People on the autism spectrum who have intellectual disabilities: How do people communicate and what support do they get?

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Introduction and Methods

As part of a wider research project into skilled support (Beadle-Brown *et al*, early online), information about communication was collected using a range of measures. These included observations of social interaction and contact from staff, the use of alternative and augmentative communication (AAC), reviews of written information, questionnaires about the needs and characteristics of the people supported and interviews with managers. An observational measure combined the Engagement in Meaningful activities and relationships (EMACR Mansell and Beadle-Brown, 2005), The Active Support Measure (ASM) (Mansell, Elliott & Beadle-Brown, 2005) and a specific measure about the nature and variety of communication methods used by staff and the people they support. In addition, a staff reported measure of adaptive functioning and communication needs was completed by each person's key worker. We looked at written information and we talked to managers. We also rated services according to how 'autism-friendly' they were.

Participants

Services were either nominated by their organisations as providing good support for these groups of people or randomly selected from Care Quality Commission lists for the same geographic areas as nominated services. There were 42 participants (from the sample of 35 residential or supported living services) identified by staff as having autism. People with autism were younger, more able in general (ABS 133 vs 97) and showed both more challenging and more self-stimulatory behaviour than those who did not have autism. They also tended to live in smaller settings.

Results

Participant communication and effectiveness of use (%)	Autism N=42	Not autism n= 58
Rated by staff as not using verbal communication	50	66
Communication observed		
No communication	7	9
Any verbal	38	36
Any vocalisation	38	59
Any gestures on their own	33	22
Gestures + vocalisation	21	14
Gestures + verbal	10	19
Object of reference	5	3
Object of ref. + vocalisation	2	3
Object of ref . + verbal	5	3
Symbols	5	2
Signs	2	5
Signs + vocalisation	2	4
Signs + verbal	5	2
Communication effective most of the time (inc all)	61	59
Communication effective all of the time	26	25

Communication support from staff (%)	Autism N=42	Not autism N=58
Rated by staff as not understanding verbal	14	21
Communication observed		
No communication used by staff	2	0
Gestures alone	19	7
Gestures with verbal	50	53
Objects of reference	14	10
Objects of reference plus verbal	14	22
Photos	7	3
Symbols/photos and verbal	2	2
Sign	2	3
Sign and verbal	2	5
Verbal only	69	81
Communication rated as mostly appropriate	64	67

Staff communication was most likely to be either verbal or verbal with gestures, despite many people needing more support in terms of communication (e.g. signed communication or symbols).

Does skilled support make a difference?

One third of people were receiving skilled support. When support was skilled, people with IDD and autism were more engaged and were more likely to have good communication used with them. They were also more likely to have good support to make choices. There were few differences in the quality of life of people with and without autism, however people with autism were more likely to live in a service where people were active (i.e. engaged in activities that were not sedentary) at least some of the time - 42% compared to 17% without autism (X^2 (1, n=95)=7.209, p=.007). Individuals with autism were also engaged in complex household tasks-using gas or electrical equipment for more of the time (z=-2.16, p=.031, r=0.22), however this still represents low levels of involvement in more complex tasks overall. Those with autism were also reported by staff to participate more in daily living tasks (z=-2.570, p=.010, r=2.88). These findings may reflect higher levels of ability in the autism group.

How 'autism-friendly' were the services?

Scores relating to autism-friendliness rated on the SPELL framework (%)	Autism N=42	Not autism N=58
Percentage of people living in services where PBS was rated as well implemented overall	23	17
Overall Percentage score on SPELL	75	79
Percentage receiving good, consistent autism friendly support (SPELL)	66	76
Percentage living in a setting where the SPELL principle was clearly in practice:		
Structure	40	48
Positive approaches	56	43
Empathy	38	42
Low arousal	20	22
Links (primarily due to presence of PCP)	51	69

There was little difference in autism-friendly practice between generic and autism-specific services. Services providing person-centred active support provided the best support for people on the autism spectrum (in terms of people having something to do and support to communicate choices). The provision of visual structure was generally weak across services and there was little awareness of sensory issues.