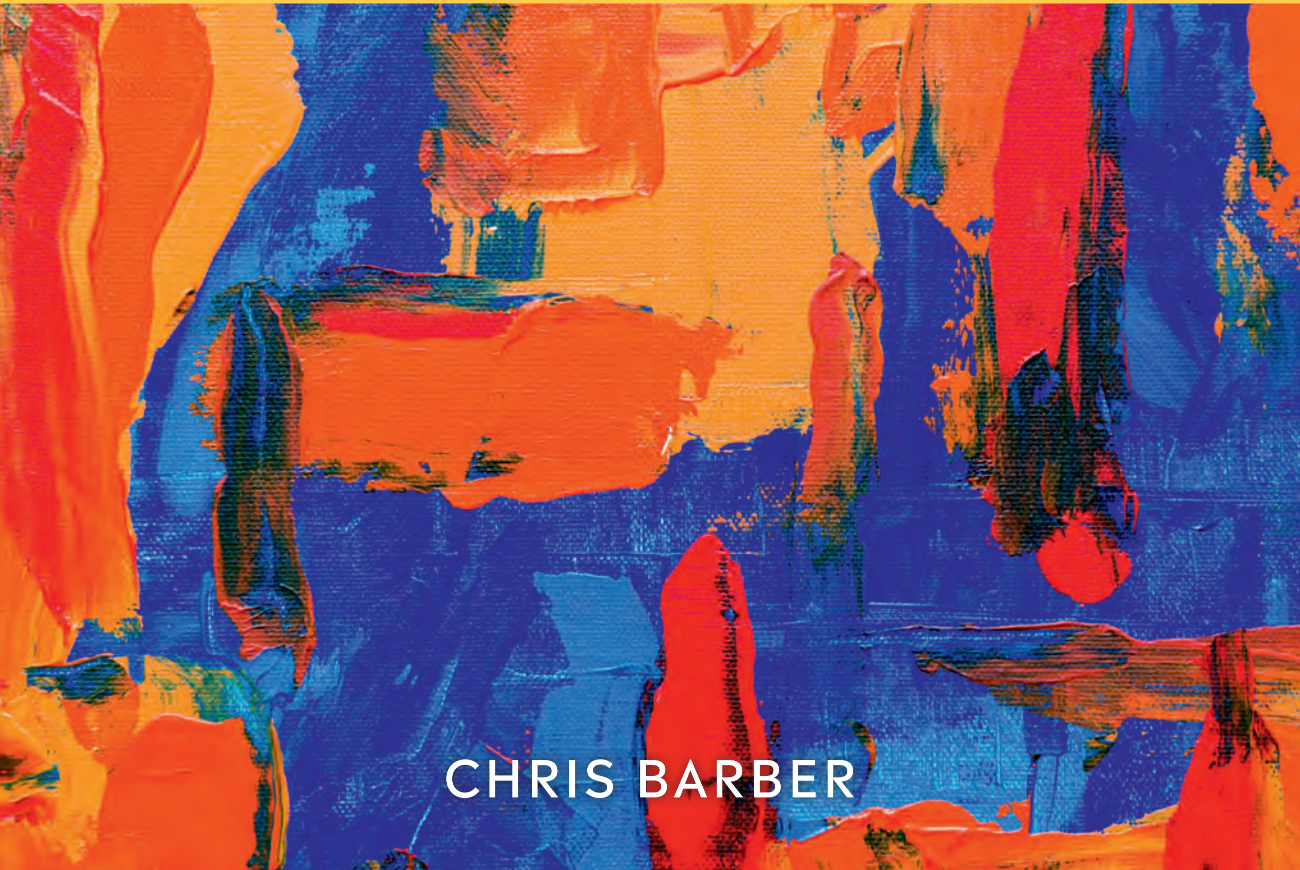
ESSENTIALS

LEARNING DISABILITIES

A non-specialist introduction for nursing, health and social care



CHRIS BARBER

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Foreword

Whilst much remains to be achieved to ensure that people with learning disabilities are fully included in society and enjoy full rights to citizenship, there have been many positive developments over recent decades. For example, over the course of my career I have seen the move from predominantly institutional service provision to more community-based forms of support. What has become very evident, however, is that people with learning disabilities continue to experience many inequalities and inequities in relation to health and healthcare. Furthermore, it is clear that to address such disparities is not just the remit of specialist learning disability services: all those working across the range of health and social care provision have a role to play.

However, if this wider responsibility is to be accepted by all health and social care practitioners it is essential that they feel confident and competent to take on this role. Of concern is that a focus on the needs of people with learning disabilities is often not adequately incorporated into the preparation of many health and social care practitioners. Consequently, they may find themselves in a situation where they lack (or feel that they lack) the knowledge and skills required to recognise and appropriately respond to the needs of people with learning disabilities. This, in turn, means that people with learning disabilities may not always receive appropriate support and they continue to experience inequitable access to healthcare.

Of course, it is important that knowledge and skills are developed through direct experience of working alongside and supporting people with learning disabilities. However, this book seeks to provide students and practitioners with the foundational knowledge they need to deliver effective support and thus increase their confidence when giving such support.

As noted above, services and supports for people with learning disabilities continue to evolve, as do our knowledge and understanding. An updated version of this book is therefore to be welcomed since it has been revised to take account of recent developments that impact on the lives of people with learning disabilities and their families. It provides not just knowledge but also aims to assist you with applying this knowledge to your practice through scenarios and reflective activities.

The closing sentences of the final chapter in this book challenge you to become a power for positive change in the lives of people with learning disabilities: a failure to do so risks them continuing to experience disparities in health and wellbeing that are avoidable. I hope, therefore, that you will not only read this volume but that you will also reflect upon how you can make a positive contribution. Do not feel that any changes you make are insignificant – if everyone working in health and social care made small positive changes in practice this would add up to wide-scale change for people with learning disabilities.

Ruth Northway (OBE, FRCN, PFHEA)
Professor of Learning Disability Nursing
University of South Wales

Preface

If you ever engage with a person with a learning disability, either in hospital, at a GP practice, in a community setting or even in the person's own home and wonder: How do I find out and understand what this person's needs are? How can I provide the best possible care for this person? Well, you are not alone and this book is definitely for you. So, welcome!

The world has changed since 2015 when the first edition of this book was published (with the title *Caring for People with Learning Disabilities*) and this current book was intended to be an updated second edition. Since being 'invited' to write this new edition which takes a whole lifetime approach (from birth to death) and covers most areas of care that the person with a learning disability is likely to need during that timeframe, the book has taken on a life of its own. It has broken free from the 'shackles' imposed by being a mere updated version of the first edition. It has become a living and breathing entity in its own right!

So, sit back and enjoy this book and if, in the process of reading it, you find something that you did not previously know and that you can use in your work as a nurse or health and social care worker when working with a person with a learning disability, then great! The book has done its job!

Chris Barber

Acknowledgements

I would like to thank my late wife Jean, who very sadly passed away during the writing of this second edition, and my son Freddie for their support and patience during the writing of this book.

Furthermore, I would like to thank the reviewers for their kind and thoughtful comments and suggestions regarding the text.

Finally, I would like to thank Mark Allen Publishing for their kind permission to reproduce text that was first published by the *British Journal of Healthcare Assistants*.

This book is dedicated to Jean. May she rest in peace.

About the author

The author is a registered nurse (learning disabilities), qualifying as such in December 1989. He has worked in a wide variety of clinical settings, both residential and community, with a wide variety of service users (those who are on the autism spectrum, those with sensory impairments, those whose behaviour 'challenges services', those who require forensic services and care and those with mental health issues). He is a parent of a young man who is also on the autism spectrum and he himself was diagnosed at the end of 2008 as being 'high-functioning autistic'. He holds an MEd from the University of Birmingham in special educational needs (autism). He sits on the editorial board of the *British Journal of Nursing*, the *British Journal of Healthcare Assistants* and the *British Journal of Mental Health Nursing*, and as well as having written a number of articles / papers on a wide variety of subjects including learning disabilities, caregivers, spirituality and autism, he is the author of *Autism and Asperger's Conditions*, published by Quay Books. Chris currently works as a visiting lecturer in learning disability nursing at Birmingham City University.

Chapter 5

Medical care and support for those with a learning disability

AIMS AND LEARNING OUTCOMES

The aims of this chapter are to:

- Highlight the support needs of those with a learning disability who access general healthcare facilities
- Highlight some of the barriers and issues that many people with a learning disability face whilst accessing healthcare services
- Set out a broad range of measures and interventions that could be put into place when working with this service user group within a 'general healthcare' setting such as a GP practice, a hospital ward or an outpatient department.

By the end of this chapter, you will be able to reflect on, describe, discuss and, where relevant, apply and/or meet:

- The care needs of a patient with a learning disability
- A number of barriers faced by those with a learning disability when they access healthcare facilities
- A number of measures and interventions that could be utilised to overcome these barriers.

5.1 Introduction

Most nurses and other health and social care professionals are likely at some point in their work to meet and provide general healthcare support and services to those with a learning disability within a number of healthcare settings. Such settings could include an Accident and Emergency (A&E) department, a general practice or health centre, an outpatient department, a surgical or medical ward or a dental practice. This chapter will focus on a number of practical issues that those with a learning disability may encounter when accessing such generalist healthcare services and settings.

ACTIVITY 5.1

Discuss with a colleague how you as a nurse or healthcare professional would provide high-quality support to those with a learning disability within the environment where you work.

In order to do this, you may like to consider the following:

- Person-centred holistic assessments
- Person-centred care planning
- MDT working
- Knowing who to ask for advice and knowing the right questions to ask
- Acknowledging the limitations of your knowledge and skills when working with this patient group.

5.2 Healthcare needs of those with a learning disability

SCENARIO 5.1

Ziva, a woman in her 30s who has high-functioning autism / Asperger's syndrome (HFA/AS) and is a university lecturer, and who also has a son with classic autism, is to be admitted to a gynaecological ward where Sally works as an occasional bank nurse, for a planned minor operation to remove uterine polyps by hysteroscopy.

SCENARIO 5.2

Marcel, a young man in his 30s with Down's syndrome who lives at home with his parents and is Ziva's brother, attends a pre-arranged 1 pm appointment at a local hospital's 'lumps and bumps' clinic (where, again, Sally works as an occasional bank nurse) for a large and painful cyst on his finger, having been referred to this clinic by his GP.

As Public Health England (PHE, 2018) states:

> *"Individuals regardless of their age, gender or label should receive care that is based on their unique needs, that is appropriate in its design and effective in its delivery."*

PHE points out that people with learning disabilities have more healthcare needs than the general population and that about 50% of people with a learning disability will have at least one significant health problem. In addition, those with a learning disability will experience the same health conditions and have the same health needs as everyone else. Many of these are relatively routine and commonplace, such as:

- flu
- respiratory, skin and other infections
- diabetes
- weight management
- musculoskeletal issues including gout

- minor injuries
- pain management
- smoking cessation
- health education
- health screening
- vaccinations
- ongoing community-based support for issues such as heart problems, dementia, strokes and mental health
- dementia care
- family planning, gynaecology and reproduction, contraception and pregnancy.

These should be dealt with by the GP or practice nurse in the same way as anyone else but with additional support as and when needed. However, there is evidence that suggests there is poor provision and uptake of relatively common screening and health management opportunities such as cervical screening in women with a learning disability; such poor provision and uptake stems from stigma regarding learning disability and health care and may result in further stigma (Byrnes *et al.,* 2019).

Some forms of minor injury such as those incurred during sports activities, for example, and other health conditions may need the input of appropriate 'out of hours' services, 'walk-in' minor injury units or A&E departments. But, again, this is normal and many people without an additional learning disability will use these services at some point in their lives.

Other health conditions may require a more specialist medical or nursing input including:

- diagnosis and care of cancers
- diagnosis and care of dementia
- complex issues around gynaecology
- strokes and heart attacks
- renal issues
- endocrine and neurological disorders.

Again, this is normal and is part and parcel of being human. Indeed, Barber (2001) made this clear in his paper on the professional development of nurses with regard to those on the autism spectrum. Although Barber's focus was on those with an autism spectrum condition twenty years ago, his point is applicable to those who have a learning disability today.

However, many of those with a learning disability will experience specific health conditions often associated with their specific form of learning disability or syndrome. For example, respiratory, circulatory and cardiac problems are often associated with people who have Down's syndrome (see the checklist given in Down's Syndrome Association (2021) and RCGP (undated) as indicators of the forms of health issues that those with a learning disability are likely to experience). Again, prevalence of epilepsy is often higher in those with a learning disability than elsewhere in society (Epilepsy Action, 2018).

In previous decades, most relatively minor healthcare interventions for those with a learning disability were carried out within the old mental handicap hospitals. By 'relatively minor' is meant the type of healthcare issues one would usually see the GP, community nurse, optician or dentist about. Indeed, such hospitals tended to be very self-contained and provided more or less everything that the person with a learning disability needed. However, with the closure of these large and often isolated hospitals during the 1980s and 1990s, the provision of healthcare services was transferred to mainstream acute and community healthcare providers.

5.3 Roles of the nurse

There are a number of specific practical suggestions that could be useful to nurses, HCAs, student nurses and other health and social care professionals when working within a generalist healthcare setting. Such settings are likely to include a GP practice or community health centre, an A&E or out of hours unit, an outpatient unit or a surgical or medical ward. Some of the following practical suggestions may be more useful than others, whilst some may be easier to implement and may be cheaper to act upon than others. However, quality must never be sacrificed in order to keep down costs. Do not forget that the framework suggested by the twelve activities of daily living in order to provide high-quality holistic care, highlighted in *Chapter 3*, could be useful here.

PAUSE FOR THOUGHT 5.1

What do you consider to be the steps required to ensure that Ziva and Marcel are admitted 'hassle free' to the ward or department where Sally works?

As a first step, the nurse or other health and care professional, when working with a person with a learning disability, must be aware of the possibility for 'diagnostic overshadowing' which is defined as "once a diagnosis is made of a major condition… a tendency to attribute all other problems to that diagnosis, thereby leaving other co-existing conditions undiagnosed" (Neurotrauma Law Nexus, undated). In other words, health conditions may be seen as a consequence of having a learning disability rather than as health conditions in their own right and treated accordingly (Blair, 2017). The nurse needs to see beyond the diagnosis and 'label' of learning disability to both the health condition and the person with that health condition. It must never be forgotten that the person with a health condition is a person first and has the right to be engaged with as such.

5.3.1 Access the support of the learning disability liaison nurse

In order to provide better support for both Marcel and Ziva during their stay at the hospital, a learning disability liaison nurse (LDLN) would be invaluable. An LDLN is a specialist learning disability trained nurse who supports people with a learning disability while they are in hospital to make sure they get the care they need.

Where there is an LDLN, it's important that they meet the patient as soon as possible after they arrive at the hospital. This is so that the LDLN can find out everything they need to know about the patient's learning disability and health condition and the help they will need while in hospital. It may be possible to arrange a meeting before the hospital stay.

The learning disability liaison nurse can assist with:

- coordination of care – at points of attendance, admission and discharge
- education within clinical areas and contributing to programmes of education
- support and advice for acute care staff in relation to personalised care and service delivery
- collaboration between the agencies involved in service delivery to ensure effective seamless care by undertaking home visits
- development and enhancement of standards of care for all patients with a learning disability attending the acute hospital
- promotion of effective communication with those involved in the patient's care – whether they are community- or hospital-based
- support of a relative or a family member with a learning disability who is affected by the patient's illness / hospital stay
- promoting safety and minimising risk
- provision of accessible information about treatments
- promotion of positive experiences and outcomes (NHS Lothian, 2020).

ACTIVITY 5.2

Arrange to meet your local learning disability liaison nurse and discuss any concerns that you may have about meeting the nursing needs of any previous, current or potential future patients / service users with a learning disability who may be in your care.

5.3.2 Assess, assess and assess

This may sound obvious, but it is imperative that every service user or patient who has a learning disability must be treated as an individual. It may therefore not be appropriate to approach, assess or treat:

- a young child with a learning disability in exactly the same way as you would a teenager or an adult with a learning disability, or
- a person with severe or profound learning disability in the same way as a person with a mild or moderate learning disability.

Each of these people will have differing information, care and support needs. Therefore, not only must the patient assessment be absolutely thorough, but it must be holistic, person-centred, appropriate to the individual and fit for purpose. It may be necessary to use a set of assessments that have been devised specifically to meet the communication needs of those with a learning disability, or to adapt or amend existing assessment tools that may not address those needs directly. For example, it may be necessary to substitute words and numerical scales with simple line drawings or pictures. One such example could be the Wong–Baker FACES® Pain Rating Scale (*Figure 5.1*) where service users are asked to choose one of six faces that best depicts the pain they are experiencing.

©1983 Wong-Baker FACES Foundation. www.WongBakerFACES.org
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Figure 5.1 *Wong–Baker FACES® pain rating scale.*

ACTIVITY 5.3

Discuss with a colleague how you could adapt existing nursing assessment tools to make these useable for those with a moderate and a severe learning disability.

5.3.3 Accessible information

It is vital for the service user or patient with a learning disability to have information that is simple, easy to understand, timely, accurate, and in a format that the patient can use. Although Ziva works as a university lecturer, the manner in which she processes information, particularly when stressed, may require such information to be presented in ways other than written or verbal. As the information levels and needs will vary from person to person and from condition to condition and even from day to day, the type and level of information that is offered will likewise have to vary, as will the ways in which this information is presented. Such communication issues will be highlighted during assessments.

It is important, here, to be imaginative and creative in how appropriate information is offered, particularly within tight financial and time constraints. However, what must be borne in mind when providing information to people with a learning disability is that without appropriate information, the patient's or service user's ability to give informed consent to treatment will be threatened and may even not exist. This could have potentially profound practical, legal and ethical consequences for both the patient and the nursing and medical staff.

ACTIVITY 5.4

Produce a simple and 'easy read' leaflet that explains to a potential patient with a learning disability the services offered in the clinical environment where you work. Try to obtain the funding necessary to print such a leaflet.

5.3.4 Communication

Communication is the central key, the linchpin to everything that the nurse does with the patient or service user and is essential in order to gain consent to any intervention or care. It must be borne in mind that communication is not a one-way process (e.g. from nurse to patient) but is an active multiway process involving a minimum of two people but likely to involve many more. However, the person with a profound learning disability, such as Thomas from *Chapter 4*, may be totally non-verbal or may communicate through facial expressions and other forms of body language, through pre-verbal 'grunts' or through sign languages such as Makaton (a simpler form of British Sign Language). Therefore, it is vital for Sally to take the time and really observe, to really get to know the patient so that she can pick up on the various hidden nuances in their behaviour, facial expressions and body language in order to ascertain what it is they are communicating.

In order to communicate, particularly with those who may be 'less-abled', imagination may be needed in presenting or acquiring information effectively. Similarly, imaginative forms of communication may be required when engaging in social communication with a person with a learning disability such as chatting about the weather, the football results or even just saying 'hello'.

ACTIVITY 5.5

Reflect and note down how and why you could change the way you communicate with a person with a moderate and severe learning disability.

5.3.5 Pre-admittance visits

If it is feasible, arranging pre-admittance visits for patients who have a learning disability may be very useful in order to familiarise that person with the routines, procedures, sights, sounds, smells and people within a hospital ward, outpatient department or dental surgery. Cumella and Martin (2000) cite examples of hospitals arranging such visits, recording video footage of 'life on a hospital ward' for those with a learning disability or preparing very simple pre-admittance information sheets and leaflets using a combination of actual photos, pictures and line drawings. NICE (2019) suggests that people growing older with a learning disability should meet hospital staff before any planned hospital admission, to agree arrangements that make the stay easier for them.

However, such pre-admittance visits can be resource-intensive and prohibitive in terms of money and time and in an environment that is increasingly budget-conscious, it may be difficult to justify such resources for what could be a relatively small number of patients. Having said that, do contact and talk to the learning disability liaison nurse for advice on how to produce accessible pre-admittance information. Also, by using relatively scarce resources in an imaginative and creative manner, it may be possible to produce simple and cheap information and videos for those with a learning disability. Finally, the Mencap website (www.mencap.org.uk) may provide useful suggestions regarding pre-admittance visits and information.

ACTIVITY 5.6

How would you arrange a pre-admittance visit by a person with a learning disability onto the ward or department on which you work? Write down your thoughts and discuss them with a colleague.

5.3.6 Timing of appointments

SCENARIO 5.2– CONTINUED

Marcel, a young man in his 30s with Down's syndrome, attended a pre-arranged 1 pm appointment at a local hospital's 'lumps and bumps' clinic for a large and painful cyst on his finger, having been referred to this clinic by his GP. When Marcel arrived at this clinic, there were about a dozen other people waiting to be seen. A notice appeared on the clinic wall advising the patients that there was a 50-minute delay, which stretched to 55 and then 60 minutes. Marcel did not understand the delay or the reason for it and rapidly became agitated and anxious. Marcel started to pace up and down the waiting area, becoming more verbally and then physically agitated and aggressive, scratching and biting himself on his arms. The clinic staff asked the hospital security to escort Marcel out of the clinic and the hospital, saying that his behaviour was disruptive and was scaring other patients. Consequently, because Marcel was not seen by the clinic, his cyst was not diagnosed at this appointment as being pre-cancerous, which it actually was.

PAUSE FOR THOUGHT 5.2

How would you support Marcel in this particular situation?

Many of those with a learning disability, particularly those who are also on the autism spectrum, will have set and rigid daily routines which, if disrupted, may result in a 'behaviour meltdown'. Again, many of those with a learning disability will experience anxiety and stress and perhaps extreme anxiety if exposed to unfamiliar environments, smells and sounds and unexplained delays. Thus, it is important to keep disruption and resultant anxiety to an absolute minimum. One way to achieve this is to schedule medical appointments for fairly quiet times, either very early appointments or the last appointments of the day, so that there are fewer people around and noise levels are lower, which will lead to lower levels of sensory stimulation and arousal. If Marcel or Ziva need to visit the GP practice, health centre or outpatient department for any reason it may also be helpful to book a 'double appointment' in order to allow time for information to be given to the patient and for the patient to be able to ask questions regarding their health and treatment.

It would be very helpful if Marcel and Ziva could have any GP appointments with the same GP at each appointment. This would allow the GP and the patient to get to know each other and the patient would not feel that they have to repeat themselves to different doctors whom they see. It would certainly be helpful not to have a 'general appointment time' but, instead, to have specific appointment times. A nine o'clock appointment must mean 09.00 and not 09.30 or 10.00. This is less likely to heighten anxiety levels with a resultant 'behavioural meltdown' such as was experienced and expressed by Marcel. If appointments are delayed significantly for any reason, and in the real world this may very likely be the case, ongoing explanations for the delay and reassurance using language and terms that the patient with a learning disability is likely to understand, would be useful. As with Marcel, it may be helpful to lead the patient into a quiet room or area or to allow the patient to 'jump the queue'.

ACTIVITY 5.7

Reflect on the possible impact on and consequences for a person with a learning disability who is having to wait over an hour for their outpatient appointment, and then note down three things that you can do to ensure that people are seen at the time given on their appointment letter.

5.3.7 Hospital passports

PAUSE FOR THOUGHT 5.3

What, if anything, is wrong about the following question: "*Does he take sugar?*"

Northway *et al.* (2017) reviewed 60 hospital passports in use in the UK and found that they could enhance patient safety and person-centred care, but that they varied considerably in format and in the information contained. Some standardisation is required, but typically such documents (which may also be referred to as 'personal passbooks', 'communication passports', etc.) would include the following information:

- A photograph of the person
- Information about key contacts and health needs
- The patient's likes and dislikes
- How they communicate
- Any dietary needs and food allergies
- Mobility issues
- Personal care issues
- Personal faith community contacts if needed
- Any medication that is being taken.

If nurses and HCAs are familiar with and read such passbooks, the need to ask whether the patient takes sugar in his tea or coffee becomes largely redundant.

However, as a way of starting a conversation with a patient who has a learning disability, it may be useful to ask the patient if he or she has sugar in their coffee or tea. The point here is that the question should become "Do *you* take sugar?" rather than "Does *he* take sugar?" and could be used as social politeness in the same way as with any other person. Marcel would very much prefer it if the health professionals caring for him were to talk to him, not at or about him! However, those with a learning disability may not be able to verbally communicate, thus it is imperative to read their passbook and communicate with them in ways that they can understand and participate in.

Each hospital is likely to have its own version of this type of passbook but the format of using simple language and pictures to present information is likely be very similar. This passbook will be completed by the person with a learning disability or by someone who knows this person well. If such a passbook does not exist where Sally works, it may be worth contacting the learning disability liaison nurse for advice on how to design and produce one.

ACTIVITY 5.8

Obtain a hospital passport from your local learning disability liaison nurse. Having read it, note any ways that the passport can be amended in line with the aims and objectives of your work environment.

5.3.8 Support during admittance

We are now going to consider support during admittance in the context of our two scenario patients.

SCENARIO 5.1 – CONTINUED: ZIVA

It may be helpful for Ziva to receive a text message the day before her appointment to remind her. Ziva, who was accompanied to the hospital by her husband, could be met at the hospital entrance by a 'buddy'. Such a 'buddy' could be arranged by the hospital's LDLN and may well be a volunteer. The role of the 'buddy' will be to explain to Ziva where her ward is and to take her there, to explain hospital and ward procedures and layout and to be a 'friendly face' in what can often be seen as a hostile and frightening environment. Once on the ward, a full medical history and assessment that is relevant to the procedure must be taken. Ziva must be fully involved in the assessment, being treated as a person and not as a medical condition. As part of this assessment, Ziva's mobility and self-care abilities will be considered.

As Ziva is articulate and is able to communicate verbally, a passbook is not likely to be needed. However, due to her Asperger's syndrome Ziva might ask for information to be offered initially using simple rather than complex language and jargon. She should be offered the opportunity to ask questions, which must be answered honestly. This could take place in a side room as this would be more likely to afford Ziva quietness and may be less stressful for her.

SCENARIO 5.1 – CONTINUED: MARCEL

Marcel was fully able to communicate with the hospital staff at the outpatients clinic that he attended. However, the clinic staff failed to communicate effectively with him and this caused Marcel a lot of anxiety and resulted in 'inappropriate behaviour' on his part, which in turn resulted in him being unable to attend his initial appointment. However, the hospital-based LDLN, who ideally should have been involved at the outset and even prior to Marcel's appointment, was able to intervene at the request of Marcel's parents and Marcel was offered another appointment at the clinic. During this second appointment, Marcel was supported by the liaison nurse and his parents.

ACTIVITY 5.9

Write down how you could make reasonable adjustments during the process of admitting a person with a learning disability onto your ward. Does this look any different from how you would admit a person who does not have a learning disability onto your ward?

5.3.9 Support before the procedure

As the named nurse for Marcel and Ziva, Sally will discuss with them the various options for their respective conditions (it is more likely that the permanent rather than the bank staff would act as the named nurse). With Ziva, the option would be whether to have her polyps removed by hysteroscopy under either local or general anaesthetic. Sally will assess Ziva's ability to process and understand information and explain to her what this procedure actually entails in terms that she will be able to understand. Sally will give Ziva an information leaflet on the procedure and answer any questions that Ziva has.

Marcel will be offered support from the LDLN during his second appointment. The LDLN will work with Sally to ensure that Marcel is made aware of any delays in being seen and the reasons for these delays, and that Marcel is reassured.

ACTIVITY 5.10

Write down three ways that you could support a patient with a learning disability *prior to* undergoing a surgical procedure. Are these the same as when supporting a 'non-learning disabled' person undergoing the same procedure?

5.3.10 Support during the procedure

Ziva will be offered the choice between having the polyps removed under local or general anaesthetic. If, as is likely, Ziva opts for the former, she will be conscious throughout. Therefore, the procedure will be explained to her step by step, while her husband could be given the option of using the staff room and having a welcome cup of coffee while he waits for her to return to the ward.

Marcel will be supported by the LDLN throughout his second appointment at the 'lumps and bumps' clinic. It will be suggested to Marcel that because of the small risk of the cyst being cancerous, a biopsy could be advisable. The liaison nurse will explain to Marcel and his parents what this means and what it will involve.

ACTIVITY 5.11

Write down three ways that you could support a patient with a learning disability who is undergoing a surgical procedure. Are these the same as when supporting a 'non-learning disabled' person undergoing the same procedure?

5.3.11 Support after the procedure

After the polyps are removed, Ziva will be taken back to the side room on the gynaecology ward and be offered pain relief, verbal reassurance and careful monitoring. Any questions that Ziva may have about the polyps and the procedure will be answered by her named nurse.

After the excision of the cyst for biopsy, Marcel will be given pain relief, an explanation of what should happen next, reassurance and a follow-up appointment.

In some senses, the care that both Marcel and Ziva should expect will be no different from the care that any patient undergoing similar, or indeed any, procedures should expect. However, given that Marcel, certainly, and Ziva to a certain extent, are going to experience language barriers due to their disabilities, it is important to be aware of the need to adapt communication styles and forms in order to offer reassurance and to ensure that the right information is given in the right way to facilitate understanding and consent.

ACTIVITY 5.12

Write down three ways that you could support a patient with a learning disability who has just undergone a surgical procedure. Are these the same as when supporting a 'non-learning disabled' person who has undergone the same procedure?

5.3.12 Discharge

Given that discharge planning should commence when the patient is admitted onto the ward or department and should not be seen as an afterthought at the end of the stay, the key to a successful discharge for both Ziva and Marcel will be communication, team working and appropriate referrals. As the nurse allocated to Ziva, Sally is likely to be involved in drawing up her discharge plan. Ziva must be offered information about general gynaecology as well as condition-specific aftercare in a format that she can access and understand, taking into account any communication and information processing issues that may affect those with Asperger's. Ziva should be reminded of the importance of having someone at home to look after her for a day or two. Ziva will be referred back to her GP for general check-ups and the results of tests that were carried out on the removed polyps, as some polyps may be cancerous in nature.

Marcel's discharge plan will likewise be thorough. Marcel and his parents will be offered easy to read information about the aftercare of a person who has had a cyst biopsy. A follow-up appointment should be made during which the results of the cyst biopsy will be explained. As a result of the biopsy, a referral to a cancer specialist should be made.

ACTIVITY 5.13

Consider the consequences for the patient if the discharge care plan is left to the last minute. Could or does this happen where you work? What actions could you take to ensure that any discharge care plans are 'fit for purpose'?

5.3.13 Follow-up

Follow-up in Ziva's case could be a phone call from the hospital learning disability liaison nurse two or three weeks after discharge. This would be to find out how she is now and how any follow-up appointments with her GP went.

Marcel would also be contacted by the learning disability liaison nurse and might receive home visits from the dietitian, the physiotherapist and the community learning disability nurse who might have liaised with the cancer specialists at the hospital. The community learning disability nurse would ensure that Marcel is resting and looking after himself properly. They would also arrange for any further health checks to be made.

ACTIVITY 5.14

Devise a simple protocol which sets out appropriate and costed post-discharge follow-up that will include the input and roles of all stakeholders and care professionals. If you are in a position to do so, obtain senior management approval for the protocol and then implement it.

5.4 Professional development opportunities

According to Mencap there are continuing failures in care for people with a learning disability and several reports related to poor care, some of which have resulted in the deaths of those with a learning disability and/or autism. Since March 2007 when Mencap published *Death by Indifference*, further deaths have been reported to Mencap, deaths which families blame on hospital blunders, poorly trained staff and indifference (Mencap, 2018). Again, there have been several reports into the abuses carried out at Winterbourne View and Whorlton Hall involving people with a learning disability and/or autism (DH, 2012; NHS England, 2014; BBC, 2019).

There is thus a need for nurses at all levels to receive awareness raising and basic training in learning disability care as part of their ongoing professional development programmes. This need was highlighted as a result of a government consultation exercise during the first few months of 2019.

The consultation was initiated after the death of the teenager Oliver McGowan, following which his mother Paula launched a parliamentary petition asking for all doctors and nurses to receive mandatory training in learning disability and autism awareness (see www.olivermcgowan.org for more details of the campaign). She argued fiercely that autism must be included in such training. On 22 October 2018, her petition was debated on the floor of the House of Commons and gained cross-party support. As a direct consequence the UK government announced that all NHS and social care staff would receive The Oliver McGowan Mandatory Training in Learning Disability and Autism. The need for such training was reinforced through the subsequent report on the government's consultation on the mandatory training of health and social care professionals regarding learning disability and autism (Department of Health and Social Care, 2019).

There are core capability frameworks for supporting people with learning disabilities and/or autism (see *Chapter 1* and the *Resources* section), and the Oliver McGowan Mandatory Training in Learning Disability and Autism is being developed (HEE, 2021) in conjunction with partners including Mencap and the National Autistic Society (Mencap, 2021). Opportunities for professional development will become available, and you will be expected to attain the capabilities appropriate to your level of role and to undertake the mandatory training.

ACTIVITY 5.15

Contact either the local or regional Mencap office or the hospital-based LDLN for advice and suggestions as to how to access appropriate training / professional development that would cover the issues of what learning disability is and is not, its causes, as well as how to provide high-quality care to a patient who has a learning disability.

5.5 Conclusion

Those with a learning disability are as likely as anyone else to experience health issues and illnesses that require either the support of community-based healthcare such as GP practices or admittance to a general hospital. Nurses' knowledge about learning disability care is historically not as good as it should be and this has contributed to the needless deaths in general hospitals that resulted in the 2007 Mencap report *Death by Indifference*. However, those with a learning disability have a right to high-quality healthcare and medical and nursing care and there is much that the nurse, student nurse and HCA working within a 'generalist' healthcare setting could do to ensure that high-quality care is delivered.

CHAPTER SUMMARY

Key points to take away from *Chapter 5*:

- ☑ Those with a learning disability are as likely to experience health issues and illnesses as anyone else.
- ☑ Historically, nurses and HCAs working in general healthcare settings are not trained to work with those who have a learning disability.
- ☑ There are a number of ways that hospital and community-based nurses could improve the quality of the nursing support experienced by those with a learning disability whilst accessing healthcare facilities.
- ☑ These include carrying out holistic assessments, providing appropriate information, pre-admission visits, timing of appointments, patient-held information 'passbooks' and communication.

Questions

Question 5.1	What are the healthcare needs of those with a learning disability?
Question 5.2	How would you assess the holistic care needs of a patient with a learning disability that is in your care?
Question 5.3	List ten barriers to accessing healthcare that are often faced by those with a learning disability. For each of these barriers, how would you challenge these barriers in your daily work?
Question 5.4	For each of the barriers that you have listed in your answer to *Question 5.3*, how would you assist a person with a learning disability to challenge and overcome them?

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