

This article first appeared in the Summer 99 issue of *Speech & Language Therapy in Practice*, pp. 4-6.

Whose needs come first?

The variable use of objects of reference with children and adults with severe and profound learning disabilities raises many questions. Advisory teacher Keith Park challenges us to address issues of individualisation, theory and practice, multidisciplinary collaboration and working with parents.

The term 'objects of reference' refers to the use of objects as a means of communication. Although this may have much to offer people with profound and multiple learning disabilities, there remain important issues of both theory and practice that have not yet been addressed. The apparently ad hoc method of using objects of reference, and the apparent lack of evaluation studies, mean that the quality of practice is extremely variable, and there seems to be little consideration of the importance of the social context within which objects of reference are intended to be used (McClarty, 1995; 1997).

Objects of reference were first described by Jan van Dijk in the mid-1960s as a means of communication for people with congenital deafblindness. Since then, although the literature is scarce, there have been some examples of work in the United States, Australia, Denmark, and the United Kingdom. A full review of this literature is in an article entitled 'How Do Objects Become Objects Of Reference' (Park, 1997a). As the title suggests, the article is also concerned with the development of a theoretical model of object use that might shed some light on some murky subject matter! Most of the literature reviewed deals with the use of objects of reference with children and adults who are already communicating intentionally. There is very little, if any, literature on its potential use with individuals with profound and multiple learning disabilities who are not communicating with intent.

Representational objects

The literature review (Park, 1997a) identified one particular issue in the use of objects of reference with people with profound and multiple learning difficulties in that the objects of reference - chosen by teachers or therapists to represent significant activities, objects, or people - may be representational. In other words, the objects may stand for, or represent, something other than themselves: a purse or wallet for shopping, a piece of material to indicate the sensory room and so on. Using objects of reference may appeal to us because we think they have a 'common sense' value: they are permanent, manipulable, and concrete. Most of the literature reviewed, however, suggests using them in a way that pre-supposes that the user understands the distance between vehicle (the object itself) and referent (the concept to which it refers). For example, why should a purse represent or 'stand for' shopping? How do we know what an object may or may not represent for someone else? How can we validate the assumptions of our practice? On a theoretical level, we might ask how objects become objects of reference: how does meaning develop?

Provisional model

The literature review (Park, 1997a) proposed that a provisional model of object use might be designed by using three terms from semiotic theory: index, icon and symbol. These are described by Elizabeth Bates in her pioneering work on early communication and language as follows:

1. Index

"Signs that relate to the things they stand for because they participate in or are actually part of the event or object for which they stand"

2. Icon

"Signs that are related to the things they stand for by virtue of some physical resemblance"

3. Symbol

"Signs that are related to the things they stand for by an arbitrary bond agreed upon by those who use the symbol" (* Bates, 1976, p2).

Communication needs

These terms can be illustrated by two teenagers, Alex and Anna, and their communication needs.

Pre-intentional communication may be described as being idiosyncratic, context-dependent and individually directed. Alex, who is 16 and has multiple disabilities, has been observed by his carer, at dinner times, to 'flutter' the fingers of his right hand, a behaviour that the staff who know him best have interpreted as meaning "This is nice/I like this/I am comfortable with this." This behaviour is, in one sense, unique to Alex, and so it is idiosyncratic; it only ever occurs at dinner times and so it is context-dependent. It is pre-intentional communication in that Alex is not intentionally transmitting a message, although the staff are able to interpret it as having a meaning. This is a result of their efforts to communicate to Alex certain essential items: he has been encouraged to feel the plate and spoon, smell the food, listen to the carer talk to him and allowed time to respond in his own individual way. In this way the communication is individually-directed in that it aims to help him make sense of his environment.

The final stage of intentional communication -when people begin to use words, signs, symbols, objects or any other communication media - can be described as conventional, context-independent and socially directed. For example, Anna, also 16, is in a school leavers' group. All of the teenagers in her group have a severe visual impairment and severe learning difficulties. The group shares an objects of reference board that indicates school activities, school personnel and school rooms. The system of objects of reference has been developed to be the same for all the group (conventional), it is used across home and school environments (context-independent) and one of its aims is communication between the members of the group (socially directed).

It seems reasonable to conclude that Alex's and Anna's objects would not be appropriate for each other. Alex's objects include a spoon for cooking (the same one he is helped to use in stirring the various mixtures) and an armband for swimming (the same one he wears in the hydrotherapy pool). Anna's, and those of her peers, include an audio tape case stuck on a piece of card for 'leisure time' (after dinner when the students stay in their classroom and play their own choice of music); a crushed can on a piece of card for the current project (crushing cans for an ecology project); a guide cane for 'walking/mobility training'; a purse for shopping (this is also stuck on a card and is not used in the activity); a bus ticket on a piece of card for 'going on the bus.'

Standardisation

What would happen if Alex and Anna attended a school where a standardised use of objects was being implemented? As has been remarked so memorably, "Is there life after toilet and biscuit?" I am not suggesting that standardisation is a priori a wrong decision, but it is important to encourage discussion in this very complex area. For learners who do not communicate with intent, a communication strategy needs to be idiosyncratic, context-dependent and individually-directed. In other words, before there are objects of reference, there are objects. In many cases, people are being given 'objects of reference' before they have been able to develop any understanding of signification (that is, that one thing can stand for another). Would Anna's objects of reference be appropriate for Alex?

Theory and practice

So how do objects become objects of reference? Objects may become objects of reference because of their 'canonicity': this refers to the 'canonical, or socially standard, function of the object' (Sinha, 1988, 105-106). The development of canonical object use describes the process of how objects become objects of reference, and this is an area of practice and theory that needs much attention. Would this investigation be appropriate for academics or practitioners?

Many of us may feel uncomfortable when discussing issues from a theoretical perspective, but I would argue that it is essential - especially if we do feel uncomfortable about it. Many teachers, and perhaps therapists, may feel that some academics within their field of work are too removed from practice. This may be so, but an academic might justifiably reply by saying that practitioners are anti-theoretical. Two years ago when I was invited to give a presentation on the use of objects of reference the organiser told me quite emphatically: "this is a practical workshop that provides practical answers to practical questions. We don't want any theory or funny business like that." I ignored the comment - and, of course, people were quite happy to discuss theory when it was made clear how it related to our issues of practice. If we wish to complain about academics being divorced from reality, we cannot divorce ourselves from theory. A famous radical politician once said that theory without practice is barren and practice without theory is blind. Cynics might reply this was one thing that Lenin got right!

Individualisation

When considering the use of objects of reference with someone, it may be helpful to consider the 'MMF' principle (Park, 1997b): choosing objects that are Meaningful, Motivating and Frequent. These real examples illustrate that objects of reference - and the concepts to which they refer need to be relevant to the individual user and not to the therapist or teacher. In a recent article (Park, 1997b) I asked, jokingly, if anyone knew of someone of school age with severe and profound learning disabilities who was using an object for modern foreign languages. This was evidently not a joke. I have subsequently found anecdotal evidence that suggests that many people in this situation are given a separate object for each National Curriculum subject with the justification of "this is what we teach at school."

1. Meaningful

Angela does not like to sit down and this made school life very difficult for the class staff. One day, when they had managed to persuade Angela to sit down, her teacher gave her a string of beads, and Angela sat at the table with the others for nearly 15 minutes. This was quite a breakthrough, and so, building on this success, Angela was given the string of beads every time she was expected to sit down with a group. After a while, Angela was persuaded to leave the beads on the back of the chair and to participate more in the group activity. This strategy has been very effective, and the string of beads - for Angela - means something like "sitting down with the others and doing things". Angela's teacher can then differentiate the activities in her teaching file according to the National Curriculum subjects. When the activity is finished, Angela is encouraged to drop the beads into a small cardboard box that is presented to her. She then knows that she is free to wander around the room for a while. The 'meaning' of the beads from Angela's perspective has been socially constructed, and not arbitrarily imposed.

2. Motivating

One of the highlights of Jill's week is when she has her hair washed. The bottle of shampoo is her object of reference for 'hair washing.' One unforgettable day, only six weeks after the weekly hair washing routine had started, Jill picked up the bottle of shampoo and gave it to a member of staff. According to the school staff, this was the first time ever in school that Jill, then 18 years old, had made an intentional communication. Her teacher once said to me "Why does everyone have objects of reference for toilet? My granddaughter is two and doesn't have an established toileting care routine, but she would rather talk about the Teletubbies!"

3. Frequent

Abdul loves going to watch rugby matches but can only go twice a year. His special hat is kept out of sight until a day or so before he goes to a match. However, he also enjoys going to the video shop to hire a video, and this object of reference - the plastic ticket given out by the shop - is kept out on permanent display as a frequent and realistic item of choice.

More work needed

This article is based on the issues discussed during my presentation to the RCSLT SIG in AAC. It was sad to see that among the fifty or so people, there was just one example of successful home use of objects of reference. As one therapist ruefully pointed out, it seems that service users exist to make professionals feel they are providing a professional service. Clearly, much more work needs to be done here.

Recently I met a parent of a four year old child with disabilities who is successfully using objects of reference at home (without any therapist or teacher being involved!) The school where she starts later this year has a standardised approach to the use of objects of reference. When I asked the mother what she thought about this, she replied that she was going to meet with the speech and language therapist and the class teacher, discuss the needs of her child, and they would then draw up a list of communication aims and methods that would be shared between school and home. She added that this agreement would then be one of the items discussed at each annual review. I asked what she thought of standardised systems. She said "my daughter's needs come first." Parent power may sound like a cliché, but it is one we should hear more often.

Uneven quality

Several of the people at the SIG meeting had positive examples of co-operation between therapists

and teachers, and this was encouraging. However, there was a general agreement that communication is far too important to be left to any one profession or person, and perhaps the uneven quality of practice concerning objects of reference may point out the need for a much closer collaboration between therapists and teachers, and most importantly parents.

Collaboration

Objects of reference is just one subject among many that are important for multidisciplinary collaboration: eating and drinking difficulties, augmentative communication in general, and of course involving parents in using communication systems at home. The Sense Family Centre at Ealing welcomes the opportunity to continue to develop multidisciplinary collaboration between speech and language therapists and teachers in the very complex area of augmentative and alternative communication with people who have severe and profound learning disabilities and multi-sensory impairments. In particular, we would like to hear from therapists who have experience of or an opinion on:

1. individualisation/standardisation of objects of reference
2. successful home use of objects of reference
3. working with children with multi-sensory impairments.

This article is from the Summer 1999 issue of *Speech & Language Therapy in Practice*.

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Acknowledgement

Coming to the SIG AAC meeting as a teacher to talk mainly to speech and language therapists, I learned that therapists have a positive attitude towards multidisciplinary collaboration, a readiness to discuss theoretical issues and, perhaps most importantly, an enthusiasm for their work. I would like to thank Gillian Nelms and her colleagues for inviting me.

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Reflections

- Do I give sufficient weight to the needs of individuals?
- Do I impose meaning on clients, or allow it to develop?
- Do I ensure communication systems work in real life?