

A three way model of communication for children and adults with autism and intellectual disability living in residential care

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Editorial comment

In this paper, the author sets out the rationale for proposing that there are three key elements necessary for enabling effective communication between staff and autistic individuals with a learning disability. The three elements needed are for the person to be taught an effective means to communicate, secondly, for staff to understand and have knowledge and competence in using this system, and thirdly, for the environment within the setting to be conducive to good communication, providing the means, the reasons and the opportunities to communicate. The rationale is largely literature based and argues that when the three elements are in place, quality of life is enhanced and the incidence of behaviours which challenge others decreases.

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Introduction

Individuals with an intellectual disability or autism frequently have difficulties with social interaction and communication (American Psychiatric Association, 2013; Belva et al, 2012). It is estimated that between 30 to 50 per cent of people with autism do not use verbal speech or remain minimally verbal (Tager-Flusberg and Kasari, 2013; National Research Council, 2001) and may require the assistance of augmentative and alternative communication (AAC) aids (Ganz et al, 2011) during childhood and into adulthood (Trembath et al, 2014).

Without an effective communication system, children and adults may communicate their needs and feelings (Chiang, 2008; Kevan, 2003) or their physical discomfort (De Winter, Jansen and Evenhuis, 2011; Oliver and Richards, 2010) by means which can challenge others or themselves. They may engage in self-injury (Richards et

al, 2012; Emerson et al, 2001) or be physical challenging to others (Ruddick et al, 2015; Poppes, Van Der Putten and Vlaskamp, 2010). They may also have significant care needs (Iemmi et al, 2016; Charnak and Bonniau, 2016) and a reduced awareness of danger (Fisher, Moskowitz and Hodapp, 2013; Greenspan, Switzky and Woods, 2011) and may be placed in residential care settings (Iemmi et al, 2016; Gray et al, 2014; Mansell, 2007). In these settings, best practice recommendations state that effective and person centred communication is essential to maintain quality of life (Royal College of Speech and Language Therapists, 2013).

In this paper, the literature on some interventions to develop a person's communicative competence will be reviewed, together with studies on training used to improve the communication skills of support staff.

The author proposes a triadic or three way model of communication and makes recommendations for future practice.

Communication and individuals with autism and an intellectual disability

Significant difficulties in both non verbal and verbal communication and interaction are a core feature of those with intellectual disability (Antaki et al, 2017; Goldbart, Chadwick and Buell, 2014) and/or autism (American Psychiatric Association, 2013; Happé, 2005; Frith, 2003). Failure to make reasonable adjustments to meet the different communication needs of these individuals can result in poor service design and delivery, health inequalities and exclusion (Royal College of Speech and Language Therapists, 2013; Jones, 2000). Other verbal language differences are also commonly reported within the literature, including pedantic speech patterns, pronominal reversal and echolalia (Mergl and Azoni, 2015; DeVilliers et al, 2007; Ghaziuddin and Gerstein, 1996; Ferrari and Matthews, 1983).

Effective communication and residential care settings

There are a number of potential barriers to effective communication within residential care settings as well as approaches for actively promoting communication (some of which have been summarised in *Table 1*).

In order to overcome these barriers, it is our ethical duty to make reasonable adjustments to the services provided, to ensure that communication between individuals and support staff is tailored to the needs of each individual. In doing so, we can ensure that people with autism or intellectual disability can live without unnecessary restrictive practices and achieve as full a quality of life as possible (Beadle-Brown, 2006). This is reflected in recent guidance from the Royal College of Speech and Language Therapists (RCSLT) who stated in 2013 that:

"Implementing good communication is proactive and ethical as it prevents reactive and unethical restrictive interventions" (RCSLT, 2013 page 2).

Table 1: Barriers and promoters of effective communication within the service

| Barriers to effective communication | Reference |
|---|----------------------|
| Complexity of equipment | |
| Lack of technical support | |
| Difficulties with use | Baxter et al (2012b) |
| Negative response from communicative partners | |
| Time management | |
| Low levels of staffing | |
| Misinformation about service users' abilities | Firth et al (2008) |
| Relationship with the service user | |
| Environmental pressures | |
| Concerns regarding consent | Bodicoat (2013) |

| Promoters of effective communication amongst staff | Reference |
|--|--------------------|
| Gender of communicative partner | |
| Familiarity with disability | Beck et al (2010) |
| Autism awareness training | Clark et al (2016) |

To achieve this aim, the author proposes that the first component of the communication triad should be a focus on developing and enhancing the individual's communicative skills.

The first element: an individual's communicative understanding and competence

Care settings will often take action to support people to improve their communicative skills. Commonly, the individual may be lacking a basic understanding of the primary concepts of communication and its function, such as how to request, refuse or attract somebody's attention (Tager-Flusberg, Paul and Lord, 2005, Newson, 2001). Noens and Van Berckelaer-Onnes (2004, page 202) argue that "when communicative competence is increased, quality of life can improve substantially" and that communicative competence, not just communicative means, should be the focus for assessment. Communicative competence is essential as introducing communicative systems, such as symbols or pictures, without the necessary prerequisite skills can result in an increase of behaviours which challenge others (Noens and Van Berckelaer-Onnes, 2004).

Augmentative and alternative communication

Augmentative and alternative communication (AAC) aims to overcome the common communication difficulties experienced by children and adults with limited communication (Beukelman and Mirenda, 2005). It aims to support expressive communication and comprehension rather than merely replacing the use of natural speech and is divided into two distinct intervention types:

- unaided communication (which relies on physical signs or gestures and requires no supplementary resources)
- aided communication (which relies on additional external equipment such as visual symbols, photos or a computer)

In their epidemiological study, Creer et al (2016) identified both autism and intellectual disability as two out of nine key medical conditions where the use of AAC could be beneficial. Similarly, in another review, Baxter et al (2012) reviewed 65 papers reporting on the use of high tech AAC and found that this was beneficial across a broad range of diagnoses and ages.

The Picture Exchange Communication System (Bondy and Frost, 1994)

A commonly used picture or symbol based intervention, under the AAC umbrella, is the Picture Exchange Communication System (PECS) developed by Bondy and Frost (1994). PECS was designed to teach individuals with autism "a rapidly acquired, self-initiated functional communication system" (Bondy and Frost, 2001 page 728). A number of studies have reported that the use of PECS has led to a reduction in the incidence of behaviours which challenge others (see Barbosa et al, 2018; Cooper, 2017; Charlop-Christy et al, 2002; Frea, Arnold and Vittimberga, 2001).

The use of computer technology to enhance communication skills

With the development of modern technology, many organisations are moving away from the labour intensive production of laminated symbols and use computer software instead. In 2017, Alzrayer, Banda and Koul showed the development of increasingly complex requesting skills in four young children on the autism spectrum when using specialist communication software. Similar studies on the positive effects of tablet computers have been reported in earlier studies by Gevarter et al (2014) and Xin and Leonard (2015) and in a later paper by Lorah (2018). Conversely, in a randomised control trial of 54 young children with autism, Fletcher-Watson et al (2016) found little impact when using tablet computers to improve real world social communication skills.

In a study on the attitudes of parents and professionals towards tablet computers, Clarke, Austin and Craike (2015) found that both parents, and professionals held a favourable outlook towards their use. However, despite their pro-tablet attitude, professionals showed limited use of such devices in their practice, indicating a potential lack of confidence, training issues or the need for an increased evidence base (Price, 2011; Hennessey, Ruthven and Brindley, 2005). When comparing the efficacy of PECS against a tablet computer with a communication application, Hill and Flores (2014) and Lorah et al (2013) found mixed results, perhaps as a result of personal choice regarding which system the individuals used – although tablet computers clearly

seem to hold an advantage as they are less cumbersome, more user intuitive and less socially stigmatising (Kagohara et al, 2013).

The second element: staff knowledge and competence and their attitudes towards methods of communication

The evidence suggests that a key responsibility on staff should be to ensure that individuals are given the correct support to use different methods of communication (RCSLT, 2013). The effectiveness of communication will be lowered if only one of the communicative partners possesses the necessary skills or if staff hold negative attitudes towards the methods used (Beukelman and Mirenda, 2005). The author therefore proposes that a second element of the communication model should be the development of staff's knowledge and understanding on the communication needs of those they support, the methods they use and how communication can be enhanced and encouraged. All too often, one or two members in an organisation might attend the full training about an approach such as PECS, TEACCH or intensive interaction or computer software, and other staff members are expected to use this with much less training and information on its rationale and practice. It may then be done incorrectly and/or with less enthusiasm.

Staff knowledge and attitudes to communication

In addition to understanding the communication and the needs of children with autism and autistic adults, it is also important they are informed as to how they can alter their own communication (eg limit their own spoken language; use other forms of communication; build in special interests). As Milton (2012) has written, there is a 'double empathy' problem where staff do not understand the person with autism and vice versa and we have to work on both fronts. Alternative means are being developed to enable the voice of those with limited verbal ability to communicate more effectively but there is some way to go in this work.

Staff training aims to alter knowledge and attitudes (Tilahun et al, 2017; Rose et al, 2014; Le Blanc, Richardson and Burns, 2009) but it is important to ascertain to what extent this is successful and how change

can be maintained. Smidt et al (2007) for example, found a decrease in behaviours of concern following a four week staff training programme which focused on attitudes and beliefs about challenging behaviour and communication. However, they found that unfortunately this decrease was not maintained over time, so there is a need for frequent refresher training or discussion. In a study to identify levels of AAC training in England, Wallis, Bloch and Clarke (2017) found there was no consensus as to what training should be delivered and that it tended to vary in both quality and depth.

Shared skills and solo competencies

Some communication interventions such as PECS or Makaton can be defined as 'shared skills' where a level of training and competence is required by both the staff member and the service user. Other interventions can be described as 'solo competencies' where it is only the staff member that requires the training and the development of a skill, eg Intensive Interaction – now preferred to be known as responsive communication by Phoebe Caldwell – one of its main proponents (Firth, Berry and Irvine, 2010; Nind and Hewitt, 1994). Firth, Poyser and Guthrie (2013) found that the implementation of an Intensive Interaction training programme increased service users' willingness to initiate social contact, with a corresponding increase in engagement through joint attention and facial expression. Similarly, Weedle (2016) found that Intensive Intervention led to increased sociability, reduction of distress and a corresponding increase in wellbeing.

The third element: the communicative environment and culture

While there is a clear indication of the beneficial effects of the development of communicative competence and staff knowledge on communication, there appears to be less literature on what is needed to create an effective communicative environment. The World Health Organisation in 2011 stated that the physical, social or attitudinal environments "can either disable people with impairments or foster their participation and inclusion" (World Health Organisation, 2011 page 169). The author believes from his own experience of working in autism specific care settings, that the physical, social and attitudinal shortfalls in the communicative

environment commonly fail individuals with autism and intellectual disability, as a result of the communicative culture of the organisation.

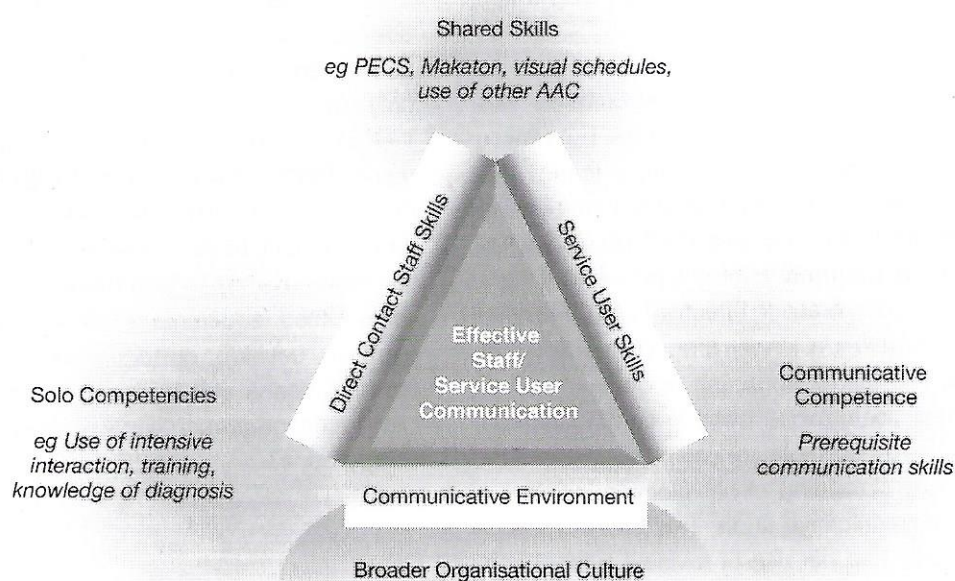
In 2007, Hodge identified some common cultural problems facing individuals using AAC. These included not being given enough time to finish their answers, with others finishing their sentences for them, or non disabled people talking across them. Getting the communicative environment right is fundamental to people living meaningful lives and maintaining good quality of life (RCSLT, 2013). This may involve widespread organisational and cultural change. Organisational culture relates to established practices and subjective values (Schein, 2010). Effective organisations have regular focused staff discussions on practice and its rationale which can lead to changes in practice in the light of new understandings. Particular ways of working and thinking are often well embedded and where there is little discussion and/or low staff turnover, old ideas might be retained when other new approaches might be more effective. The use of coaching and mentoring can also help to build staff knowledge and enhance practice.

The three way communication triad for residential care

From the literature, it is clear that effective communication in residential care services relies not only on the individual skills of the service users and their support staff, but also on the underpinning communicative environment and wider workplace culture. This includes good and up to date knowledge and understanding of autism and intellectual disability and how these two conditions affect communication. To this end, the author proposes that service providers should have an understanding of the triadic model outlined below (see Figure 1).

Each element of the triad works in combination with the other to deliver a fluid flow of information between those who use the services and those who provide their care. The effectiveness of this communicative flow however is related to the efficiency of the weakest element in the triad. It is therefore essential that all three aspects are strong and present in equal measure for consistent and effective communication to occur. For instance, an individual who can use PECS to a high level to request activities, pain relief or food, who is supported by care

Figure 1: The triadic model of communication



staff who are also fully competent with PECS, will still struggle to communicate effectively in a poor communicative culture where for example, their required symbols are lost and not replaced. Similarly, having an individual who is capable of using Makaton, will be of no benefit if there is only one member of their staff team who is Makaton fluent.

In the worst case scenario, individuals with autism or intellectual disability may be highly skilled in communication techniques, but this will be meaningless if the communicative environment or culture they live in is such that staffing levels, high numbers of agency workers or work pressures mean that communicative attempts by the individual are missed, misinterpreted or, worst still, ignored.

This conceptual model was developed by the author after it he felt that there could be a substantial improvement in the quality of communication between staff members and service users in a setting within which he worked. A three point audit process was implemented across the organisation to assess each aspect of the communication triad. Staff members were asked to self evaluate their current level of communicative skill using an online data collection tool (36 per cent of staff responded), while the current and historic communication abilities of service users were assessed using a specially developed audit instrument.

The quality of the communicative environments was established following onsite observations by service managers or members of the therapy team. This triple audit process confirmed that improvement was needed in all three key areas of the triad and while improvements to staff and service user training were implemented quickly, creating effective communicative environments requires a longer term cultural change. The effect of this triadic approach to communication has been most useful when used in person centred interventions. As an example, for one person, concerns about the hourly shredding of her clothing initiated a three point communicative audit. This process identified that not only had her use of a visual symbol and traffic light system decreased, but so had the corresponding communicative skill mix of her staff team.

The communicative environment was found to be good and specific training interventions for both the service user and the staff team saw a marked reduction in her shredding behaviours.

Similarly, for another person who became very avoidant of demands, a three way audit of the communication showed that while he had relatively good verbal skills, the approach of the staff team (which assumed a higher level of understanding than was the case) and the general communicative environment was unintentionally placing high levels of demand on him. This subtle, but ever present, level of demand was resulting in daily challenges including verbal or physical challenge and a refusal to participate in basic personal care and education. Training and mentorship of the staff team regarding the idiosyncrasies of this person's communication, saw a significant decrease in both verbal and physical challenges as well as a reintegration back into education.

Concluding comments

Following an inclusive communication philosophy (RCSLT, 2013), it should be the ethical responsibility of service providers to ensure that the knowledge, skills and practice of staff about communication match those of the individuals they support. Service user skills, staff competencies and most importantly the underpinning communicative environment should be regularly audited and a clear plan implemented to advance not only the solo competencies of staff members but also their shared skills with the service user (such as the use of PECS, Makaton or AAC). Both staff skills and those of the service users should be developed in harmony, so that the communicative skills of the staff team increase in line with those of the person. Strong value based leadership is needed by senior management to develop opportunities for communication and the means and reasons to communicate, taking clear account of each service users preferences and competence.

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