Journal of Applied Research in Intellectual Disabilities

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ORIGINAL ARTICLE OPEN ACCESS

(Not) Going Out and Barriers to Leaving the House for People With Intellectual Disabilities Through the COVID-19 Pandemic in the UK

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Received: 5 June 2024 | **Revised:** 27 August 2024 | **Accepted:** 9 September 2024

Funding: This work was supported by the UK Research and Innovation (Medical Research Council), Department for Health and Social Care (National Institute for Health Research) as part of the UKRI-DHSC COVID-19 Rapid Response Rolling Call (grant number COV0196) and the National Institute for Health Research Policy Research Programme (grant number NIHR204404).

Keywords: community | COVID-19 | intellectual disabilities | learning disability | social participation

ABSTRACT

Background: People with intellectual disabilities commonly experience multiple barriers to 'going out'.

Aims: This paper explores what barriers prevented people from going out, and if the extent and nature of going out changed over time for people with intellectual disabilities as the COVID-19 pandemic progressed.

Methods: Data are drawn from a wider study that explored, at four time points, the experiences of people with intellectual disabilities through the COVID-19 pandemic in the United Kingdom.

Findings: The number of people leaving the house for almost all reasons increased over time through the pandemic, except for some outdoor participation and exercise. However, there was a significant decrease in outdoor exercise at the final time point of the study. Reliance on other people and a lack of availability of support were identified as barriers.

Conclusion: A combination of factors restricted the extent to which people were going out even after COVID-19 protections were lifted.

1 | Introduction

Article 30 of the Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations 2006) articulates the rights of disabled people to participate in cultural life, recreation, leisure and sport on an equal basis with others. However, people with intellectual disabilities have reduced opportunities for leaving their homes for a range of purposes, including routine daily activities such as shopping; social activities such as meeting with friends and family; cultural activities; fun and hobbies; or health and exercise (Taylor-Roberts et al. 2019; Verdonschot et al. 2009). Researchers have often referred to taking part in this collection of activities as 'community and social participation'. Despite community participation often being viewed as a goal for social inclusion (Jenaro et al. 2005), it is a complex concept which has been defined and measured in a range of ways (Taylor-Roberts et al. 2019). For example, Chang et al. (2013, 772) define community participation as:

'active involvement in activities that are intrinsically social and either occur outside the home or are part of a nondomestic role'. The research presented in the current paper is largely situated in the body of research around community and social participation, but we take the broader view of community participation used by Verdonschot et al. (2009) that includes day-to-day activities of leaving the house; including domestic activities such as shopping and activities that take place outside the house that are not necessarily directly social (e.g., going for a walk). In part, this broader approach is due to the research taking place during the COVID-19 pandemic, when there was a greater significance to leaving the house due to social distancing restrictions. However, we also deliberately chose the broader perspective of going out/leaving the house to avoid trivialising the importance of social participation, belonging and relationships that derive from taking part in a range of activities in day-to-day lives.

Research that explores the community and social participation of people with intellectual disabilities is important due to the interconnectedness of going out with social connections, good quality of life, good mental health, healthy lifestyles and good physical health. Given reported higher levels of loneliness among people with intellectual disabilities (Alexandra, Angela, and Ali 2018; Gilmore and Cuskelly 2014; Malli et al. 2022), participation in community and social participation activities is important because it can reduce the risk of mental health issues and loneliness (Robinson and Idle 2023; Scott and Havercamp 2014) and is associated with better quality of life (Schalock et al. 2002). People's choices about going out of the house are also important because they can be one of many crucial everyday choices (O'Donovan, McCallion, and McCarron 2017) that are associated with identity building, autonomy and a sense of control over people's own lives.

There are known barriers that can prevent many people with intellectual disabilities from fully participating in community activities and having a full social life (Merrells, Buchanan, and Waters 2019; Mooney, Rafique, and Tilly 2019). A review (Dowling et al. 2012) concluded that lack of transport, lack of support and financial constraints constituted the main barriers to involvement in leisure activities. Transport is crucial in being able to go places and has been identified as a barrier to going out (Friedman and Rizzolo 2016), crucially because of a necessary reliance on other people (Dudley, Emery, and Nicholas 2012). More recently, Charnley et al. (2019) identified injuries, conditions or health problems; limited availability of appropriate leisure facilities; and fears for personal safety as barriers to taking part in leisure activities. While Dowling et al. (2012) and Charnley et al. (2019) have identified barriers associated with participation in leisure activities, there are similar barriers to 'leaving the house' to participate in other activities such as exercise (Caton et al. 2012; Messent, Cooke, and Long 1990), employment (Meltzer, Robinson, and Fisher 2019), volunteering (Wicki and Meier 2016) and socialising (Abbott and Mcconkey 2006).

From a review of research in this area, Amado et al. (2013) concluded that most previous research around community participation is carried out with people in 'paid formal services' with less research evidence around the experiences of people who live on their own or with their families. The current study is significant as it contributes to this understanding with a particular focus on going out in the context of people's experiences through the COVID-19 pandemic. The worldwide pandemic and its associated social distancing regulations had significant implications for people being able to go out and take part in the usual range of community and social activities. These regulations were of particular relevance for people with intellectual disabilities who had a disproportionately higher risk of hospitalisation and death from COVID-19 (Sosenko et al. 2023), and often rely on contact with other people to realise activities that take place outside of their homes. There is now growing evidence of the mental health impact of the pandemic (Flynn et al. 2021a, 2021b; Hatton et al. 2023) and that this impact has been significantly underestimated (Gabrielsson et al. 2023).

The current study advances understanding of the impact of the pandemic on community and social participation by presenting both quantitative and qualitative findings from a wider study that explored, at four time points, the experiences of people with intellectual disabilities through the COVID-19 pandemic in the United Kingdom (Flynn et al 2021a, 2021b; Hatton et al. 2023). Using the data collected through that study, we aimed to answer the following research questions:

1. How did the extent and nature of going out change over time for people with intellectual disabilities as the COVID-19 pandemic progressed?
2. What barriers prevented people with intellectual disabilities from going out during the COVID-19 pandemic?

2 | Methods

2.1 | Participants

Two groups of people were recruited for the study: adults with intellectual disabilities who were interviewed by a researcher (Cohort 1), and adults with intellectual disabilities who would not be able to take part in an interview, where family or paid carers reported about the person's life via an online survey (Cohort 2). Selected demographic information is presented in Table 1 for both cohorts at the final of four time points (Wave 4) of the study. People from all four countries in the United Kingdom were well represented (see Table 1).

For Cohort 1, most participants were aged 16–44 years (67.5%), just over half were men (51.3%), the majority were White British (88.6%), 22.1% were also autistic and 10.7% were people with Down syndrome. Most people in Cohort 1 were living with their family (41.3%), living alone or with a partner (37.6%), with few people living with other people with intellectual disabilities in some form of supported housing or residential accommodation (19.4%). Among those people not living alone, 12.3% reported looking after someone they lived with.

For Cohort 2, most people with intellectual disabilities were aged 16–44 (83.1%), a majority were men (52.3%), and the majority were White British (90.8%). Respondents reported that the term 'Profound and Multiple Learning Disabilities' (PMLD) applied

TABLE 1 | Demographic and living circumstances of participants at Wave 4.

	Cohort 1 (Wave 4, $n = 298$)	Cohort 2 (Wave 4, $n = 153$)
Gender		
Man	153 (51.3%)	80 (52.3%)
Woman	139 (46.6%)	71 (46.4%)
Other	2 (0.7%)	0 (0.0%)
Do not want to answer	1 (0.3%)	0 (0.0%)
Age		
16–24	27 (9.1%)	42 (27.5%)
25–34	89 (29.9%)	54 (35.3%)
35–44	85 (28.5%)	31 (20.3%)
45–54	48 (16.1%)	14 (9.2%)
55–64	29 (9.7%)	6 (3.9%)
65+	13 (4.4%)	4 (2.6%)
Ethnicity		
White British	264 (88.6%)	139 (90.8%)
White—Irish, Roma, Gypsy or Irish Traveller, Other	13 (4.4%)	7 (4.7%)
Asian	3 (1.0%)	1 (0.7%)
Black	9 (3.0%)	0 (0.0%)
Mixed/multiple ethnicities	5 (1.7%)	5 (4.1%)
Do not want to answer	2 (0.7%)	1 (0.7%)
Down syndrome		
Yes	32 (10.7%)	27 (24.2%)
Professional label of autism or Asperger's syndrome		
Yes	68 (22.1%)	68 (44.4%)
No, but waiting for an assessment or self-identifies (Cohort 1) or carer/supporter identifies person (Cohort 2) as autistic	5 (1.7%)	19 (12.5%)
Term 'Profound and multiple learning disabilities' (PMLD) applies to person		
Yes	n/a	68 (44.4%)
Country the participant lives in		
England	85 (28.5%)	63 (41.2%)
Northern Ireland	50 (16.8%)	14 (9.2%)
Scotland	79 (26.5%)	50 (32.7%)
Wales	84 (28.2%)	26 (17.0%)
Living situation		
Lives alone with no support from staff	24 (8.1%)	1 (0.7%)
Lives alone with support staff coming into home	70 (23.5%)	12 (7.9%)
Lives with partner with no support from staff	10 (3.4%)	0 (0.0%)
Lives with partner with support staff coming into home	8 (2.7%)	0 (0.0%)
Lives with family with no support from staff	112 (37.6%)	59 (38.6%)
Lives with family with support staff coming into home	11 (3.7%)	31 (20.3%)

(Continues)

TABLE 1 | (Continued)

	Cohort 1 (Wave 4, $n = 298$)	Cohort 2 (Wave 4, $n = 153$)
Lives in a Shared Lives arrangement	3 (1.0%)	6 (3.9%)
Lives with other people with intellectual disabilities, with no support from staff	1 (0.3%)	0 (0.0%)
Lives with other people with intellectual disabilities, with support from staff	57 (19.1%)	39 (25.5%)
Lives in other living situations	1 (0.3%)	4 (2.6%)
Person looks after someone they live with ($n = 203$)		
Yes	25 (12.3%)	n/a
Cohort 2 only—Relationship of the respondent to the person with intellectual disabilities		
Family carer	n/a	142 (92.8%)
Support worker or paid carer	n/a	9 (5.9%)
Shared Lives carer	n/a	2 (1.3%)

to almost half of people in Cohort 2 (44.4%), 24.2% were people with Down syndrome and 44.4% were autistic. Most adults with intellectual disabilities in Cohort 2 were living with their family (59.1%), relatively few people were living alone (8.6%), and a quarter of people were living with other people with intellectual disabilities, usually in some form of supported housing or residential accommodation (25.5%).

2.2 | Procedure

The study involved four waves of data collection: Wave 1 December 2020 to February 2021 (largely during a national UK 'lockdown'); Wave 2 April 2021 to May 2021 (as public health protections were beginning to ease); Wave 3 July 2021 to August 2021 (when, at least in England, almost all public health protections were removed); Wave 4 September 2022 to December 2022 (largely in the months of October and November, when public health protections and free COVID-19 testing had stopped).

The selection and wording of questions were finalised through extensive consultation with groups of people with intellectual disabilities (particularly for Cohort 1 interviews) and family organisations (particularly for Cohort 2 surveys) at each data collection Wave, to maximise relevance and accessibility. Due to rapidly changing circumstances throughout the project due to the phases of UK pandemic restrictions, the inclusion and wording of questions could vary from wave to wave—the wording of questions is indicated in each table in the current paper.

Recruitment of people into the study at Waves 1 and 2 was facilitated through collaborating organisations in each country, social media and wider networks of intellectual disability and family organisations. Potential participants could express interest in the study via telephone, e-mail, social media or clicking a link to the survey (for family carers and support staff only) on the research project website. Contact details of people who had indicated an interest in taking part in Cohort 1 were sent to research teams in the relevant country, who contacted each person to talk through the project and send them the easy read participant information sheet. If people were still interested in taking part, at least 24 h later, the interviewer arranged to go through the consent process and, if the person consented, conduct the interview. For Cohort 2, the survey (including consent process) was available online. No participants received an honorarium for participating. For Waves 3 and 4, participants who had taken part in previous waves and indicated a willingness to be contacted again were invited to take part.

For Cohort 1, trained research interviewers directly interviewed adults with intellectual disabilities via Zoom, telephone, Microsoft Teams, WhatsApp video call, Messenger video call or FaceTime, depending on the interviewee's preference. All interviewees had the capacity to take part in the interviews and gave their consent to do so. Data were entered directly into a Qualtrics survey during the interviews by the interviewers. Three people at Wave 4 preferred to self-complete an online version of the survey. Participants could also have a supporter of their choice present at the interview. In all cases, flexibility was paramount to ensure that people could participate in their preferred way. Interviews typically took 45 min and were usually completed in one sitting. All interviewers had experience of research interviewing and were trained via online training sessions within each country.

For Cohort 2, information was collected via an online Qualtrics survey about adults with intellectual disabilities who were not able to take part in an interview with a researcher. To gather data on this group, we surveyed their family carers or paid support staff. At Wave 4, 93.2% of respondents were family carers of an adult with intellectual disabilities and 5.7% of respondents were paid support staff of an adult with intellectual disabilities. The remaining 1.0% of respondents were other people who knew the adult with intellectual disabilities very well (e.g., a friend).

2.3 | Measures

For the analyses included in this paper, questions focused on demographic factors, whether people had ever had COVID-19 and whether they had three or more COVID-19 vaccine doses, whether people had enough money to do what they wanted to do (adapted from Hatton et al. 2022), whether people had left their house in the last week for a variety of reasons (adapted from the Office for National Statistics Opinions and Lifestyle Survey [COVID-19 module] ONS 2022), how people got around and whether anything got in the way of going out when people wanted to go somewhere (adapted from questions used in Hatton et al. 2022).

2.4 | Data Analysis

In Cohort 1, 358 participants were interviewed at Wave 4. All quantitative analyses were conducted on the 298 people who had provided data at all four waves. In Cohort 2, we received completed online surveys at Wave 4 concerning 192 people with intellectual disabilities. All quantitative analyses were conducted on the 153 respondents who had provided data at all four waves. Cohort 1 and Cohort 2 data sets were analysed separately throughout, using SPSS 28.

For each specific question relating to going out of the house in the last week (Cohort 1—Table 2; Cohort 2—Table 3), Cochran's *Q* non-parametric repeated measures analyses were conducted to investigate whether overall there were differences in the proportions of people leaving the house for that reason across Waves 1–4. If there was an overall effect at $p < 0.01$, McNemar's tests were conducted to investigate differences from Waves 1 to 2, Waves 2 to 3, and Waves 3 to 4. Using Wave 4 data only, Mann–Whitney *U*-tests were used to examine associations between going out for a greater range of reasons and whether participants had COVID-19, whether they had been vaccinated three or more times, and whether participants were considered to have enough money to do the things they wanted to do.

For analysis of the open-ended responses, qualitative content analysis (an interpretive form of content analysis) (Hsieh and Shannon 2005) was used to identify commonalities in the data. Analysis was an iterative process. Author 1, read and re-read all responses and created an initial coding framework and coded all responses. To establish reliability, Author 2 coded 20% of randomly selected responses. Some participants' responses contained more than one concept, so each new concept was recorded separately, but each concept was only coded to one code. Where there was disagreement, S.C. and C.H. discussed the coding, reached agreement, then checked other codes from the wider data set relevant to the discussion. For Cohort 1, there was an initial 76% coding agreement. After discussion, one initial code was broken down into two codes and a new code was added. For Cohort 2, there was an initial 79% coding agreement; after discussion, disagreements were resolved and one new code was added.

2.5 | Ethical Approval

Research ethics approval was sought and obtained from the Manchester Metropolitan University Faculty of Health, Psychology and Social Care Faculty Research Ethics Committee for all four waves of data collection. For Cohort 1, informed audio-recorded consent was obtained from each participant before the interview began; for Cohort 2, consent was obtained at the start of the survey.

3 | Results

3.1 | Quantitative Results

Table 2 shows the number of participants in Cohort 1 who reported leaving the house for a variety of reasons in the week before being interviewed, over all four waves of the project.

Overall, the proportion of people from Cohort 1 leaving the house for almost all reasons increased over time across the project waves ($p < 0.001$), with the exception of 'leaving the house to provide care or support for someone who needs your help', which was fairly consistent (6%–10%) over all four waves and 'visiting a park or local green space', where there was a significant overall difference between waves at $p < 0.005$, but no specific significant differences between Waves 1 and 2, Waves 2 and 3, or Waves 3 and 4.

People leaving the house to go to work or work experience significantly increased overall from Waves 1 (17%) to 4 (51%), with significant increases from Waves 1 to 2, Waves 2 to 3, and Waves 3 to 4. Going shopping for food, medicine and other essentials increased overall from Waves 1 (62%) to 4 (83%), with a significant increase from Waves 1 to 2 but no significant differences from Waves 2 to 3 or Waves 3 to 4. Visiting a hairdresser or barber increased overall from Waves 1 (6%) to 4 (17%), with a significant increase from Waves 1 to 2 but no significant differences from Waves 2 to 3 or Waves 3 to 4. Using public transport increased overall from Waves 1 (21%) to 4 (58%), with significant increases from Waves 1 to 2 to Waves 2 to 3, but no statistically significant difference from Waves 3 to 4.

Meeting up with people in their homes increased overall across the four waves (Wave 1—15%; Wave 4—46%), with significant increases from Waves 1 to 2 and Waves 2 to 3, but no significant difference from Waves 3 to 4. Visiting a cinema, theatre or nightclub increased overall from Waves 1 (1%) to 4 (16%), with a significant increase from Waves 2 to 3 but no significant differences from Waves 1 to 2 or Waves 3 to 4. There was an overall difference across all four waves in collecting takeaway food or drinks from a takeaway, café, bar or pub, with a significant increase from Waves 1 (18%) to 2 (36%), but no significant differences from Waves 2 to 3 or Waves 3 to 4. Participants were only asked in Wave 4, but 66% of people had visited a café, restaurant, pub or bar.

Doing exercise/sport in a gym, sports hall or leisure centre increased significantly from Waves 1 (5%) to 4 (27%), with no significant difference from Waves 1 to 2 but significant increases from Waves 2 to 3 and Waves 3 to 4. Doing exercise/sport somewhere outdoors changed overall from Waves 1 to 4, with a significant increase from Waved 1 (68%) to 2 (78%), no significant difference between Waves 2 and 3, and a significant decrease from Waves 3 (82%) to 4 (70%).

TABLE 2 | Leaving the house in the last week. Cohort 1 ($n = 298$), Waves 1–4.

In the last week, have you gone out to…	Wave 1	Wave 2	Wave 3	Wave 4	Cochran's *Q* (overall W1–W4)
	n (%)	*n* (%)	*n* (%)	*n* (%)	McNemar tests (W1–W2; W2–W3; W3–W4)
					All $p < 0.001$
Work/work experience	51 (17%)	80 (27%)	105 (35%)	153 (51%)	**$\chi^2 = 119.11$; df = 3; $p < 0.001$ W1 < W2 < W3 < W4**
Meet up with people in their home	45 (15%)	76 (26%)	136 (46%)	138 (46%)	**$\chi^2 = 115.16$; df = 3; $p < 0.001$ W1 < W2 < W3 = W4**
Go shopping for food, medicine and other essentials	184 (62%)	239 (80%)	242 (81%)	248 (83%)	**$\chi^2 = 69.22$; df = 3; $p < 0.001$ W1 < W2 = W3 = W4**
Collect takeaway food or drinks from a takeaway, café, bar or pub	55 (18%)	107 (36%)	137 (46%)	116 (39%)	**$\chi^2 = 62.63$; df = 3; $p < 0.001$ W1 < W2 = W3 = W4**
Visit a hairdresser or barber	18 (6%)	55 (18%)	62 (21%)	52 (17%)	**$\chi^2 = 32.09$; df = 3; $p < 0.001$ W1 < W2 = W3 = W4**
Visit a cinema, theatre or night club	2 (1%)	3 (1%)	53 (18%)	48 (16%)	**$\chi^2 = 91.81$; df = 3; $p < 0.001$ W1 = W2 < W3 = W4**
Do exercise/sport in a gym, sports hall or leisure centre	15 (5%)	12 (4%)	51 (17%)	81 (27%)	**$\chi^2 = 116.40$; df = 3; $p < 0.001$ W1 = W2 < W3 < W4**
Do exercise/sport somewhere outdoors, like walking, running or cycling	203 (68%)	231 (78%)	244 (82%)	208 (70%)	**$\chi^2 = 30.41$; df = 3; $p < 0.001$ W1 < W2 = W3 > W4**
Visit a park or local green space	143 (48%)	166 (56%)	176 (59%)	160 (54%)	**$\chi^2 = 12.70$; df = 3; $p = 0.005$ W1 = W2 = W3 = W4**
Go to a place of worship, like a church, mosque, temple or synagogue	18 (6%)	39 (13%)	46 (15%)	68 (23%)	**$\chi^2 = 64.18$; df = 3; $p < 0.001$ W1 < W2 = W3 < W4**
Provide care or support for someone who needs your help	23 (8%)	18 (6%)	30 (10%)	20 (7%)	$\chi^2 = 4.72$; df = 3; $p = 0.19$ (no McNemar tests calculated)
Use public transport, like a bus or a train	63 (21%)	102 (34%)	162 (54%)	173 (58%)	**$\chi^2 = 156.11$; df = 3; $p < 0.001$ W1 < W2 < W3 = W4**
Go somewhere in a private car	n/a	n/a	n/a	181 (61%)	n/a
Go to a café, restaurant, pub or bar	n/a	n/a	n/a	196 (66%)	n/a

Note: Bold values indicate statistical significance at $p < 0.01$.

Going to a place of worship increased overall from Waves 1 (6%) to 4 (23%), with significant increases from Waves 1 to 2 and Waves 3 to 4 but no significant difference from Waves 2 to 3.

At Wave 4, in Cohort 1 in the preceding week, people had been out on average in 6.2 different places/ways (range 0–12): 4 people (1.3%) had not been out in any of the ways listed; 11 people (3.7%) had been out in 1–2 ways; 54 people (18.2%) had been out in 3–4 ways; 81 people (27.2%) had been out in 5–6 ways; 106 people (35.6%) had been out in 7–8 ways; and 42 people (14.0%) had been out in 9 or more ways. People in Cohort 1 were more likely to have left the house for a greater range of reasons at Wave 4 if they had already had COVID-19 (Mann–Whitney $U = 8110$, $p = 0.003$) and if they reported having enough money to do the things they wanted to do (Mann–Whitney $U = 4073.5$, $p < 0.001$).

Table 3 shows the proportion of people with intellectual disabilities in Cohort 2 who were reported to be leaving the house for a variety of reasons in the week before being surveyed, over all four waves of the project.

Overall, the proportion of people in Cohort 2 leaving the house for almost all reasons increased over time ($p < 0.001$), with the exception of leaving the house to collect takeaway food or drinks (5%–14% of people at different time points) and leaving the house to do exercise/sport somewhere outdoors, like running, walking or cycling (24%–32% of people at different time points).

People with intellectual disabilities leaving the house to go to work or work experience overall increased through the waves from Waves 1 (1%) to 4 (12%), although there were no significant differences between specific waves (Waves 1 to 2, Waves 2 to 3

TABLE 3 | Leaving the house in the last week. Cohort 2 ($n = 153$), Waves 1–4.

In the last week, has the person you support/care for gone out to...	Wave 1	Wave 2	Wave 3	Wave 4	Cochran's Q (overall W1–W4)
	n (%)	*n* (%)	*n* (%)	*n* (%)	McNemar tests (W1–W2; W2–W3; W3–W4)
					All $p < 0.001$
Work/work experience	1 (1%)	6 (4%)	16 (10%)	19 (12%)	**$\chi^2 = 32.77$; df = 3; $p < 0.001$ W1 = W2 = W3 = W4**
Meet up with people in their home	3 (2%)	10 (7%)	28 (18%)	32 (21%)	**$\chi^2 = 39.20$; df = 3; $p < 0.001$ W1 = W2 < W3 = W4**
Go shopping for food, medicine and other essentials	26 (17%)	40 (26%)	50 (33%)	83 (54%)	**$\chi^2 = 84.33$; df = 3; $p < 0.001$ W1 = W2 = W3 < W4**
Collect takeaway food or drinks from a takeaway, café, bar or pub	8 (5%)	19 (12%)	22 (14%)	17 (11%)	$\chi^2 = 9.91$; df = 3; $p = 0.019$ (no McNemar tests calculated)
Visit a hairdresser or barber	0 (0%)	22 (14%)	25 (16%)	25 (16%)	**$\chi^2 = 37.73$; df = 3; $p < 0.001$ W1 < W2 = W3 = W4**
Visit a cinema, theatre or night club	0 (0%)	0 (0%)	19 (12%)	21 (14%)	**$\chi^2 = 45.38$; df = 3; $p < 0.001$ W1 = W2 < W3 = W4**
Do exercise/sport in a gym, sports hall or leisure centre	1 (1%)	7 (5%)	17 (11%)	33 (22%)	**$\chi^2 = 56.81$; df = 3; $p < 0.001$ W1 = W2 = W3 < W4**
Do exercise/sport somewhere outdoors, like walking, running or cycling	37 (24%)	47 (31%)	49 (32%)	41 (27%)	$\chi^2 = 4.63$; df = 3; $p = 0.201$ (no McNemar tests calculated)
Visit a park or local green space	60 (39%)	84 (55%)	95 (62%)	83 (54%)	**$\chi^2 = 25.79$; df = 3; $p < 0.001$ W1 < W2 = W3 = W4**
Go to a place of worship, like a church, mosque, temple or synagogue	1 (1%)	7 (5%)	4 (3%)	15 (10%)	**$\chi^2 = 22.12$; df = 3; $p < 0.001$ W1 = W2 = W3 < W4**
Use public transport, like a bus or a train	4 (3%)	9 (6%)	14 (9%)	34 (22%)	**$\chi^2 = 52.31$; df = 3; $p < 0.001$ W1 = W2 = W3 < W4**
Go somewhere in a private car	75 (49%)	103 (67%)	111 (73%)	115 (75%)	**$\chi^2 = 41.55$; df = 3; $p < 0.001$ W1 < W2 = W3 = W4**
Go to a café, restaurant, pub or bar	n/a	n/a	n/a	81 (53%)	n/a

Note: Bold values indicate statistical significance at $p < 0.01$.

and Waves 3 to 4). The number of people going shopping for food, medicine and other essentials also increased overall from Waves 1 (17%) to 4 (54%), with no significant differences from Waves 1 to 2 or Waves 2 to 3, but a significant increase from Waves 3 to 4. Visiting a hairdresser or barber increased overall from Waves 1 (0%) to 4 (16%), with a significant increase from Waves 1 to 2 but no significant differences from Waves 2 to 3 or Waves 3 to 4. Using public transport increased overall from Waves 1 (3%) to 4 (22%), with no significant differences from Waves 1 to 2 or Waves 2 to 3, but a significant increase from Waves 3 to 4. Going somewhere in a private car increased overall from Waves 1 (49%) to 4 (75%), with a significant increase from Waves 1 to 2 but no significant differences from Waves 2 to 3 or Waves 3 to 4.

Meeting up with people in their homes increased overall from Waves 1 (2%) to 4 (21%), with a significant increase from Waves 2 to 3 but no significant differences from Waves 1 to 2 or Waves 3 to 4. Going to a cinema, theatre or nightclub increased overall from Waves 1 (0%) to 4 (14%), with a significant increase from Waves 2 to 3 but no significant differences from Waves 1 to 2 or Waves 3 to 4. As with Cohort 1, the question was only asked in Wave 4, but 53% of people with intellectual disabilities had been to a café, restaurant or bar in the previous week.

Doing exercise/sport in a gym, sports hall or leisure centre increased overall from Waves 1 (1%) to 4 (22%), with no significant differences from Waves 1 to 2 or Waves 2 to 3, but a significant increase from Waves 3 to 4. Visiting a park or local green space increased significantly overall from Waves 1 (39%) to 4 (54%), with a significant increase from Waves 1 to 2 but no significant differences from Waves 2 to 3 or Waves 3 to 4. Going to a place of worship increased overall from Waves 1 (1%) to 4 (10%), with no significant differences from Waves 1 to 2 or Waves 2 to 3, but a significant increase from Waves 3 to 4.

At Wave 4, in Cohort 2 in the last week, people had been out on average in 3.9 different places/ways (range 0–12): 10 people (6.5%) had not been out in any of the ways listed; 41 people

(26.8%) had been out in 1–2 ways; 41 people (26.8%) had been out in 3–4 ways; 41 people (26.8%) had been out in 5–6 ways; and 20 people (13.1%) had been out in 7 or more ways. For people in Cohort 2, there were no associations between leaving the house for a greater range of reasons at Wave 4 and having had COVID-19, having had 3+ vaccinations, or having enough money to do the things people wanted to do.

Table 4 shows both cohorts at Wave 4 responses to questions about how people typically got to places and whether people had any support they needed to get out of the house. For Cohort 1, people most commonly used the bus or tram to get to places (69%), closely followed by walking, using a wheelchair or a mobility scooter (62%). For Cohort 2, people were most commonly driven by family/friends/personal assistant (PA) in a car (82%). When asked if people need someone to go with them when they want to go somewhere, responses for Cohort 1 were quite evenly split, with 39% saying no, 36% saying yes and 25% saying that it depended on where and how far they were going. For Cohort 2, 87% said that the person they supported needed someone to go with them, 10% said it would depend where and how far they were going and only 1% said no. In Cohort 1, most people said there was usually someone around who could help (43%), or that it did not apply to them (40%). For Cohort 2, 40% said there was usually someone around to help, but nearly a third (31%) said that all outings had to be planned in advance.

TABLE 4 | Wave 4: Getting to places (Cohort 1, $n = 298$; Cohort 2, $n = 153$).

	Cohort 1, *n* (%)	Cohort 2, *n* (%)
How do you/does the person you support/care for usually get to places?		
Walk/wheelchair/mobility scooter	184 (62%)	61 (40%)
Drive myself/themselves	6 (2%)	0 (0%)
Driven by family/friends/PA in a car	163 (55%)	125 (82%)
Driven in a car/minibus with other people with intellectual disabilities	44 (15%)	30 (20%)
Taxi	103 (35%)	20 (13%)
Bus/tram	204 (69%)	28 (18%)
Train/metro/tube	78 (26%)	8 (5%)
Bike	10 (3%)	3 (2%)
When you/the person you support/care for wants to go somewhere, do you/they usually need someone to go with you/them?		
Yes	107 (36%)	133 (87%)
No	116 (39%)	2 (1%)
It depends on where and how far they are going	74 (25%)	15 (10%)
Is there usually someone around who can help you/the person you support/care for when you/they want to go somewhere?		
Yes, there is usually someone around who can help	128 (43%)	61 (40%)
Usually have to wait	6 (2%)	1 (1%)
Sometimes there is someone around, some days there is not	22 (7%)	24 (16%)
All outings have to be planned in advance	20 (7%)	47 (31%)
This does not apply	121 (40%)	14 (9%)

3.2 | Qualitative Results

At Wave 4, participants were asked 'Does anything get in the way of you going out when you want to go somewhere?'. Across the range of responses to this 'open box' question that specifically identified a barrier, codes were identified and ranked in the order of mentions by participants. Table 5 shows for Cohort 1 the number and percentage of participants mentioning each barrier to going out. Some participants did not answer this question and others said that nothing got in the way of them going out, resulting in 171 responses to this question.

The five most commonly mentioned barriers to leaving the house for people with intellectual disabilities in Cohort 1 were: availability of support, their confidence, weather, transport issues and their mental health/anxiety.

Availability of support was mentioned by 42% of participants who responded. This code includes responses relating to the availability of paid carers, availability of family members and/or specific availability of paid carers with the ability to drive.

> If the day centre is short staffed, I have to do different things.

> If there are not enough staff on or someone who can drive it's difficult to go out or do activities.

> If mum is too busy, then I can't go because am not able to go on my own.

> My house manager gets in the way sometimes. I tell her about places I want to go to well in advance, but she often forgets and fails to sort out transport for me.

Issues relating to personal safety (including specifically at nighttime), crowds, or the need for planning any activity that meant leaving the house were coded as 'confidence' and were mentioned by 14% of people.

> Just if I'm planning a new route, I need help as last time I got lost up a hill.

TABLE 5 | Wave 4: 'Does anything get in the way of you going out when you want to go somewhere?' (Cohort 1, $n = 171$).

Code	Number (and %) of participants mentioning item (total sample = 171)
Availability of support (paid support, family member, drivers)	71 (42%)
Confidence (safety issues, night-time, crowds, needs planning)	24 (14%)
Weather	22 (13%)
Transport issues	21 (12%)
Mental health/anxiety	13 (8%)
Physical health issues	12 (7%)
Other responsibilities (caring, household duties)	11 (6%)
Money	8 (5%)
Access barriers	8 (5%)
Restrictions (by others)	6 (4%)
Motivation	5 (3%)
Covid	2 (1%)

> I don't feel confident going out on my own but sometimes I just have to, but it does stress me out.

> Now the dark nights are coming in I don't want to go out as much.

> When there is too much of a crowd around me I need to go home.

Weather was identified as a barrier to going out by 13% of participants from Cohort 1.

> I don't go out when it's snowing or icy on the floor, because of my disability my mobility is not so good.

> If the weather is too bad I don't like going out.

In relation to transport, 12% of participants who identified a barrier to going out mentioned issues relating to overcrowding, safety on transport, a preference for avoiding public transport at night time, or the need for planning a trip or route.

> Sometimes it because of lack of transport because of where I live the public buses are not regular.

> Sometimes when you are trying to get on the bus, there is only one wheelchair space and it is taken, so then I can't get on the bus. It is also impossible to book a wheelchair accessible taxi when it is busy, so I can't always get to my self-advocacy group.

> Busses not turning up.

Mental health, depression, and/or anxiety, was mentioned by 8% of people with intellectual disabilities in Cohort 1 as a barrier to going out.

> If I'm going through some difficult moment with my anxiety condition.

> Mental health. That's the big one because when it's really bad, I can't see my friends and that makes it worse.

> Sometimes I don't go out because of my anxiety and depression.

TABLE 6 | Wave 4: 'Does anything get in the way of the person going out when they want to go somewhere?' (Cohort 2, $n = 120$).

Code	Number (and %) of participants mentioning item (total sample = 120)
Availability of support (paid support, family member, drivers)	79 (66%)
Physical health	12 (10%)
Access	11 (9%)
Complex planning	9 (8%)
Mental health/anxiety	6 (5%)
Transport issues	5 (4%)
Restrictions (by others)	3 (3%)
Weather	3 (3%)
Money	2 (2%)
Communication barriers	2 (2%)
Covid	2 (2%)
Confidence	1 (1%)
Other commitments	1 (1%)
Motivation	1 (1%)

Table 6 shows for Cohort 2 the number and percentage of respondents mentioning each barrier to going out. Some respondents did not answer this question and others said that nothing got in the way of the person with intellectual disabilities going out, resulting in 120 responses to this question.

For Cohort 2, there were only two barriers mentioned by 10% or more of respondents who completed the survey: availability of support (66%) and physical health (10%).

In terms of availability of support, respondents referred to problems with availability of paid carers (including staff shortages and demands of supporting people with a range of different needs), specific issues with barriers that were a result of lack of availability of drivers, and issues with their own availability as family members.

> Staff being available who are able to drive her Motability car.

> Short staff or staff having to carry out other day to day activities which they then don't have time to go out.

> Massively understaffed, impossible to recruit. All aspects of care completely propped up by family support. My brother has PMLD and requires 24/7 2:1 support and his team is only staffed with 34 non family PA hours a week.

> Yes, I need to accompany them, but I also have to take care of their sibling and have to work.

There were also some responses in this category that referred to a dissatisfaction with availability of good support.

> Shortage of support staff-agency staff don't know clients well enough to take them out.

> Lack of support that is paid for, meeting carers needs not his.

In terms of physical health, respondents mentioned a number of physical health issues which could cause barriers to going out of the house.

> Yes allergies can be so bad resulting in having to stay indoors without the appropriate medications.

> His poor mobility.

> His epilepsy.

4 | Discussion

For both cohorts of people with intellectual disabilities in this study, the number of people leaving the house for almost all reasons increased over time through the COVID-19 pandemic period. Although people with intellectual disabilities are known to experience multiple barriers to going out, the data presented here suggest that their community and social participation (and therefore their lives), were adversely impacted during the pandemic through the following of social distancing measures but were beginning to make a recovery by the end of 2022.

People with more support needs (Cohort 2) were generally less likely to be going out to a broad range of places, although we could not directly compare these data due to different reporters (self vs. proxy). At Wave 4, when asked if they had been out in the last week to a variety of different places, people in Cohort 1 had been out on average to 6.2 different places/ways compared to 3.9 different places/ways for people in Cohort 2. Although the number of times someone goes out does not necessarily equate with any sense of belonging (Amado et al. 2013), findings support previous research that has shown an association between the severity of disability and participation in leisure activities (Beadle-Brown et al. 2016; Emerson and Hatton 2008).

Despite overall evidence of the adverse impact of the pandemic, there are some trends in the data that align with those of the general population to suggest a positive impact of the pandemic in relation to outdoor exercise. According to the UK's Office for National Statistics, among the general population, people exercised more during lockdowns (ONS 2021). Similarly, in the current study, both doing exercise/sport somewhere outdoors, like walking, running or cycling and visiting a park or local green space increased between data collection Waves 1 and 3 (see Table 2). However, an estimated 1.1 million fewer people across the United Kingdom gained health benefits from spending time in nature in 2022 compared with 2years earlier, suggesting that the increase in visits to nature during the pandemic may have been temporary (ONS 2023). This trend was replicated in the current study, where Wave 4 data showed that for Cohort 1, there was a significant decrease in outdoor exercise between Waves 3 and 4.

While the data in this study is oriented towards exploring the extent and nature of going out in relation to the COVID-19 pandemic, much of the data presented relates specifically to Wave 4 of the wider study (data collected largely in the months of October and November 2022, when public health protections and free COVID-19 testing had stopped). While this period could not be defined as 'post-pandemic', the data presented here illustrate that people were going out significantly more at this time than they had been since late 2020. So, at Wave 4, when people were asked about ways that they travel and about barriers to going out, responses may have reflected not only pandemic experiences but also those of long-standing life circumstances. Despite this study being carried out in the context of the COVID-19 pandemic; when asked about barriers, people were asked a very broad question: 'Does anything get in the way of you going out when you want to go somewhere?'. With lockdowns and restrictions likely to be at 'centre stage' in people's lives, few participants responded with a pandemic-specific response, identifying barriers that were perhaps more long-standing issues in their lives.

The role of support has consistently been shown to be an important factor in the community and social participation of people with intellectual disabilities (Verdonschot et al. 2009). In the current study, this reliance on other people was highlighted in

the Wave 4 results. For Cohort 1, 36% of people said they needed someone to go with them when they needed to go somewhere and 25% said whether they needed someone to go with them depended on where or how far they were going. For Cohort 2 (people with more complex needs), 87% of people needed someone to go with them. In line with the quantitative findings, the qualitative findings showed that the most commonly identified barrier to going out was the availability of support. The importance of availability (or lack) of support has been a persistent finding in previous research even prior to the pandemic which has shown that without it, it becomes preventative in going out (McCausland et al. 2022).

Findings also highlighted other barriers to going out, such as the individual's confidence, weather, transport issues, mental health/anxiety and barriers associated with physical health, indicating that a combination of factors might prevent people from going out. As previously mentioned, participation in community and social activities is important because it can reduce the risk of mental health issues and loneliness (Robinson and Idle 2023; Scott and Havercamp 2014). Respondents' reference to their confidence, and mental health and anxiety could be associated with the change in lifestyle caused by the COVID-19 pandemic with respect to concerns about both the virus but also people being less used to going out. Additionally, people in Cohort 1 (but not Cohort 2) were more likely to have left the house for a greater range of reasons at Wave 4 if they reported having enough money to do the things they wanted to do.

5 | Conclusion

This study is the first to systematically track the extent to which people with intellectual disabilities were leaving their houses throughout and beyond public health protections imposed during the COVID-19 pandemic. It is clear that people with intellectual disabilities and those around them contributed to public safety by staying at home when protections were in place, with increases in going out over time partly reflecting protections being lifted. A combination of factors appeared to be limiting the extent to which people with intellectual disabilities were going out, even sometime after all public health protections had been lifted. These factors included the availability of support, financial constraints, the accessibility of public transport, mental and physical health issues, the weather, and worries about personal safety. Reliance on other people and a lack of availability of support was a barrier to people going out, which meant that people did some outdoor activities and exercised more during the pandemic than they did as protections were lifted. While many barriers have been reported in pre-pandemic research, their combination and interaction after very difficult pandemic experiences require urgent multifaceted policy attention. Ideally, policy attention would address understaffing as well as maintaining or developing an education and/or training focus on the health and well-being benefits associated with social and community participation. An ongoing research, policy and practice focus on ensuring people with intellectual disabilities are adequately supported to go out should be a priority if people with intellectual disabilities are going to lead fulfilling lives as part of people's communities.

Author Contributions

Sue Caton: conceptualisation, qualitative analysis, wrote the first draft, writing – review and editing. **Chris Hatton:** conceptualisation, quantitative analysis, writing – original draft preparation, writing – review and editing. **Jill Bradshaw:** conceptualisation, writing – review and editing. **Andrew Jahoda:** conceptualisation, writing – review and editing. **Rosemary Kelly:** writing – review and editing. **Roseann Maguire:** writing – review and editing. **Edward Oloidi:** writing – review and editing. **Laurence Taggart:** conceptualisation, writing – review and editing. **Stuart Todd:** conceptualisation, writing – review and editing. **Richard P. Hastings:** conceptualisation, writing – original draft preparation, writing – review and editing.

Acknowledgements

Thank you to the following collaborating organisations without whom this project would not be possible: All Wales People First, Learning Disability Wales, All Wales Forum of Parents and Carers of People with Learning Disabilities, Scottish Commission for Learning Disability, Promoting a More Inclusive Society (PAMIS), Positive Futures, Mencap Northern Ireland, Learning Disability England, PMLD Link, Positive Futures, CAN Northern Ireland, Families Involved in Northern Ireland (FINI). Research reported in this paper was funded by the UK Research and Innovation (Medical Research Council) and supported by the Department for Health and Social Care (National Institute for Health Research) as part of the UKRI-DHSC COVID-19 Rapid Response Rolling Call (grant number COV0196), and also the National Institute for Health Research Policy Research Programme (grant number NIHR204404). The views expressed in this publication are those of the authors and not necessarily those of DHSC, NIHR, UKRI or MRC. For the purpose of open access, the authors have applied a Creative Commons Attribution (CC BY) licence to any Author Accepted Manuscript version arising from this submission.

Ethics Statement

Research ethics approval was sought and obtained from the Manchester Metropolitan University Faculty of Health and Education Research Ethics Committee.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

A quantitative data set will be archived online in a form that will be available to researchers after all waves of data collection for the project have been completed.

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