Short Report: A comparison of the sensory needs of autistic adults with and without intellectual disabilities

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Background:

Autistic people commonly report differing sensory experiences. This research aimed to find out about sensory issues and the sensory environments of autistic adults who did and did not have intellectual disabilities.

Method:

Online questionnaires were designed to identify sensory needs. The survey was completed by 138 autistic adults who self-reported and 58 informants reporting about autistic adults who had intellectual disabilities.

Results:

Autistic adults self-reported high numbers of sensory needs compared with informant reports of the needs of autistic adults who had intellectual disabilities.

Interpretation:

It is possible that informants under-reported issues for autistic adults with intellectual disabilities. Some sensory needs are harder to observe and people with intellectual disabilities may find it difficult to communicate such needs.

Conclusion:

The authors propose that better methods of supporting communication of 'harder to observe' sensory needs should be developed. Further research is needed.

Keywords

autistic people, autistic people with intellectual disabilities, sensory needs

Introduction

Autistic people have reported sensory differences since the earliest published autobiographical accounts. Despite the importance of sensory experiences in the lives of autistic people, there is still limited research and consensus on appropriate methods to assess such sensory differences. As little is known, this research aimed to find out about sensory issues and the sensory environments of autistic adults who did and did not have intellectual disabilities.

Method

An online survey using Qualtrics was distributed via social media. Demographic characteristics were not recorded to reduce participant burden. An informant-based survey with 39 items (table 1) was adapted from the Sensory Assessment (Autism Education Trust, 2022). An assessment of the environment with 31 items (see table 2) was further developed by mapping possible adjustments based on the individual checklist items with the aim of evaluating whether or not identified needs were met. Assessments were influenced by both observations and interviews in adult social care.

The survey required people to describe the environment (e.g. home, work, day provision) and then asked participants to select, from a choice of three options, the statement which best described the environment. Participants could also select 'not applicable' or don't know. For each area, the statements were designed to show full, partial and no support for a particular sensory need. Participants identified any sensory issues by indicating whether each item was a sensory need, not a sensory need or unknown.

The research was approved by the Tizard Centre ethics committee. Survey one was designed for informants to complete regarding autistic adults with intellectual disabilities who were unable to self-report. A self-report version of the survey was also made available. This included two new items. The autistic communities were involved in this study both as

members of the research team and as part of the advisory group. Incomplete surveys were treated as withdrawals and only complete surveys were analysed.

Analysis

The analysis was primarily descriptive and explored the nature of sensory needs recorded. SPSS was used. A "Match" variable was calculated to indicate where identified sensory needs appeared to be met within the environment. Where the environmental element was in place for an identified need, this was coded as a "full match". If the environmental element was partially in place, this was coded as a "partial match". "No match" was coded when a need had been identified but the environment did not appear to accommodate this need.

Associations between the respondent group and sensory need variables or the environment-need match variables were analysed using chi-square analysis as the data was independent and categorical. Mann-Whitney U tests were used to explore the differences between the two respondent groups on a) the total number of needs identified, b) the number of don't know responses, c) and the number of Full matches. Mann-Whitney U tests were also used to look at differences in the number of matches by environment. Bonferroni adjustments were used in interpretation of statistical significance.

Results

Participants

Forty five percent of participants (n=196) of the 434 people who accessed the survey went on to complete the survey. This included 58 family carers or paid support staff of autistic people who had intellectual disabilities (54.7% of the 106 people who opened the survey) and 138 autistic people who self-reported (42% of the 328 people who opened the survey).

Sensory issues

For participants with an intellectual disability, the mean number of issues identified by informants was 17 (range 6-32, max score 37). The mean percentage of items identified as an issue was 46% (range 16-85%). For those who did not have an intellectual disability, the mean number of self-reported issues was 21 (range 0-32, max score 39). The mean percentage of items identified as an issue was 54% (0 – 82%). Informants completing the questionnaire for autistic adults with intellectual disabilities were less likely to report sensory issues ($Z=4.576$ $p<0.001$). They were more likely to respond 'don't know' (mean average of 45% 'don't know') in comparison with a mean average of 16% of 'don't know' responses in the sample completing self-reports ($z=5.395$ $p<0.001$). Table 1 presents the item-by-item descriptive statistics and chi-square results for comparison between those with and without intellectual disabilities.

INSERT TABLE 1 ABOUT HERE

The environment

Family carers and paid support staff of autistic people with intellectual disabilities completed the survey about a variety of environments, including home (64%), day provision (24%), short breaks (10%) and other (2%). For self-reports, 28% of participants answered about their home environment, 40% about work, 10% about education and 18% about other environments.

The match between identified sensory needs and the support provided in the environment.

Family carers/paid support staff for autistic people with an intellectual disability reported support for an issue being in place for significantly more items (Mann whitney $z=5.720$ $p<0.001$). Those without intellectual disabilities had significantly more items scored as not in

place (Mann Whitney z = 6.249, p<0.001). There were no differences in terms of the numbers who responded 'not sure' or 'don't know', 'partially in place' or 'not applicable'.

The number of full matches (where a sensory need was fully met in the environment) was different between the two groups. For participants with intellectual disabilities, the average number of full matches was 7.6 (range 1-21, SD 4.15). For those who were autistic, the average number of full matches was 5.1 (range 0-12, SD 4.47). Family carers/paid support staff for autistic people with an intellectual disability reported that the person they supported/cared for were more likely to have their needs met (i.e. there was a full match between environment and individual need) (Mann Whitney z = 4.177, n= 196, p<0.001).

For autistic adults who did not have intellectual disabilities, identified needs were significantly less likely to be met in a work environment than in a home environment. This was not accounted for by respondents who reported about a work environment having a different number of identified needs at home (average number 22) than at work (average number 21).

On 17 items, the environment was rated as having support for an area in place even though a need in that area had not been identified for 25% or more of the sample of people with intellectual disability. For those without intellectual disabilities, the same was true for 14 items (See Table 2). Table 2 also presents the item-by-item descriptives for percentage match and the chi-square results for the comparison of full-matches for those with and without intellectual disabilities.

INSERT TABLE 2 ABOUT HERE

Discussion

The trend of higher reporting of sensory issues amongst autistic adults compared with carer proxy observations) were found across multiple sensory domains. Proxy reports from carers contained more 'don't know' responses in terms of whether or not each item was an issue.). Informants reported more 'matches' between identified needs and the sensory environment than those who self-reported, though caution is needed here as issues may have been under-reported. Those who self-reported were less likely to report needs having been met in a work environment. For some items, support was described as being in place despite that need not having been identified. For both groups, many identified sensory needs remained unmet.

Limitations

Having fewer autistic participants with intellectual disability within the sample, influenced by lockdown procedures and the impact on services and families, limits the extent to which differences can be analysed. Using informant responses for people with intellectual disability could be considered a limitation but given the limited and contradictory findings related to the sensory issues and differences of people with intellectual disabilities (Werkman et al., 2022), attempting to do so was felt to be important.

The questionnaire was inclusive of those self-identifying as well as those who were formally diagnosed. However, it is acknowledged that the sample may not have included autistic people who don't have an intellectual disability but who don't use social media. It is possible that those recruited this way may be a distinct group.

To aid ease of completion and reduce participant burden, no further information was requested, no independent checks were made of the data and space was given for participants to elaborate on their responses. It is not possible to know whether the data accurately reflects practice. Many people were living in different ways during the pandemic (altered work

environments, restrictions on number of people etc.) and so environments may have been atypical.

Differences in sensory needs?

Significant differences were found on some items between informant and self-report responses. For some items, self-reports were higher than informant reports (e.g. 'Distressed by certain sounds' was reported by 93% of autistic adults compared to 69% of proxy reports of autistic adults with intellectual disability. Similarly large differences were found in proximity issues ('Prefers to sit at back or front of group': 89%-67%), tactile issues ('Enjoys feel of certain material's: 90%-54%), sensory integration differences ('Finds it easier to listen when no looking at a person': 82%-57%) and issues relating to smell ('Dislikes everyday smells': 80%-21% with 55% of proxy accounts reporting 'don't know'). This general trend was reversed however on three questions, two of which related to sensory seeking ('Bangs objects and doors': 20%-64% and 'Is attracted to sound and noise': 27%-60%) and one related to awareness of temperature ('Seems unaware of temperature': 13%-67%).

Implications

Further research is needed to look at these differences in further depth. Some sensory issues may be more pronounced for autistic people with intellectual disabilities but more difficult to assess from the perspective of an onlooker unless clearly indicated through the autistic person's actions. Such differences could have serious implications for practice, when interventions are largely based upon behavioural observation, and non-autistic people may struggle to empathise with autistic ways of being in the world (Milton, 2012). Exploration alternative methods of supporting communication of these harder to observe sensory needs is an important area for future research.

It may be the case that autistic adults without intellectual disability might mask particular sensory seeking behaviour in fear of social sanction and stigma (Pearson & Rose, 2021). Whilst these findings can only indicate potential issues in these areas, further research is needed to address how autistic people experience the sensorium and how best to adjust environments to support such needs.

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The authors report that there are no competing interests to declare

Anonymised data is available from the first author on reasonable request

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Table 1: Identification of sensory needs for overall sample and for each those with and without intellectual disability

Item on sensory checklist	*Percentage of whole sample identifying as an issue*	*Informant responses for autistic adults with intellectual disabilities %*			*Self-report responses for autistic adults with no intellectual disabilities %*			*Chi-square analysis – number reporting sensory issue*
		Yes	No	Don't know	Yes	No	Don't know	** significant at p<0.0013 (Bonferroni adjustment)*
Finds crowded areas difficult	93	86	14	0	96	3	1	Not sig
Distressed by certain sounds	86	69	21	10	93	4	3	$\chi 2 = 20.997$*
Prefers to sit at back or front of group	83	67	16	17	89	6	5	$\chi 2 = 13.788$*
Is startled when approached by others	81	60	36	3	89	9	2	$\chi 2 = 22.815$*
Dislikes bright lights	80	N/A			80	16	4	N/A
Likes a hug if chosen to do so	79	65	33	2	84	15	1	Not sig
Enjoys feel of certain materials	79	54	16	30	90	9	2	$\chi 2 = 37.125$*
Resist change to routine	79	78	19	3	79	15	6	Not Sig.
Dislikes feel of certain fabrics and substance	78	59	12	29	86	11	3	$\chi 2 = 30.628$*
Dislikes certain food and drink	78	79	19	2	78	17	5	Not Sig.

Item on sensory checklist	*Percentage of whole sample identifying*	*Informant responses for autistic adults with intellectual disabilities %*			*Self-report responses for autistic adults with no intellectual disabilities %*			*Chi-square analysis – number reporting sensory issue*
Covers ears when hears certain sounds	76	67	29	4	79	18	3	Not Sig.
Finds it easier to listen when not looking at a person	75	57	29	14	82	9	9	$\chi 2 = 13.794$*
Can hear sounds that others do not hear	72	57	9	34	78	9	12	$\chi 2 = 13.050$*
Quite clumsy, bumps into objects and people	70	45	53	2	80	13	7	$\chi 2 = 35.917$*
Dislikes untidy or cluttered environments	67	62	29	9	70	24	7	Not Sig.
Dislikes everyday smells	63	21	24	55	80	17	4	$\chi 2 = 84.845$*
Dislikes fluorescent lights	63	25	40	35	78	17	5	$\chi 2 = 54.431$*
Does not like shaking hands or being hugged	58	62	36	2	57	32	12	Not Sig.
Needs additional cue to recognise people	58	N/A			58	33	9	N/A
Enjoys certain patterns, e.g., brickwork, strips	54	22	50	28	67	29	4	$\chi 2 = 39.698$*
Does not know where body is in space	53	48	41	10	55	33	12	Not Sig.
Poor balance	53	42	58	0	57	36	7	$\chi 2 = 9.916$*
Likes to have food presented in a certain way	52	60	34	9	35	32	4	Not Sig.

Item on sensory checklist	*Percentage of whole sample identifying*	*Informant responses for autistic adults with intellectual disabilities %*			*Self-report responses for autistic adults with no intellectual disabilities %*			*Chi-square analysis – number reporting sensory issue*
Seeks pressure	43	22	74	3	52	41	7	$\chi 2 = 17.656$*
Needs purpose or function of areas to be clearly communicated	39	38	48	14	40	51	9	Not Sig.
Is fascinated by shiny objects	38	31	53	16	41	50	9	Not Sig.
Is attracted to sound and noise	37	60	31	9	27	64	9	$\chi 2 = 19.893$*
Seeks out certain smells	37	16	32	52	46	51	3	$\chi 2 = 68.181$*
Eats and chews materials which are not edible	37	43	55	2	34	61	5	Not Sig.
Hugs very tightly	36	28	67	5	39	51	9	Not Sig.
Licks and taps objects and people	36	42	58	0	33	60	7	Not Sig.
Bangs objects and doors	33	64	34	2	20	64	16	$\chi 2 = 36.695$*
Will attempt to avoid bright colours	31	12	60	28	38	55	7	$\chi 2 = 22.659$*
Seems unaware of temperature	29	67	19	14	13	80	87	$\chi 2 = 66.129$*
Has a fear of heights, lifts, stairs, escalators	28	30	51	19	27	70	3	$\chi 2 = 16.589$*

Item on sensory checklist	*Percentage of whole sample identifying*	*Informant responses for autistic adults with intellectual disabilities %*			*Self-report responses for autistic adults with no intellectual disabilities %*			*Chi-square analysis – number reporting sensory issue*
Is attracted to light	24	21	55	24	25	67	8	Not Sig.
Has a strong preference for seeking colour	22	3	67	30	30	61	10	$\chi 2 = 23.678$*
Dislikes crunchy or chewy food	19	36	60	3	12	80	8	$\chi 2 = 16.577$*
Appears not to see certain colours	7	5	42	53	8	82	10	$\chi 2 = 41.768$*

Table 2: Match between identified needs and the support provided in the environment.

Environmental item	Whole sample		Autistic with intellectual disabilities		Autistic adult Without intellectual disabilities		Chi-square on number with full-match	% in place where no need recorded		
	% Full match with need	% Partial match with need	% Full match with need	% Partial match with need	% Full match with need	% Partial match with need	** significant at p<0.0016 (Bonferroni adjustment)*	Whole sample	With intellectual disabilities	No itellectual disabilities
Enough lighting	73	27	75	25	72	28	Not sig.	63	32	70
Staff clearly identified	67	0	N/A	N/A	67	0	N/A	38	N/A	38
Can avoid higher areas/lifts etc	60	35	76	16	33	6	Not sig.	45	34	69
Opportunities to make noise and sound	56	36	75	25	39	45	$\chi 2 = 14.990$*	33	19	47
Opportunities to touch	54	35	48	48	55	32	Not sig.	8	11	6
Preferred food and drinks always available	50	39	67	30	41	43	Not sig.	15	18	12
Clear signage	47	31	48	24	47	35	Not sig.	34	41	31
Can use preferred way of greeting	47	39	78	20	34	47	$\chi 2 = 31.409$*	2	2	2
Food presented as preferred	46	30	67	27	31	31	$\chi 2 = 13.172$*	32	27	39

Environmental item	Whole sample		Autistic with intellectual disabilities		Autistic adult Without intellectual disabilities		Chi-square on number with full-match	% in place where no need recorded		
	% Full match with need	% Partial match with need	% Full match with need	% Partial match with need	% Full match with need	% Partial match with need	* *significant at p<0.0016 (Bonferroni adjustment)*	Whole sample	With intellectual disabilities	No itellectual disabilities
Opportunities to smell	43	40	57	33	41	41	Not sig.	36	17	41
Predictability in environment	41	53	56	42	35	57	Not sig.	14	16	14
People understand re eye contact	40	43	64	33	32	46	Not sig.	16	28	3
Many different colours	40	51	5	0	37	54	Not sig.	57	64	52
Environment organised to be easy to move around	40	48	71	29	30	54	$\chi 2 = 19.554$*	17	35	0
No flickering lights	39	35	71	29	34	36	Not sig.	29	42	19
Can avoid disliked fabric etc.	38	29	37	59	38	20	$\chi 2 = 19.589$*	9	7	10
Can avoid crowded areas	38	38	67	33	26	41	$\chi 2 = 32.743$*	8	8	8
Can choose where to sit	38	49	59	41	32	51	Not sig.	10	17	5

Environmental item	Whole sample		Autistic with intellectual disabilities		Autistic adult Without intellectual disabilities		Chi-square on number with full-match	% in place where no need recorded		
	% Full match with need	% Partial match with need	% Full match with need	% Partial match with need	% Full match with need	% Partial match with need	* *significant at p<0.0016 (Bonferroni adjustment)*	Whole sample	With intellectual disabilities	No itellectual disabilities
Many patterns	37	41	77	23	31	44	Not Sig.	26	42	18
No bright colours	32	53	57	43	28	55	Not sig.	47	57	38
Opportunities to chew	29	33	46	41	20	29	Not Sig.	37	33	40
Environment tidy	27	53	58	39	15	58	$\chi 2 = 28.328$*	20	19	22
Enough shiny or colourful objects	27	55	44	50	21	57	Not sig.	46	44	48
Colours adjusted to help people see edges	25	38	33	33	20	40	Not sig.	75	50	88
Quiet areas available and warnings re noise	25	47	54	44	15	48	$\chi 2 = 32.287$*	4	7	0
People aware of startling	21	26	44	47	14	20	$\chi 2 = 31.6$*	18	32	0
Lighting adjustable	20	40	N/A	N/A	20	40	N/A	19	N/A	19

Environmental item	Whole sample		Autistic with intellectual disabilities		Autistic adult Without intellectual disabilities		Chi-square on number with full-match	% in place where no need recorded		
	% Full match with need	% Partial match with need	% Full match with need	% Partial match with need	% Full match with need	% Partial match with need	* *significant at p<0.0016 (Bonferroni adjustment)*	Whole sample	With intellectual disabilities	No itellectual disabilities
Opportunities for deep pressure	18	31	56	31	11	31	$\chi 2 = 20.669$*	25	36	10
Opportunities to tap, lick, etc	16	47	17	78	16	25	$\chi 2 = 19.199$*	61	67	55
Can avoid smells	15	33	25	75	14	30	Not sig.	13	17	11
Can control temperature	11	26	11	29	11	22	Not sig.	71	38	88