

Royal College of Speech and Language Therapists

Five Good Communication Standards

Reasonable adjustments to communication that individuals with learning disability and/or autism in specialist hospital and residential settings should expect

Foreword

Transforming Care: a National Response to Winterbourne View Hospital¹ found failings around how we care for people with learning disabilities or autism with complex needs. It stated the need for improved quality and safety standards before better outcomes for individuals will be achieved. The report identified outcomes for individuals with a learning disability and/or autism plus mental health conditions or behaviours described as challenging, who live in specialist hospital and residential settings. These included:

- being safe
- being treated with compassion, dignity and respect
- being involved in decisions about their care
- knowing those around them and looking after them are well supported
- making choices in their daily life
- receiving good quality general health care

All these outcomes are underpinned by good communication. Most people with learning disabilities have some speech, language and communication difficulties. These can be hidden or over looked. Everyone needs to know what good communication support 'looks like' and what reasonable adjustments they can expect. Implementing good communication is a proactive, ethical strategy that may reduce both the likelihood of needing restrictive approaches and interventions, and the occurrence of other cases of abuse and punishment as occurred at Winterbourne View.

Not making reasonable adjustments to meet communication needs will mean people with learning disabilities continue to be vulnerable to a range of risks. These include the continuing failure to design, commission and provide best-practice services, alongside continuing health inequalities faced by individuals, in contravention of legal responsibilities². To help providers of specialist hospital and residential services, the Royal College of Speech and Language Therapists (RCSLT) recommends 5 good practice standards around speech, language and communication.

¹ Department of Health (2012) Transforming Care: a National Response to Winterbourne View Hospital

² Emerson E and Baines S (2010) Health inequalities and people with learning disabilities in the UK: 2010. Improving Health and Lives: Learning Disabilities Observatory. *Department of Health*
www.improvinghealthandlives.org.uk

Key recommendations

This paper introduces the 5 Good Communication Standards for best practice. These will ensure reasonable adjustments are made to meet the speech, language and communication needs of individuals with learning disabilities or autism in specialist hospital and residential settings. These standards are drawn together using practitioner knowledge from expert Speech and Language Therapists across England, Scotland and Wales, using the RCSLT specialist networks. Additional consultation took place via the national Learning Disability Professional Senate which includes representation from professional bodies, families and carers, the Department of Health and other organisations.

The 5 Good Communication Standards are intended as a practical resource to support families, carers, staff, professionals, providers and commissioners to make a difference to the lives of individuals using specialist residential services. As a result of these standards all stakeholders should be able to know

- What good communication looks like
- Whether good communication is happening
- About useful resources to promote good communication

Introduction

Up to 90% of people with learning disabilities have communication difficulties. Around half have significant difficulties with both expressing themselves and understanding what others say³. Additionally only 5% - 10% of people with learning disabilities have recognised literacy skills and most are not be able to access standard written information⁴. The incidence of additional sensory impairments, including sight and hearing, is much greater than the general population with up to 40% of people with learning disabilities having a hearing loss that is often missed and undiagnosed⁵. People with Autism have lifelong communication impairments around social communication, social interaction and social imagination⁶.

For this population, communication is therefore a significant individual risk factor contributing to both mental well being and behaviour described as challenging. However it is also an environmental risk factor. Evidence shows staff do not generally interact with people they support in a way that enables these individuals to achieve greater levels of independence, participation or integration ⁷. This indicates that providers of specialist hospital and residential services need to develop this expertise. Staff supporting individuals need the skills to make reasonable adjustments to develop meaningful communication and engagement.

^{3 8} RCSLT (2010) Adults with Learning Disabilities: Position Paper. Royal College of Speech and language Therapists

⁴ All-Party Parliamentary Group for Education (2011) Report of the Inquiry into Overcoming the Barriers to Literacy

⁵ Emerson E and Baines S (2010) Health inequalities and people with learning disabilities in the UK: 2010. Improving Health and Lives: Learning Disabilities Observatory. *Department of Health*

⁶ Department of Health (2010) Fulfilling and rewarding lives: the strategy for adults with autism in England. NICE

⁷ Mansell, J (2007) Services for people with learning disability and challenging behaviour or mental health needs. Department of health

Good communication only exists as part of positive everyday relationships. Without good communication people struggle to learn, achieve, make friends and interact – all fundamental for citizenship and humanity and central to improving quality of life⁸. Good communication crosses all dimensions of care, support and enablement. Without good communication people may be at risk of⁹:

- A lack of choices and involvement in everyday decisions
- Limited relationships
- Increased vulnerability to abuse and hate crime
- Low mood, anxiety and depression, and withdrawal from community life
- Reduced employment and housing opportunities; increased placement breakdowns
- Lower standard of healthcare, diagnostic overshadowing, and more in-patient admissions. Nursing staff unable to implement 8 Principles of Nursing Practice¹⁰
- Over reliance by staff on restrictive approaches and interventions
- Overuse of specialist learning disability services and “out of county” placements
- Increase use of behaviour which challenges, mental health distress or offending
- Not accessing verbally mediated therapeutic input focussed on criminal offences
- Staff teams consistently over estimating an individual's abilities, impacting negatively on staff perceptions, affecting the individual's overall care
- Poor compliance with the legal requirements for Mental Capacity Act (England) and Adults with incapacity Act (Scotland), Human Rights Act, Disability Discrimination Act

Good communication reduces these risks. It enables inclusive relationships, supporting individuals to have choice, control, greater independence and improved health outcomes. Sustainable improvements in communication can only be achieved through a 'whole systems approach' to reasonable adjustments, including:

- a range of learning opportunities for staff
- ongoing supervision that is psychologically minded and considers their own thoughts about the individuals they work with and how this impacts on their relationship and the therapeutic environment
- access to resources, skills and knowledge to support communication
- good communication strategies, guidelines and standards
- referral to specialist speech and language therapists for specific assessment and treatment
- broader access to multi-disciplinary specialist services to empower and help providers of specialist hospital and residential services to communicate well across the whole system

Providers of specialist hospital and residential services need to evidence their whole systems approach to good communication. Good communication is all about inclusion: respecting the person and taking an individualised approach, whatever communication methods work best for an individual. Inclusive or total communication means sharing information in a way that everybody can understand¹¹. It is about being aware and valuing all the different ways a person may use to communicate. Good communication

⁸ Bercow, J (2008) Review of Services for Children and Young People (0-19) with Speech, Language and Communication Needs. Department for Children, Schools and Families

¹⁰ RCN Principles of Nursing (2013) <http://www.rcn.org.uk/development/practice/principles>

¹¹ Scottish Government (2011) Principles of Inclusive Communication: An information and self-assessment tool for public authorities www.scotland.gov.uk

should support individuals to make and understand choices, express feelings and needs, and involve themselves in the world around them. Providers need to access and use a wide range of tools, techniques and technologies. The support needed will vary from person to person but the outcome for an individual should mean individual's can say:¹²

- Whatever communication methods work best for me are used and valued by others
- People communicate effectively with me because of their underpinning knowledge, skills and attitude
- People actively listen to me and take time to support my communication
- I get the professional support I need to enable me to communicate to my full potential
- The communication tools, techniques or technology I need is freely available to me throughout my life
- Policies and strategies that affect me take into account my communication and include me in appropriate ways

Many people with learning disabilities or autism, with complex mental health conditions or behaviours described as challenging, are dependent on others for good communication. The RCSLT has identified 5 recommended Good Communication Standards for providers of specialist hospital and residential services to meet the speech, language and communication needs of individuals. These standards provide a framework by which families, carers, friends, professionals and commissioners can know if a service has made reasonable adjustments to their communication practice. Each standard is clearly defined in terms of what the standard is, what good looks like and how others will know. Useful resources and references are also included.

The 5 Good Communication Standards are:

Standard 1: There is a detailed description of how best to communicate with individuals

Standard 2: Services demonstrate how they support individuals with communication needs to be involved with decisions about their care and their services

Standard 3 : Staff value and use competently the best approaches to communication with each individual they support

Standard 4: Services create opportunities, relationships and environments that make individuals want to communicate

Standard 5: Individuals are supported to understand and express their needs in relation to their health and well being

¹² Thurman, S (2009) Communication is a basic Human right. BILD, Kidderminster

About developing the standards

Following the Winterbourne View Review, a concordat¹³ was developed by the Department of Health. As part of the Learning Disability Professional Senate¹⁴ the RCSLT was a signatory committing to:

“working together, with individuals and their families and with the groups that represent them, to deliver real change. Our shared objective is to see the health and care system get to grips with past failings by listening to this very vulnerable group of people and their families, meeting their needs and working together to commission the range of support which will enable them to lead fulfilling and safe lives in their communities”.

The concordat outlines a programme of action and as part of this the RCSLTs agreed to produce good practice standards for commissioners and providers, to promote reasonable adjustments required to meet the speech, language and communication needs of people with learning disabilities in specialist learning disability or autism hospital and residential settings. The development of these recommendations has been through the specialist RCSLT National Forum for Adults with learning Disabilities. The Project and Editorial Lead is Dr Della Money, as current RCSLT representative at the Learning Disability Professional Senate. The working party has been the RCSLT ALD Forum Steering Group:

Dr Della Money, RCSLT Advisor, FRCSLT, Professional Senate Representative
Ms Viki Baker, MRCSLT, Chair of the ALD Forum Steering Group
Ms Jane Parr, RCSLT Advisor, MRCSLT
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Consultation has taken place through

- The ALD forum Network who link to regions and Clinical Excellent Networks
- The Learning Disability Professional Senate – which includes members from the
- The Inclusive Communication Working Party
- Nottinghamshire Healthcare NHS Trust Community of Interest

Status: The document has been to the RCSLT Programme Board in June 2013 for advice, support and ratification, prior to being submitted to the Post Winterbourne View Implementation Programme Board on either 4th July or 28th November

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¹³ Winterbourne View Review: Concordat: A Programme of Action.

¹⁴ The Learning Disability Professional Senate includes the Royal College of Psychiatrists, the Royal College of Nursing, the College of Occupational Therapists, the Royal College of General Practitioners, the College of Social Work, Chartered Society of Physiotherapy, the Royal College of Speech and Language Therapists, other professional bodies include the British Association of Social Workers and the British Psychological Society.

Standard 1:

There is a detailed description of how best to communicate with individuals

In order to communicate effectively it is essential that everyone understands and values an individual's speech, language and communication needs. Individuals should be supported and involved, together with people who know them best, to develop a rich description of the best ways to interact together. This description needs to be agreed, active, regularly updated and readily available. This description is sometimes referred to as a communication passport, guideline or profile. It includes the best ways of supporting their understanding and expression, the best methods of promoting interaction and involvement and describes 'how to be with someone'

What does good look like?

A clear description of an individual's communication should include information on:

- understanding communication from others (such as hearing, concentration, memory, comprehension of words and sentences, understanding of contexts, routines and non-verbal language)
- expressing communication to others (words and sentences, clarity of speech, use of signs, symbols and other visual resources, objects, facial expression and body language)
- describing whether communication and behaviour is intentional
- taking part in communication with others (conversation skills, social skills, interactive skills) and understanding others intentions
- the best times and people to communicate important information
- what makes a good communication environment or context for the individual (noise, space, sensory information, access to areas)
- other aspects that impact on communication for that individual

The description should be easy to understand and clearly identify how communication partners need to adapt their communication to support the individual. It should provide clear examples. When communication needs are complex speech and language therapists should support the process. These descriptions are particularly important at times of transition to help individuals understand changes in their life.

How you will know?

1. Communication Passports, Profiles, Dictionaries or Guidelines are readily available
2. Individuals and their families and friends are involved
3. People who know the individual well can recognise their family member or friend through the description
4. Staff can provide a thoughtful description of how they adapt their communication in line with the guidance
5. Individual's communication responded to positively, as detailed in their description
6. individual's communication needs are referred to in all their care plans
7. Descriptions are individual, current and up to date

Useful resources

- Coakes, L (2004) *It's My Book: Creating ownership of a communication passport* (first published in *Communication Matters Journal*, Vol 18, number 1 (2004) Available from <http://www.communicationpassports.org.uk/Resources/Passport-Articles/>
- Matthews, A *Communication Dictionaries and Communication Passports* [www.helensandresonassociates.co.uk] Available from <http://www.communicationpassports.org.uk/Resources/Passport-Articles/>
- Millar, S. & Caldwell, M. (1997) *Personal Communication Passports*. (Paper presented at the SENSE Conference, Westpark Centre, University of Dundee, 13 September 1997). Available from <http://www.communicationpassports.org.uk/Resources/Passport-Articles/>
- Millar, S. (2006) *Auditing passports*. Available from: <http://www.communicationpassports.org.uk/Resources/Good-Practice/>
- Millar, S. and Coakes (2006/2007) *An Evaluation of Attitudes to Passports*. CALL Centre Study. Available from <http://www.communicationpassports.org.uk/Resources/Evaluation-and-Research/>
- Lord, S. (2002a) Recipe for a Conversation RCSLT Bulletin Issue 602, June 2002 (p 10-11)
- Powell, H. and Kwiatek, E. (2006) Integrated care pathways in intellectual disability nursing. In: Gates, B. (2006) *Care Planning and Delivery in Intellectual Disability Nursing*. Thames Valley University: London.

Standard 2:

Services demonstrate how they support individuals with communication needs to be involved with decisions about their care and their services

Individuals with speech, language and communication needs are often either excluded from patient experience feedback processes or included in a tokenistic way. There is a risk their needs and opinions are assumed, misinterpreted or ignored. All communication needs to be inclusive. For service providers, this means making sure they recognise that people understand and express themselves in different ways. For individuals this means getting information and expressing themselves in ways that meet their needs¹⁵. Inclusive Communication is an approach that seeks to 'create a supportive and effective communication environment, using every available means of communication to understand and be understood' ¹⁶. For services to demonstrate inclusion and involvement innovative and creative solutions to understanding the views of individuals are often required due to the nature of communication needs.

What does good look like?

Shared decision making should be evident in everyday decisions as well as more complex decisions about future interventions. A range of communication strategies (i.e. practicable steps) are evidently used at each stage of the decision making process, in line with the statutory framework outlined in the Mental Capacity Act¹⁷. Decision makers seek support from others to ensure all practical steps are taken and to liaise with others to ensure a multi-agency/inter-agency best interest decision is taken. Information is presented in a way that is easier for the person to understand (accessible information), more time is allowed, behaviour is recognised as an indication of how the person feels; different, inclusive methods of communication are used. If someone is assessed as lacking capacity to make the main decision they are still encouraged to contribute the smaller aspects of the decision

For individuals to give feedback on their experience of services, a range of communication options and strategies are available. These include the production and use of accessible information, signing, individualised techniques and observations. The views of individuals with complex communication needs are sought by building up an understanding of their likes and dislikes and reviewing their preferences over time. Feedback is also sought from a range of proxies including family and friends, advocates, and professionals to build up a more complete picture of the individual's views and preferences. More specialist support from a third party such as Speech and Language Therapy is sought where appropriate.

¹⁵ Scottish Government (2011) Principles of Inclusive Communication: An information and self-assessment tool for public authorities www.scotland.gov.uk

¹⁶ RCSLT (2003) Communicating Quality 3

¹⁷ MCA Mental Capacity Act (2005); Mental Capacity Act Code of Practice (2007) and Scottish Government (2008) Adults with incapacity (Scotland) Act 2000 Communication and Assessing capacity- a guide for social work and healthcare staff

How you will know?

1. Staff demonstrate they understand how individuals show they like or dislike something, and these preferences are used to build up the individual's day
2. Staff understand how visual approaches as part of Inclusive Communication (ie using signs, pictures, symbols or photos) support decision making and involvement and can give examples of how they are used
3. "Patient Stories" have informed service development
4. Evidence of culture of asking opinions, acting on the feedback and changing accordingly. Individuals report they feel involved
5. Access to and use of PALS, complaints procedures and advocacy is clear and variety of support provided to ensure meaningful process, including accessible information and involvement of family and friends who know the person
6. Accessible resources are available that provide information about a range of decisions e.g. from daily menu choices through to information about specific interventions. The use of the accessible resources will be evident
7. Capacity assessments are completed for each significant decision. Decision makers ensure all practical steps are taken as part of the capacity assessment. This includes documented evidence about whether the person understood information about the decision and the consequences, whether they were able to retain and weigh the information and how they communicated their decision
8. When all practicable steps have been taken, if the person is assessed as lacking capacity then a full multi-disciplinary and inter-agency best interest assessment will be completed. The best interest documentation should show how the person was encouraged to participate, how their wishes and feelings were established, the possible courses of action and likely outcomes
9. Where individuals do not have capacity there is clear evidence that individuals are still encouraged to contribute to smaller aspects of the decision and every effort is made to ensure their views and preferences are fed into the decision making process.

Useful resources

- CHANGE (2010) How to make information accessible: a guide to producing easy read documents. Leeds, CHANGE.
- Department of Health (2010) Making written information easier to understand for people with learning disabilities. London: Department of Health.
- Mander, C. (2010). Portsmouth Accessible Information Website: www.accessibleinfo.co.uk
- Mencap (2002) Am I making myself clear? Mencap's guidelines for accessible writing. Mencap
- Mencap (2002) Making ourselves clear: Mencap's minimum standards for accessible writing. Mencap

- www.inclusivecommunicationscotland.org.uk
- Grove N (2000) See what I mean (SWIM) Guidelines to aid understanding of communication by people with severe and profound learning disabilities. Kidderminster: BILD publications
- BILD (2009) Hearing from the Seldom heard. Kidderminster- BILD
- Coupe-O'Kane, J., & Goldbart, J. (1998). *Communication Before Speech - Development and Assessment* (2nd ed.). London: David Fulton.
- Finlay, W. M. L., Antaki, C., & Walton, C. (2007). On not being noticed: Intellectual disabilities and the nonvocal register. *Intellectual and Developmental Disabilities*, 45(4), 227-245.
- Grove, N., Bunning, K., Porter, J., & Olsson, C. (1999). See What I Mean: Interpreting the Meaning of Communication by People with Severe and Profound Intellectual Disabilities: Theoretical and Methodological Issues. *Journal of Applied Research in Intellectual Disabilities*, 12(3), 190-203.
- Goldbart, J & Marshall, J. (2011) Listening to Proxies for Children with Speech, Language and Communication Needs. In S. Roulstone and S. McLeod (Editors) *Listening to Children and Young People with Speech, Language and Communication Needs*. J and R Press.
- NHS Leicestershire Health Informatics Service (2013) If You listen you will hear us, Guidelines on involving people with profound and multiple learning disabilities. www.leicspart.nhs.uk/InformationLibrary-Easyreadinformation.aspx
- Talking Mats (2013) www.talkingmats.com Talking Mats:- a well researched communication framework that enables some people who have difficulties communicating to express their views.
- Helen Sanderson Associates (2013) Person-Centred Thinking Tools. www.helensandersonassociates.co.uk

Standard 3 : Staff value and use competently the best approaches to communication with each individual they support

Staff working in specialist hospital and residential services must recognise communication difficulties. Staff must believe that they need to change their communication style to support the service user, and have the knowledge and skills to adapt their communication levels, styles and methods. Staff are aware of factors that impact on communication, especially hearing, sight and sensory integration. They understand that what they say and how they say it matters, and can impact positively or negatively on the individual. Staff understand how good communication underpins informed consent and capacity. Staff are able to promote the individual's understanding and expression and create opportunities for positive communication.

What does good look like?

The Judith Trust¹⁸ underlined the need for:

- Staff who are people of goodwill and willing to learn
- Manageable tasks, with clear indicators of success and a work/life balance
- Recognition and appreciation for the efforts
- A safe environment and culture of learning not blame
- Sufficient training , supervision and monitoring

Learning and development plans need to be in place to support staff to learn the appropriate communication skills. Competencies relating to communication are embedded within a training and development framework, running from induction to specialist practice. Members of the workforce act as Communication Champions/Advocates.

On- going supervision is essential to support them to adapt their communication and build up their understanding of the communication needs of the individuals that they work with. Supervision must be embedded in psychologically minded practice. This means staff are supported to be interested, and recognise both their own feelings in relation to the people they work with and how they communicate with them.

If both the above is in place, staff working in specialist hospital and residential services will demonstrate their understanding of an individual's communication and sensory needs and adapt their communication accordingly. These adaptations could include simplification of language, use of a range of ways of communicating or observing and responding to the individual's behaviour. They will have opportunities throughout the individual's day to communicate together for a range of reasons, not just meeting their needs and wishes, and have time for positive relationships.

¹⁸ Stenfert Kroese B and Rose J (2011) Mental health Services for Adults with Learning Disabilities, The Judith Trust

How you will know?

1. A communication strategy for good communication is in place (across either an environment or an organisation). Staff are aware of the main goals and there is evidence of relevant visual communication strategies throughout the environment
2. A Learning and development framework focussing on communication exists and is evidenced through Personal Development Plans/ Appraisals
3. Easy access to a variety of communication learning and development opportunities from induction for all staff, to specialist training provided around individuals evidenced through healthcare records and staff portfolios
4. Supervision evidences psychologically minded practice –reflecting both an attitude (interest) and a skill (ability for insight), directly linking between how people feel about the people they support and how this impacts on their communication
5. Positive communication between staff and a variety of individuals is observed, including a 'positive attitude' to using augmentative communication strategies
6. Staff have tools such as Communication Checklists or Screening Questionnaires and know when they need extra support around communication and sensory issues. Staff know how to access appropriate specialist speech and language therapy advice and make timely and appropriate referrals
7. Individuals are supported by carers who speak their language in a way that they can understand. Staff demonstrate use of Inclusive Communication appropriate to the needs of the individual they are supporting. They access and use appropriate communication support tools produce good information for individuals
8. Staff know how to maintain any specialist equipment needed to support/enhance communication, along with appropriate and regular assessment for the best one for the individual, taking into account their changing needs and developments in technology
9. Staff use positive body language and facial expression, promoting dignity and respect
10. Training and care plans around Positive Behaviour Strategies recognise communication difficulties as a significant risk factor and include good individualised and clear proactive and reactive communication strategies

Useful resources

- www.skillsforhealth.org.uk
- Positive Behaviour strategies
- Thurman, S (2011) Communicating effectively with people with a learning disability Kidderminster- BILD and Exeter- Learning Matters
- Various local and national manuals and training materials
- Nyklicek, I and Denollet, J (2009), Development and Evaluation of the Balanced Index of Psychological Mindedness (BIPM). Psychological Assessment, 2009, Vol. 21, No. 1, 32-44

Standard 4:
Services create opportunities, relationships and environments that make individuals want to communicate

An understanding, welcoming and socially rich environment is fundamental to relationships for all individuals, and particularly people with communication needs. Relationships are central to wellbeing. Getting the communication environment right will contribute to enabling people to live value and meaningful lives. Individuals need to have the opportunity to communicate about all the things that all people talk about in everyday life such as dreams, hopes, fears, choices as well as everyday wants and needs.

Good Communication needs to be considered broadly - it is not just about meeting needs and wants. Good communication is about social interactions – greetings, sharing stories and fun. It is the quality of interaction that contributes to overall emotional and mental wellbeing- providing a sense of belonging, involvement and inclusion. Interaction may not necessarily involve speech. For someone without formal language interactive approaches are a way of 'being' with another person, making meaningful contact with those who are hard to reach. It may be about very basic early developmental interaction and communication and relationship building

What does good look like?

Warm and genuine interactions, for social as well as functional reasons, are observed by staff, managers, professionals, families, friends and all visitors. People with a learning disability and those who support them relate to each other easily. Personalised communication strategies are part and parcel of the individual's life.

The impact of sensory impairments as well as sensory processing or integration is recognised and acted upon to support individuals who find it difficult to process and act upon information received through their senses.

Interactive approaches are just one way of establishing and maintaining contact with people on their own terms and in a concrete way of showing respect and commitment to involving them as much as possible in controlling their own life.

How you will know?

1. When you enter, you feel welcomed, understood and relaxed to be yourself
2. There are visual communication supports in the environment which are clearly tailor made to the people living there e.g. personalised visual timetables, staff photo rotas, individual mealtime mats, 'my life' books, use of signing systems. A range of media and purpose is evident including supporting individuals to manage worries and engage in a meaningful way
3. Staff are observed "having a chat" with people who do not use formal language, using approaches such as Intensive Interaction. They are observed having fun
4. There is a place for carers and people with a learning disability to discuss how they feel and this is supported by a range of communication tools
5. Staff, if asked, can explain how they make the most of every opportunity to enable the individuals they support to express themselves and understand what is being said to them
6. Staff are observed spending time with an individual for no purpose other than interaction and communication
7. Opportunities for interaction and involvement created
8. Staff are observed to use a social style of interaction which includes sharing, showing or commenting, not solely directing and questioning

Useful resources

- Baumeister, R.F. & Leary, M.R. (1995). The need to belong: Desire for interpersonal attachment as a fundamental human motivation. *Psychological Bulletin*, 117, 497-529.
- Caldwell, P (2001) You don't know what it's like. Finding ways of building relationships with people with severe learning disabilities, autistic spectrum disorder and other impairments. Pavilion
- Grove, N (2009) Learning to tell: a handbook for inclusive storytelling. Kidderminster: BILD publications.
- Nind, M. & Hewett, D. (2001) A Practical Guide to Intensive Interaction. Kidderminster: BILD publications.
- British Institute of Learning Disabilities (2004), Factsheet: Intensive Interaction, [online] (URL: <http://www.mencap.org.uk/sites/default/files/documents/Bild%20factsheet%20about%20intensive%20interaction.pdf>)
- Means, Reasons and Opportunities Model for Communication IN:
Money, D and Thurman, S (2002) Inclusive Communication. Speech and Language Therapy in Practice
Money, D (2001) Speech and language therapy management models, in The management of communication needs of clients with learning disabilities. Whurr Publishers

- Macintyre Great Interactions - aimed at improving the interactions of all staff who work with people with learning disabilities (URL www.macintyrecharity.org)
- Mencap. Resources/ guides/ Involve me. [online] (URL: <http://www.mencap.org.uk/what-we-do/our-projects/involve-me/resources-involve-me>)
- Makaton - language programme using signs and symbols to help people to communicate (URL: <http://ace.psc.ac.uk/courses/category.php?c=24>)
- PSC Symbols (Picture Communication Symbols – Mayer/Johnson) (URL: <http://www.mayer-johnson.co.uk/category/symbols-and-photos>)
- Pyramid Educational Consultants UK - training provider of The Picture Exchange Communication System (PECS) and the Pyramid Approach in the UK and Ireland (URL: <http://www.pecs.org.uk/index.htm>)
- Sign along - sign-supported communication for people with learning difficulties – (URL: <http://www.signalong.org.uk/>)
- Somerset County Council - Total communication: (URL: <http://www.somerset.gov.uk/irj/public/services/directory/service?rid=/wpccontent/Sites/SCC/Web%20Pages/Services/Services/Community/Somerset%20Total%20Communication>)
- Talking Mats – Communication Tool (URL: <http://www.talkingmats.com/>)
- Widgit – symbols for inclusion and accessibility (URL: <http://www.widgit.com/>)

Standard 5: Individuals are supported to understand and express their needs in relation to their health and well being

People with learning disabilities face avoidable health inequalities. Limited communication and health literacy reduces capacity to convey health needs effectively to others¹⁹. It is essential to consider communication needs in order to support individuals with their health. Arriving at a diagnosis can prove difficult if a person cannot describe signs and symptoms easily, or their behaviour is misunderstood and misconstrued. Staff need to be aware of how individuals communicate about their health and how they show that they are in pain. This includes considering ill health as a cause for changes in behaviour.

Knowing how much a person can understand is also essential in making a decision about their capacity to have a health treatment. It is also required to meet the principles of Nursing Practice that everyone can expect²⁰ including being treated with compassion and dignity and providing person-centred care.

What does good look like?

All people with a learning disability have an equal right to Healthcare²¹. Every step of the care pathway needs to be adjusted so people with autism or learning disabilities can receive equal treatment²². Proper planning around reasonable adjustments takes place before all appointments and discussions around health and well being. Adjustments should include consideration around appointment times and duration, support required and the information provided about medication and other treatments in accessible formats.

Staff should know about Health Passports, Health Action Plans, Hospital Traffic Lights or Hospital Passports and Books. All these resources provide health or hospital staff often colour coded information about the person during a health or hospital appointment or hospital stay. They all include information about an individual's communication, as well as care needs and any potential hazards, such as a risk of choking, known allergies and epilepsy.

People with learning disabilities may not express discomfort or pain in a way that health staff understand or recognise. Therefore information about the individual should include details of how the person communicates pain and distress, and staff need to be trained to use this information and react appropriately. Staff need to be aware of potential health risks and relevant referral pathways.

¹⁹ Emerson E and Baines S (2010) Health inequalities and people with learning disabilities in the UK: 2010. Improving Health and Lives: Learning Disabilities Observatory. *Department of Health*
www.improvinghealthandlives.org.uk

²⁰ RCN Principles of Nursing (2013) <http://www.rcn.org.uk/development/practice/principles>

²¹ Mencap (2013) Getting it right Charter for Clinical Commissioning Groups

²² NTDi National Development Team for inclusion (2012) Reasonably Adjusted? Mental Health Services and Support for People with Autism and People with Learning Disabilities. Department of Health

How you will know?

1. Health Passports or similar in place and used by staff
2. Evidence of capacity assessments and consent or Best Interests meeting regarding health assessment and treatment decisions are available
3. Evidence of considering communication needs in all documents around an individuals health
4. Staff know how individuals express pain and discomfort and act accordingly
5. Primary and secondary healthcare able to meet needs without referral to specialist services
6. There is accessible information about food choices, including accessible menus reflecting individuals preferences and needs with evidence of involvement
7. Accessible information is specifically tailored to meet communication needs of individuals, explaining their health conditions and how to manage them
8. If appropriate, good practice guidance on eating, drinking and /or swallowing (dysphagia) is readily available including information on food and fluid consistencies and strategies required. Personal Place mats are available with key information that others need to know to make mealtimes safe and enjoyable
9. Staff understand why individuals have special dietary requirements, medications and interventions and their associated risks -such as food and drink either required or to be avoided, modified textures, sensory feedback issues

Useful resources

- Sue Turner and Carol Robinson April 2011 Improving Health and Lives; Learning Disabilities Observatory, *Department of Health*
- Improving Health and Lives; Learning Disabilities Observatory, 2010; How do People with Learning Disabilities Die?
- 'NPSA 2007; Ensuring Safer Practice for adults with learning disabilities who have dysphagia' 1 The guide can be downloaded at:
<http://www.nrls.npsa.nhs.uk/resources>
- Centre for research on families and [relationship - DisDAT – Disability Distress Assessment Tool](http://www.crfr.ac.uk/projects/completed-projects/disdat/) (online) (URL: <http://www.crfr.ac.uk/projects/completed-projects/disdat/>)
- Personal Place Mats NPSA 2007 <http://www.communicationpassports.org.uk>
- Heslop.P, Blair.P, Flemming.P, Hoghton. M, Marriott. A, Russ. L ,(2013), *CIPOLD (The Confidential Inquiry into premature deaths of people with learning disabilities)*; Norah Fry Research Centre, University of Bristol