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Making it work

Shared decision-making and people with learning disabilities

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Contents

What do we mean by shared decision-making in the context of learning disabilities?

Shared decision-making is a process in which people with learning disabilities and health care professionals work in partnership to decide on tests, treatments, management, or support packages, based on clinical evidence and the person's informed choices. It allows for the inclusion of different perspectives, and the viewpoints of both the health care professional and the person with a learning disability.

It also involves the provision of evidence-based information about options, outcomes, and uncertainties, together with additional professional support and guidance, and a system for recording and implementing patients' informed preferences.

"The most important reason for practising shared decision-making is that it is the right thing to do. Communication of unbiased and understandable information on treatment or self-management support options, benefits, harms, and uncertainties is an ethical imperative and failure to provide this should be taken as evidence of poor quality care."

(Coulter and Ellins, 2011, page 11)

What does shared decision-making with people with learning disabilities actually entail?

Shared decision-making with people with learning disabilities will bring health care professionals and nurses in particular, into a process in which both parties jointly decide on health care treatments, management plans and support packages, based on the best available evidence and the informed choices of people with learning disabilities.

This process will very often involve the person's family, supporters and those closest to the person with a learning disability; the aim is to reach an agreement on the best course of action whilst at the same time acting in the person's best interests.

People with learning disabilities want information about their health presented in a meaningful way, and the chance to have an equal say about their care. The proper practice of shared decision-making will involve people with a learning disability as equal partners in their health care, giving individuals an opportunity to actively participate in their own care, and bringing the potential for raising the quality and effectiveness of health care within the NHS in relation to people with learning disabilities.

A number of tools to support shared decision-making with people with learning disabilities have already been developed, or are in development, including:

Health action plans

Information from Department of Health (DH) archives states: *'A person with learning disabilities having their own Health Action Plan can help the person to be healthy. A Health Action Plan provides the person with information about things they can do to be healthy and about help available. If you are a young person or adult with learning disabilities, the Department of Health says you should have a Health Action Plan. This booklet tells you more about Health Action Plans and how to get one'.*

Department of Health (2007), *Valuing People Support Team (VPST),* London: DH. Available at: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4079650.pdf(accessed 8 June 2013)

Personal health records

These are patient-held health care records for people with learning disabilities. For more information, see:

Turk and Burchell *Developing and evaluating personal health records for adults with learning disabilities,* available at: www.scie-socialcareonline.org.uk (accessed 22 May 2013).

Cruickshank et al (2012) 2020health report, *Personal Health Records-putting patients in control?* This explores how the NHS can exploit available technology to give all NHS patients access to online GP records. Available at: www.2020health.org/2020health/Publications (accessed 8 June 2013)

Personal health budgets

Personal health budgets are designed to afford greater independence to people needing health or social care by giving them an allocation of money to spend on services or products of their own choosing.

For more information, see personal health budgets at:
www.gov.uk/government/publications/understanding-personal-health-budgets

An RCN briefing on personal health budgets is available at www.rcn.org.uk/policy

Person-centred plans

Person-centred planning is key to ensuring that every individual with learning disabilities is being supported and treated properly.

For more information see:

Department of Health (2010) *Personalisation through person-centred planning* and *the impact of person-centred planning*. Available at: www.pcpmn.cswebsites.org/Libraries/Local/805/Docs/Personalisation%20through%20Person%20Centred%20Planning.pdf (accessed 22 May 2013)

Institute for Health Research (2005) *The impact of person-centred planning.* This was commissioned by the Department of Health. Available at: www.learningdisabilities.org.uk/publications (accessed 22 May 2013).

Circles of support

A circle of support is a group of family, friends, and supportive workers who come together to give support and friendship to a person.

The circle helps the person with a learning disability do the things they would like to do and achieve new things in their life. Circles are a way of achieving person-centred support, and are constructed dependent upon a person's situation and what they want to happen in their life.

Information is available at www.circlesnetwork.org.uk (accessed 22 May 2013).

See also: *Circles of Support and Mutual Caring* (Towers, 2010), available at: www.learningdisabilities.org.uk/publications (accessed 8 June 2013).

How does shared decision-making work?

Across the UK, shared decision-making is implicit in health care strategies in all four countries, furthermore the Department of Health in England has articulated the vision of shared decision-making in the phrase 'nothing about me, without me*'.*

The concept can now be seen to be at the centre of NHS health care reforms in England, as illustrated in *Leading the way to shared decision-making. The critical steps for the NHS Commissioning Board to make 'no decision about me, without me' a reality (*The Health Foundation 2012). Available at: www.health.org.uk (accessed 22 May 2013).

There is a wide range of examples from across NHS provision where shared decision-making can be used with people with learning disabilities, for instance:

- choosing whether to undergo a screening or diagnostic test
- giving consent to medical or surgical procedures
- implementation of treatment plans
- implementation of health education, lifestyle, and self care advice
- undergoing psychological or mental health interventions
- agreeing to and taking medication
- planning for complex and/or long-term health needs.

The Department of Health guidance on consent: *Seeking consent: working with people with learning disabilities* is available at: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4067019.pdf (accessed 8 June 2013)

Northern Ireland consent guidelines are available at: www.dhsspsni.gov.uk/public_health_consent (accessed 22 May 2013).

For shared decision-making to be successful as a health care tool investment is required in three key areas of service delivery:

- the professionals charged with delivering care
- the health care system supporting them
- the people with learning disabilities themselves.

The professionals charged with delivering care

To develop quality shared decision-making with people with learning disabilities the NHS will need to develop:

1. health information in a way that is appropriate to the person with learning disabilities, their families, and supporters. This information should contain evidence-based treatment options and both the benefits and harms of any health interventions including uncertainties and risks. Examples could be:

    - a shared decision-making discussion, or, for more complex decisions, repeated discussions with health professionals, which may require the information to be broken down to be more easily understood, enabling the person with learning disabilities to absorb information at their own pace. (Permission from the person with learning disabilities should be obtained before sharing information with other family members and carers. It should not be automatically assumed that families and carers have access to personal information about an adult with learning disabilities, however in many cases individuals with a learning disability will be best supported by the people who love and care for them, most often families)
    - provision of easy-read or pictorial information outlining the choices, consequences, risks and expected outcomes
    - computer-based information or interactive websites
    - DVDs or online information that includes filmed interviews or procedures with patients and professionals
    - support of specialist staff such as speech and language therapists and community learning disability nurses.

    The intention is to enable the person with learning disabilities, their families, and carers to explore in as much detail as they wish with as much time as is needed

2. provision of decision aids that are applicable to people with learning disabilities and could be utilised by health professionals, families and supporters to help the person with learning disabilities consider their options.

   An understanding of the mental capacity legislation in their country will be essential to health care staff utilising decision aids.

   Decision aids are different from patient information materials because they do not tell people what to do. Instead, they set out the facts and help people to consider options. More information is available at http://sdm.rightcare.nhs.uk/pda (accessed 8 June 2013).

   They contain:

   - a description of the condition and symptoms
   - the likely prognosis with and without treatment
   - the treatment and self-management support options and outcome probabilities
   - what's known from the evidence and not known (uncertainties)
   - illustrations to help people understand what it would be like to experience some of the most frequent side-effects or complications of the treatment options
   - a means of helping people clarify their preferences
   - references and sources of further information
   - the authors' credentials, funding source and declarations of conflict of interest

3. professional support, guidance, and health coaching with a clinician. The clinician will need to be knowledgeable about the health issue and sensitive to the particular needs of the person with learning disabilities. This clinician (or clinicians working in partnership) should also be skilled in offering support to families caring for people with learning disabilities especially in circumstances where the person has a profound disability with multiple associated health issues.

   The aim of professional support, guidance and coaching is to help people with learning disabilities, families and carers, if appropriate, to develop the knowledge, skills and confidence to manage the person's own health and health care, and for the individual to make treatment decisions and/or lifestyle changes accordingly.

   Health coaching is a skilled task involving listening, open and closed questioning, support for discussion and non-directive guiding. Face-to-face health coaching by the same person is preferable for people with a learning disability as relationships and trust may take time to establish.

   These skills are not taught routinely in professional courses, so staff may require additional training, this will be particularly important in relation to people with learning disabilities. Learning disability nurses may be ideally placed to undertake this role in partnership with general health care colleagues.

4. a record of discussions, decisions and an implementation plan that is person-centred. These could be incorporated into health action plans, personal health records, or hospital passports.

Clinicians must also have an understanding of the mental capacity legislation in their own country and implications for consent.

For *Understanding the Mental Capacity Act* see:

www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act
www.scie.org.uk/topic/careneeds/mentalcapacity

Once a decision is made, it is important to document this in the person's notes or electronic medical record and any personal health record. If the person has used a decision aid, it is also helpful to keep a record of this. Specially designed electronic templates could make the task easier. The record of decisions or the care plan should be accessible to people with learning disabilities as well as health professionals and can be used for a number of different purposes:

- as a medico-legal record of the shared decision-making process
- to help co-ordinate care when patients are receiving treatment or support from a range of different professionals or agencies
- as a personal health record that can be continually updated to support behaviour change if the person decides to undertake a lifestyle or behaviour change
- to inform a larger-scale commissioning strategy.

The health care system supporting individuals

It is the responsibility of health care (and increasingly health and social care) commissioners to ensure that health care is distributed appropriately, equitably and efficiently amongst the populations they serve. In doing so, they must also remain responsive to the wishes and concerns of individual patients. However, there is evidence that people with learning disabilities have poor access to health care, poor experiences and worse outcomes than other populations. (Emerson et al 2011). Available at: www.improvinghealthandlives.org.uk/publications/year/2011

Effective investments in health care are likely to include:

- provision of Independent Mental Capacity Advocate services, or 'health advocacy' services when required
- appointment of learning disability acute liaison nurses
- appointment of health facilitator (for people with learning disabilities) posts in GP practices
- appointment of learning disability nurses on clinical commissioning boards
- development of decision aids that are applicable to patients with learning disabilities
- support that enables people with learning disabilities, their families, and other agencies such as colleagues in social care or education systems to co-design, co-commission, and co-produce health care support with health practitioners
- health care systems that record:
    - a patient-centred process

  - an individual’s informed choices which include documented conversations about risk and consent whilst taking account of the mental capacity legislation
  - implementation of health care plans
  - progress and adjustments
  - outcomes
  - accountability.

Enabling better choices

As well as a moral imperative, there is much evidence showing sound financial reasons for investing in health care and support for people with learning disabilities. We know that well-informed people make better choices, often avoid the most costly and invasive procedures and are much more likely to adopt lifestyle changes leading to better health outcomes. There is no reason to assume this will not be the case for people with learning disabilities.

People with learning disabilities could source health information from trusted organisations such as NHS Choices or charities specialising in health conditions for example Alzheimer’s Society, Diabetes UK or the British Heart Foundation and seek support via local advocacy groups.

What are the priorities and challenges of shared decision-making and patients with learning disabilities?

Shared decision-making together with person-centred approaches to health care provision is a model which contrasts sharply with the traditional ‘patrician’ medical model. The contrast is especially apparent in individuals with a learning disability, who we know are vulnerable to poor practice in health care systems. This is evidenced in:

- *Six Lives: the provision of public services to people with learning disabilities*, available at www.ombudsman.org.uk/improving-public-service/reports-and-consultations/reports/health/six-lives-the-provision-of-public-services-to-people-with-learning-disabilities (accessed 8 June 2013)

- Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) www.bris.ac.uk/cipold/fullfinalreport.pdf accessed 8 June 2013).

Examples of good practice and shared decision-making with people with learning disabilities

Consultations and discussions may take longer and health professionals may need the assistance of specialist staff, for example learning disability nurses, speech and language therapists, or psychologists.

It may be that the person has a circle of support, in which case their expertise and support can be drawn upon to help with the shared decision-making process.

For more information visit www.learningdisabilities.org.uk/our-work (accessed 22 May 2013).

Example one

Simon lives in a community home, has autism, and is able to understand and indicate his preferences using a communication aid; he does not communicate verbally. His appointments with his GP are always made at the end of the GP's clinic to allow for extra time. Simon is supported by his community learning disability (LD) nurse during the consultation, and has regular input from a speech and language therapist.

Before these appointments Simon's support staff help him to write down any health concerns, queries, and questions for his GP.

Some examples of these questions are:

- do I need to take medicine and what is it for?
- will I get better without any treatment?
- what are my other choices for treatment?
- what does this drug do?
- how long should I use it?
- what are the benefits and side effects of this treatment?
- is there anything I can do to avoid side effects?
- can I take this medicine with the other drugs I'm taking?
- when should I stop taking this drug?
- when should we talk about whether I need to keep taking it?
- what should I do if I miss a dose?
- what else can I do to help myself get better?

Information is taken from the consultations and forms part of Simon's health action plan. Back at his home he has a circle of support, which includes his family and friends as well as his support staff. Collective help and discussion with Simon helps him decide how to implement any health recommendations, such as improving exercise, alleviating anxiety, and addressing any distressed behaviours he may be exhibiting.

Simon always sees the same GP, who has built up a positive and trusting relationship with him, and is attuned to his communication difficulties and anxiety levels. The GP knows that Simon has a CLD nurse and a speech and language therapist who can assist him to present complex health information in a way that is meaningful to Simon. All the health professionals involved in Simon's care have a good understanding of the mental capacity legislation.

For Simon this means:

- Simon should have as much help as possible to make his own decisions
- people supporting Simon should assess if he can make a particular decision
- even if Simon cannot make a complicated decision for himself, this does not mean that he cannot make more straightforward decisions
- even if someone has to make a decision on Simon's behalf he must still be involved in this as much as possible
- anyone making a decision on Simon's behalf must do so in his best interests.

Example two

Mohammed has severe learning disabilities, he uses a wheelchair but is unable to move independently or communicate verbally. He lives with his elderly mother, who has cared for him for 45 years, and they have a very close and loving relationship.

Because of her intimate knowledge, Mohammed’s mother is able to anticipate his needs and wishes and is able to spot any changes in his behaviour that may indicate when he is hungry, unwell, distressed, or in pain.

He has recently been diagnosed with terminal cancer, and his mother’s knowledge is vital to the decision-making process.

The community learning disability nurse and the palliative care team talk through the illness, prognosis, and likely progression of the illness with Mohammed using pictures and simple language.

Mohammed’s mother uses her intimate knowledge of Mohammed to assist in the development of his end of life care plan, and helps health care professionals understand and ensure that the plan contains necessary cultural and religious elements.

Mohammed and his mother are able to make decisions on treatments and options based on the information presented to them, and NHS staff are able to implement the use of decision-making tools to help Mohamed and his mother make decisions that are right for them.

Example three

Margaret has discovered a lump in her breast and needs to go into hospital for surgery.

She lives independently but has some support from social services. Margaret's GP has asked the local community learning disability team to help plan her admission and support her while in hospital.

Margaret and a learning disability hospital liaison nurse draw up a list of questions:

- how can I prepare for surgery, can I visit the hospital and meet the staff?
- will I be able to take a plan into hospital with me? (called a hospital passport)
- can someone stay with me while I'm in hospital?
- do I need to make any special arrangements when I go home?

These questions, and the consequent answers, are then used as the basis of a hospital admission plan, drawn up in collaboration with her GP, ward staff, the surgical team, and social services.

Looking to the future

There is great potential to shift the culture in the care provided for people with learning disabilities from the traditional ‘passive patient’ and ‘expert health professional’ to one of shared care and decision-making.

In essence, shared decision-making represents a redistribution of power and choice, together with responsibility, to the individual with learning disabilities, towards a more equal partnership with their health professionals.

It is now widely accepted by health professionals that people with learning disabilities and their families are motivated to discuss options, consider advice and follow agreed treatment plans when they understand the reasons and thinking behind health supports.

However, it is, and should remain, the responsibility of health care professionals to ensure that people with learning disabilities are included in the further development of shared decision-making across the NHS.

With specific regard to the changes taking place in England, those responsible for taking forward the new commissioning arrangements, at both clinical commissioning group and NHS commissioning board level, will need to factor the needs of people with learning disabilities into their plans at as early as stage as possible.

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Further reading

Accessible health information: Prodigy and Easyhealth leaflets
www.easyhealth.org.uk

Decision aids
http://sdm.rightcare.nhs.uk/pda

NHS England 2013 Operating Framework (Reference Pg 22)
www.gov.uk/government/uploads/system/uploads/attachment_data/file/152683/dh_131428.pdf

NICE Medicines adherence guidance: involving patients in decisions about prescribed medicines and supporting adherence
www.nice.org.uk/guidance

NICE Shared decision-making and self-management
www.nice.org.uk/guidance

Patient-centred care
www.patient-centeredcare.org/index.html

Picker Europe SDM Library
www.pickereurope.org/sharingdecisions

Right Care shared decision-making
www.rightcare.nhs.uk/index.php/shared-decision-making

The Health Foundation
Shared decision making resource centre
http://shareddecisionmaking.health.org.uk

The Health Foundation 'Magic' Programme
www.health.org.uk/publications/the-magic-programme-evaluation

The Kings Fund - Making shared decision-making a reality, no decision about me, without me,
www.kingsfund.org.uk/publications

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