

Chapter 3

Socioeconomics in complex care

NMC Future Nurse: Standards of Proficiency for Registered Nurses

This chapter will address the following platforms and proficiencies:

Platform 1: Being an accountable professional

- 1.9 understand the need to base all decisions regarding care and interventions on people's needs and preferences, recognising and addressing any personal and external factors that may unduly influence their decisions
- 1.14 provide and promote non-discriminatory, person-centred and sensitive care at all times, reflecting on people's values and beliefs, diverse backgrounds, cultural characteristics, language requirements, needs and preferences, taking account of any need for adjustments

Platform 2: Promoting health and preventing ill health

- 2.3 understand the factors that may lead to inequalities in health outcomes
- 2.7 understand and explain the contribution of social influences, health literacy, individual circumstances, behaviours and lifestyle choices to mental, physical and behavioural health outcomes

Platform 7: Coordinating care

- 7.9 facilitate equitable access to healthcare for people who are vulnerable or have a disability, demonstrate the ability to advocate on their behalf when required, and make necessary reasonable adjustments to the assessment, planning and delivery of their care
- 7.13 demonstrate an understanding of the importance of exercising political awareness throughout their career, to maximise the influence and effect of registered nursing on quality of care, patient safety and cost-effectiveness

Chapter aims

After reading this chapter, you will be able to:

- understand the impact of the benefit system on claimants
- discuss the disability price tag
- understand the impact of socioeconomics on the lives of people with complex care needs.

Introduction

In the previous chapter, we looked at the broader context of living with complex care, including political and sociological determinants of health, policies and procedures. Let us now explore some of those in action and the impact that they can have. In this chapter, we will look at the benefit system in the UK and the impact that has on people with complex conditions. We will explore the disability price tag and the other socio-economic factors that impact on a person living with complexity.

We know that the higher the socioeconomic status a person holds, the lower the prevalence of health problems, illness, disease and death (Alvarez-Galvez, 2016). This relationship works both ways – the worse the health problems, the greater the impact on a person's socioeconomic status. Their findings made it clear that, in the UK, income is a major factor in determining health status. There are many ways to look at socioeconomics and complex needs; we could consider the cost-per-case to the NHS, the disability price tag, the cost burden to the country or many others. Let us start by putting a person at the heart of this discussion and explore the story that Bettie shared with us, before broadening our view.

Case study: Bettie

This is written from Bettie's point of view, in her own words.

When it became clear that I could no longer work in my career as a nurse, a profession that I had worked hard at for over 22 years, I was devastated. I was exhausted though, having suffered from a breakdown and ending up in a psychiatric hospital. Working as a practice sister at the same practice where I was a patient was not without problems and I was under pressure from my employers to return to work following my breakdown. When I saw my GP for appointments regarding my mental health, they were unable to see me as a patient with needs. Instead, they saw me as a member of their team that they could no longer be without. Something had to give and that was me, but without my income and with a family to support I was faced with having to see if I was eligible to claim a benefit. The form was several pages long and
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required me to go into details about why I couldn't work, what symptoms I had and how they affected me. I felt on trial and it was like reliving all my painful, traumatic experiences again.

I knew I had done nothing wrong in the past to put me in this position, and I knew I was doing nothing wrong by seeking help from the system that I had been paying into for years yet I still felt guilty.

Luckily, I was successful in my claim for Employment and Support Allowance but after a year I was called into the Benefits Office for them to see me physically and assess my claim. I felt yet again that I was being judged and not believed.

Even now, every time the post drops through the letterbox I expect to see a letter informing me that my benefits have been stopped.

In this scenario, we can see how easily someone can go from a stable financial position, in work, to struggling financially. We can see the emotions entangled in the act of claiming the benefits people are entitled to and how complex the system itself is.

Activity 3.1 Critical thinking

Take a moment to reflect on the story Bettie shared with us. Consider the impact it might have to work in a job you love and experience what she did. Consider then the pressure of attempting to fill in the forms, to claim an income, while you are unwell.

As this activity is based on your own thoughts, no outline answer is given at the end of this chapter.

Day and Shaw (2020) found that there were themes of fear and trepidation for people living on benefits, and the impact of the media's narrative of 'scroungers' feeding into more stigma and people's own issues with identifying as disabled to claim benefits. Add to that the challenges of navigating a system that is complex and has a reputation for requiring people applying for PIP to go to appeal to be successful and you can see why it may be daunting.

The UK benefit system

We discussed this a little in Chapter 2, but here we will focus on PIP. It replaced the Disability Living Allowance (DLA) but was changed in 2017, amid great protest from patient groups such as the MS Society, Parkinson's UK and Mind. In Scotland, PIP was replaced by the Adult Disability Payment (ADP) in 2021, with fewer face-to-face assessments planned and with considerable consultation with people who have been through the PIP process as part of the design. PIP is meant to provide support with extra costs

of living with a disability or long-term condition. Employment and Support Allowance (ESA) is to provide money for people who cannot work; this requires a work capability assessment (WCA).

The face-to-face assessments are seen as being too technical, with little humanity and claimants feeling disrespected and a lack of understanding; the narrative in the papers of ‘scroungers’ and the impact of this assessment dehumanised people (Day and Shaw, 2020). Statistics from the Tribunal Service show that 73 per cent of appeals for PIP and ESA overturn the original denial of benefits for the claimant and that claimants received a better award. The appeals process requires the person to have the knowledge and energy to do it; this is a complex system and the challenge of appealing may be difficult without support. The time permitted to return the form, four weeks, was too short; many found they could not get the evidence or that they needed help to complete the long, complex form (MS Society, 2019).

Box 3.1 Appeal success rates for individual benefits

- Employment and Support Allowance (ESA): 77 per cent
- Personal Independence Payment (PIP): 76 per cent
- Disability Living Allowance (DLA): 69 per cent
- Universal Credit (UC): 61 per cent

At the level of appeals there is an expectation that when you apply for a benefit you will have to either prepare in advance to defend it or find the energy and resources to do so. This might mean ordering notes and searching for evidence to provide or asking those providing your care for supporting letters. You may need to find the financial resources to survive until those benefits are granted.

One important fact to know is that these benefits are gateways to other financial supports, such as Carer’s Allowance and the Motability scheme. In addition, there is the risk of sanctions (a fine or cancellation of benefits). Of those people who responded to Mind’s survey, 10 per cent had been sanctioned; 89 per cent of those threatened with sanctions had worsened mental health (Mind, 2017).

Activity 3.2 Reflection

Pause here for a moment and reflect on your income, or that of your family. What would happen if you became too ill to work tomorrow? Go the benefit pages and work out which benefits you would claim, how and whether that would cover the costs of your living (including emergencies such as a car or washing machine break down).

As this activity is based on your own thoughts, no outline answer is given at the end of this chapter.

The Vimes 'boots' index

An author once had a character express frustration at economic imbalances:

The reason that the rich were so rich, Vimes reasoned, was because they managed to spend less money.

Take boots, for example. He earned thirty-eight dollars a month plus allowances. A really good pair of leather boots cost fifty dollars. But an affordable pair of boots, which were sort of OK for a season or two and then leaked like hell when the cardboard gave out, cost about ten dollars. [...] But the thing was that good boots lasted for years and years. A man who could afford fifty dollars had a pair of boots that'd still be keeping his feet dry in ten years' time, while the poor man who could only afford cheap boots would have spent a hundred dollars on boots in the same time and would still have wet feet.

This was the Captain Samuel Vimes 'Boots' theory of socioeconomic unfairness.

(Pratchett, 2013, p. 35)

Jack Monroe used this to illustrate her discussion on the consumer price index (which includes the price of champagne), highlighting the change in the poorest end of the market compared to the more expensive end. That is a poverty price tag, and when we bring it back to our people living with complex needs we investigate the disability price tag.

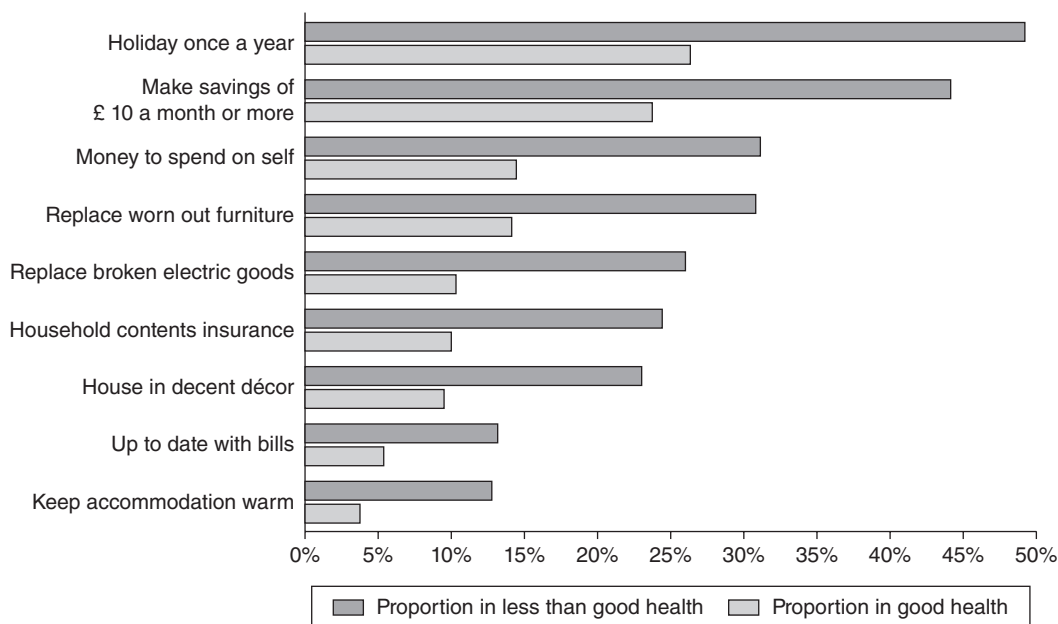


Figure 3.1 Material deprivation (The King's Fund, 2021)

The disability price tag

Living with disability costs more, increasing inequality; the disability price tag *is the additional monthly income a disabled person would need in order to enjoy the same standard of living as a non-disabled person* (Scope, 2019). This is around £583 a month, rising to more than £1000 for one in five. One in four families face that extra £1000 a month. If you look at Figure 3.1 you can see that the longer lines (those in less than good health) are less likely to be able to afford different items or services.

The term used by The King's Fund is 'material deprivation', which means when someone cannot afford necessities (The King's Fund, 2021). Look at the bottom of Figure 3.1; 13 per cent of people in the study were not able to afford to keep their home warm, three times higher than those in good health, before the cost-of-living crisis.

Activity 3.3 Reflection

The inability to pay for basic needs to be met, such as utility bills, is a massive barrier to health and well-being. A person living with a respiratory condition may risk worsening of their condition, leading to infection and admission, should their home be insufficiently heated. A person with poor mobility may fall and remain on the floor for a long period of time, risking pneumonia.

Building on Activity 3.2, reflect on the outcome of that if you were living with a complex need.

As this activity is based on your own thoughts, no outline answer is given at the end of this chapter.

In the most deprived of Scotland's population, life expectancies are thirteen years shorter for men and nine years for women compared to the most affluent areas. Other literature supports this finding that deprived people spend more time in poor health before death than the higher areas of affluence (Barnett et al., 2012; Scottish Government, 2020). Multi-morbidity is strongly linked to socioeconomic deprivation (Joseph Rowntree Foundation, 2015); the poorer you are, the more likely you are to be dealing with the issues we have discussed, struggling to pay bills and keep houses warm.

The impact this has on families who have children with complex needs is demonstrated well by Woodgate et al. (2015) (see Chapter 10). You can see that holidays, social life, work and couples time all become less likely. This study did not only include socio-economic factors in the cause of these differences, but the link is two-way – it is more expensive to have complexity in your life and you are less likely to be able to work. This may mean that the parents need to consider the work they can do, such as Rosemary and her son Harry.

Activity 3.4 Critical thinking

Rosemary and Harry

You previously met Rosemary and Harry, a young boy with haemophilia. One of the primary risks for people with haemophilia is that of a bleed. This varies in significance – a bleed into a joint is exceptionally painful, whereas a bleed into the skull may be fatal. As a family, they decided that Harry would not be restricted in his activities by his condition, and he takes part in martial arts and other exercise activities.

If a bleed occurs, it is vital to take him to the specialist treatment centre an hour away as soon as possible; this may happen regularly. Rosemary and her husband must have a plan for one of them to leave and take him to the hospital at a moment's notice.

What impact might this have on Rosemary's employment? What contingency planning may they have to do for both parents to work?

A brief outline is provided at the end of the chapter.

Having an employer who is tolerant of their employees leaving their workplace abruptly like that on a regular basis is unlikely. Although the law says that employers should do all they can do to support someone to get back to work, it informs them that they can fire someone if they cannot do their job because there are no reasonable adjustments (UK Government, n.d.). Although Rosemary is lucky in that she is educated, in a profession that allows the flexibility and employed by an organisation that can adapt should she need to leave, many are not.

Impact

Now we know that people living in deprivation are more likely to have complexity, people with poor health are less likely to be able to cover essentials such as heating and bills and this extends to parenting a child with complex needs.

Broadening the view again, let's look at the impact of this in relation to things such as hospital admissions; people with lower incomes are more likely to be readmitted to hospital within the next year, and length of stay and chances of dying are higher than those with better incomes (Schjødt et al., 2019). This was in a similar system to the UK (the person getting the prescription must pay a fee); people with lower incomes were less likely to get their prescriptions filled.

Although this information relates to all long-term conditions, it impacts those living with complex conditions; the mismatch between the way our society operates and their needs becomes set in stark relief here, where basic needs such as food, housing, etc. are not available without great stress. We are frequently told that long-term conditions are a 'tsunami', worsened by the impact of the pandemic, structural racism and

determinants of health (Califf, 2021). The upstream decisions made by those in the room when policies are formed impact every aspect of life.

Cost to the NHS or social care of an individual with multi-morbidity, which many people living with complexity experience, is no different to having two people, with one condition. In fact, Adomako-Mensah et al. (2020) found that there is a reduction in cost. They suggest that this may be because the person can be seen in a single appointment, reducing costs compared to two people having two appointments. Another possibility is that care is overlapping or inadequate; the lack of joined up care between mental and physical health is a major issue for people living with complexity – they often experience both, with the likelihood of mental health problems rising the more physical health issues a person has (Barnett et al., 2012), and we think this is likely to be true for the reverse, since mental health is often linked with a reduction in physical health. This is more likely in deprived areas than in more affluent areas.

Cost-effective systems

So let us look a little into what cost-effective systems mean.

There are different measures: cost analysis, cost utility analysis, cost–benefit analysis and cost-effectiveness analysis. Each compares the benefits of an intervention with the costs, but with different measurements of the outcomes of that. Cost analysis measures costs in money. Cost utility analysis uses health state preference scores such as healthy years or quality-adjusted life years. Cost–benefit analysis uses money vs outcomes. Cost-effectiveness analysis looks at one consequence, and how effective the activity is compared to the alternatives – it may measure years of life gained, quality-adjusted life years, diagnosis made, blood pressure reduction, cholesterol change and so on (Drummond et al., 2015). This can be found in much of the medical literature – that is, randomised controlled trials.

NICE definition of quality-adjusted life year

A measure of the state of health of a person or group in which the benefits, in terms of length of life, are adjusted to reflect the quality of life. One quality-adjusted life year (QALY) is equal to one year of life in perfect health, calculated by estimating the years of life remaining for a patient following a particular treatment or intervention and weighting each year with a quality-of-life score (on a 0 to 1 scale). It is often measured in terms of the person's ability to carry out the activities of daily life, and freedom from pain and mental disturbance (National Institute for Health and Care Excellence, n.d.)

This measure of cost-effectiveness can either be used to inform coverage decisions or ration care (deciding what care is provided or not) but it always is used to influence the choice of activities that make good use of resources. This might be preventative medicine (cervical smears, vaccination programmes or testing); it is commonly used by

NICE, and they have a clear aim to maximise health gain with limited resources (Cylus et al., 2016).

It is common to use bed-days saved within the NHS: how many of these units can be saved by prevention of an admission by a team. It is vital to remember that the outcome we measure becomes the target those within the service will aim for. You can take the four-hour rule from emergency care as an example of this; a more nuanced rule that meets the needs for more urgent conditions such as sepsis may be a more useful active measurement and driver (Campbell et al., 2017).

In comparing healthcare systems, you often see the comparison of how much of the gross domestic product was spent on health compared to how much death rates decreased. Studies have shown that the NHS is a system that has good cost-effectiveness compared to others, such as the US (Pritchard and Wallace, 2011).

Complex care teams and services

Relating that back to our people living with complexity, you can see the drivers for the creation of teams working to support them within the community and preventing unnecessary admissions. The need to access certain skills and for professionals to work through the barriers to integration of health and social care is vital.

Case study: Bettie

The complex care team received a referral for Bettie. She had multiple health conditions including diabetes, cataracts, leg ulcers, thrush and obesity. Bettie was struggling to manage her activities of daily living (ADLs) and was regularly missing medical appointments. Bettie struggled to clean her home, which was becoming very untidy, dirty and had cat faeces and urine on the floor. She spent most of the time in bed in her lounge.

Activity 3.5 Critical thinking

Consider which skills and professionals might be useful to Bettie's case?

A brief outline is provided at the end of the chapter.

Nursing and cost-effectiveness

The NMC has argued that investment in nursing is a path to more cost-effectiveness in our healthcare system (Crisp et al., 2018). Certainly, in preventative medicine with screening and health promotion nursing holds a central role. Crisp and colleagues

speak about universal healthcare and the fact that is vital in helping people to live healthy lives and experience well-being, alongside the benefits to global health security and epidemic preparedness, something we have experienced in the pandemic.

Money is not the sole driver in care, but it can cause considerable harm to both individuals and communities of patients. You can explore many well-known scandals but the Contaminated Blood Scandal or Death by Indifference are good places to start since they demonstrate the role healthcare professionals can play in this harm, for good or bad (Haemophilia Society, n.d.; UK Government, 2013; Mencap, 2012).

Case study: Michael

Michael is twenty years old. He has a diagnosis of severe learning disabilities, autism and epilepsy and has two to three tonic-clonic seizures per week. Michael lives in a residential care home with five other people with learning disabilities in a modern housing estate. He attends a day centre in his local area and travels there in a minibus with eleven other 'clients'. He is in a class with ten other pupils with varying levels of learning and physical disability, all of whom use verbal language and communication. One student in the class has short but noisy outbursts at least once a day, occasionally with physical violence directed at other students and staff (staff have relevant training to support with this).

Michael speaks in short sentences, mainly in response to a request or command, and occasionally when he asks for someone or something. He can read and write a few simple words, count to twenty and has some numeracy skills. He recognises money and knows that notes (£5, £10, etc.) are 'bigger' than coins, but struggles with recognising correct change. Michael chooses his own clothes, but they are often considered 'too old' and formal for him. He buys them with the support of his key worker, Freda, who is 58 years old and has known him since he was a baby.

Michael speaks very loudly, appearing to derive pleasure from the sensation. Michael will jump and spin around, and flaps his hands, sometimes letting out a high-pitched cry, which he seems to enjoy the sensation of. Michael likes to sit on swings in a playground, appearing to enjoy the sensory experience. Occasionally, Michael's behaviour can escalate into an outburst including screaming and breaking things, but he has never been violent towards others. Staff have training to support him at these times.

Michael's behaviours are more likely to escalate if he is tired (sometimes he does not sleep at night), and either just before or after an epileptic seizure (unless he sleeps after it). Michael likes to spend time on his own and can withdraw from group activities in the day centre. He likes to keep things organised and tidy, and his clothes and possessions are neatly categorised and kept in their place.

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Michael takes time to get used to new, busy, bustling and noisy environments, or other people who are noisy and rushing around, but can do so with support and time. Michael does not like to be touched very much, although he will accept a firm hand on his arm or elbow to guide him somewhere if he knows and trusts the person. Michael likes Kylie Minogue videos and music, and he loves Harry Potter, including looking at books and magazines, and on film. Michael responds well to routine and structure, liking familiar activities and people.

Michael has limited contact with his family (occasional visits from a brother), but he does have some people who are important in his life and that he responds to positively:

- Freda, his key worker;
- Kevin, a community Learning Disabilities Nurse, who has known him for a long time and sees Michael three or four times a year for updates, reviews and general contact;
- Bob, who was a key worker for Michael when he was young and first came into services in short-term (respite) care and as a young man in residential services. Bob has stayed in contact with Michael over the years and visits to take him out about once a month. He attends review meetings and acts as an official advocate for Michael in meetings. Michael loves Bob and is at his most relaxed, friendly and communicative when he is with Bob.

Activity 3.6 Decision-making

Working with people with complex needs means that we should make reasonable adjustments to adapt our methods of delivering healthcare to their individual requirements. Consider Michael's case study, and reflect on the adjustments you might have to make in your treatment with them? How would you know they needed them?

A brief outline answer is given at the end of the chapter.

Countering health disparities

Within our healthcare system, despite it being universal healthcare, free at the point of contact, there remain inequalities and disparities. We can see this in problems that are not addressed in national policies; Salway et al. (2020) highlight the risk of hepatitis B in people who migrated from East Asia, or safeguarding legislation in female genital mutilation, which has increased negative stereotyping of the Somali community in some regions of the UK. Even basics such as oral health can be an area where health disparities can be found; people with learning disabilities have a higher prevalence of oral health issues (Wilson et al., 2019). Throughout the healthcare system,

examples of inequalities can be found. Remember the inequalities and disability price tag for people who live with complexity and that they are more likely to experience deprivation already.

As nurses, we need to be aware of the impact of this on our patients; in complexity, people are more likely to be affected by these issues. McFarland and MacDonald (2019) put this firmly in the realm of nursing responsibilities – providing health education, promoting health and recovery, and supporting health protection. We work on the front line in every aspect of healthcare, providing holistic care in almost every circumstance a human may find themselves in, from before birth to death. Working in this role with people living with complexity in their lives requires us to work as part of a team to tackle that disparity and inequality on an individual and population level. Being aware of the resources available to our patients and advocating for further support for them are key aspects for us as nurses. We must balance this advocacy for our patients in our area with an awareness of the impact of unequal and inaccessible services when compared across the UK. We can advocate for policy change, taking leadership roles from politics to roles within organisations such as NHS England, Public Health England and the World Health Organization.

Chapter summary

Let us think back to Bettie and Rosemary; consider how socioeconomics impact their lives. Bettie's fight with the benefit system was a challenge she chose to share with us all. Rosemary, whose son accesses a specialist unit, is lucky enough to have a job that can be flexible for when she must take him there for his routine emergency care.

On every level in the lives of people with complexity, socioeconomics plays a part, one that cannot be overlooked and should be addressed by nurses who care for them.

Activities: brief outline answers

Activity 3.4 Critical thinking (page 42)

Rosemary and Harry

Rosemary was lucky that she had an employer who could, most of the time, manage her need to leave abruptly. In certain professions this is possible but in many it is not. In shift work, for example, leaving frequently without warning may have a catastrophic impact on employment.

Her husband adapted his working hours, so he was able to do the same on certain days of the week. She enrolled her family in the plan, arranging for car seats to be in three family member's cars so that any one of them was prepared to take him to the specialist centre. This did happen several times.

Because Harry is not an only child, this departure for the specialist centre required someone to be available to care for his sibling, who may need picking up from school.

Activity 3.5 Critical thinking (page 44)

The ability of the full extended MDT team to make the connection and support her in making choices around her needs and engagement with the team is vital. They would be able to assess all health and social needs, and act as a multidisciplinary team. By design, they work across organisational boundaries. With the issues she has, she could have ended up being admitted to a hospital or to a care home. Bettie herself was clear that she wished to remain in her home, and several actions were taken to ensure that was the case.

Adaptions within her house allowed her to manage with a small care package that the team arranged. In addition, the team prioritised her wish to communicate with her family more easily, obtaining a laptop through a grant and arranging lessons for her to learn how to use it.

Activity 3.6 Decision-making (page 46)

Potential adjustments for Michael in healthcare interactions:

- extra time for appointments;
- appointments at quiet times;
- pre-appointment visits to services to get used to the environment and people;
- consistent/repeated staff;
- appointments at home if possible;
- visual aids, such as ‘objects of reference’, pictures, ‘social stories’ (see Chapter 9);
- include a sensory experience that calms Michael and may help him engage in a consultation or conversation such as swinging, or accepting that he may make high-pitched sounds to calm himself;
- include a consistent, familiar member of Michael’s support team in appointment to help him manage it;
- awareness training for your staff about autism, complex and challenging behaviours and learning disabilities.

How do you know you need to make these adjustments?

We suggest:

- thorough and individualised assessment processes to understand and meet Michael’s needs;
- multidisciplinary team working to obtain full information from a range of professionals who know Michael well;
- involving Michael’s family and other carers in discussions and care planning to ensure a fully rounded picture of him;
- developing a strong, positive values base towards people with learning disabilities and autism, and promoting inclusion and individualised care will ensure this becomes embedded in your care practice.

Annotated further reading

Day, W. and Shaw, R. (2020) When benefit eligibility and patient-led care intersect. Living in the UK with chronic illness: experiences of the work capability assessment. *Journal of Health Psychology*, 135910532095347.

This study demonstrated that capturing the experience of people in situations like this is vital to understanding what is happening.

Crisp, N., Brownie, S. and Refsum, C. (2018) Nursing and midwifery: the key to the rapid and cost-effective expansion of high quality universal healthcare. *Doha, Qatar, World Innovation Summit for Health*, 1–39.

This report gives a thoughtful view from nursing and is worth a full read.

Useful websites

<https://www.kingsfund.org.uk/publications/what-are-health-inequalities>

This site provides a thoughtful view on health inequalities, among other issues. They tend to be evidence-based and balanced in their approach.

<https://www.countyhealthrankings.org/explore-health-rankings/measures-data-sources/county-health-rankings-model/health-factors/social-and-economic-factors>

This page allows you to explore the issues in more depth, providing information from the world.