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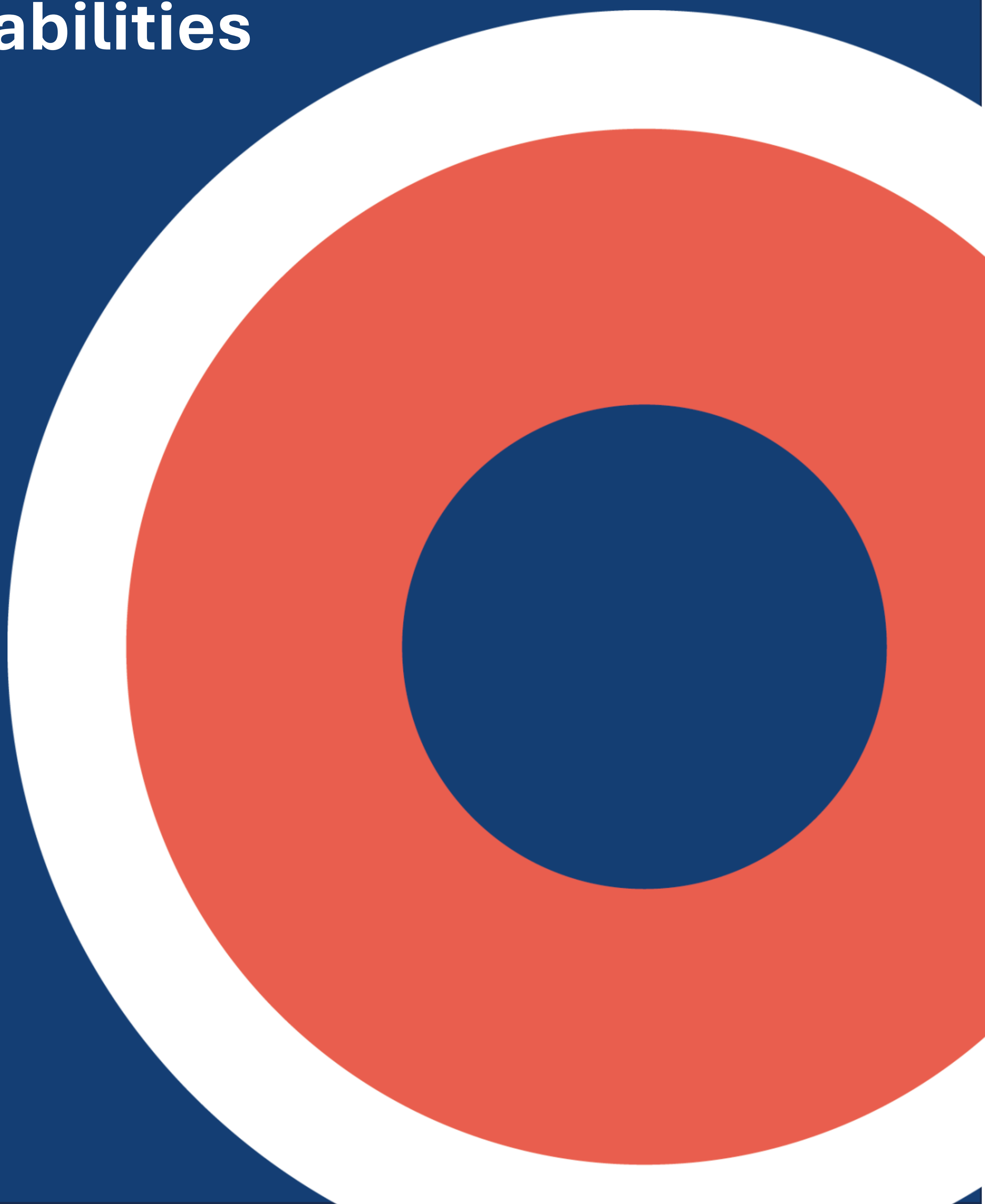
Families' Perspectives on Out of Area Placements for People with Learning Disabilities



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The five individuals who took the time to share their stories…

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Additional information

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Executive Summary

There is a recognition that people's voices often are unheard or lost when someone with a learning disability is placed away from their home and their community. This study examines family perspectives on out-of-area placements focusing on how these placements are made, delivered and supported.

Reflecting on academic research undertaken over twenty years ago around the placement of people with a learning disability in residential settings away from their home authority, this research explores the experience of families' today. And the message from families is clear; in-area support, delivered in a timely manner by well-paid, well-trained staff, is highly valued. It helps retain, repair or even strengthen, family bonds and from a service perspective it ensures a valuable resource – families – can continue to help support people with a learning disability to live well and to live independently. All too often, the experience of families is that this does not happen out-of-area.

Taking a lead from four of the themes identified – unpreparedness, the impact of distance on family networks, poor service quality and the family voice - a number of recommendations for practitioners, commissioners and researchers are proposed, including:

> **Value in-area provision.** Families consistently highlight that local placements are highly valued and contribute to better outcomes.
>
> **Maintain a clear focus on keeping the person in-area**. If, as a last resort, an out of area placement becomes necessary, be explicit from the outset - with the individual, their family, and the provider – that the placement is short-term only and that alternative, permanent accommodation within the local area will be secured as soon as possible. Families experience is that out-of-area placements all too easily drift.
>
> **Work alongside the family throughout the placement** to ensure the provider actively engages with the family's rich knowledge of their relative; knowledge that is too often overlooked or undervalued.
>
> **Staff pay and quality of care**: Feedback from families indicates greater confidence in providers where staff are paid well. They associate better paid staff with lower turnover, improved continuity and higher quality of care;

factors that reduce placement breakdowns. This should be reflected in policy and commissioning strategies.

Cost versus value: Families note that lower or mid-cost placements do not necessarily represent best value. Their experience suggests that in-house and higher-cost in-area placements offer greater stability and demonstrably better outcomes.

Further research should amplify unheard voices. These perspectives have been largely absent from the evidence base, but hold significant potential to aid knowledge transfer, inspire aspirational thinking and drive meaningful and positive change in policy and practice

Economic and outcome analysis: A detailed comparative analysis of costs and outcomes for out-of-area placements versus in-area and in-house provision is essential. This should include direct financial costs, hidden costs (e.g. social work time, placement breakdowns) and long-term outcomes for individuals and families.

Introduction

At any given time, across the ten Greater Manchester (GM) authorities, around ten per cent of people with a learning disability live somewhere other than the local authority area they grew up in or are ordinarily from (MQIS June 2025). This might be elsewhere in the GM locality, or it might be further afield in the North West region or beyond, but either way, for these individuals, this means living some distance from the family home, from friends and relatives and from their communities. Whilst for some, this may have been a positive choice, for many, there is likely to have been very little in the way of voice, choice or control with arrangements often made in moments of family crisis. That these out of area (OOA) placements are made in the context of the Care Act 2014, which places a duty on local authorities to ensure that people living in their areas have access to a range of appropriate, high-quality services and to work collaboratively with their communities to provide or arrange services that promote wellbeing and independence, is of key significance. The Greater Manchester Learning Disability Strategy 2018 recognises this along with the challenges faced. Indeed, the GM-wide commitment to ensuring people are able to live in their communities with the support they need is further underlined in Living Well at Home Adult Social Care Transformation (GM ADASS October 2025): "We want all people to live in the place we call home with the people and things we love in communities where we look out for one another doing the things that matter to us".

Despite this policy and legislative framework - a framework that has increasingly sought to recognise the richness and complexity of people's lives and to promote truly co-produced, person-centred care - the MQIS data shows similar numbers of people placed OOA over the last few years with little evidence, certainly from a practice perspective, that this has changed much, if at all, over recent decades. A review of the academic literature reveals significant research activity in the late 1990s and early 2000s, but very little since. This raises an important question; have the circumstances that lead to OOA placements - social work teams struggling to plan proactively with individuals, limited flexible or agile crisis responses, a shortage of appropriate residential or supported living options locally, for example - changed significantly over the intervening period? If these challenges persist, what are the implications for those affected, particularly given the recognition that individuals' voices are often diminished or lost when they move away from their home and communities? What might this mean for practitioners and commissioners today?

This study aims to go some way towards exploring the perspectives of, and issues for, family members. With a focus on when, why and how decisions about placements were made, on what worked well and what didn't work well, mindful of current policy and practice, but also reflecting on issues highlighted in the research twenty years previously, it looks to place the voice of those directly and indirectly affected by out of area placements in an service and policy informed context.

Literature Review

A systematic search of the literature regarding research into, and policy pertaining to, out of area placements for people with a learning disability was undertaken utilising key academic databases (primarily Web of Science) but also including the relevant grey literature via Overton. Screening employed the following parameters:

- Primary Population: Does the study primarily focus on people with learning disabilities?
- Placement Type: Does the study examine long-term/permanent out-of-area residential placements (not temporary respite care)?
- Study Design: Is the study either primary research (quantitative, qualitative, or mixed methods) OR a systematic review/meta-analysis?
- Outcomes Reported: Does the study report on at least one of the following outcomes: quality of life, mental/physical health, social integration, access to services, or cost implications?
- Age Group: Does the study include participants aged 16 years or older?

The academic literature review only included articles that have been peer reviewed and written in English, whilst articles written prior to 1995 were excluded. The review eventually produced in the region of fifteen articles:

Summary of thematic analysis

Theme 1: Quality of life and service provision

- **Variable service quality and quality of life.** Several studies reported that many individuals in OOA placements experienced poor service quality and limited social integration Beadle-Brown et al. (2013); Perry et al. (2007), Beadle-Brown et al. (2006). Beadle-Brown et al. (2006) found that at least a third of people in OOA placements experienced very poor care and support and associated poor quality of life. Perry et al. (2007), raised concerns that OOA placements did not always provide positive quality of life outcomes. There were some positive exceptions; Forrester-Jones et al. (2005) reported that individuals in small group homes, hostels and supported accommodation were more likely to report close and supportive relationships, though these settings also saw more critical behaviour. Further, Perry et al. (2013), found that in-area placements had more advantages in quality of care and life, whilst OOA placements often had lower costs. Chinn et al. (2011), highlighted limited opportunities for engagement, education, and cultural practice in OOA psychiatric units with only occasional positive experiences.

Theme 2: Family and social network Impact

- **Distance strains family and social networks**. A number of studies reported that OOA placements strained family relationships and reduced opportunities for

family contact and involvement Beadle-Brown et al. (2006), Beadle-Brown et al. (2013), Chinn et al. (2011). Beadle-Brown et al. noted that distance was a major difficulty for both family and social worker involvement and family carers often feared losing the placement. Chinn et al. (2011), found that being placed far from home put additional strain on family relationships and limited opportunities for socialisation and cultural practices. Beadle-Brown et al. (2006) observed that visits to families were sometimes better in OOA placements, though this was not the norm.

- **Social network composition**. In the studies that addressed social networks, OOA placements were often dominated by staff and other service users with limited integration into the wider community Forrester-Jones et al. (2005). Forrester-Jones et al. (2005), also found that only a third of social network members were unrelated to learning disability services, indicating ongoing segregation.

Theme 3: System-level challenges

- **Resource and capacity issues**. Insufficient in-area supported accommodation, compounded by under-resourced social work teams were the most frequently cited reasons for OOA placements Beadle-Brown et al. (2006), Beadle-Brown et al. (2103), Perry et al. (2013), Pritchard & Roy (2006), McGill & Poynter, (2012).
- **Financial and policy incentives**. Several studies highlighted financial or policy structures that unintentionally encouraged OOA placements Beadle-Brown et al. (2006), Beadle-Brown et al. (2103), Pritchard & Roy (2006), McGill & Poynter (2012). Pritchard & Roy, (2006) and McGill & Poynter (2012), both emphasised the high cost of external placements and the need for better local capacity and coordinated commissioning.
- **Care management complexity**. Care management was complicated by distance with increased workload for local teams, reduced provision for local residents and difficulties in monitoring and coordinating care for the placing authority Beadle-Brown et al. (2013), Pritchard & Roy (2006). McGill & Poynter (2012) also noted a lack of clear discharge plans and limited evidence of resource redirection from OOA placements back to local services.

Methodology

Mindful that many OOA placements are made during family crisis and, that resource pressures are such that once made, placements are not always routinely reviewed, the research aimed, first and foremost, to gain some insight into, and understanding of, the placement process from the perspective of family members and to use this to co-produce some policy and good practice recommendations. Whilst to some extent, this work re-visits empirical research undertaken twenty plus years ago around the placement of people with a learning disability in settings away from their home authority, primarily it is an attempt to take a qualitative interviewing approach – rather than the social survey based approach largely used in previous research – to a process that

remains a key activity for ASC practitioners and to place family voices front and centre. This approach, in a sense, reflects social work practice; qualitative interviews are particularly useful when research seeks depth, nuance, and complexity rather than broad, surface-level patterns typical of surveys. They enable exploration of social processes, change, organisation, and meaning through rich, contextual accounts, offering insights that large-scale comparative analyses cannot provide.

Four semi-structured interviews were undertaken. The participants each had a family member who has a learning disability who lives in, or has recently been living in, an out of area residential setting; that is to say, somewhere other than the GM authority they ordinarily live in or, where they live in a neighbouring GM authority, more than 10 miles from the family home. All four were over 16 years of age and live in Greater Manchester. Given the potential for experiences to have been difficult and for feelings to be painful, it was decided that the OOA placements explored with family members had to have been made a minimum of twelve months previously.

Data from the Greater Manchester Integrated Care Partnership MQIS dashboard indicates that, despite fluctuations over time, the number of people placed OOA by each of the GM authorities is broadly similar. One might reasonably conclude that all ten face similar issues resulting in OOA placements and that none have an approach that in any significant way mitigates against OOA placements. Hence, in terms of facilitating this research, learning disability teams from three GM authorities – Bury, Rochdale and Tameside – representative of all ten, were used to identify and engage participants and acted as the conduit for all consent and information sharing issues. The teams circulated a recruitment flyer briefly outlining the aims of the research and what participation would entail with the families of people they support. Interested people/potential participants had the opportunity to make contact via the University email address provided. These were then followed up via email and/or telephone.

Interview arrangements offered were as flexible and person-centred as possible with, in the eventuality, all four participants interviewed face-to-face in their own home. Participants had the option to have someone accompany them if they chose - three were interviewed on their own and a fourth as a married couple together – and, since interviews were audio recorded, ground rules around confidentiality and use of data/information were shared ahead of the interview and again at the start of the interview. Participants were able to pause or stop the interview at any point if feeling uncomfortable or distressed and possible sources of support were highlighted prior to the interview commencing.

The interviews were semi-structured and focused on three key themes:

- The circumstances immediately prior to their family member being placed OOA

- Their views on the OOA placement(s) meeting their family member's immediate needs and wider, longer-term needs
- Barriers and opportunities to their family member returning home/back to their local area

Participants were provided with an information sheet and consent form (see Appendix 1) outlining all the procedures involved in participating in the research, including how confidentiality will be ensured via anonymisation of the data and removal of any personal identifiable information and secure, password encrypted storage of the information gathered on University of Manchester systems. As part of this, participants were assured that their involvement in the project would not, in any way, affect the care their family member currently receives.

For all four families (five individuals, one interview was with a married couple), these OOA placements (and the subsequent return in-area), have happened in the last five years or so.

The recordings of all four interviews were transcribed and a reflexive thematic analysis, borrowing from Braun & Clarke (2022), loosely applied. Four participants represent a very small sample, and this is perhaps the most significant limitation of the study. Any analysis of such a small sample is limited, and this is certainly true for a thematic approach. That said, this approach proved a very good way to develop a degree of familiarity with, and immersion in, the context of the dataset and to generate initial themes.

Findings

Via a process of pattern identification and coding across the transcripts, and in accordance with Braun and Clarke's guide on the six stages of thematic analysis, the following themes were generated based around the data, the research question and research positioning, knowledge and insight.

<u>Unpreparedness</u>

All five interviewees described feeling entirely unprepared for the changing and challenging circumstances they faced in the run-up to their family member leaving the family home to live – and be supported – OOA. For them, the (on occasions, dramatic) changes in behaviour of their son or daughter, particularly when they had previously been managing and/or had appropriate support from Education and Children's Services, left them feeling overwhelmed and stressed. Often unsure as to what to do, and with individuals and relationships under considerable strain, they were having to cope and make difficult decisions quickly under pressurised circumstances.

> Participants D: “So that’s when he started to become really dark, and then that started to put a lot of pressure on our relationship, because you think what’s going wrong, why are we not managing this right? Because to be fair, up to that point we’d been pretty good at managing his behaviour all his life. It kind of felt like what are we doing wrong, why is this happening? We were desperate”.

> Participant B: “At no point over that period had I been thinking about, or talking about, the possibility of my daughter moving out. Not up until the incident [his daughter tried to strangle him]. That was the first time I talked to a social worker about my daughter not living here”.

> Participant A: “Well, there was no help, do you know what I mean? I was like, you need to get somebody to support us at home, but they couldn’t find anyone. I had all this anxiety about him”.

> Participants D: “Our relationship was really strained. We were arguing all the time with the stress. We started to really argue… we didn’t know what to do. We got so desperate we were walking round the streets in November, cold and wet [to get a break from their son]. Our whole life was upside down and our relationship was in turmoil really”.

In all four cases, albeit to varying degrees, this unpreparedness extended to Adult Social Care (ASC) too. Despite, in each case, the previous involvement of Children’s, the individuals concerned had, for the most part, little ASC input and social workers, when they became involved, were having to work with families in crisis whilst, at the same time, familiarising themselves with the circumstances, strengths and needs of the individuals and the family dynamics. The impression in all four cases was that this meant possible interventions/options quickly, if not immediately, defaulted to OOA with no contingency plan in place.

> Participants D: “We didn’t have a social worker, and when I first rang, they were like oh, we don't know this guy, he’s not on our radar. We put our hand up and said we need help. He’s probably going to have to go into some kind of secure special care. The social worker [allocated] had recently moved from elderly care into special needs, so she didn’t really understand anything about it. She said, well, it’s probably going to take around two years to sort that out. And we were like, okay, well, you'd better get started then”.

> Participant C: “I had a social worker, but they were a bit hit and miss, to be honest. [At this point], I don't remember the last time I spoke to a social worker”.

> Participant B: “I should have written them all down [the social workers names], really because there’s been that many”.

<u>The quality of provision</u>

Interviewees had common concerns about the quality of the OOA provision they experienced. Whilst some of it – or elements of some of it – was good, all expressed varying degrees of concern about much of it, and this was often in stark contrast to their views on the current placements; all in-area, three of them in-house. OOA placements are costly, and frequent moves between failing placements add significant ‘hidden’ costs in terms of social work and adult social care time and resources. While in-area and in-house provision may be equally expensive - or even more so - evidence from the testimonies suggests that it has the potential to deliver good outcomes and so be more cost-effective in the long term. This raises important questions for further research. Whilst there is some indication (from the families’ experience), that higher-cost placements are more likely to succeed, financial pressures and internal systems often steer social workers and commissioners away from these options (and from in-house provision), except as a last resort. The testimonies in part, suggest that less expensive placements - which may be less able/likely to achieve positive outcomes – are either preferable (from a financial perspective) or the only available option in the circumstances.

> Participant B: “I didn’t feel the social input was there. They were, how can I say, left to their own devices, they’d do a little bit of input around, you know, at mealtimes and what have you, but I always felt they could put more in”.

> Participants D: “So we were then going to see him three times a week, four times a week. This place was really badly run, and although some of the staff tried it was just geared up to restrain and contain, and [son] hated it, and we hated it. We used to take him out and then whenever we went back you could see the darkness came over his face again. He was there for quite a while. He wouldn’t eat any of the food. It was slop. It was like a prison. And it got to the state where I used to go every evening [to the placement in another GM locality] to cook food for him in their kitchen so that he would eat, and we’d spend a couple of hours with him. The only difference between him being in care and him being at home was we weren’t being attacked, but all the stresses and strains were still there”.

> Participant C: “His care [there] was the worst ever, the worst ever. We had to go get him, and bring him back immediately, and that’s when he stayed with us for a month. Over the months he was there, we'd video call him, and he

looked bedraggled. He looked dirty, he looked emaciated, he just, he looked disgusting. He wasn't caring for himself, probably did a lot of smoking, because one of the guys he got friendly with smoked, I think that's all he did, sat outside smoking".

Participants D: "And then [the Birmingham-based provider] said he'll have to leave tomorrow. He'll have to leave tomorrow. The local authority was trying to find somewhere, we were trying to find somewhere where he could go temporarily. [At this point], the decision was made by ASC that the only option for him until an in-area place became available was for him to be sectioned".

Participant B: "I'd have her [his daughter at this point placed OOA] every other Saturday and gran would have her every other weekend. I'd pick her up on Friday night and she'd come back here, and I'd drop her off at teatime on Sunday. And that is basically where the dispute kicked off, because the Council were saying we're not paying £4,000 a week per head [for this]".

In their interviews, families identified a number of workforce issues that, in their experience, over multiple placements with a number of provider organisations, impacted on the quality of care: staff on minimum wage and, closely linked to this in their opinion, a high turnover of staff; hence, a lack of consistency in the support team and the regular use of agency staff and poorly or untrained, poorly supervised staff. In addition, they spoke of inexperienced managers and/or experienced managers who were overworked and lacking the resources they needed to deliver good quality care. Whilst not workforce related, a further, recurring issue, was poor accommodation; basic rooms, barely furnished, poorly decorated, little scope or encouragement to personalise space, little or underused communal space with the television on constantly. It is striking how acutely aware of these issues families are and, where the opposite is true, how they recognise and value this.

Participants D: "They [the current in-area provider] pay above the minimum wage and they train the staff, the company's managed well and their focus is not the money. Their focus is taking the people that were probably going to end up being pushed into being sectioned and giving them a way out of that, and that's what they focus on. I'm super impressed with the way that company's run, managed, and what they've been able to do. It's just they have a completely different focus. It's not on just get the money and provide the minimum, it's like, be sustainable".

Participant A: "The staff team is good there [the current in-house placement]. I mean I'm going in September - I would have never done this with any of the

> other providers - on holiday with him in a cottage. He [her son] hasn't had a holiday in all these years. And the staff have actually put themselves forward to go. So, there is no confrontation with the staff and they're wanting to. The family recently went out for the day on his birthday. My daughter came, her partner came, my grandson came, all the staff came, we all sat together".

A further possible issue, but one that participants struggled to articulate and hence tended, where they touched on it, to imply rather than be explicit about, was the number of support staff employed who had English as a second language and the impact of this, on occasions, on the care provided. This was perhaps most noticeable where families reflected on issues around physical violence and the use of restraint suggesting that the causes were, in part, around linguistic and cultural misunderstandings regarding autism and learning disability.

> Participants D: "I think the common theme that we encountered is staff who are not really trained properly. They're not experienced and they're on the minimum wage and most of them were from different cultures that didn't really understand what was going on. And we can tell you this is commonplace".

> Participant A: "But then half the staff started leaving and we got all the ones on visas. So, it was like going backwards. I was going up and was like, you [her son] haven't been anywhere all week, or he's been walking round charity shops buying stuff that he's already got. It's like they weren't dealing with behaviours; he was obsessing, he was heightened. I had witnessed him running off, he was dirty, his flat was dirty".

> Participant C: "He didn't stay there very long, at all. They didn't understand him; they weren't willing to understand him. They didn't know [my son] properly, they didn't know what made him tick.

> Participant B: "When I went to pick her up the staff didn't seem that involved. It wasn't a friendly atmosphere, it was, sort of, clinical. I always felt, come on, you know, you can do more, you can do more".

In some instances, there is a sense listening to families, that these issues are compounded by managers of homes feeling, in some way, under pressure to take anyone, whether they feel they can meet their needs or not.

> Participants D: "These placements are businesses, and businesses want to make money, and they are geared to making profit, that's why they exist. So, I

> think the default is to go for the cheapest labour option, pay the minimum wage and don't invest, but take the money".

> Participant C: "The staff were not the best, I don't think, professional. My son clashed with the staff, or they found fault with him, but I would think, you know what he's like, you've been told, don't take the job if you can't hack it. You know, obviously, they might be being paid absolute minimum wage, and yes, I get it, but it's affecting me, and my son. I was getting very bitter by this point thinking, you're now causing me a problem".

Family voice

A consistent, reoccurring theme across all the testimonies was that parents crucial and intimate knowledge of their family member was often overlooked, lost or ignored in the run up to an OOA placement or in the weeks and months following. Again, not always, but often enough for it to be of significant concern to families and hence, of some relevance in terms of driving change and improvement in practice going forward. On occasions, families describe a 'we know best' attitude from providers where their knowledge was seen as somehow unimportant, irrelevant or irritating.

> Participant D: "And we were saying to them he's very challenging and can be very violent. This was going on and on during the tour [of the potential placement prior to their son moving in]. And they actually got to the point where they said, we understand, we get it, that's what we deal with here. And we were like, okay, great. We deal with extreme violence, special needs. We're like, okay, but we just want to make sure you know. And he eventually went there. Three days later, he had to leave".

Often, the rich, very personal, person-centred information being over-looked or ignored was about the day-to-day habits, needs, likes and dislikes of their son or daughter around things like diet, personal and oral hygiene, clothes and activities; things that clearly are of great significance to parents and their family member and that should also be important, in terms of care and support planning, to the provider. These were often the issues that families found the most distressing and the most difficult to address.

> Participants D: "In the space of him leaving home to leaving Leicester, ten months, he put on four stone. He was tall, slender [before he went] and he became this big, fat guy. He had gum disease - this really is one of my bugbears, oral hygiene - because he can't clean his own teeth. I really looked after his teeth. In fact, I don't think they even cleaned them. So, every time we went there I booked, well, not every time because it was usually a Sunday, so

we had to go extra times every few weeks, him an appointment at the local dentist".

Participant A: "My son likes swimming, [so I said to them] go and take him swimming, burn some of his energy off. We had some sort of MDT with the advocate, his social worker and her manager. The staff reported that he couldn't swim. And he can swim, I've been in the pool with him, he's absolutely doing lengths. Then we figured out that the staff were sat on the side. We were like, where is the interaction, where is the stimulation? He was getting in the baby pool and just sitting there".

Although it should be stressed that participants described examples of good OOA provision, their experience with most OOA placements was in some contrast to that of the current, successful, in-area placements where time was taken to listen and plan prior to the placement and that this openness and commitment to good communication and collaboration continues following the move.

Participant C: "So, I went there [the in-area, in-house placement, prior to her son moving there] and I met loads of different staff, all doing different roles. We had flipcharts, we were doing training, all of us together. They were asking me about my son, and somebody was writing things down while I was talking. It was fantastic. It was the best thing that has ever happened to us with regard to him. Everybody cared, everybody. My son mattered to a point where he'd never mattered before then".

Participant A: The manager [at the current, in-house, placement], will ask me if [her son] has any issues and I've got no fear of going to the office and stating. I feel like the manager would listen and he will address it, and he won't try and cover it up because I feel like he's honest".

Participants D: [The current in-area provider said] "We'll spend time assessing…we'll use that time to review and if we think that we can meet his needs and give him a permanent place then we'll make that decision based on our experience with him. And he went there and almost straight away he just fell into line. There were still some incidents. I think it took him a couple of nights before he was sleeping through. He didn't have his music or his TV on all night [and] within a week he was a different person".

Participant C: "You finally felt like you could relax when he returned [to in-area] and was supported by the support he currently has. That was a kind of, moment".

Participant B: “There's good communication right the way through it [the current in-house provision], whether it’s the staff taking her out, or whether they’re in the communal areas or they’re in the flat, there’s always a good input. You’re always going and thinking, oh, you know, actually this is right for her. It feels better, a lot better”.

Distance

The distance families had to travel was a constant theme, particularly, in the context of placements that they didn’t trust or where they had concerns about the quality of care, where they felt compelled to go more often than they would otherwise have chosen to. Placements outside GM – Leicester, Birmingham, Yorkshire, for example – were one thing, but placements in GM were, invariably, as problematic.

Participant B: [A single carer following the death of his wife, with a son at home also with a learning difficulty] “It [his daughters in-GM OOA placement] is quite a distance, an hour, in total; a mad drive [on a Friday evening], come back, make tea. And then obviously on the Sunday after the Friday of picking her up, drop her off again so you could be shattered. And I’m thinking, I could do with somewhere a little bit closer”.

Participant C: “He still had [medical] appointments. We had no help, nobody drove anyone, it was us. We’d drive at six in the morning, earlier sometimes, to get him. Three hours there, three hours back, to the hospital”.
Participant A: “Sometimes my brother would take me [near Halifax], sometimes my friend would take me, family members have taken me. Or I would get the train. So, no support for any travel because I was on benefits because I was my son’s sole carer, so there was no sort of support from social care at all for me to get there, they shipped him up there, but they weren’t offering anything”.

Participant C: [OOA placement in another GM authority for her son was] “I'd say over an hour’s drive. But it could, you know, [be longer] with traffic. We work full time, Monday to Friday, so we used to go after work. We'd literally get on that motorway and go and have some tea out”.

It is worth noting, that in all four cases, the distance of the OOA placement from the placing authority impacted not just extended family; much valued contact with grandparents was often reduced or lost as well as social workers ability/inclination to visit, check-in and review.

Discussion

Given the limitations, already noted, of this research – small sample size and self-selected participants, arguably with a story to tell – it would be easy to read too much into these testimonies. That said, whilst all four families were careful to point out that at various points in time, the support their family member received OOA was good quality, person-centred and appreciated, it is nonetheless difficult not to conclude that had the current, final placements – all in-area, three in-house – been the *original* placements, then the experiences of, and outcomes for, all the individuals concerned would have been very different indeed. It is telling that each of the participants found the experience of an OOA placement periodically stressful at best and stressful throughout at worst. Some told of the toll it took on their mental health and on their relationships; all were clear that, to varying degrees, the experience was no less stressful or unhealthy or unsatisfactory for their loved ones.

The co-produced GM Learning Disability Strategy 2018 makes this very pertinent point: "Many people are placed out of area. This is wrong and we need to do something to change it, so it doesn't continue to happen in the future. Although we have less money than before, we still have a lot of money to support people with a learning disability, and we need to spend it differently so that we get good outcomes for everybody. We need health and social care services to be more flexible and offer a more personalised approach so that we can do things differently and so that power and control sit with people and not services". The reality remains, however, that often there is no option but to look OOA for support and so, whilst the focus for ASC should remain very much on people staying in-area, a better understanding of why and how OOA placements do not always deliver against assessed outcomes, and sometimes fail altogether, would help address the sort of issues experienced by the families interviewed.

Comparison with the findings from the research twenty plus years ago would, at least on a surface level, suggest little has changed in terms of how people experience OOA placements. Each of the four testimonies, touch on all of the themes highlighted in the literature review; poor quality of life and service provision issues, the largely negative impact on family life and social networks and system-level challenges.

This begs several questions: if policy has recognised that OOA placements are problematic, has this impacted on practice? If it has, are families seeing a difference? If so, how? If not, why? Are there (still) barriers to change and improvement and if so, what are they and can we change them? Given the significant costs – both financial and human – of OOA care, a deeper understanding of the issues could help drive change. Further research feels timely.

Of interest from a practice and commissioning perspective, the experience of the four families is that the cost, certainly in its widest sense, of multiple, failed OOA placements, is considerable. All four individuals are now in well-functioning placements in-area; settled and healthy, in regular contact with family and meaningfully engaged with their local communities to a degree that could not have been said, for the most part, whilst OOA.

All the participants described some or all of the following at the now successful in-area placements:

- Well paid staff
- Well trained staff
- Well managed staff
- A consistent staff team that remains in place over time, providing stability and continuity of care
- Experienced managers many of whom have progressed through the service
- Staff teams with the time and the skills to plan the transition in and to manage and flex support over time
- Staff and managers supported to liaise with family and to take their knowledge and views on-board
- Good quality accommodation

Notwithstanding the ongoing and very real financial pressures faced in ASC, perhaps addressing the above is where part of the answer lies? Why is it that the participants interviewed were far less likely to see this where their son or daughter was placed OOA? Agreeing, in conversation with providers, and, if appropriate, with reference to tools like CareCubed, annual uplifts that reflect the true costs that providers face and that allow them to pay a wage that helps with both the recruitment and retention of quality staff is a good starting point. Families are clear that they have seen the benefits – in terms of person-centred, outcomes focussed support – that come when staff are paid well and that they, as carers, benefit from too.

Building capacity in area should mean fewer OOA placements are required in the first instance as well as allowing more people to return to area with the support they need and with family nearby. In terms of market shaping, this may also mean in turn, that poorer quality provision is used less and ultimately becomes unsustainable leaving only good quality providers in the market. The GM Provider Framework – Helping People to Live Well at Home, should, over time, help commissioners and social workers feel more informed

about, and confident with, the providers they are working with. Dedicated OOA quality and review officers, keeping tabs on placements, building collaborative, supportive relationships with providers – in other words, an approach similar to well-established practice in-area - and liaising with learning disability social worker colleagues will also help.

Conclusions

The decision to place a family member OOA is not something that families take lightly and is one - these testimonies imply - that can have significant implications not only for those immediately affected, but also for ASC practitioners and the public purse. Whilst this is recognised in policy and has previously been highlighted in research, families remain clear that improvement is required. The challenge now is for ASC to drive change and improve practice. Perhaps the clearest message of all from the families interviewed is that local provision, delivered in a timely manner by well trained staff employed with good pay and conditions, is highly valued. In-area support helps retain – and in some cases repair or even strengthen – family bonds and support. From a service perspective, it ensures a valuable resource – families – can continue to help support people with a learning disability to live well and to live independently, whilst on a human level, listening to these stories, it could be concluded that typically, support provided in, and by, the communities people live in, is altogether healthier and happier and better; for the individuals, their families and for the wider workforce.

Hearing these powerful testimonies, about the considerable negative impact on people's health and wellbeing when things go wrong and about how, by building on the strengths of people and communities, there is so much to be gained when things go right, reminds us that people are more likely to have trust and confidence in services through partnership working; when they feel listened to and when they are part of the decision-making process and when support is consistent, timely and forward-thinking rather than reactive. Families are clear that this is far more likely to be the case when provision is 'on the doorstep'. Further, more detailed, rigorous research, co-produced with learning disabled people, their families and involving social care practitioners, will undoubtedly help inform this.

Recommendations

For the families interviewed, there were some very specific issues in common regarding diagnosed autism and learning disability, the transition for their young person from Children's services into ASC and around preparation for adulthood. There is a wealth of policy and strategy documents and good practice guidance available around these issues – increasingly, some, like Pembrokeshire County Council's delivery model, Pembrokeshire County Transitions from children to adults - IMPACT, coproduced with young people and their families – but this is not within the scope of this research and the

following recommendations recognise that older adults with a learning disability also, on occasions, are placed OOA. Hence, they focus very specifically on what happens once the decision has been made for someone to be placed OOA.

Principally, they are aimed at informing social work practice and at shaping local commissioning strategy, but also it is hoped that they might highlight an area of social care practice that could benefit from further, more rigorous academic research.

Actionable suggestions for social workers:

1. **Maintain a clear focus on keeping the person in-area** whether in the family home or living independently wherever possible.
2. **If an OOA placement becomes necessary**, be explicit from the outset - with the individual, their family, and the provider – that the placement is **short-term only**; alternative, permanent accommodation and support **within the local area** will be secured as soon as possible.
3. **Start planning from day one** for the person's return to their home area. Families report that OOA placements often drift, and the longer they continue, the harder it becomes to arrange a return.
4. **Work alongside the family throughout the placement** to ensure the provider actively engages with the family's rich knowledge of their relative; knowledge that is too often overlooked or undervalued.
5. Any concerns raised by the family about the support provided are addressed **swiftly and comprehensively**.
6. **Involve families in regular reviews and, where necessary, multi-disciplinary team (MDT) meetings** to maintain transparency and shared decision-making.

Actionable suggestions for policymakers and commissioners:

1. **Value in-area provision**: Families consistently highlight that local placements are highly valued and contribute to better outcomes.
2. **Staff pay and quality of care**: Feedback from families indicates greater confidence in providers where staff are paid well. Better pay is associated with lower turnover, improved continuity, and higher quality of care; factors that reduce placement breakdowns. This should be reflected in policy and commissioning strategies.
3. **Language and cultural competence**: Families report challenges when support staff have English as a second language, particularly where this leads to communication difficulties or cultural misunderstandings impacting on the health and wellbeing of individuals with autism and/or learning disabilities. Commissioners should address this within:

    - Workforce recruitment and retention strategies

- Market-shaping approaches
- Service specifications and training requirements

4. **Cost versus value**: Families note that lower or mid-cost placements do not necessarily represent best value. Their experience suggests that in-house and higher-cost in-area placements offer greater stability and demonstrably better outcomes. Conversely, multiple lower-cost OO A placements – particularly those made in haste - may result in poorer outcomes and higher overall costs when factoring in additional social work time and resources.

Suggestions for further research:

1. **Shift in research focus**: Previous studies on OOA placements have largely concentrated on measurable outcomes. Coproducing research with families offers an opportunity to capture powerful, lived experiences; stories that provide deep insight into what it means to live away from home.
2. **Amplifying unheard voices**: These perspectives have been largely absent from the evidence base but hold significant potential to:
    - Aid knowledge transfer
    - Inspire aspirational thinking
    - Drive meaningful and positive change in policy and practice
3. **Economic and outcome analysis**: A detailed comparative analysis of costs and outcomes for OOA placements versus in-area and in-house provision is essential. This should include:
    - Direct financial costs
    - Hidden costs (e.g., social work time, placement breakdowns)
    - Long-term outcomes for individuals and families

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Appendix 1

Families' Perspectives on Out of Area Placements for People with Learning Disabilities

Participant Information Sheet (PIS)

You are being invited to take part in a research study into out of area placements for people with a learning disability. The study aims to explore the particular perspectives and experiences of family members. It will be focussed on how placements are delivered, managed and supported. There is generally a recognition that people's voices often are unheard or lost when someone is placed away from their home. This study is a small, but no-less significant opportunity to have your experience heard, acknowledged and recorded in the context of a piece of research that will be shared across Greater Manchester and beyond, and that may help shape and improve practice in the future.

Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to participate and by all means, discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information.

About the research

- **Who will conduct the research?**

The research is being undertaken by Dave Wilson. Dave is on an 18-month secondment from Tameside Council working with The University of Manchester (Alison Littlewood, Programme Manager), in collaboration with Manchester Metropolitan University (Dr Caroline Leah, Principal Investigator) and the Greater Manchester Combined Authority as a Research Champion to develop and promote academic research into social care issues. Dave has over 30 years' experience working in Adult Social Care as a social worker and a Commissioner.

- **What is the purpose of the research?**

The research aims to re-visit research undertaken over twenty years ago around the placement of people with a learning disability in residential or supported living settings away from their home authority; specifically, from the perspective of family members and mindful of the current policy and practice context. The research will explore if these placements - and the circumstances that led to them - have changed in relation to the current and local practice and policy context.

To help inform the research, we would like to hear, first hand, the experiences of family members with a relative who has a learning disability and who now lives – or who has recently lived - out of area in a residential or supported living placement. We are keen to involve family members from across Greater Manchester and have approached a

number of local authority learning disability teams to recruit participants. The research will take the form of individual interviews with four to six family members participating.

- **Am I suitable to take part?**

To take part:

- You must be over 16 years of age
- Have a family member who has a learning disability and who lives in, or has recently been living in, an out of area residential setting. That is to say, somewhere other than the Greater Manchester authority they ordinarily live in or, where they live in a neighbouring GM authority, more than 10 miles away
- The Out of Area placement will have been made a minimum of 12 months ago
- You cannot be involved in any complaint procedures or any OOA placements where an individual was subject to safeguarding enquiries
- You must live in Greater Manchester

- **Will the outcomes of the research be published?**

One of the aims of the Research Champion role is to promote the uptake of academic research in social care so that Adult Social Care departments generally, and practitioners specifically, see the value of it and how it can be used to inform and improve practice. It is hoped that the final study will be published in an academic journal, possibly presented at a conference and shared with colleagues in the universities and the ten Greater Manchester authorities. As a participant, if you agree, you will be informed of the findings, and the final article will be shared once written up. Please note that you won't be identifiable in any of the findings presented.

- **Who has reviewed the research project?**

The project has been reviewed by The University of Manchester's Proportionate Research Ethics Committee (Reference: 2025-22256-40970).

- **Who is funding the research project?**

The project is funded by the National Institute for Health and Social Care Research (NIHR) Applied Research Collaboration Greater Manchester (ARC-GM).

<u>What would my involvement be?</u>

- **What would I be asked to do if I took part?**

You will be asked to take part in an audio-recorded one-to-one interview, either in person or via Zoom or Teams to suit. The interview will last up to 90 minutes including consenting procedures. You will have the opportunity to talk openly and candidly about your experience, the challenges and opportunities, the positives and the negatives.

Any data relating to you or your family member will be anonymised. Your name, address or anything else that may identify you will not be used in the final article and the same applies to your family member.

The interview will be as informal as possible by way of helping you to feel comfortable with some 'ground-rules' in place to ensure you feel safe sharing your story. Please feel

free to be accompanied by a family member or friend should you feel the need; whilst they may not participate directly in the interview, they can be with you throughout for support.

If you decide to take part, please be assured that your involvement in the study will not affect the service/experience of your family member in any way.

➢ **Will I be compensated for taking part?**

Yes, you will receive a £15 'Love to Shop' voucher for taking part in the interview and any travel expenses incurred will be refunded via a University of Manchester expenses form. Vouchers will be emailed to you at the end of the interview from the University of Manchester finance team, who will need your name and email address details in order to send this.

➢ **What happens if I do not want to take part or if I change my mind?**

It is up to you to decide whether or not to take part, if you are unsure or want to ask further questions then you can contact Dave Wilson using the details at the end of this information sheet. If you do decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form. You are free to withdraw at any time without giving a reason and without detriment to yourself. However, it will not be possible to remove your data from the project once it has been anonymised as we will not be able to identify your specific data. This does not affect your data protection rights.

If you decide not to take part, you do not need to do anything further.
Participants are free to decline the audio recording of the interview if they wish (the interviewer would take notes) and are also able to stop the recording at any time by asking the researcher. If you ask for the interview to be terminated any notes or recordings will be destroyed

Data Protection and Confidentiality

➢ **What information will you collect about me?**

In order to participate in this research project, we will need to collect information that could identify you, called "personal identifiable information". Specifically, we will need to collect:

- Name
- Local Authority where your family member is originally from
- Local Authority where your family member has been placed
- Relationship to family member
- Record of consent

The audio recordings will:

- Consist of voice only during the interview discussion
- Be obtained using a tape recorder in the room or if online we will record voice only

- **Under what legal basis are you collecting this information?**

We are collecting and storing this personal identifiable information in accordance with UK data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is "a public interest task" and "a process necessary for research purposes".

- **What are my rights in relation to the information you will collect about me?**

You have a number of rights under data protection law regarding your personal information. For example, you can request a copy of the information we hold about you, including audio recordings.
If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our [Privacy Notice for Research](https://documents.manchester.ac.uk/display.aspx?DocID=37095) accessed here https://documents.manchester.ac.uk/display.aspx?DocID=37095.

- **Will my participation in the study be confidential and my personal identifiable information be protected?**

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way:

- Any identifying information will be stored securely and separately from your study data. To ensure confidentiality, participants will be assigned initially with an ID number with a key linking this ID number to your details only known to the research team.
- Once data has been analysed, we will destroy the key which then anonymises your data.
- Your consent form (including your name and signature) will be retained separately for 5 years after the end of the study in a locked filing cabinet on University premises.
- We will not store your contact details for future studies.

For audio recordings, please note the following information:

Audio recordings will be used to create transcripts, these will be created by 1st Class Secretarial, an approved University of Manchester transcription service supplier who have a confidentiality agreement in place between their organisation and the University. All personal identifiable information will be removed in the final transcript. Once audio recordings have been transcribed, the audio files will be deleted. Only the research team and the approved transcription provider will have access to the recordings.

If Zoom/Teams are used to conduct interviews, then please note the following information:

If requested by the participant, interview may be conducted via Zoom/Teams. This may mean that your personal data is transferred to a country outside of the European Economic Area, some of which have not yet been determined by the United Kingdom to

have an adequate level of data protection. Appropriate legal mechanisms to ensure these transfers are compliant with the Data Protection Act 2018 and the UK General Data Protection Regulation are in place. The recordings will be removed from the above third-party platform and stored on University of Manchester managed file storage as soon as possible following the completion of data collection.

Potential Disclosures

If, during our conversation, you disclose any information regarding practice that could be considered risky and/or unlawful in the residential setting where your family member lives and/or which means you may be at risk of harming yourself or others, we will be required to break confidentiality to put you in touch with the correct support. This may involve signposting you to relevant support services and/or raising a safeguarding even if the disclosure is historical.

Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

What if I have a complaint?

If you have a complaint that you wish to direct to members of the research team, please contact Alison Littlewood in the first instance (alison.j.littlewood@manchester.ac.uk) or telephone 0161 306 8109.

If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from Alison, then please contact: The Research Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 0161 306 8089.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.
You also have a right to complain to the Information Commissioner's Office about complaints relating to your personal identifiable information - https://ico.org.uk/make-a-complaint/ or Tel 0303 123 1113

Contact Details

If you have any queries about the study or if you are interested in taking part, then please contact the researcher:

DAVE WILSON
David.wilson-5@manchester.ac.uk
Telephone: 07974821336

For more information, please contact Alison Littlewood
alison.j.littlewood@manchester.ac.uk

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