DOCUMENT RESUME

ED 308 646 EC 220 509

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TITLE	Unexpected Communication Attainments by Persons Diagnosed as Autistic and Intellectually Impaired.
INSTITUTION	DEAL Communication Centre, Caulfield (Australia).
PUB DATE	Oct 88
NOTE	19p.
PUB TYPE	Reports - Descriptive (141)
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	*Autism; Clinical Diagnosis; *Communication Aids (for Disabled); *Communication Skills; Computer Assisted Testing; Foreign Countries; Generalization; Individualized Instruction; *Mental Retardation; Neurological Impairments; *Spelling; *Training Methods; Transfer of Training
IDENTIFIERS	Canada

ABSTRACT

The paper describes the effects of a communication training program provided at the DEAL Communicaton Center Victoria, Australia, to 34 clients with diagnoses of autism or intellectual impairment with autistic tendencies. Client ages ranged from preschool to adult with 24 aged between 6 and 18 years. The treatment module consists of three 2-hour sessions with most clients receiving more than one module. Assessment utilized a highly motivating voice-output computer. Training involved physical hands-on guidance by the trainer with the ultimate goal of fully independent communication using any appropriate strategy (speech, sign, communication displays, or spelling.) Nine of the group attained fluent independent communication by spelling with an additional 14 communicating well with facilitation. Some spelling clients use voice output communication aids and most use mini-typewriters or small alphabet boards. Manual signing and finger spelling is used by only one client. The most time consuming aspect of the training was generalization to other communication partners and locations. Results have implications for the diagnosis and prognosis of persons who are mistakenly identified as autistic but have neurological damage which interferes with free expression. (DB)

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UNEXPECTED COMMUNICATION ATTAINMENTS BY PERSONS DIAGNOSED AS AUTISTIC AND INTELLECTUALLY IMPAIRED

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October, 1988

UNEXPECTED COMMUNICATION ATTAINMENTS BY PERSONS DIAGNOSED AS AUTISTIC AND INTELLECTUALLY IMPAIRED

1. Client Group

DEAL Communication Centre was established in 1986 to assist people with no speech or with dysfunctional speech find alternative means of communication. DEAL is staffed by an inter-disciplinary team consisting of speech therapists, occupational therapist, physiotherapist and teacher, with practical support provided by a computer programmer and a technician. A inter-disciplinary approach is adopted with individual clients. Between January 1986 and the end of 1987 the Centre saw 365 clients with severe communication impairments. DEAL's basic treatment module consists of three 2-hour sessions, and most clients who enter treatment receive more than one module. 34 clients referred to the Centre with diagnoses of autism and intellectual impairment or intellectual impairment with autistic tendencies attended three or more assessment and treatment sessions at DEAL.

The performance when using augmentative communication systems of this "autistic" group has raised important questions about the nature of the autistic syndrome.

2. Clients

All clients had been diagnosed as being autistic or as having autistic tendencies before attending DEAL. While individual diagnosticians may have used different checklists all 34 of these clients met the

diagnostic criteria for autistic disorder as outlined in the Diagnostic and Statistical Manual, Third Edition, 1987 Revision (DSM III-R). On presentation only 3 clients of the 34 used speech, writing, or signing for communication at a level above that of indicating immediate needs (exact breakdowns are given in the table below). Those clients with more than a few words of speech all exhibited severe echolalia and perseverative and repetitive speech. Twenty-six had been labelled as moderately, severely or profoundly intellectually impaired previous to attending DEAL. The remaining six had been labelled as mildly intellectually impaired.

On referral 1 client was aged under 6, 23 were aged between 6 and 18, and 10 were aged between 19 and 30.

Age of onset was not supplied in all cases. The oldest time of onset known in this group is 5 years. The male-female ratio in the client group is 21 to 13, lower than that usually recorded in autistic populations; however, it has been suggested that male-female ratios among severely autistic (i.e. mute) populations are generally less extreme (Lotter, 1974; Lord & Schopler, 1985).

3. Physical Abnormalities

It has been repeatedly established that persons diagnosed as autistic have a high incidence of neurological disorders (Debisse & Coleman, 1986), including akinesia and bradykinesia (Maurer & Damasio, 1982), abnormalities of postural fixation and righting (Lotter, 1966; Maurer & Damasio, 1982), involuntary movements (chorea, athetosis, dystonia) (Maurer & Damasio, 1982), alterations of muscular tone (Maurer & Damasio, 1982), "a symmetrical and

often expressionless face, with little spontaneous movement" (Maurer & Damasio, 1982; Wing, 1980), nonlateralized handedness (Fein, Waterhouse, et al., 1985;Tsai, 1984), substitution of peripheral vision for central vision (Oppenheim, 1977; Wing L. & Wing J., 1971), epilepsy (Rutter, 1976), hand incoordination and unusual grip, handflapping, toewalking, unusual startle reflex (Nelson, 1984), and sleep disturbance.

This group had a high incidence of these problems. In addition, many had readily observable physical problems affecting hand function such as severely impaired eye-hand co-ordination, abnormal muscle tone (usually low, occasionally high) and disorders of initiation, inhibition and perseveration[1]. Other more specific problems, including immature grasp, inability to isolate the index finger, shoulder girdle weakness and radial/ulnar muscle imbalance were often apparent during the interdisciplinary assessment procedure. In most cases it appeared that the clients diagnosed as autistic had had no previous contact with physical therapists.

4. Communication Programme

During the client's first appointment at DEAL a team member interviewed the client's caregiver, obtained a history, and sought details of the client's current means of communication, if any. (While many clients had been involved in manual signing programs prior to their attendance at DEAL, only three of this group presented with more than the most basic sign vocabulary, and most were not spontaneously generating any signs) The team then appraised the client's physical presentation and attempted to remedy any problems likely to affect performance. Clients were given wrist support by a therapist where necessary to compensate

for poor muscle tone or to inhibit excessive movement and were given special gloves, splints, or hands-on assistance to enable a single finger to be extended for pointing. A physical prompt was given if the client failed to move in response to a request or to answer a question. It was sometimes necessary to inhibit movement in the hand not in use or to maintain the client's head in the midline to facilitate eye contact with the material.

Assessment commenced with the client being asked to point to named pictures. When there was reluctance the client's hand was held firmly over the target area so that only a small voluntary movement was required for a choice to be registered. However great the amount of external assistance required, once a movement could be recognized as an attempt to point and the client had made some correct responses the complexity of the tasks was gradually increased.

In order to assess clients' level of comprehension of auditory and visual language they were tested using a small dedicated computer with speech output. It allowed the sequential presentation of short tasks involving picture recognition, colour, shape and size recognition, word and picture matching, word recognition, and assembling a sentence from single typewritten words. Clients who succeeded in composing a meaningful sentence were assessed for letter recognition and asked to spell simple words. If recognizable attempts at the spelling task were made the client was encouraged to spell original sentences in response to questions. All spelling tasks were performed with one finger on keyboards covered with plastic keyguards to prevent more than one key being depressed at a stroke. Special efforts were made to find assessment tools which would be unfamiliar to the clients, and which would have no

resemblence to commonly-used tests. Voice-output equipment was found to be highly motivating. In addition, a special effort was made to use equipment and procedures which demanded minimal fine motor skills. All assessment was open-ended, and all clients were encouraged to proceed as far as possible through the assessment regardless of their presentation or previous diagnoses.

In some respects DEAL's communication program resembles that recorded in Oppenheim (1977). Oppenheim commented in relation to the teaching of writing that "we find that it is usually necessary to guide the child's hand for a considerable period of time. Gradually, however, we are able to fade this to a mere touch of a finger on the child's writing hand... Ultimately, however, the finger-touching can be eliminated, and the child does write without it, although some children want the touch of a finger on some other bodily surface, such as the head, in order to write." A similiar phenomenon with a different task is recorded in Wing (1980); "If you want him to do up his buttons ... stand behind him and hold his hands firmly but not too tightly... At first his fingers will feel limp... but eventually you will begin to feel some tension in his hands... in the end he is doing the job himself. He will probably continue to need the touch of your hand on his arm to encourage him for some time, but in the end you can remove even this support..."

Most clients in the present study initally required hands-on training in order to attain desired patterns of movement, and many continued to seek physical contact from their communication partners well beyond the time when such contact served any physical purpose. This has also been the experience at Vangenduse in Copenhagen, where fourteen young adults diagnosed as emotionally disturbed and severely intellectually impaired are now

communicating by spelling . "None of them seems able to write without support from a social worker's hand. This is either because of anxiety about taking responsibility alone... or because that is the norm..." (Johnson, 1988)

The ultimate aim of the programme is fully independent communication using whatever strategy gives the client most freedom of communication - speech, sign, communication displays, spelling. Nine of the client group have so far attained (though may not always choose to use) fluent independent communication by spelling and it is expected that most of those now spelling sentences with facilitation will follow suit. As has been widely reported, the speech problems shown are resistant to therapy intervention, though significant improvements have been seen in several younger clients as they increase their use of written communication. Communication displays containing symbols and words or sentences are used both by clients without spelling skills sufficient for communication and by clients with such skills as an adjunct to spelt communication, which is necessarily slow. Of those using spelling as their main means of communication, a minority of clients use VOCAs (voice output communication aids) and the majority use mini-typewriters such as Canon Communicators or small alphabet boards with plastic guards to make their letter selection unambiguous. Manual signing and finger spelling is a functional means of communication for only one client, the same client who uses handwriting. The manual skills of this person are significantly in advance of any other client in the group, though still below the average of the general population.

The most time-consuming aspect of treatment is the generalization to other communication partners and locations of skills

demonstrated at the communication centre with centre staff. Communication is first transferred to another person, usually a caregiver, in the setting of the DEAL Centre. After communication is reliably established with this person at the Centre, staff support attempts to transfer the skill to other locations and to an expanding range of partners. Team members will visit residential or day placements to facilitate skill transfer if necessary.

5. Communication Outcomes

DEAL Clients, 1986-1987;

Clients labelled autistic who have attended DEAL 3 or more times

(N=34)

Communication Outside DEAL

Most sophisticated communication strategies used with caregivers/teachers (September 1988)

Most sophisticated communication skills on referral	No.	Spells sentces	Spells words	Limited signing	Yes/no	Limited speech	Body language	Lost to follow-up
Body language	14	7	1	0	1	0	1	4
Yes/no	1	1	0	0	0	0	0	0
Limited speech	3	3	0	0	0	0	0	0
Limited sp - echolalia	10	7	1	0	0	1	0	1
Limited speech/signs	2	2	0	0	0	0	0	0
Limited signing	3[2]	2	0	1	0	0	0	0
Signing/Writing	1[3]	1	0	0	0	0	0	0
Total	34	23	2	1	1	1	1	5

Of the 34 clients,

* 23 are communicating with caregivers and/or teachers by spelling sentences, of whom nine are able to work without facilitation;
* 2 are communicating with caregivers and/or teachers by spelling single words;
* 1 is using yes/no signals;
* 3 are communicating with teachers and/or caregivers at the same level as that before attending the Centre;

* 5 were lost to follow-up.

In general the most advanced communication strategy indicated is also the one most commonly used. Clients often complain about the slowness of spelling, but once they are fluent they are frequently reluctant to use faster but less specific strategies. They often resist any attempt by their partner to speed up communication by anticipating the end of a word or phrase, and will insist on spelling every letter.

6. Communication Level

In many cases, early communication through spelling sentences was at a sophisticated level eg "I believe my problems are du(sic) to not being able to talk" ,"I like it when mum gets upset, because it means she has to give attention to me." While spelling was often phonetic, grammar was usually satisfactory, and the communication showed little evidence of severe cognitive abnormality or language disorder, although some individuals revealed obsessions in their writing. No clients showed problems with grammar which failed to respond to instruction[4]. More subtle specific word-finding problems and auditory memory problems have shown up in some clients over time. Several clients have a history of fluctuating receptive language problems, in two cases of such severity to lead to the person being considered deaf; both cases of "elective deafness" have resolved as expressive communication has improved. All clients show gaps in their awareness of conversational conventions and most are extremely egocentric in their choice of conversation topics. Despite the difficulties outlined, staff would support Oppenheim (1977) in her assertion that the abilities with written

language shown by this group "lead us to question <the> assertion that autistic people lack the ability to handle syntax or structure of language".

As in most cases clients achieved typewritten communication in a small number of sessions (total number of sessions range between 3 and 20, and the mean number of sessions is 9) it seems unlikely that they were learning language, or even spelling; they were being assisted to express language and use lexographic skills that they had developed previously. Some clients are recorded as having been passive students in literacy programmes and some had considerable exposure to flash cards as young children, but most had not received any intentional instruction. Parents often commented that their child has always been interested in books, but that they had assumed that the child was looking at the pictures, or just liked to turn pages. Some of these clients enjoy age-appropriate television programmes and are selective about what they watch. More are recorded as being interested only in the advertisements (which in Australia have a highly repetitive print content). Several hyperactive clients on their first visits to the centre ran from poster to poster, appearing to ignore the pictures in favour of the words underneath. One young adult bought the evening paper regularly, and another bought a TV guide. While it had been accepted that those two clients could read, their lack of speech and writing skills had meant that their comprehension had not been assessed and no systematic approach to using literacy skills for communication had been attempted. Those clients with speech were initially unsuccessful at oral reading tasks though able to answer comprehension questions correctly by typing.

Sophisticated word recognition abilities have previously been recorded in groups of people diagnosed as autistic (Cobrinik, 1974; Whitehouse & Harris, 1984); however, these have been stigmatized as hyperlexia, the assumption being that because a person's oral reading skills are greater than predicted by his or her IQ scores, are not used for expressive communication, and are not reflected in his or her social skills, the person is not able to comprehend what he or she reads. Detailed examination of the patterns of spelling errors made by clients may shed some light on the various methods by which they have gained their literacy skills. Approximately half the group spell almost perfectly, often well above age level, with the only errors being odd words which they may have not seen written. A few clients spell phonetically, and the remainder present as average spellers. The spelling of the phonetic spellers improved markedly in the first few months of therapy, during which time caregivers and teachers encouraged them to look through books and magazines and used every opportunity to increase their exposure to print.

7. Intelligence

Recent estimates of the intelligence of the people diagnosed as autistic have suggested that the majority are significantly retarded. In a widely quoted study De Myer et al (1974) list 6.2% of their sample as having IQs above 68, 20% as being mildly retarded (IQs 67-52), 25.8% as being moderately retarded (IQs 51-36), 40% as being severely retarded (IQs 35-20), and 8% as being profoundly retarded (IQs <20). Mute and echolalic children averaged verbal IQ scores of 27 and 19 respectively All of the DEAL clients reported here were on presentation either mute, echolalic, or able to use fewer than 20 words of speech.

DEAL has not attempted to carry out intelligence testing on any of its clients. However, in the light of the fact that in the community at large it is generally the case that fluent written communication is not achieved before the age of seven years, and as it is reasonable to conclude that a degree of neurological impairment sufficient to impair both oral and written communication severely would also have an affect on the ability to take IQ tests, it seems appropriate to make a re-assessment of the abilities of this group, a re-assessment which takes into account their neurological impairments. It is clear that choice of test battery could have a significant effect on overall score. Generally it would be appropriate for a multi-disciplinary functional assessment and any follow-up treatment programmes arising out of this functional assessment to precede any attempts at cognitive assessment. Even after intervention this group shows such a range of skills and deficits that it is not clear whether any global intelligence score would provide useful information.

8. Outcomes

As none of these clients has been communicating for more than two years it is impossible to give a long-term prognosis. It should also be noted that DEAL's therapy is directed purely towards improving communication skills, and any further training in social adjustment is given by caregivers or teachers. It has been observed that when people diagnosed as severely autistic lose their autistic behaviours they do not necessarily improve their IQ scores (Rutter and Lockyer, 1967). Similiarly, an improvement in communication skills does not mean that the autistic behaviours disappear. The persisting speech impairments and physical difficulties of these people, their long habituation to deviant behaviour, the peculiar

social circumstances that have evolved around them, and, possibly, continuing cognitive impairments mean that most will continue to present as autistic. However, a subjective assessment by parents and caregivers indicates that in many cases their deviant behaviours are diminished, in some cases very significantly. Behavioural improvements are also recorded in Oppenheim (1977), Johnson (1988), and Rimland (1988), who records a number of examples of communication through spelling resulting in "quantum behaviour improvement". After communication is obtained it becomes possible to address the extreme lack of self-esteem and the conditioned expectations of failure which appear to be endemic in this population. An unpublished study of the social impact of learning to communicate on thirteen DEAL clients, 9 of whom are also treated in this article, found that "Self-esteem and confidence has increased, leading to increased happiness and reduced behaviour problems." (Lazarus, 1988) Five school age clients in this group have been integrated into mainstream primary and secondary school classrooms for the first time in 1988 and are coping satisfactorily with the standard curriculum for their age group, and more are hoping to follow in 1989. One teenager, previously assessed as having an IQ of 50, recently topped her high school in the Australia-wide mathematics competition.

19. Diagnostic Categories

This group would appear to suffer from a disability where neurological damage, involving both interference with gross and fine motor control and difficulties in initiation and inhibition, very severely handicaps their expressive communication. These clients can all be described as having motor dyspraxias[5], varying in extent, that prevent them from writing or gesturing freely. Imitation of

gestures or facial expressions is generally significantly impaired. Those who are mute or who only have a few words of speech also have oral dyspraxia and/or aphasia; those with echolalia have aphasia, sometimes complicated by oral dyspraxia and/or dysarthria. Both groups seem able to evade these handicaps to a significant extent through the use of communication equipment and strategies requiring little physical dexterity.

In view of the extra difficulties added by this study to the existing problems inherent in the concepts of autism and intellectual disability it would seem essential to return to a basic redefinition of this population. What is required is a new terminology that separates, as the terms 'autism' and 'intellectual disability' do not, observable physical characteristics from behavioural interactions, and which avoids as far as possible basing assessments on assumptions as to the cognitive significance of levels of social functioning or physical skills.

It is hoped to present a detailed motor and oral assessment of those clients available to follow-up in future articles. The significance of the outcomes achieved to date appears to warrant publication without delay.

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October 1988

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1 See Poeck, K, 1988, The Relation Between Aphasia and Motor Apraxia, in Rose F. Whurr R and Wyke M., Eds, Aphasia, Whurr, London for a discussion of the relation between aphasia, apraxia, and perseveration.

2 These clients were all using less than 50 signs.

3 With the exception of this client, L , writing skills were limited either to lists of obsessions such as phone numbers or shop names or to copying words or phrases. L's expression was more fluent and she used more sophisticated sentence structure when typing than when writing.

4 L., who was also the client most successful at using sign language, had the syntactical problems most resistant to correction. She had special problems with definite and indefinite articles and tenses.

5 Bannister defined apraxia as "The inability to carry out a purposive movement, the nature of which the patient understands, in the absence of severe paralysis, sensory loss, and ataxia" - Bannister R., 1985, Brain's Clinical Neurology, 6th ed. London, Oxford University Press. In the case of many of these clients it was not clear that they did understand the nature of the movements required until they were able to communicate, whereupon it was possible to ask them to describe actions, or to induce them to direct staff to carry out a sequence of actions that they themselves were unable to perform.