# Chapter 1

# The nature of care planning and delivery in intellectual disability nursing

Zuzana Matousova-Done and Bob Gates

# Introduction

The practice setting for intellectual disability nursing is difficult to define because it is located in a complex landscape of service provision. This includes, for example, residential care homes, independent living homes, supported living arrangements, as well as people with intellectual disabilities living in their own homes as well as family homes. There are also larger service configurations and very specialist settings, such as treatment and assessment services and challenging behaviour units, as well as specialist health or social care settings, such as hospices or homes for older people. Therefore much of the care planning and delivery of intellectual nurses now no longer takes place in traditional settings; rather it takes place in within the context of multi-disciplinary and multi-agency settings (Alaszewski et al., 2001). However, because of professional requirements for intellectual disability nurses, regardless of where people with intellectual disabilities live, if they are in receipt of nursing care this should be guided by a care plan, whether the care comprises short intensive nursing interventions or long periods of care and support (Nursing and Midwifery Council, 2004c).

This chapter will introduce the reader to the nature of care planning, personcentred planning, care management, health action planning, life planning and the care programme approach. The reader will also be introduced to relevant and contemporary social policy, as well as the Nursing and Midwifery Council's guidelines, competencies and expectations of professional practice as they apply to nursing and their planning and delivery of care. This chapter will advocate the need for robust, professionally prepared care plans based on a systematic nursing assessment. In addition to this, reference to the nursing process and models of nursing and their appropriateness to care planning and delivery will be highlighted and explored.

# The nature of care planning and its delivery

1

This first section describes the nature of care planning and delivery whilst simultaneously making distinctions with other 'caring' terminology. The language

of human services is littered with an (un)impressive array of words, phrases and initiatives that are used in the armoury of 'caring professionals', concerning care, care planning and delivery. This terminology includes care planning, person-centred care planning, care management, health action planning, life planning and the care programme approach. Perhaps this is why it is common to find students and newly qualified practitioners in health and social care settings unclear at times about what is being referred to when such terminology is used, or what their specific role and responsibilities are; this is particularly so in the case of the intellectual disability nurse. It is hoped that this chapter will demystify some of this terminology and in this respect provide a useful foundation for the remaining chapters of this book.

In describing this caring terminology it is necessary to briefly explore each of the terms identified, and outline their specific meaning, not just for the convenience of this book but because they apply to the practice of intellectual disability nursing. This is illustrated by Fig. 1.1 which depicts the nature of the inter-relationship of care planning and delivery and caring terminology in intellectual disability nursing. This figure shows that at the heart of all that we do is the individual. Intellectual disability nurses must always remember this

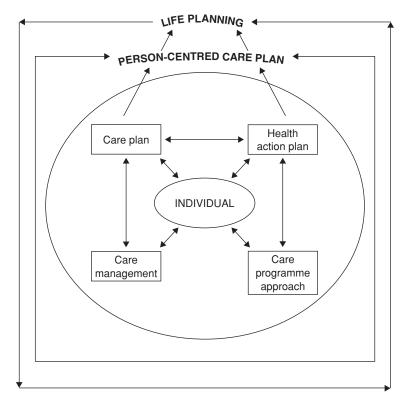


Fig. 1.1 The inter-relationship of care planning and delivery and caring terminology in intellectual disability nursing.

regardless of the environment or context of the interaction between the nurse and the person with intellectual disabilities they are supporting. It can be seen in Fig. 1.1 that some people with intellectual disabilities may have a care plan or health action plan, or be the subject of the care programme approach. These can all be seen to be located within a person-centred care plan, where all that is constructed is done so in partnership with the person with intellectual disabilities and their families or carers. It can also be seen that the process of care management is located in Fig. 1.1; this is where packages of care are constructed for some individuals with intellectual disabilities. Usually these care packages include reference to residential provision, day care provision and sometimes leisure and recreational provision. This process is usually undertaken by care managers, who typically come from a range of different professional backgrounds in intellectual disabilities, including nurses, occupational therapists and physiotherapists, but more usually, social workers. Once again good care management should put the individual at the heart of constructing a care package for an individual.

In Fig. 1.1 all of these different elements of caring terminology are shown to be first located with the broad philosophy of what has become universally known as person-centred care planning, and this is depicted within a process of life planning. This collective caring terminology is discussed more specifically below before an exploration of the nursing process and the use of nursing models to guide the planning and delivery of intellectual disability nursing care.

#### Care plan

Essentially this is a written document that articulates a plan of care for an individual with intellectual disabilities. This plan will typically identify what this person can and will do in their day-to-day living and what support they need to do so. This process of constructing a care plan is complex and can potentially involve a large number of people and sources of information. The use of a nursing model can help to make this process more manageable and thereby enhance care (Newton, 1991). Planning care and its delivery has different emphases depending on its purpose, function and who carries out the assessment. For example, a person with intellectual disabilities living in a community setting will require different information to be collected from health, generic and social care assessments as opposed to someone detained under the Mental Health Act in a treatment and assessment unit. It is the case that in the preceding example both of these assessments will look at different areas of need; however the overall process of care planning and its delivery should ideally take into consideration all the assessed needs/areas, and the construction of any care plan should reflect and include these. For example, an occupational therapist might assess the daily living skills of a person with intellectual disabilities living in the community, whereas a clinical psychologist might assess the behavioural needs of someone in a treatment and assessment unit; a social worker might assess someone with learning disabilities as to whether

they meet eligibility criteria for services (and to identify which service is appropriate) and, finally, a nurse might assess the health needs of an individual. All of these contributions might well assist in the construction of an overall care plan for someone with intellectual disabilities.

# Person-centred care planning

Person-centred care planning forms an integral part of the care planning process (Department of Health, 2001; Thompson and Cobb, 2004). Person-centred planning refers to a philosophy or set of values based on the idea that care planning should begin with the individual (Department of Health, 2001). It can also be thought of as a set of tools designed to help people with intellectual disabilities and services make plans which reflect an individual's desires and aspirations (Sanderson et al., 1997). Chapters 3 and 4 provide full and extensive discussion on person-centred care planning.

#### Care management

This is a system of assessing individual needs and, from this, constructing a 'package of care' to meet those needs. Care managers play a pivotal role in helping people to achieve valued, fulfilling lifestyles; they can be instrumental in commissioning new initiatives built around the needs of the person, rather than expecting them to fit into existing provision, however inappropriate. It has been observed that care managers occupy a crucial point which straddles human services and the wider community (Duffy and Sanderson, 2004). A really effective care manager is likely to practise in a person-centred way, and probably has some characteristics in common with a 'service broker' (Brandon and Towe, 1989). Intellectual disability nurses are in a strong position to carry out this role, given their specialist training and understanding of the service user's perspective based on their partnership approach. Good care management practice involves working in a person-centred way. However, one could argue that care management is still often applied as an 'administrative tool for cost management' (Walker, 1993, p. 219).

# Health action planning

Health action plans are personal action plans that detail the actions needed to improve and maintain an individual's health (Department of Health, 2001). The government has introduced health action plans in an attempt to reduce some of the health inequalities that people with intellectual disabilities experience (Howells, 1986; van Schrojenstein Lantman de Valk et al., 2000; Elliott et al., 2003; Mencap, 2004). These should form part of a person-centred care plan and should be developed using the same philosophy. Nurses must recognise that they have to balance a duty of care with respect for the client's right to make choices (Nursing and Midwifery Council, 2004c). The development of

4

health action plans should be supported by primary health care services (Department of Health, 2001) and, with this in mind, some primary care trusts in the UK have introduced annual health checks for people with intellectual disabilities.

#### Care programme approach

This is a method for assessing, planning and co-ordinating care and support for people identified as using mental health services (including some people with intellectual disabilities) by establishing the intervention needed and who can best provide this. It is usually employed when a person is vulnerable or presenting a risk to others and typically there have been various professionals and agencies involved in an individual's life. Thiru et al. (2002) have described the care programme approach as:

'a framework for heath and social care assessment, including risk assessment, within a comprehensive, person centred, multi-disciplinary care planning process.' (Thiru et al., 2002, p. 11)

In the standard model, a full review would take place at least annually, and six-monthly in the case of an enhanced care programme approach. Individual provider organisations may arrange for more flexible reviews as necessary; a person may move between care programme approach levels (see Chapter 7) as their needs change. Although they may initially appear to be in conflict, person-centred care planning and other more directive forms of care planning, such as the care programme approach, need not be mutually exclusive. Intellectual disability nurses supporting service users in a forensic setting, in which clients' freedom is restricted, must still integrate the principles of person-centred care planning into their daily practice. The key principles of the care programme approach – assessment, care co-ordination, care planning, evaluation and review – are also prominent in care management.

#### Life planning

To a lesser or greater extent we all think about and plan for our lives in different ways. Some of us have very clear ideas about what we want in life, why we want it and how we will achieve it. We all of us plan for children, careers and old age. Adopting a person-centred approach, life planning is about whom we are, what our needs, wishes and dreams are and how we go about trying to achieve them. We constantly make life plans around holidays, living arrangements, careers, money, shopping and relationships, and we talk of these plans to families and friends. Regardless of who we are, no one person is in complete control of all events in their life and neither is any one person at the complete mercy of destiny or fate. There is an interface between the extent which an individual can exert a greater or lesser influence over the course of their life. It is the extent of this influence that is of crucial importance

for people with intellectual disability. For the most part a number of people with intellectual disabilities are quite capable of determining what they want from their lives, but some people may need considerable help from their family, friends and carers; sometimes intellectual disability nurses can contribute to this.

#### Summary

Within the context of this book, care planning and delivery will refer to a specific document that delineates a plan of care that is prescribed by a nurse, and that this plan can be followed and delivered by another nurse, or, in the context of intellectual disability service provision, this increasingly includes unqualified social care staff. There are at least four steps to the systematic construction of a care plan and its subsequent delivery. Firstly, a comprehensive needs assessment (physical, psychological, social and spiritual) has to be completed. If a nurse is required to work with someone with intellectual disabilities and/or their families, it is necessary that their needs are assessed and incorporated into the individual care plan, taking their desires, wishes and aspirations into account. The nurse will need to work closely with the clients' family, care providers and other professionals as this broad approach may bring very important and essential information to light for assessment, as well as care plan development, its approach, delivery and management. This first stage is followed by the construction of a written care plan that is then implemented and followed by ongoing review and evaluation.

#### The use of the nursing process and nursing models

The nursing process can best be described as a framework for planning individualised care for patients/clients with intellectual disabilities. It should be understood that because it is a *process*, this process never finishes, as the clients'/patients' needs constantly change and it is the nurses' responsibility to respond to these changing needs wherever necessary. The nursing process is usually depicted as comprising four or five stages depending on the resources available and work setting, and includes: diagnosis, assessment, planning, implementing and evaluation. Not only is the nursing process and its use critical to the success of a number of imperatives of professional and social policy, Fitness for Practice (UKCC, 1999), Making a Difference (Department of Health, 1999), and the National Health Service Plan (Department of Health, 2000b), but its use also enables nurses to construct and deliver their care in a systematic manner.

The nursing process should be undertaken using a collaborative and participative approach with other professionals, gathering and implementing resources, in order to improve the care process (Department of Health, 2000b; Department of Health, 2001). Jones (1999) has claimed that the intellectual

6

disability nurse's approach to care is probably the best example of holistic care, as intellectual disability nurses

'support their clients' health needs, social inclusion, welfare, educational requirements and act as advocates mainly for people with poor or no communication skills.' (Jones, 1999, p. 61)

#### Assessment

Arguably assessment is the most important part of care planning and delivery. It includes areas such as health and health needs, daily living skills, activity programmes, mobility, mental health, risks to the client, finance, respite, social events/outings, support requirements, spiritual needs and, possibly, accommodation issues (Department of Health, 2000b; Sox, 2004a). If the assessment is not undertaken properly, or the information provided is not accurate, people with intellectual disabilities may miss out on many life opportunities.

Assessing the needs of people with intellectual disabilities is not an easy task. It is important to consider what kind of information is needed in order to complete the assessment successfully. It is a necessity for the professional performing the assessment to establish a good relationship and rapport with the client, his or her family and the care providers involved in the client's care in order to gain more detailed knowledge of the current and previous needs of the client. Because assessment plays such a major part in care planning in practice, nurses frequently use instruments and tools to assist them in assessing a person's needs and this is sometimes, although not always, combined with an appropriate nursing model used as a guide; this often depends on the care setting, area, resources, local policy and the purpose of the assessment.

In relation to the assessment of health many nurses, community learning disability teams and residential settings have developed their own health assessment forms or questionnaires or have adopted the now widely used 'OK' health check (Matthews, 2004). The 'OK' health check is helpful in identifying physical conditions found more frequently in clients with intellectual disabilities, such as dental disease, epilepsy, mental health problems, hearing and/or sight impairments (Matthews, 2004; Royal College of Nursing, 2004). Other sections include, for example, mobility, sexuality and necessary screenings and continence issues. Additionally, the 'OK' health check list identifies the health needs, staff training needs and action or areas needed for development in order to improve the health of people with intellectual disabilities living in the community (Matthews and Hegarty, 1997; Matthews, 2004). A part of the assessment also includes physical examination, which could be completed by a nurse or a general practitioner, including the measurement of biometric data, such as pulse, blood pressure and respiration rate.

Assessing an individual in a familiar or client-chosen environment may result in a better contribution from them and also may assist in obtaining more valid information for the assessment. In addition to this, offering convenient

appointments and recognising and demonstrating sensitivity toward the personal, social and cultural circumstances of the client and all members involved in their care may enhance the foundation of the assessment further (Barr, 2003). The intellectual disability nurse performing the assessment must not be judgmental or critical, and must always act in a professional manner as described in the Nursing and Midwifery Council's *Code of Professional Conduct* (Nursing and Midwifery Council, 2004c). Accurately assessing clients' needs often depends on the assessor's ability to listen and observe, and their knowledge and use of verbal and non-verbal communication as well as the careful use of open and closed questions.

Before the assessment commences it is important to inform the client and everyone involved in the process about 'the rationale, scope and nature of the assessment, including clarification of the extent of confidentiality' (Barr, 2003), so that all those involved can decide how much information they want to provide.

It is important to clarify that the assessment can be both objective and subjective in nature. The intellectual disability nurse should look at the needs of the person with intellectual disabilities from different perspectives, bringing into the assessment views of others that will enrich the assessment. For example, there could be different emphases drawn on what the client needs from a professional view and the view of the client themselves, which could be addressed through a friend, relative, supporter or advocate. Once needs have been assessed and identified, the written planning of care should commence.

#### Planning

Care planning is an essential part of an individual's life (Sox, 2003b); Grant et al. (1998) have suggested that care plans:

'should respond to physical, psychological and social aspects identified in the assessment and provide opportunities for family members to build on existing strengths and develop coping resources.' (Grant et al., 1998)

A care plan must not be based on assumptions and therefore it must be realistic (Barr, 2004) and set goals that should be achievable and reviewed regularly, as the needs of the individual with intellectual disability may change. The process of care planning is also an opportunity to review existing services and resources in order to find the best possible service, which will suit the client's identified needs and provide the best possible care. The approach to the care planning throughout all of the stages of the nursing process must be person centred and this is especially so in the construction of a care plan (Department of Health, 2001).

The structure and format of care plans are variable; examples of different types of care plans are shown throughout this book. Some for example overtly adopt a nursing model that guides the content and ways in which the care plan is constructed (see Chapter 13); others are orientated toward using the

8

nursing process approach to record the assessment, identified care needs, subsequent goals of intervention and plan of care followed by evaluation strategies (see Chapter 8), whereas others identify a more accessible client-centred approach (see Chapter 12). These are all variations on a theme and all are legitimate and all belong to the wider family of care plans as they all hold the person with intellectual disabilities as central to the care planning process. Whatever format is used, once the care plan is constructed it is important that everybody involved is provided with a copy of the care plan in an accessible format so they understand its context and can refer to it when necessary (Barr, 2003).

#### Implementation

Successful implementation of a care plan to meet the assessed needs of an individual is crucial and perhaps the most challenging part of the nursing process. Wherever appropriate it is vital for people with intellectual disabilities to be fully supported and involved throughout implementation of care in order for them to continue to make decisions and choices about their health and lifestyle as well as achieving any goals agreed in the care plan.

Target dates are set for the achievements of short- and long-term goals, and these should be reviewed on a regular basis during implementation of a care plan and reviewed regularly at review meetings. A care plan co-ordinator should be identified who will be responsible for the implementation of the care planning process; this co-ordinator could be a nurse, a social worker, a manager of the establishment where the client lives, a client's key worker or their health facilitator. Ideally the care plan co-ordinator should be known to all and easily approachable and contactable by everyone involved in the implementation of the care plan. Good communication plays a pivotal role in the success or otherwise of implementing care plans. Poor communication between the client, professionals involved, family and other carers may result in unnecessary stress and the withdrawal of important key individuals from care planning at a later stage. This can lead to a plan of care breaking down at the stage of implementation because of inconsistencies and, as Barr (2003) has suggested, unreliable management, poor communication channels and a lack of accountability may lead to loosening of the structure of the partnership between all involved.

#### Evaluation

9

Evaluation is concerned with the effectiveness of the assessment, the care plan itself and the implementation of that care. Before one arrives at a formal evaluation point for care it is desirable that care is reviewed and that interventions are monitored on an ongoing basis. All dates for such reviews should be agreed during the planning process and should be clearly documented on the care plan (Barr, 2003). In addition to these ongoing reviews more formal

evaluation of care might take place as follows: 6 weeks after establishing a new care plan, then at 3 months, then at 6-monthly intervals. Everyone involved in the construction of the care plan and the implementation of that care should have the opportunity to prepare for and attend both the reviews and more formal evaluation events (Barr, 2003).

Evaluation of care provides an opportunity to re-examine and reflect on the process of nursing. This might typically include examining the accuracy and completeness of the initial assessment, reflecting whether the set goals are realistic and therefore achievable and the appropriateness of any agreed actions. Furthermore, it provides an opportunity for all of those involved in care planning and delivery to consider each other's contributions and to learn what types of support and interventions were more effective and helpful for the person with intellectual disabilities. Additionally team members have to be prepared to acknowledge that not all care planned or delivered meets the expectations of all those involved, and this makes it important that:

'the accountability for actions and omissions in services should be transparent to all involved.' (Barr, 2003)

#### Reader activity 1.1

Identify someone with intellectual disabilities you have recently worked with. Identify when their care plan was last formally evaluated. Who was involved in the process? What was the outcome of any action points generated by the evaluation? If there has not been a formal evaluation in the last 6 weeks, why this is, and what can be done to ensure regular and formal evaluation of care plans?

# The use of nursing models

Models, within the context of nursing, have been variously defined; for example McFarlane (1986) has described them as 'a representation of reality', while other commentators use similar descriptions, such as 'ways of organising a complex phenomenon or some kind of conceptual or diagrammatic representation of what nursing means' (McKenna, 1997). In this book it is advocated that nursing models should be used as a flexible framework to stimulate and organise thoughts to assist in leading to the development of a logical care plan that is sufficiently robust and practical that it is likely to be used in practice settings. In response to both social and political influences the arena of intellectual disability care models and that of care planning have changed considerably: so, therefore, has the practice of intellectual disability nurses (Alaszewski et al., 2001). For example, during the last century, intellectual disability services were dominated by a medical model of care which emphasised the biological needs of people and the need to 'cure' physical problems

in order to allow a person to function in society (Aggleton and Chalmers, 2000). The majority of people with intellectual disabilities have now moved out of long-stay hospitals, but there remains a concern that the powerful effects of the medical model continue to influence care provided in smaller community-based residences. Klotz (2004) has argued that the use of the medical model has pathologised and objectified people with intellectual disabilities leading to them being seen as 'less human'. Therefore, if nurses are to adopt some kind of model to guide their care in practice it must remembered that the use of such a model must hold the person with intellectual disabilities as central to any care-planning process, and that the nurse must be mindful they use such a model to promote what is best for that person.

There are numerous nursing models that can be adapted and used in a variety of health and social care settings. Some nursing models, such as Orem's self-care or Roper's activities of daily living, are well known and seemingly most used. It should be remembered that they may not be seen as relevant or ideal for all people with intellectual disabilities, but they can generally be adapted relatively easily and then become ideal frameworks for the assessment of health as well as more general needs. For example, it has been argued that some people with profound disabilities require considerable support with self-care (Kozier et al., 1998) and therefore the use of using Orem's self-care model may not be appropriate for them. However this is countered by an argument that Orem's self-care model focuses on learned behaviours of selfcare ability (Orem, 1991) to maintain life, health and well-being (Mayo, 1997) and can be approached from different dimensions/perspectives. Therefore it offers guidance to a person considering their disability to regain or develop all or some level of self-care and it may also identify areas of self-care where the client will require support. As has been said there are numerous models of nursing and their use or otherwise is still very much contested (McKenna, 1997). Notwithstanding this, the reader is advised to seek additional and a much detailed treatment of this subject before forming any strong opinions on this matter (Meleis, 1997; McKenna, 1997). In this chapter we briefly explore three models of nursing but other examples of their use, along with the nursing process, are identified in more detail in Part 2 of this book.

# Roper, Logan and Tierney (1980)

Roper et al. (2002) have described the course of life as something that starts at conception and lasts until death. During this course they identify activities of living that individuals engage in and these include maintaining a safe environment, communicating, breathing, eating and drinking, eliminating, personal cleansing and dressing, controlling body temperature, mobilising, working and playing, expressing sexuality, sleeping and dying (Roper et al., 2002). Each of these activities might be seen to be conceptualised as lying on a continuum from dependence to independence. At times during the course of life we may be more dependent on others to meet our needs and this, it is

argued, is where the role of nursing is authenticated: in helping people move towards independence in all activities of daily living. Their model also identifies a range of factors that impact on the individual and affect their levels of dependence/independence and these include biological, psychological, sociocultural, environmental and politico-economic variables. The activities of daily living themselves are not too dissimilar to a number of assessments commonly used in intellectual disability nursing and this model can therefore be adjusted accordingly (Gray, 2003). By way of contrast Brittle (2004) has claimed that this approach is not appropriate for intellectual disability nurses as it does not cover issues such as participation in the community, leisure, education, housing and employment. Notwithstanding this, in Chapter 13, an attempt is made to demonstrate how this model of nursing might be applied to the care of someone with profound intellectual disabilities and complex needs.

# Peplau (1952)

This is a model of nursing where the individual is seen as a unique self system comprising the biological and physiological alongside interpersonal characteristics (Meleis, 1997). This model is often advocated for working with people with mental health problems because it is psychodynamic in nature and focuses on the nurse–client therapeutic relationship. This is developed through overlapping phases such as orientation, identification, exploitation and resolution (Forchuk et al., 1989). These phases are used in order to help a client to deal with certain behaviours or mental illness and direct them to further growth. As said, this model is mainly used for care planning of people with mental health problems; however, it can be adopted, once adjusted, in the care of people with dual diagnosis (see Chapter 8).

#### Aldridge (2004)

Aldridge (2004) has proposed a model for intellectual disability practice that he refers to as *Ecology of Health Model* and that was developed out of the *Ordinary Living Model* for intellectual disability nurses (Aldridge, 1987). This 'ecological' model takes into consideration all aspects of an individual's health and their and their families' relationship with their community (Jacques, 2004). In this model the person is seen as having physical and psychological components that form self and that exist in a social environment. This self interacts with the environment, and this interaction between self and environment forms an ecological system. Aldridge (2004) has proposed that this 'ecological' viewpoint informs the model's explanation of health, which maybe defined as:

'a dynamic and ever-changing state of individually defined optimal functioning and well-being, determined by the interplay between the individual's internal physiology and psychology and their external environment.' (Aldridge, 2004, p. 172)

#### Case illustration 1.1

Ayesha is 16 years old and attends a special school. She has just moved into the '16 plus' department where the focus will be on the development of social and independent living skills. She can stay on at school until she is 19, a rather prolonged sixth form perhaps, without an academic focus.

She lives with her parents and younger brother. She has a mild hemiplegia on her left side, which gives her an awkward gait. Ayesha often knocks things over and bumps into things and her over enthusiasm results in a lack of co-ordination and balance. Her speech is very difficult to understand even when the listener is reasonably familiar with her and very nearly impossible for strangers to understand. She uses a combination of Makaton and her own set of creative signs and gestures. Ayesha generally manages to show a remarkable level of persistence and patience with such 'stupid' others. She needs to, given that she loves to talk and fires incessant questions, being bright and endlessly curious about the world.

Ayesha can also become frustrated, impatient and angry; because of her lack of co-ordination, sometimes she does not seem to know how hard she pinches and grabs. This has caused much concern between the school and her family over the years, possibly more so now as she grows bigger and stronger. Her parents have attended many 'something must be done' meetings and still dread the notes home from school.

Like all teenagers, Ayesha wants relationships, both platonic and romantic. However, her lack of social skills sometimes makes this difficult and frustrating for her. Her humorous charm nevertheless often gains her favour and forgiveness. She, of course, rebels against parental authority in her own creative and unique ways. Her parents struggle, whether they are dealing with a normal teenager or a disabled teenager. Ayesha can go from charming and amusing to stubborn and back again very quickly. Her wilfulness can make life very difficult, but her parents also know that given her disabilities, such a trait is probably necessary in order for her to get on in her life.

Ayeshas' brother Zaffar has become somewhat emotionally distant from his sister. At times Zaffar has felt pushed out from the family. He does not bring his friends home and although very intelligent, he is regarded as something of an underachiever at school. He sometimes expresses resentment at what he regards as the preferential treatment of his sister, particularly in relation to discipline.

Ayesha is approaching an age when the notion of independence is becoming more relevant. Whilst life within the family remains a struggle at times, thoughts about Ayesha's future evoke mostly anxiety. How will she cope outside the protection of her family? Whilst she is developing the skills necessary for an independent life, her understanding of the responsibilities that come with this remains limited.

#### Reader activity 1.2

Spend some time reading Case illustration 1.1. A transitional meeting has been called at Ayesha's school and you have been asked to go along as the local community nurse. The agreement is to draw up some kind of care plan for her for the next few years. Think what your role might be at such a meeting. Would you need to develop a nursing care plan, or would you document your role into the overall construction of a person-centred care plan/life plan? Who should attend such a meeting, who will speak for Ayesha, if she needs anyone? What if any specific interventions could or should you offer Ayesha and her family?

# The role of the intellectual disability nurse in care planning

Intellectual disability nurses have many dimensions and responsibilities within their role (UKCC, 1998); however, supporting people with intellectual disabilities to reach their goals in the form of living their lives as fully and independently as possible is by far the most vital. This role must always be practised in adherence to the Nursing and Midwifery Council Professional Code of Conduct (Nursing and Midwifery Council, 2004c) and this includes a range of practice-related issues that have direct bearing on care planning and delivery; these are shown in Box 1.1.

The Nursing and Midwifery Council Professional Code of Conduct was republished in November 2004 and replaced the United Kingdom Central Council for Nursing, Midwifery and Health Visiting Code of Conduct, together with the Scope of Professional Practice and the Guidelines for Professional Practice. As the regulatory body, the Nursing and Midwifery Council is

# Box 1.1 Practice-related issues for care planning and delivery (UKCC, 1998)

- Accountability
- Consent
- Inter-disciplinary working
- Evidence-based practice
- Advocacy
- Autonomy
- Relationships
- Confidentiality
- Risk management

required to protect the public by ensuring that nurses, midwives and specialist community public health professionals provide, maintain and set high standards of education, training, conduct and performance to their clients and patients (Nursing and Midwifery Council, 2004a, b). Registered nurses and specialist community health practitioners are personally accountable for their own practice and they must be aware that their Professional Code of Conduct (Nursing and Midwifery Council, 2004c) requires them to:

- Treat clients as individuals and with respect
- Obtain consent before any treatment or care is given
- Protect confidential information
- Co-operate with others within the team
- Maintain own professional knowledge and competence
- Be trustworthy
- Identify and minimise potential risks to clients and patients

As registered professionals they have a duty of care and they have to act within the best interests of their clients at all times and this necessarily includes the planning and delivery of care. Therefore it is vital to document nursing care and this too should adhere to the requirements of the Nursing and Midwifery Council, and so should not contain abbreviations or jargon, should be accessible to clients, ensure confidentiality, be written clearly, be factual and accurate and should not be able to be erased (Nursing and Midwifery Council, 2002). Failure to maintain a good standard of record keeping of nursing care, or the use of the nursing process can lead to a breakdown in the quality of provided care (Nursing and Midwifery Council, 2002). Furthermore, this could also have legal implications following the misconduct of record keeping and a nurse could be removed from the professional register; the reader may wish to refer to Chapter 5 that deals with the legal and ethical aspects of care planning and delivery. Also of use to the reader is a text by Gates et al. (2004) that deals with general and specific issues related to accountability in nursing practice.

#### Reader activity 1.3

Spend some time locating as many different types of care plan format as you can. You may find it helpful to undertake this activity with a colleague or even as a group either on pre-registration or post qualifying programme of study. Identify what is common to each and what separates them. Are some more socially/medically/nursing orientated than others? How central to the care plan is the person with intellectual disabilities and what was involved in its construction? Which care plan is superior and what criteria would you use to make such a decision?

# Conclusion

In this chapter the reader has been introduced to the nature of care planning, person-centred care planning, care management, health action planning and the care programme approach. The reader has also been introduced to some relevant and contemporary social policy as well as the Nursing and Midwifery Council's guidelines, competencies and expectations of professional practice as they apply to nursing and their planning and delivery. This chapter has also advocated the need for robust, professionally prepared care plans based on a systematic nursing assessment. In addition to this, reference has been made to nursing models and their appropriateness to care planning and delivery. In subsequent chapters of Part 1 of this text attendant issues that nurses must also consider in care planning and delivery are considered and these include integrated care pathways, life planning, person-centred care planning, legal and ethical issues of care planning and delivery, and, finally, risk assessment and risk management in intellectual disability nursing.

# References

- Aggleton, P. and Chalmers, H. (2000) *Nursing Models and Nursing Practice*, 2nd edn. Basingstoke: Palgrave.
- Alaszewski, A., Motherby, E., Gates, B., Ayer, S. and Manthorpe, J. (2001) *Diversity and Change: The Changing Roles and Education of Learning Disability Nurses*. London: English National Board.
- Aldridge, J. (1987) Initiating the use of a nursing model: the importance of systematic care planning a ward clinician's perspective. In: *Mental Handicap: Facilitating Holistic Care* (Barber, P., ed.). London: Hodder and Stoughton.
- Aldridge, J. (2004) Intellectual disability nursing: a model for practice. In: *Learning Disability Nursing* (Turnbull, J., ed.). Oxford: Blackwell Publishing.
- Barr, O. (2003) Working effectively with families of people with intellectual disabilities. In: *Learning Disabilities: Toward Inclusion*, 4th edn, (Gates, B. ed.). Edinburgh: Churchill Livingstone.
- Bonfenbrenner, V. (1979) *The Ecology of Human Development*. Cambridge, Mass: Harward University Press.
- Brandon, D. and Towe, N. (1989) *Free to Choose: An Introduction to Service Brokerage*. Surrey: Hexagon Publishing.
- Brittle, R. (2004) Managing the needs of people who have a learning disability. *Nursing Times* **100** (10), 28–9.
- Circles Network (2004) *The Models of Disability* [online]. Available from: www.circlesnetwork.org/models\_of\_disability.htm. (Accessed 14 January 2005)
- Department of Health (1999) Making a Difference: Strengthening the Nursing, Midwifery and Health Visiting Contribution to Health and Healthcare. London: Department of Health.

Department of Health (2000a) Nurses, Midwives and Health Visitors (training) Amendment Rules: Approval Order 2000. London: Department of Health.

Department of Health (2000b) The NHS Plan. London: Stationery Office.

- Department of Health (2001) Valuing People: a New Strategy for Learning Disability for the 21st Century. Towards Person Centred Approaches: Planning with People. London: Department of Health.
- Duffy, S. and Sanderson, H. (2004) Person centred planning and care management. *Learning Disability Practice* **7** (6), 12–16.
- Elliott, J., Hatton, C. and Emerson, E. (2003) The health of people with intellectual disabilities in the uk: evidence and implications for the NHS. *Journal of Integrated Care* **11** (3), 9–17.
- Forchuk, C., Beaton, S., Crawford, L., Ide, L., Voorberg, N. and Bethune, J. (1989) Incorporating Peplau's theory and case management. *Journal of Psychosocial Nursing* and Mental Health Services 27 (2), 35–8.
- Gates, B. ed. (2003) *Learning Disabilities: Toward Inclusion*, 4th edn. Edinburgh: Churchill Livingstone.
- Gates, B., Wolverson, M. and Wray, J. (2004) Accountability and clinical governance in learning disability nursing. In: *Accountability in Nursing and Midwifery* (Watson, R. and Tilley, S., eds.). Oxford: Blackwell Publishing.
- Gilbert, P. (2003) *Social Care Services and the Social Perspectives* [online]. Medicine Publishing Company. Available from: www.intellectualdisability.info/values/ social\_care\_pg.html. (Accessed 29 December 2004)
- Grant, G., Ramcharan, P., McGrath, M., Nolan, M. and Keady, J. (1998) Rewards and gratifications among family caregivers: towards a refined model of caring and coping. *Journal of Intellectual Disability Research* **42** (1), 58–71.
- Gray, C. (2003) Supporting Independence for People with Intellectual Disabilities [online]. Nurses Network. Available from: www.nursesnetwork.co.uk/envo/models.php?op =modload&name=News&file=article&sid=3. (Accessed 23 December 2005)
- Howells, G. (1986) Are the health needs of mentally handicapped adults being met? *Journal of the Royal College of General Practitioners* **36** (2), 449–53.
- Jacques, R. (2004) *Intellectual about Intellectual Disabilities and Health: Family Issues* [online]. Medicine Publishing Company. Available from: www.intellectualdisability.info/ families/family\_issues\_rj.html. (Accessed 23 February 2005)
- Jones, S. (1999) Learning disability nursing holistic care at its best. *Nursing Standard* **13** (52), 61.
- Klotz, J. (2004) Sociocultural study of intellectual disability: moving beyond labelling and social constructionist perspectives. *British Journal of Learning Disabilities* **32**, 93– 4.
- Kozier, B., Erb, G., Blais, K., Wilkerson, J.M. and Van Leuven, K. (1998) Fundamentals of Nursing: Concepts, Process, and Practice, 5th edn. Menlo Park, CA: Addison Wesley Longman.
- Mansell, I. (2002) Intellectual aides. Nursing Standard 6 (17), 112.
- Matthews, D.R. and Hegarty, J. (1997) The 'OK' Health Checks and health assessment checklist for people with learning disabilities. *British Journal of Learning Disabilities* **25** (4), 138–43.
- Matthews, D.R. (2004) *The 'OK' Health Check: Health Facilitation and Health Action Planning*, 3rd edn. Preston: Fairfield Publications.
- Mayo, A. (1997) Orem's Self-Care Model: a Professional Nursing Practice Model. Available from: http://members.aol.com/annmrn/nursing\_portfolio\_I\_index.html. (Accessed 22 December 2004)
- Mazrui, J. (2003) *Empowerment* [online]. Available from: www.empowermentzone.com. (Accessed 13 January 2005)

McFarlane, J.K. (1986) Looking to the future. In: *Models for Nursing* (Kershaw, B. and Salvage, J., eds.). Chichester: John Wiley and Sons.

McKenna, H. (1997) Nursing Theories and Models. London: Routledge.

- Meleis, A.I. (1997) *Theoretical Nursing: Development and Progress*, 2nd edn. Philadelphia: Lippincott.
- Mencap (2004) *Treat Me Right: Better Healthcare for People with an Intellectual Disability.* London: Mencap.

Newton, C. (1991) The Roper-Logan-Tierney Model in Action. Hampshire: MacMillan Press.

- Nursing and Midwifery Council (2002) Guidelines for records and record keeping. London: Nursing and Midwifery Council.
- Nursing and Midwifery Council (2004a) *About the NMC* [online]. Nursing and Midwifery Council: London. Available from: www.nmc-uk.org/nmc/main/about/ \$aboutUsMain. (Accessed 19 February 2005)

Nursing and Midwifery Council (2004b) *Complaints about Unfitness to Practice: A Guide for Members of the Public.* London: Nursing and Midwifery Council.

Nursing and Midwifery Council (2004c) *The NMC Code of Professional Conduct: Standards for Conduct, Performance and Ethics.* London: Nursing and Midwifery Council.

Orem, D.E. (1991) Nursing: Concepts of Practice. St Louis: Mosby.

Peplau, H.E. (1952) Interpersonal Relationships in Nursing: A Conceptual Framework of Reference for Psychodynamic Nursing. New York: G.P. Putnam & Son.

- Roper, N., Logan, W. and Tierney, A. (2002) *The Elements of Nursing*, 4th edn. Edinburgh: Churchill Livingstone.
- Royal College of Nursing (2004) Supporting people with intellectual difficulties [online]. London: Royal College of Nursing. Available from: rcn.org.uk/news/congress2004/ display.php?ID=1060&N=25. (Accessed 23 January 2005)
- Sanderson, H., Kennedy, K., Ritchie, P., and Goodwin, G. (1997) *People, Plans and Possibilities: Exploring Person-Centred Planning*. Edinburgh: Scottish Human Services Publications.
- Sox, H.F. (2004a) *Care Plans. Comprehensive Care Planning for Long Term Care Facilities: A Guide to Resident Assessment Protocols (RAPs) and Interdisciplinary Care Plans.* Volume 1. Ohio: Robin Technologies Inc.

Sox, H.F. (2004b) *What is a Care Plan?* [online]. Westerville. Available from: www.careplans.com. (Accessed 23 December 2004)

- Thiru, S., Hayton, P. and Stevens, E. (2002) Assertive outreach. *Learning Disability Practice* **5** (9), 10–13.
- Thompson, J. and Cobb, J. (2004) Person centred health action planning. *Learning Disability Practice* **7** (5), 12–20.
- United Kingdom Central Council for Nursing, Midwifery and Health Visiting (1998) *Guidelines for Mental Health and Learning Disabilities Nursing*. London: United Kingdom Central Council for Nursing, Midwifery and Health Visiting.
- United Kingdom Central Council for Nursing, Midwifery and Health Visiting (1999) *Fitness for Practice*. London: United Kingdom Central Council for Nursing, Midwifery and Health Visiting.
- van Schrojenstein Lantman de Valk, H.M., Metsemakers, J.F., Haveman, M.J. and Crebolder, H.F. (2000) Health problems in people with intellectual disability in general practice: a comparative study. *Family Practitioner* **17** (5), 405–7.
- Walker, A. (1993) Community care policy: from consensus to conflict. In: *Community Care: A Reader* (Bornat J., Pereira C., Pilgrim D. and Williams F., eds.). Basingstoke: Macmillan/Open University.

Watson, R. and Tilley, S. (eds) (2004) *Accountability in Nursing and Midwifery*. Oxford: Blackwell Publishing.

# Further reading and resources

- Beardshaw, V. and Towel, D. (1990) Assessment and Case Management: Implications for the Implementation of Caring for People. Briefing paper No.10. London: King's Fund Institute.
- Cambridge, P. (1999) Building care management competence in services for people with learning disabilities. *British Journal of Social Work* 29 June, 393–415.
- Cambridge, P. and Carnaby, S. (eds) (2005) *Person Centred Planning and Care Management with People with Learning Disabilities*. London: Jessica Kingsley Publication.
- Concannon, L. (2005) Planning for Life: Involving Adults with Learning Disabilities in Service Planning. London: Routledge.
- Cesta, T. and Tahan, H. (2003) Case Manager's Survival Guide: Winning Strategies for Clinical Practice, 2nd edn. St. Louis: Mosby.
- Challis, D., Chesterman, R., Luckett, R., Stewart, K. and Chessum, R. (2002) *Case Management in Social and Primary Health Care.* Ashgate: Aldershot.
- Department of Health (1996) *CPA: Taking Stock and Moving on.* London: Department of Health.
- Department of Health (1999) *Co-ordinating Care: The Care Programme Approach and Care Management.* London: Department of Health.
- Department of Health/Social Services Inspectorate (1991) Care Management and Assessment: Manager's Guide. London: Stationery Office.
- Duffy, S. and the Valuing People Support Team (2004) Workbook on Person Centred Care Management: Person Centred Approaches: Next Steps. London: Paradigm.
- Ellis, J.R. (2004) *Managing and Coordinating Nursing Care*, 4th edn. Philadelphia: Lippincott Williams & Wilkins.
- Gilbert, A.P. (2000) *Social Welfare: Care Planning and the Politics of Trust.* DPhil thesis. Buckingham: Open University.
- Gilbert, T. (2003) Exploring the dynamics of power: a Foucaldian analysis of care planning in learning disabilities services. *Nursing Inquiry* **10** (1), 37–46.
- Hogg, J. (1986) *Profound Retardation and Multiple Impairment*. Vol. 3: Medical and Physical Care and Management. London: Chapman and Hall.
- Lewis, J., Bernstock, V., Bovell, V. and Wookey, F. (1997) Implementing care management: issues in relation to the new community care. *British Journal of Social Work* 27 Feb, 5–24.
- Monks, K.M. (2003) *Home Health Nursing Assessment and Care Planning*, 4th edn. St. Louis: Mosby.
- McNally, S. (2003) Helping to empower people. In: *Learning Disabilities: Toward Inclusion*, 4th edn, (Gates B., ed.). Edinburgh: Churchill Livingstone.
- Paffrey, C. (2000) *Key Concepts in Health Care Policy and Planning: An Introductory Text.* Basingstoke: Macmillan.
- Papadopoulos, A. (1992) Case Management in Practice: An Introductory Guide to Developing Case Management Systems for Vulnerable People. Bicester: Winslow.
- Swearingen, P.L. (2003) All-in-one Care Planning Resource Medical-surgical, Paediatric, Maternity and Psychiatric Nursing Care Plans. St. Louis: Mosby.

- 20 Care planning and delivery in intellectual disability nursing
- Towell, D. and Beardshaw, V. (1991) *Enabling Community Integration: The Role of Public Authorities in Promoting 'An Ordinary Life' for People with Learning Disabilities in 1990s.* London: Kings Fund Institute.
- Wilcock, P., Carnpion-Smith, C. and Elston, S. (2003) *Practice Professional Development Planning Guide for Primary Care.* Abingdon: Radcliffe Medical.

#### Useful websites

Healthcare Commission: hai.org.uk Provides useful information on the performance of health care organisations.

Commission for Social Care Inspection: www.csci.org.uk Provides useful information on the performance of social care organisations.

Department of Health: www.dh.gov.uk *Provides useful information on health and social care policy as well as guidance and publications.* 

www.intellectualdisability.info This is an excellent resource with much useful information of intellectual disabilities and health. The site is maintained by Sheila Hollins, Jane Brenal and Jan Hubert.

Foundation for People with Learning Disabilities: www.learningdisabilities.org.uk This site has a wealth of information on aspects as far ranging as publications, policy, news and events, as well as an excellent links page.

National Institute for Health and Clinical Excellence: www.nice.org.uk This provides national guidance on the promotion of good health and the prevention and treatment of ill health.

Nursing and Midwifery Council: www.nmc-uk.org Provides useful information and guidance for nurses.

American Nurses Association: www.nursingworld.org Some useful material on care planning can be found here.

National Electronic Library for Health: www.nelh.nhs.uk Excellent search and retrieval facilities on all aspects of health.

22/3/06, 4:30 PM