five suitable activities, a level families described as *"barely a local offer at all"*.

One area, North Tyneside, had a larger cluster of potentially suitable activities, including sensory rooms, inclusive swimming and family support groups. Even here, parents stressed that suitability had to be deduced by cross-checking information, phoning providers or relying on what other parents had told them.

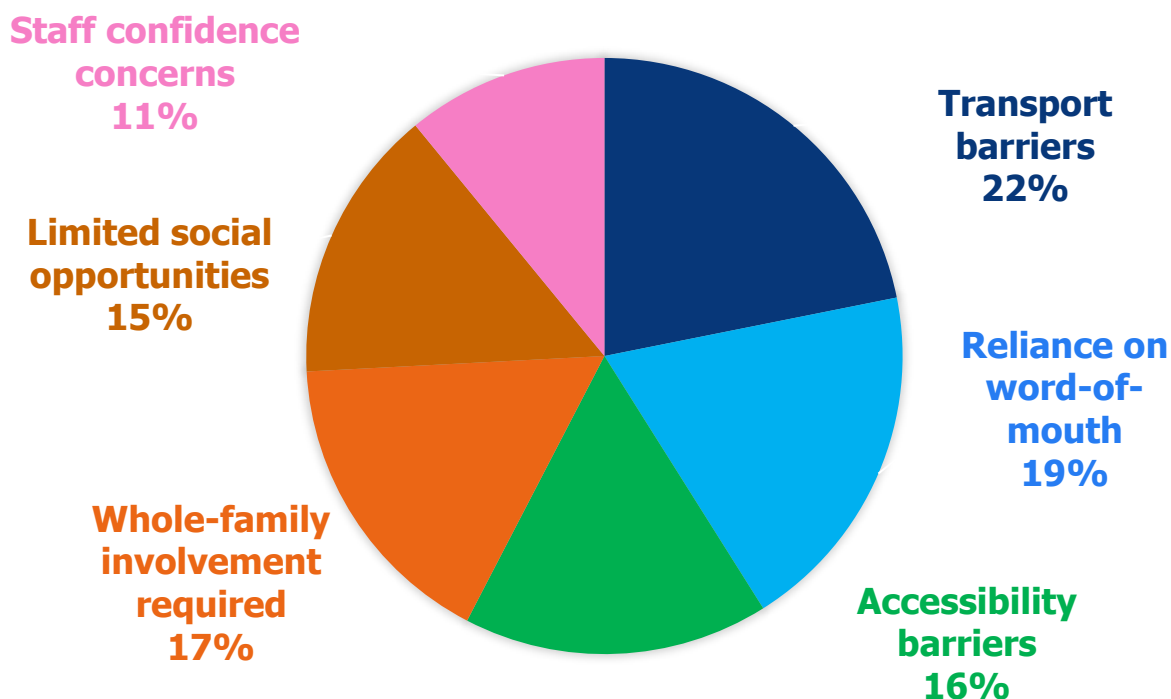
Parents frequently travelled across local authority boundaries to access activities they trusted. Travel times of **45 to 60 minutes** were typical for families in rural or semi-rural areas, with some travelling up to **18 miles** to reach hydrotherapy, sensory centres, or specialist charitable providers. This pattern of cross-border reliance is one of the strongest indicators that current local provision is insufficient.

SEND inspection reports provide further context. Authorities with stronger inspection findings, such as Hartlepool, where inspectors highlighted **strategic vision, co-production and cross-agency working** tended to have clearer Local Offer structures, even if the level of PMLD specific provision remained limited.

In contrast, areas with earlier CQC or SEND inspection findings pointing to **inconsistent experiences and increased family stress** often had the most fragmented or out-of-date Local Offers.

Despite these challenges, families consistently pointed to excellent practice within the voluntary and charitable sector. Organisations such as MAIN, Timba Dash, inclusive ice-skating programmes in Tees Valley and small parent-led groups were highly valued. These providers were often more trusted than statutory leisure centres yet were rarely clearly signposted through Local Offer systems.

THEMATICALLY ISSUES HIGHLIGHTED BY PARENTS AND CARERS



7. Local Offer Findings

The Local Offer audit provides a detailed view of how leisure information is currently structured, described and made available to families across the thirteen areas. It shows that many of the difficulties families described in interviews are built into the way systems are designed and maintained.

7.1 Structure, filters and the invisibility of profound and multiple learning disabilities

None of the Local Offers included a dedicated category or filter for "profound and multiple learning disability".

"The Local Offer is basically a Facebook page - that's not good enough."

Instead, activities were listed under broader headings such as autism, hearing impairment, visual impairment, learning difficulty, physical impairment and mental health. A child with a profound and multiple learning disability could legitimately sit under several of these categories at once.

Parents described scrolling through multiple filters, clicking in and out of activities, and still being unsure whether something would be safe, accessible or meaningful.

Searching directly for "PMLD" or "complex needs" often produced no results. One parent summed this up as "we are an afterthought". The absence of a specific category not only makes day to day searching harder, it also signals that this group has not been explicitly considered in the way local systems are planned and organised.

7.2 Volume, suitability and distribution of activities

Two areas had no suitable activities listed at all. Ten areas had between three and five suitable activities, a number so small that families described "running out of options" or feeling they had "done everything" locally.

Several Local Offers listed activities that, on the surface, might have been promising, but which lacked the level of detail families would need to make an informed decision. In some authorities, leisure listings were skewed towards early years, with a cluster of baby and toddler sensory sessions and very little explicitly offered for older children or teenagers.

In others, the only activities that might have been suitable were adult focused, raising questions about how children and young people with a profound and multiple learning disability

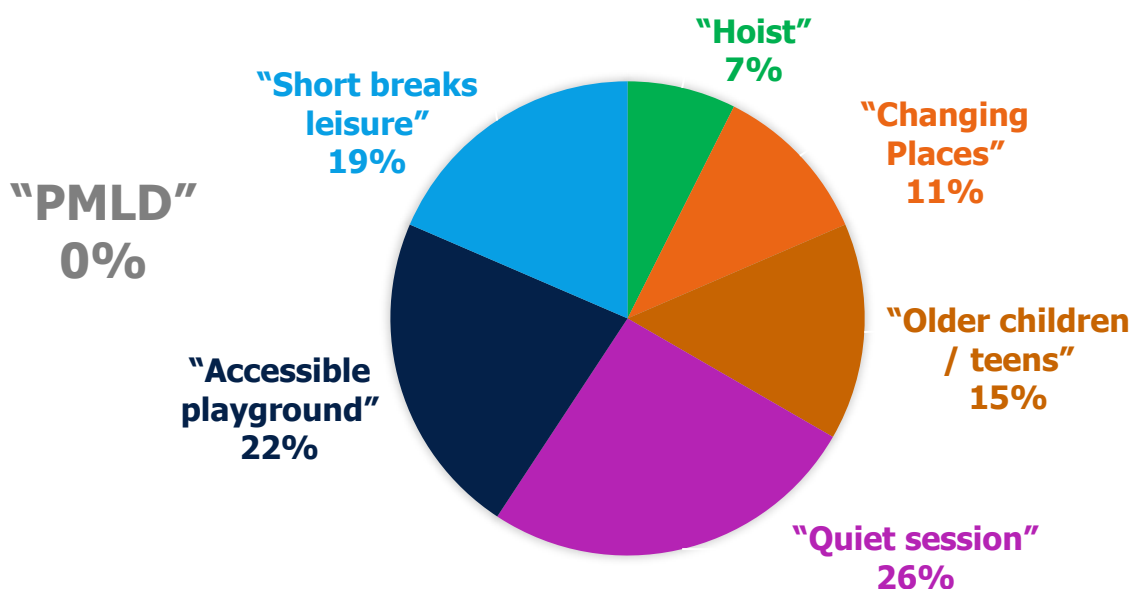
are expected to participate in community life as they grow older.

"We only know what another parent tells us."

7.3 Accessibility information and dignity

Accessibility information was one of the most consistent gaps across the region. Only four of the thirteen Local Offers provided meaningful detail about physical access, Changing Places toilets, hoists, parking, sensory environment or staff training. In the remaining areas, activities were often listed with a brief description and a venue name, but no indication of whether a wheelchair could be accommodated, whether equipment was available, or whether the space would be overwhelming.

SEARCH TERMS PARENTS USED IN LOCAL OFFER THAT YIELDED RESULTS



The absence of information about Changing Places facilities was particularly striking. Parent and carer interviews made it clear that toileting and personal care are central to whether an outing is even possible.

Families described older children who had long outgrown baby changing units, being changed on toilet floors, or deciding not to go out at all because of the indignity involved. These experiences sit uneasily alongside national expectations around dignity, CQC findings on respect and NICE guidance on meeting basic care needs.

In several cases, Local Offers did mention that a school pool or community facility could be used for hydrotherapy but did not specify who to contact or how to arrange access. Parents described this as "half a piece of information" that still left them to do the digging.

For some families, the emotional work of making multiple phone calls, facing bounced email addresses and trying to navigate unfamiliar systems was enough to deter them from pursuing an activity altogether.

7.4 Age guidance and life stage gaps

Age guidance in Local Offers was inconsistent and often unclear. In some areas, toddler sensory groups were listed as suitable for "all ages" without acknowledging that older children and teenagers with a profound and

multiple learning disability may have very different needs. In others, potentially suitable activities were only advertised for adults, leaving parents of younger children unsure whether they would be welcome.

Families repeatedly described a "cliff edge" between early years provision and later childhood.

Baby and toddler groups were relatively more common. Structured provision for older children and teenagers was patchy, hard to identify, or framed primarily around autism.

Parents said that family life became more restricted as their children grew, not because their desire to participate diminished, but because very little was designed with older children with complex needs in mind.

7.5 Information found outside the Local Offer

The audit also highlighted that Local Offers do not reflect the full landscape of provision. In several areas, more suitable activities were identified through Facebook, parent carer forums and community networks than through official listings.

For example, families in parts of Tees Valley and Hartlepool mentioned specialist sensory centres, inclusive ice skating, hydrotherapy pools, community sessions run by charities such as Down Syndrome North East, and local organisations offering genuinely inclusive

play and support. Many of these were either not listed at all, or only briefly mentioned, on the Local Offer.

This pattern was echoed in interviews. Parents talked about discovering accessible swings in local parks, specialist sporting opportunities, and small community groups, such as sensory provision or inclusive sports clubs, entirely through Facebook or word of mouth.

One parent described the Local Offer as **"basically just a Facebook page"**, meaning that it reproduced some of the same information without adding clarity, structure or reassurance.

The result is that families who are well connected, confident on social media and able to "dig" for information are more likely to find these opportunities. Those newer to the system, less confident, or not active online are more likely to miss out. In this way, the gaps in Local Offers risk reinforcing existing inequalities.

A broader theme across Local Offers is the assumption that families already know where to look. Parents frequently described receiving only 'half the information' – for example being told a school pool could be used for hydrotherapy without any contact details. Several said they only found accessible equipment or suitable venues through Facebook, WhatsApp or conversations with other parents.

This reliance on informal networks risks excluding families who are newer to the system, not online or without established support networks.

7.6 Variability, governance and improvement cultures

There were clear differences in the underlying culture and governance of Local Offers. Some areas showed signs of active maintenance, with relatively up to date listings, clearer contact information and evidence that feedback was being listened to. Others appeared static or poorly maintained, with outdated entries, broken links and bounced email addresses.

SEND inspection reports help to explain some of these differences. In areas where inspectors noted stronger strategic vision, cross agency coordination and co production with families, there were often more coherent Local Offers, even if profound and multiple learning disability specific provision was still limited. In areas where inspections highlighted weaker understanding of SEND, inconsistent experiences and increased family stress, the Local Offer tended to feel more confusing or fragmented.

This report does not aim to single out individual authorities for criticism. Rather, it seeks to show that the way Local Offers are structured is not neutral. Decisions about filters, categories, language, updating and co production all shape whether children with a profound and multiple learning disability are visible in the system, and whether their families can realistically use these

tools to plan ordinary, joyful lives.

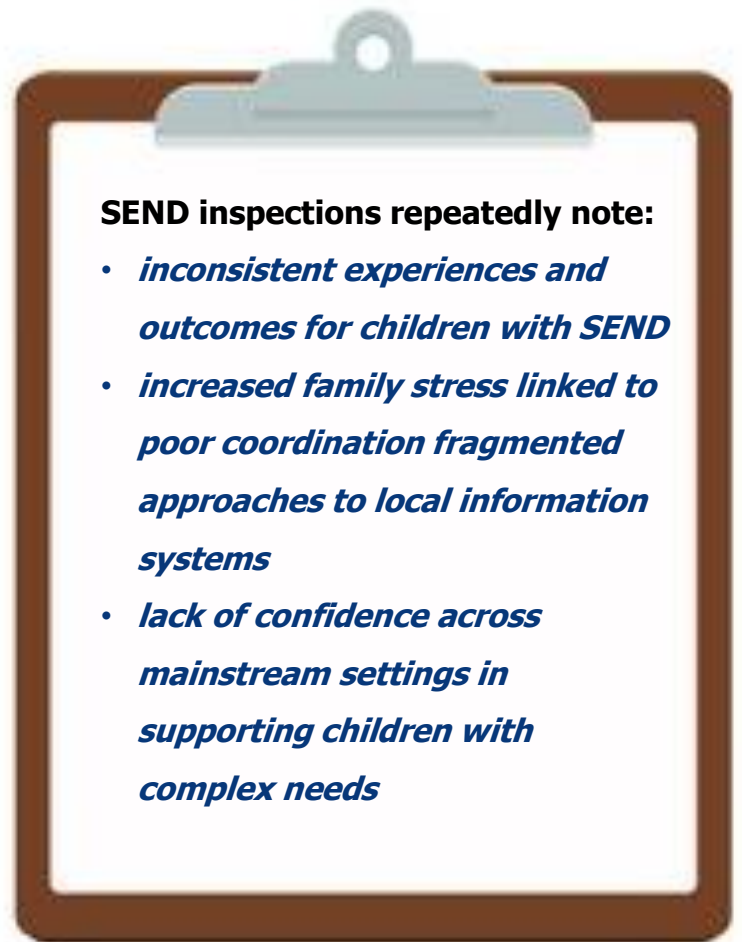
7.7 Governance, Inspection and System Culture

A broader theme across Local Offers is the assumption that families already know where to look. Parents repeatedly described receiving only “half the information” for example being told they could access a school hydrotherapy pool but without any contact details or guidance.

Many families said they only found accessible swings, sensory rooms or suitable activities by searching Facebook, WhatsApp or community forums rather than through the Local Offer itself. This reliance on informal networks risks excluding families who are newer to the system, not online or without established support networks.

It also reflects wider governance issues identified in SEND inspections, where inconsistent coordination and limited attention to profound and multiple learning disabilities result in fragmented, hard-to-navigate information.

Across the region, inspection findings and governance documentation highlight a pattern that mirrors the Local Offer audit: pockets of strong practice surrounded by inconsistent system design.



For example, recent inspection reports in several authorities reference:

- weak understanding of SEND across partners
- inconsistent access to universal and early help services
- outdated or poorly maintained information
- limited co production with parent carers

This governance picture helps explain the Local Offer findings. Where strategic vision, cross agency coordination and clear improvement cultures were noted, Local Offers tended to be more coherent, even if still lacking PMLD-specific content.

A consistent theme is that **PMLD is missing entirely from strategic framing**, which means it is also missing from:

- commissioning pathways
- Local Offer taxonomies
- accessibility standards
- staff training expectations
- monitoring frameworks

Parents are therefore navigating a system that was never intentionally designed with their children in mind.

This invisibility is not the result of individual failure but a structural oversight.

8. Parent and Carer Findings

Quotes in this section come from dozens of parents across different localities.

Parent and carer interviews provided a rich understanding of how families experience leisure across the North East and Cumbria.

The same set of questions was asked across all interviews, allowing clear thematic patterns to emerge. These themes cut across local authority boundaries and show both what works well and what is missing.

Coding of interview data allowed some of these patterns to be quantified.

Around two thirds of parents spoke about transport as a major barrier, including distance, cost, parking and the practicalities of travelling with equipment. Half spoke about the need for activities to involve the whole family. Just under half said that social opportunities for their child were limited or missing. One third raised concerns about staff confidence, and almost six in ten said they relied on Facebook or word of mouth rather than the Local Offer when looking for activities.

The sections below follow the interview framework and draw together the qualitative and quantitative findings.

8.1 Local resources

Parents were asked what resources they were aware of in their local area. Responses showed significant variation, but a consistent pattern emerged of families knowing only a small number of trusted organisations. These were often specialist charities, parent led groups, sensory providers or well-known inclusive centres. Many families named Bendrigg Trust, Sunbeams Music Trust, Calvert Lakes and local groups such as Little SENDsations, even when these were outside their immediate area.

In contrast, very few parents were able to identify suitable mainstream leisure options close to home. Several families had never used their Local Offer and did not consider it a useful resource for identifying activities.

Others had tried and given up. The phrase "we only know what another parent tells us" was common, reflecting a heavy reliance on informal networks rather than statutory information systems.

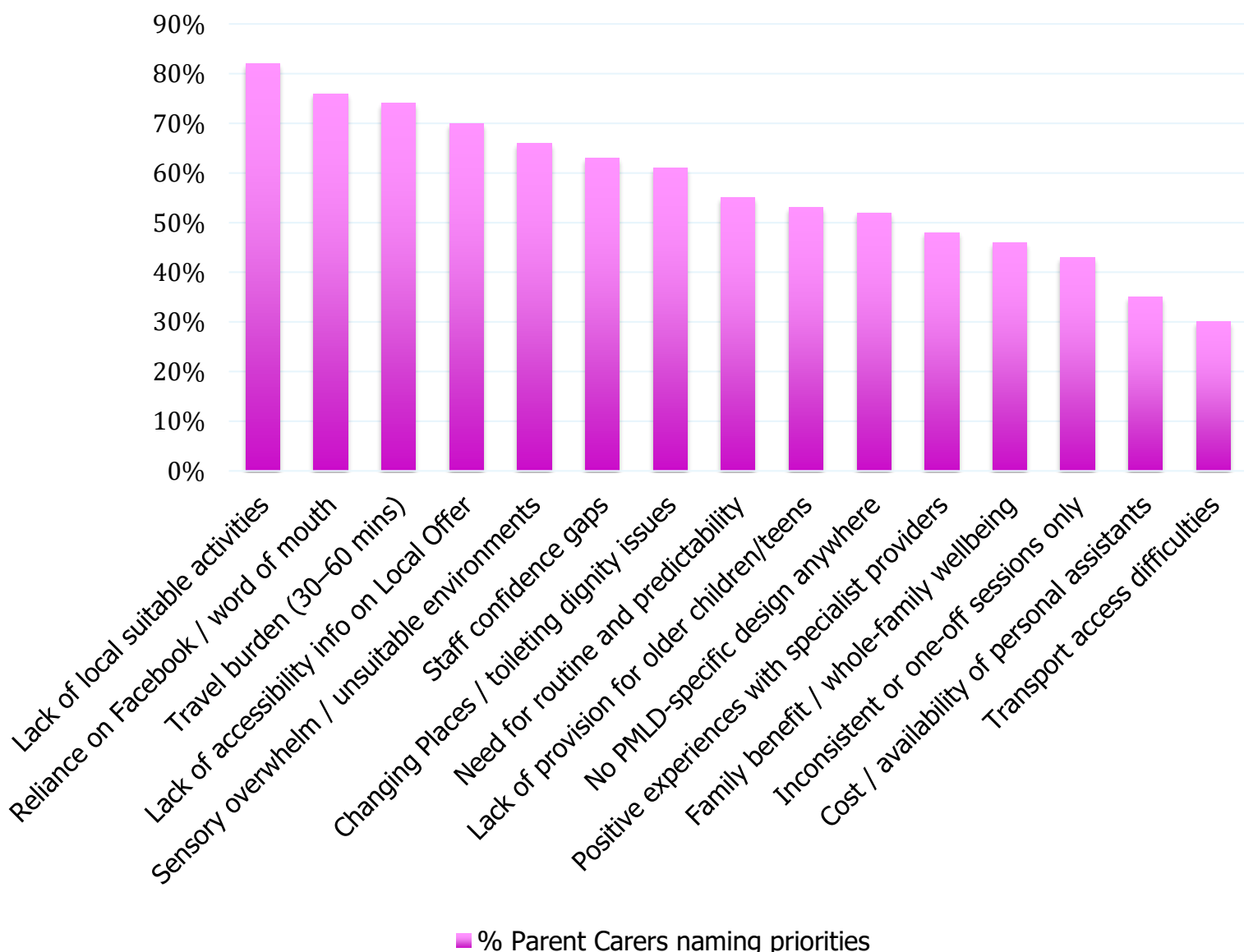
8.2 Types of leisure activities used

Families described a wide range of activities they tried to access, although many noted that options were limited or inconsistent. Commonly used activities included

swimming, sensory rooms, music sessions, adapted or quiet soft play, outdoor walks and nature spaces, hydrotherapy where this was available, adapted cycling and specialist inclusive sessions at established centres.

Parents showed considerable creativity in adapting leisure opportunities. Some created home-based sensory spaces or relied on regular drives to the coast, parks or quiet outdoor areas. These routines became important sources of stability and enjoyment, partly because structured local provision was so limited.

Parent Carer Priorities Raised (multiple responses allowed)



8.3 Activities that have been beneficial

Across interviews, the activities that worked best had consistent features: a calm or controllable sensory environment, familiar and trained staff, an accessible physical layout, small group sizes and predictable routines.

Music, water and outdoor experiences were mentioned repeatedly. Parents described children "coming alive" in settings such as Sunbeams, hydrotherapy pools or well-run sensory sessions.

These activities supported sensory regulation, emotional expression, communication and physical engagement. Parents also spoke about the impact on the wider family, with one activity often "resetting the week" or providing a rare opportunity for everyone to relax together.

8.4 Accessibility of activities

Accessibility was one of the strongest themes in interviews. Around half of parents described significant physical or sensory barriers in venues, as well as a lack of clear information in advance.

Families reported difficulties with ramps, narrow doorways, lifts, changing facilities, hoists and space for wheelchairs or medical equipment. Sensory barriers included noise, lighting, crowding and echoing environments. Many venues were simply not designed with children

with a profound and multiple learning disability in mind.

Only four out of thirteen Local Offers included any meaningful accessibility detail, so families were often left to find out through trial and error.

Several parents described getting as far as the car park and then turning back because it already felt too overwhelming or unsafe.

8.5 Suitability for children with a profound and multiple learning disability

When asked directly whether activities were suitable for children with a profound and multiple learning disability, families described a general lack of appropriate local options.

The Local Offer data shows that fewer than one in five listed activities were suitable for this group. Parents' accounts add important context. Many activities were badged as "SEND" or "autism friendly", but not designed for children with complex physical, sensory and health needs.

Some sessions relied heavily on verbal instruction or fast paced group activities. Others assumed a level of mobility or independence that was simply not realistic.

Parents said they often only knew whether something was truly suitable once they arrived. As one parent put it, "It might say 'suitable' online, but when you get there you can tell immediately that it is not."

8.6 How accommodating facilities are

Parents were asked whether facilities were accommodating. The majority said that this varied greatly and was often dependent on individual staff members.

Positive experiences were described where teams greeted families warmly, adapted sessions flexibly, communicated clearly, offered extra time or quieter spaces and took time to learn each child's signals and needs. In these settings, families felt welcomed and able to stay even when things were difficult.

Where staff were unsure, anxious or focused on rules rather than inclusion, families felt unwelcome or unsafe. Several parents said that even well intentioned staff could unintentionally exclude their child if they did not understand profound and multiple learning disability. This inconsistency was a strong deterrent to regular attendance.

8.7 Social opportunities

Social interaction is a key developmental need for children with a profound and multiple learning disability. Parents described their children thriving on being around others but also highlighted how limited social opportunities could be in practice.

Many activities were either too busy and overwhelming, or too limited in scope to provide meaningful interaction.

Mixed age groups could be challenging where the environment was not carefully managed. Opportunities to meet peers with similar needs were rare.

Where social opportunities did work well, they were often in specialist or parent led settings, with small groups, predictable routines and staff who facilitated interaction gently and creatively.

8.8 Family involvement

Families were asked whether leisure activities involved the whole family. Most said they attended as a family where possible, but this required significant planning and energy.

Common challenges included the need for two adults to support safely, balancing the needs of siblings, managing behaviour in unpredictable environments and finding enough physical space for everyone. When activities did include the whole family, parents described this as extremely valuable. It was one of the few times family life felt "ordinary", with siblings joining in rather than waiting on the sidelines. However, these experiences were not the norm. They tended to be linked to high quality providers or parent led groups rather than mainstream leisure.

8.9 Frequency and reliability of activities

Families emphasised many activities were one off, seasonal or offered only in school holidays. Regular, predictable sessions that ran weekly or termly were highly valued but uncommon.

Irregularity made it harder for children to build familiarity and confidence. It also increased planning demands on families and contributed to isolation.

Parents said that when a rare suitable activity was cancelled at short notice, it could have a disproportionate impact on their week.

8.10 Support services

Parents were asked about the availability of support during activities. Very few described activities where staff had specific training in profound and multiple learning disabilities.

Some venues had volunteers, but training and supervision were inconsistent. In most cases, families had to bring their own support or manage entirely on their own.

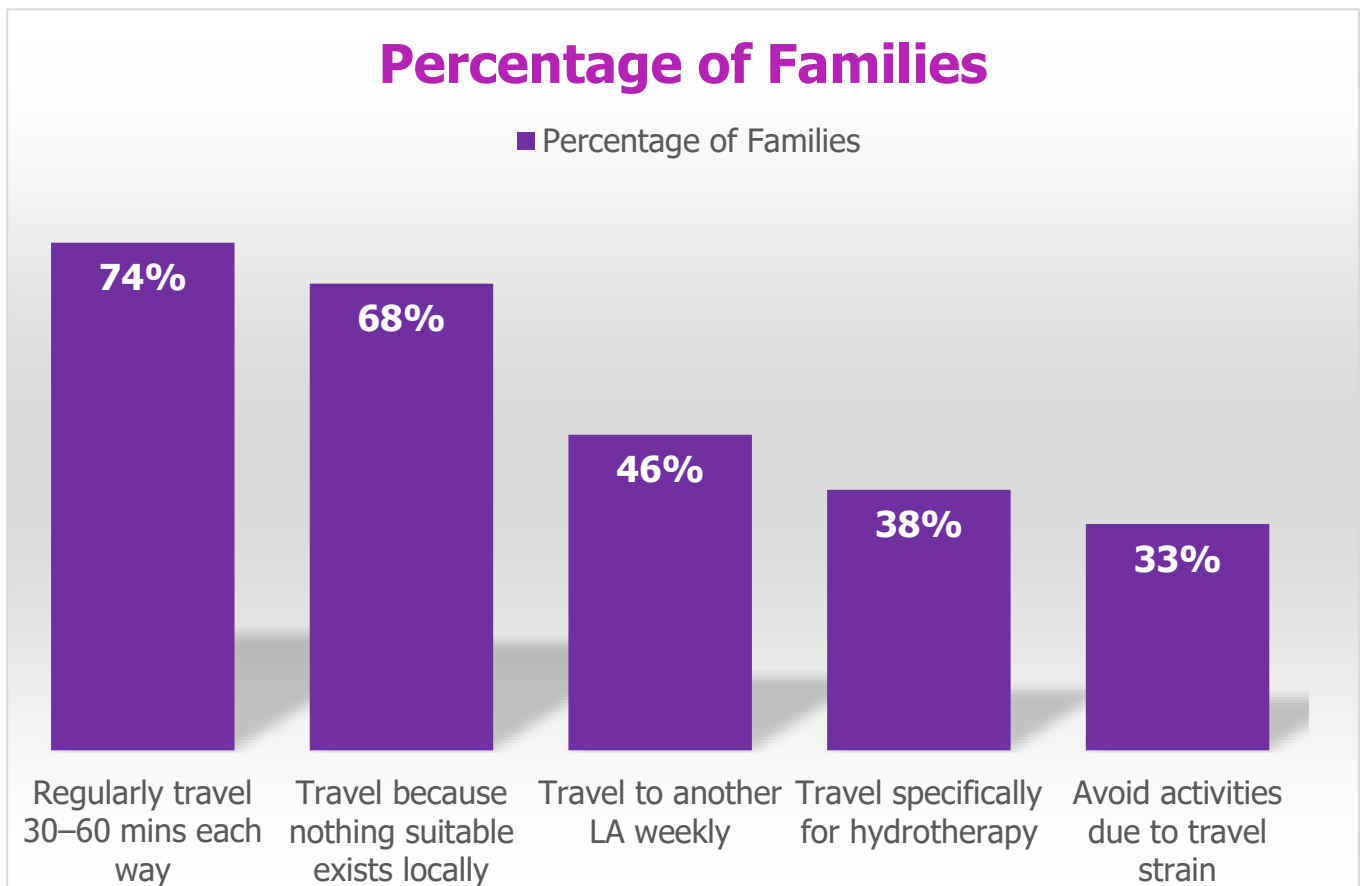
One parent said, "If something goes wrong, it is on you." This sense of responsibility was echoed across interviews.

Parents made clear that support services are essential, not optional, if leisure is to be safe and genuinely inclusive.

8.11 Transport and travel

Transport was one of the most consistent cross regional themes. As previously cited two thirds of parents described travelling 30 to 60 minutes each way for suitable activities.

Public transport was often inaccessible or impractical. Parking could be stressful, especially in city centre locations.



For families in rural areas, long journeys were routine. Some described building their entire day around a single activity because of the time and energy involved in getting there and back. The cost of fuel, the strain of travel and the need for two adults for longer trips all limited how often families could take part.

8.12 Child response and engagement

Parents described how children responded positively to activities that matched their sensory, emotional and communication needs. Positive responses included increased alertness, visible enjoyment, calmer mood, more expressive communication and greater engagement with others.

Music, water-based sessions and outdoor activities were particularly well received. Where activities were unsuitable or overwhelming, children could become distressed, and this increased families' anxiety about trying again.

8.13 Suggestions for improving leisure options

Parents offered a range of constructive suggestions for improving leisure across the region.

Common themes included clearer and more detailed accessibility information, more frequent and regular sessions, calm and sensory aware environments, more local provision, realistic timing of sessions, better use of school and community facilities and meaningful involvement of families in designing activities.

Several parents emphasised that they were not asking for specialist or rare experiences. As one parent put it, "We need something local and regular. Not special, just something she can enjoy."

These suggestions underpin the recommendations set out later in this report.



Families valued provision where staff demonstrated confidence, curiosity and respect for their child's needs and where adjustments were made proactively rather than reactively. In these settings, parents described feeling welcomed rather than tolerated, and able to relax rather than remain on constant alert.

Examples cited throughout this report include specialist music provision, adapted and inclusive sports sessions, hydrotherapy, inclusive cycling, and parent-led sensory and play organisations operating across the region. The recurrence of these examples reflects not only their quality, but the limited number of places where families felt confident that provision would be safe, meaningful and dignified.

This pattern highlights both what is possible and how narrow the current landscape remains. Families' reliance on a small number of trusted providers underscores the need to move beyond pockets of good practice toward a more intentional and equitable system of inclusive leisure.

"We visit one group regularly and they do great events, but without them, we wouldn't have done half the things we've done these last few years."

9.2 Parent-Led and Specialist Provision

Many of the features families identified as essential to inclusive leisure are most consistently found within parent-led and specialist provision, including the work of Little SENDsations, who led family engagement for this review. As a parent-led organisation, Little SENDsations bring lived experience and practical delivery insight that reflects the realities described by families across the region.

The Redcar and Cleveland Parent Carer Forum has been a lifeline for us."

Parents spoke positively about provision shaped by people who understand, from personal experience, the complexity of supporting a child with a profound and multiple learning disability.

This included heightened awareness of sensory needs, flexibility around routines and expectations, and an approach that prioritised reassurance, welcome and trust rather than scrutiny or judgement.

Families described how this type of provision reduced the emotional labour often associated with accessing leisure.

Rather than repeatedly explaining or justifying their child’s needs, parents felt more confident that staff understood their child and would adapt activities proactively. This sense of relational safety was central to whether families felt able to participate at all.

At the same time, parents were clear that the prominence of parent-led and specialist organisations reflected gaps within the wider system, rather than a preference for separate provision. While deeply valued, these organisations often operated with limited funding, small teams and uncertain sustainability.

Families expressed concern that too much responsibility for inclusion rested with a small number of trusted providers, rather than being embedded within mainstream community infrastructure.

"We are always checking whether somewhere will cope."

9.3 Reliance on Goodwill and Informal Adaptation

The reliance on parent-led and specialist provision points to a wider system in which inclusive leisure opportunities are frequently dependent on **goodwill, individual commitment and informal adaptation**, rather than deliberate planning or sustained leadership.

Parents described how access to leisure often depended on:

- The confidence or willingness of individual staff
- Personal relationships built over time
- Short-term funding or pilot activity
- Provision adapting around families rather than families being supported by the system

As a result, inclusion was experienced as inconsistent and uncertain. Families spoke of continually assessing whether activities would be safe, appropriate or emotionally manageable, and of the disappointment and disruption caused when provision was withdrawn or could no longer adapt.

This reliance on goodwill placed additional and ongoing pressure on families themselves. Parents described the cumulative work involved in identifying suitable provision, maintaining trusted relationships and managing the emotional impact of exclusion. For families of children with a profound and multiple learning disability, this labour was described as exhausting and unavoidable.

These patterns highlight a system in which inclusion is **optional rather than expected**, leaving children with the most complex needs particularly exposed to inconsistency and exclusion.

Without clearer leadership, accountability and investment, inclusive leisure remains fragile and localised, rather than forming part of a planned and equitable regional offer.

9.4 Staff confidence and training

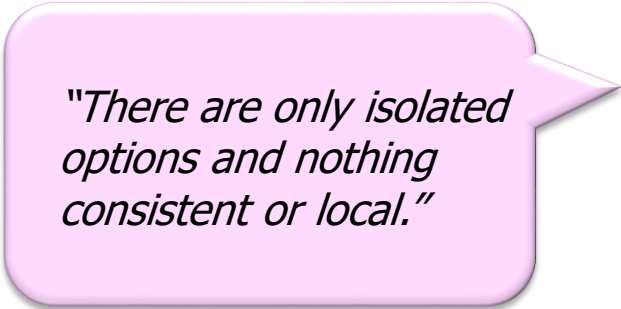
High quality leisure experiences were strongly associated with environments where staff were confident and well supported. Parents described the difference made by staff who communicated clearly and warmly, adapted routines as needed, maintained consistent team members and welcomed families without judgement.

These positive interactions had a significant impact on family confidence. Several parents said that a single skilled staff member could completely transform an outing, turning a potentially stressful experience into something safe and enjoyable.

9.5 The power of predictability

Families repeatedly described the importance of routine, consistency and predictability. Activities that were scheduled regularly, ran at the same time each week and were delivered by familiar staff allowed children to build confidence and feel secure. Predictable noise levels and clear expectations reduced anxiety for children and parents alike.

Where this level of predictability was achieved, families described steady improvements in engagement, regulation and enjoyment over time. These activities became anchors in family life.



"There are only isolated options and nothing consistent or local."

9.6 Models that could be scaled

The research indicates several promising models that local authorities, Integrated Care Boards and providers could expand across the region. These include:

- Parent led sensory play groups and family hubs
- Regular adapted sessions in mainstream leisure centres
- Partnerships between local authorities, ICBs and specialist providers
- Music and arts sessions tailored to profound and multiple learning disabilities
- Peer support based family groups that combine Leisure and connection
- Mobile or outreach sensory programmes
- Dedicated inclusive nature or outdoor activity sessions

These models already exist in pockets across the region. With strategic support and sustained funding, they could be developed into a more coherent and equitable regional offer.

9.7 Little SENDsations

Reflections

Little SENDsations offered valuable reflections throughout this research. Their experience as a parent-led organisation sits at the intersection of lived experience, community action and local system gaps. Their insights illustrate how families often step in to create the provision that statutory systems have not yet delivered.

Their work highlights several themes that reinforce the findings of this report:

Families are the experts.

Little SENDsations' sessions were designed directly from lived experience, responding to sensory, physical and emotional needs that mainstream leisure settings often overlook.

Demand far exceeds supply.

Their groups frequently reach capacity quickly, confirming the level of unmet need across the region.

Provision is built on trust.

Families described Little SENDsations as a place where their children could participate safely and confidently because staff and volunteers understood their needs without judgement.

Parent-led organisations fill system gaps.

Many families attending Little SENDsations were not able to find suitable alternatives in their local area and relied on the group for consistent leisure access.

This work should not have to compensate for system failures.

While their contribution is significant, the organisation's reflections strongly support the need for coordinated, properly funded inclusive leisure provision across the region. Their perspective is therefore not only a strength but a reminder: meaningful leisure for children with a profound and multiple learning disability is possible when services are designed with, and led by, the people who know what works.



10. Recommendations

The findings of this report make clear that leisure access for children and young people with a profound and multiple learning disability is not simply a matter of information quality or isolated gaps.

The barriers identified across the North East and Cumbria reflect structural issues in commissioning, planning, governance, accessibility and oversight. The recommendations below therefore focus on both practical and strategic changes. Together, they form a call for a coherent regional approach to inclusive leisure; one that recognises leisure as a core component of children's rights, wellbeing and participation.

10.1 The Big Ask: A Regional Inclusive Leisure Strategy

We are calling for a Regional Inclusive Leisure Strategy led jointly by local authorities, Integrated Care Boards and voluntary sector partners.

This strategy should:

- Formally recognise leisure as a key part of health, wellbeing and inclusion for children with a profound and multiple learning disability.
- Set out minimum expectations for accessibility, dignity, staffing confidence, equipment and communication.

- Establish consistent Local Offer standards including mandatory accessibility information, reliable updating and dedicated categories for profound and multiple learning disabilities.
- Create a shared, cross-regional commissioning framework so families do not face postcode-based inequalities.
- Embed co-production with families and lived experience organisations at every stage.
- Secure long-term investment in specialist and community based inclusive provision, reducing reliance on parent networks and short-term projects.

This strategy should be shaped by the evidence in this report and developed in partnership with parent carers, specialist providers and community organisations. Without a coordinated approach, the inequalities identified will persist.

10.2 Recommendations for Local Authorities

Introduce a dedicated category for profound and multiple learning disabilities on all Local Offers. Families need clear filtering that reflects their child's needs.

Provide detailed accessibility information as standard.

This must include physical access, Changing Places facilities, hoists, parking, sensory environment, staff training, equipment availability and communication support.

Ensure Local Offers are actively maintained.

Establish clear governance for updating, accuracy checking, and removing outdated entries. Broken links and missing information disproportionately affect this group.

Invest in local inclusive provision.

Work with specialist providers, parent-led groups and existing community organisations to expand activities that meet the needs of children with a profound and multiple learning disability.

Address age-related provision gaps.

Ensure activities exist for older children and teenagers, not only for early years.

Strengthen dignity and personal care standards across leisure settings.

Changing Places availability, adequate space and trained staff should be built into leisure investment.

10.3 Recommendations for Integrated Care Boards (ICBs)

Embed leisure access in health inequalities and prevention strategies.

Leisure supports sensory regulation, mental wellbeing, physical development and family resilience.

Commission inclusive community provision. This should include adapted cycling, sensory sessions, music therapy, hydrotherapy access, nature-based activities and family-friendly offers. Co-commission with local authorities.

Use pooled budgets and joint planning to reduce inequality between areas and avoid isolated, short-term funding.

Support specialist workforce development. Invest in training for leisure centre staff, community organisations and parent-led providers to build confidence in supporting children with profound and multiple learning disabilities.

10.4 Recommendations for Providers

Publish meaningful accessibility information.

Families need clarity before leaving home.

Offer predictable, routine based sessions.

Weekly or regular sessions support engagement, reduce anxiety and build familiarity.

Invest in staff training and confidence building.

Inclusive leisure is driven by relationships and skilled support.

Create sensory aware and communication friendly environments.

Use predictable routines, quieter spaces and controlled sensory input.

Design activities **with families**.

Co-production ensures activities meet real needs and increases trust.

10.5 Recommendations for National Decision Makers

Develop national guidance for inclusive leisure for children with complex needs.

This would create consistency across Local Offers and local authorities.

Include leisure accessibility within statutory SEND reviews and inspections.

CQC and Ofsted should consider how local systems support access to community life.

Create a national fund for inclusive community leisure.

Specialist community centres, parent-led organisations and voluntary sector providers require stable funding.

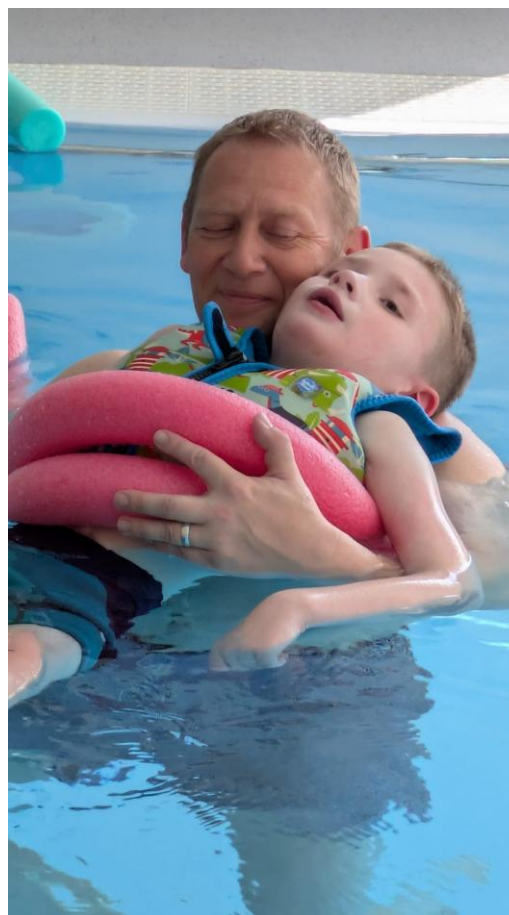
Expand Changing Places investment and ensure clear accountability for maintaining dignity in personal care across public leisure settings.

10.6 Summary of the Big Ask

At present, families are navigating a fragmented and unequal system.

The Big Ask calls for coordinated leadership across local authorities, ICBs and national bodies to ensure that children with a profound and multiple learning disability can access ordinary, joyful leisure opportunities close to home.

This will require standards, investment, co-production and strategic intent, but the evidence shows that when provision is inclusive, the benefits are profound.



RECOMMENDATIONS

THE BIG ASK: A REGIONAL INCLUSIVE LEISURE STRATEGY

A joint strategy from local authorities, Integrated Care Boards, and voluntary sector partners to make leisure accessible for children and young people with profound and multiple learning disabilities.



Recognise Leisure's Importance

Formally acknowledge leisure as vital for health, wellbeing, and inclusion.



Set Minimum Standards

Outline consistent requirements for accessibility, equipment, staffing, and communication.



Improve Information

Provide better Local Offer information, with mandatory, regularly updated listings allocated specifically for profound and multiple learning disabilities.



Create a Fair Framework

Develop a regional, cross-area commissioning framework, tackling postcode inequalities.



Embed Co-Production

Work closely with families and lived experience organisations to co-produce the strategy.

A unified approach to inclusive leisure centred on children's rights and dignity, long-term investment and true partnership.

11. Conclusion

This report shows that leisure access for children and young people with a profound and multiple learning disability remains significantly limited across the North East and Cumbria. While 324 activities were listed across thirteen Local Offers, only 60 were suitable. Several areas offered no appropriate provision at all. Families described challenges with accessibility, staffing confidence, travel distances, inconsistent information and a lack of activities designed specifically for profound and multiple learning disabilities.

At the same time, the research highlights strong examples of inclusive practice and a clear foundation to build on. Specialist providers, parent-led organisations and committed community groups show what is possible when activities are designed around sensory, physical and communication needs. These examples demonstrate the transformative impact that inclusive leisure can have on wellbeing, communication, social connection and family life.

Leisure is not an optional extra. It is a core part of children's development, identity and right to participate in community life. For children with a profound and multiple learning disability, meaningful leisure experiences rely on environments that are accessible, predictable and designed with care. Improving Local Offers, investing in inclusive provision, strengthening governance and working in partnership with families are essential steps towards reducing inequalities and ensuring that every child can enjoy ordinary, joyful opportunities close to home.

With coordinated action from local authorities, Integrated Care Boards, providers and national partners, the region can create a more inclusive leisure landscape, one where families no longer have to search endlessly, travel long distances or rely on informal networks to find activities that work. Instead, children and young people with profound and multiple learning disabilities can experience the same sense of belonging, fun and exploration that every child deserves.



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- Middlesbrough
- Newcastle upon Tyne

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- Stockton-on-Tees
- Sunderland

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https://inclusionnorth.org/our_work/whycantiplay/

#WhyCan'tIPlay

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