CASE STUDY

Access to mainstream health services: a case study of the difficulties faced by a child with learning disabilities

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Accessible summary

• People with learning disabilities need to visit the doctor like everyone else, but this is sometimes difficult.
• This paper is about a boy who needed to have a blood test.
• It took seven appointments and 15 weeks to take a blood sample.
• This paper talks about ways that medical services could get better and change to help people with learning disabilities visit the doctor.

Summary

People with learning disabilities have higher levels of health needs compared with the general population (Nocon, 2006, Background evidence for the DRC’s formal investigation into health inequalities experienced by people with learning disabilities or mental health problems. London and Manchester, Disability Rights Commission). Research has shown that these individuals receive less effective health care (Michael, 2008, Tizard Learn Disabil Rev, 13: 28) and has explored the challenges and barriers in accessing health services (Jackson Brown & Guvenir, 2009, Br J Learn Disabil, 37: 110). This case study describes the experience of a child with a severe learning disability and his family accessing mainstream health care for a simple medical procedure. Implications for how healthcare services can be organised to meet the needs of learning disabled people are discussed, addressing issues such as physical environment of surgeries and hospitals, communication between staff teams, staff skills and lack of preparedness.

Keywords Health, learning disabilities

Introduction

Children with learning disabilities have higher levels of health needs than the general population (Gurney et al. 2006; Nocon 2006), and this high level of need extends into adulthood (Barr et al. 1999).

Many people with learning disabilities have unidentified health needs. Barr et al. (1999) investigated the level of unidentified health needs within the learning disabled population by conducting health screening checks for 373 people with learning disabilities in Northern Ireland. It was concluded that many people with learning disabilities
have unmet health needs and that health screenings could lead to improved quality of life for numerous individuals. It was also noted that interdisciplinary team work was essential for this to be implemented.

A report published by MENCAP (2007), ‘Death by Indifference’, described case studies of six people with learning disabilities who died prematurely following poor health care owing to their learning disability. In 2008, the Department of Health report ‘Health care for all’ (Michael 2008) concluded that although learning disabled people have greater than average health needs, they often find it difficult to access appropriate services compared with the mainstream population. However, Dovey & Webb (2000) found that a random sample of 250 GPs in the south of the UK recognised their responsibility to their patients with learning disabilities. A common theme was that despite this sense of responsibility, a GP surgery setting may not be ideal for people with learning disabilities, in part because of unsuitable practice routines and a lack of explicit training for GPs. Indeed, mainstream healthcare services may not always be able to support people with learning disabilities effectively. A recent survey found that 46% of medics believe individuals with learning disabilities received ‘worse’ health care than the rest of the population (MENCAP 2010).

A number of studies have explored the risk factors for poor health care for people with learning disabilities. Emerson et al. (2007) investigated the health of British children and adolescents with and without learning disabilities. They found that socioeconomic status was a significant risk factor for poorer health in the children with learning disabilities. Emerson (2011) identified that people with learning disabilities who do not access learning disability services are at greater risk. For instance, they were more likely to smoke and less likely to gain health promotion advice.

Qualitative research has identified some of the challenges faced by learning disabled children when accessing health care services (e.g. Wharton et al. 2004). Jackson Brown & Guvenir (2009) conducted interviews with children with learning disabilities, their parents and also staff at the hospital they attended. The issues identified in this study included child, carer and staff anxiety, a lack of preparedness for a child’s admission to hospital, necessity of carer’s presence during medical care, inappropriate ward environments and difficulties managing children’s behaviour.

In spite of the growing awareness of the healthcare needs of people with learning disabilities, the challenges faced by these individuals remain significant. This paper describes the experiences of Yusuf and his family as they attempted to access mainstream health services.

**Background**

Yusuf, a 9-year-old boy with severe learning disabilities, an autistic spectrum disorder and challenging behaviour, lives at home with his family. During the course of a routine health examination, one of Yusuf’s primary carers was diagnosed with Hepatitis B. Yusuf requires a high level of support and personal care. His challenging behaviour (i.e. scratching and biting) often results in cuts and broken skin for himself and those supporting him. This presented a clear health risk to himself and his support staff and as a consequence Yusuf’s mother wanted a blood test for Yusuf to check for Hepatitis B.

The authors were part of Positive Behaviour Support Service supporting Yusuf at school. The events described below were written based on our direct observations and verbal reports from Yusuf’s mother at the time. The staff team kept a diary of details recorded within a day of our experiences and conversations with Yusuf’s mother, which were used to write this paper. We began by recording this as part of our routine data collection, but when our involvement became necessary by the second appointment, we recorded information with a view to writing this case study.

**Appointment 1: Week 1**

Yusuf’s mother arranged an appointment with her GP practice. During the appointment, Yusuf became distressed as the GP attempted to take blood and the procedure was not completed. A second appointment was booked with a nurse for the next week in the same GP practice. It was agreed that two of Yusuf’s school-based assistant psychology support team would attend the next appointment to help with the process.

**Appointment 2: Week 2**

The psychology support team contacted the GP practice and arranged to talk to the nurse before the appointment to discuss Yusuf’s needs with regard to the procedure. They were told to arrive 15 min before the appointment to go over the issues with the nurse. At this meeting, they were informed that the only medical staff present would be a single nurse who had never previously met Yusuf. The nurse added that she was not going to try to take a blood sample, but rather planned to give his mother a home blood testing kit.

As Yusuf had taken time off school to come to the appointment, the support team requested the nurse to make a second attempt at taking blood with the support of the psychology team. It was made clear that there would be no attempt to restrain Yusuf, but rather to communicate with him and use techniques known to calm him during the procedure. The attempt would be terminated if Yusuf’s level of distress or people’s safety became a concern.

Although it had been made clear during the original discussion with the GP practice staff that Yusuf would
find it difficult to wait for the appointment, he had to wait in the busy waiting room for 20 min. During this period, it was noted that Yusuf was clearly upset by the unfamiliar setting and noise level.

When Yusuf was called into the practice room he became distressed and escalated, repeatedly pushing staff away and running into an adjacent practice room with a number of dangerous items out on the surfaces, such as wrapped needle sharps. At this point, the appointment was terminated, and the nurse once again suggested the home testing kit. Although Yusuf’s mother was anxious about this plan, the nurse was persistent with her recommendation. The assistant psychology team added their support to Yusuf’s mother’s position, and the nurse proposed an appointment at the local Children’s Hospital where it was hoped more support would be available than at the GP practice.

Appointment 3: Week 3

The psychology team arrived early for the hospital appointment and were reassured that the medical team had plenty of time to discuss Yusuf’s needs. The phlebotomy nursing team were confident that they would be able to take the decision about when and whether the procedure should be terminated. There was no delay being seen, and Yusuf waited for <2 min before he was taken into the practice room.

Unfortunately, the team were still unable to take blood as Yusuf once again became distressed. At this point, the nursing team decided that a re-referral should be made back to his GP practice where his GP could prescribe sedatives. Yusuf could then be referred back to the hospital where he could have another appointment under sedation. Yusuf’s mother was disappointed with this outcome and frustrated at the number of appointments it required to take Yusuf’s blood.

Appointment 4 and 5: Weeks 8 and 9

As agreed with the medical team at the Children’s Hospital, Yusuf’s mother attended the GP practice to pick up sedatives and arrange another referral to the Children’s Hospital. The first time she arrived, the GP did not know about Children’s Hospital plan and requested she return at a later date after the GP had been able to confirm the arrangements. This was completed a week later.

Appointment 6: Week 12

Yusuf’s mother arrived at the Children’s Hospital, having given Yusuf a sedative an hour earlier. Unfortunately, rather than becoming calmer, Yusuf became hyperactive, escalated and aggressive, culminating in his pushing his mother down some stairs. Once again, blood could not be taken. The medical staff said Yusuf would need a ‘specialist’ anaesthetist, and this should be arranged via the GP.

Yusuf’s mother was upset at this point and said ‘I can’t do it’. Although she was concerned for Yusuf’s and the staff team’s health, at this point she could not cope with the process any longer and wanted to stop trying to obtain a blood sample.

After discussion with Yusuf’s mother and the school support team, it was decided to ask for the involvement of the Patient Advice and Liaison Service (PALS). In addition, a letter was sent to the GP by the supervising clinical psychologist describing the past events and asking for GP to liaise with the Children’s Hospital regarding the organisation of a ‘specialist’ anaesthetist. PALS were helpful, replying quickly and contacting the anaesthetic department to follow-up the case. Five weeks later, a response from the GP was received stating they had liaised with the hospital paediatric team and had organised for a stronger sedative to be administered. In addition, a medic would be present for the duration of the next appointment.

Appointment 7: Week 15

Yusuf’s mother was anxious about refusing Yusuf food for the 4 h from waking at 6 am and his appointment at 10 am. However, in the event, he was calm and the appointment went smoothly. Yusuf remained unconscious for the duration, and there was a doctor present during the entire time to ensure the procedure went to plan. The results came back 1 week later and were negative.

The key issues

Although testing for Hepatitis B is a relatively straightforward healthcare procedure, it took more than 15 weeks and seven appointments for a blood sample to be taken from Yusuf. The experience of Yusuf and his carers demonstrates a number of issues that have previously been identified for learning disabled people accessing healthcare services (Jackson Brown & Guvenir 2009; Wharton et al. 2004).

Communication

Improved communication between different staff teams and healthcare services would much increase efficiency when treating children with learning disabilities. In the case described here, had the information about the challenges experienced in the GP surgery been successfully passed on to the hospital, the hospital could have been better prepared. This would have resulted in fewer appointments and a more positive experience for Yusuf.
Staff skills
At times, the healthcare staff involved with Yusuf were not able to respond to Yusuf's needs or challenging behaviour. Yusuf required his mother and support staff from school to access the healthcare system as the GP practice staff and hospital teams did not feel confident in managing his behaviour. A positive step in adult’s learning disability services is the employment of specialist community learning disability nurses who can provide support to people with learning disabilities throughout medical procedures (e.g. Mobbs et al. 2002).

Preparedness
Better communication allowed healthcare systems to prepare for an appointment with Yusuf, and Yusuf to be seen in the most suitable environment for his needs. For example, the appointment system at the GP surgery meant that Yusuf had to wait for both appointments, which he found difficult. However, when Yusuf was referred to the Children’s Hospital, the GP surgery informed hospital staff about his needs and they were able to change their usual appointment structure so that he did not have to wait in the busy waiting area. As a consequence, he was more settled prior to the appointment.

Physical space
The waiting and practice rooms were not always suitable for Yusuf, to the point where they posed a serious health and safety risk. This could have been improved by removing unsafe materials or finding a more appropriate room to use. Again, the referral to the Children’s Hospital improved this issue as the space there was much more suitable for Yusuf's needs.

Costs
Completing this procedure led to considerable financial costs. The first appointment involved one GP, the second appointment one nurse and two assistant psychologists, and the third appointment involved three nurses and two assistant psychologists, the fourth and fifth appointment one GP, the sixth appointment three nurses, and the seventh appointment a team of both nurses and a doctor. In addition, the procedure required staff supervision and letter correspondence from a clinical psychologist and the involvement of PALS.

English as a second language
Yusuf’s mother speaks English as a second language and while her communication skills are proficient, there were times when she was clearly confused by the events. For example, at one point she thought the GP nurse was asking her to take blood intravenously from Yusuf herself. She was bewildered and upset that she would be asked to do this. In fact, the GP nurse had asked her to collect a needle prick blood sample. Later, the hospital staff told her that it was not possible to test for Hepatitis B by this method, which again left her feeling confused and uncertain.

The future
Yusuf continues to have healthcare needs, but his mother feels less confident about meeting them. At the time of writing, Yusuf had a decaying tooth and while his mother wanted to have it treated, she was reluctant to begin the process as it had been so difficult to obtain a blood test for him. Yusuf’s mother’s hesitation about finding dentist is likely to have significant implications for his health and future physical well-being.

Summary
This case study provides an example of some of the difficulties facing children with learning disabilities gaining access to health care. For Yusuf’s mother, there was a sense that the GP and hospital staff looked to move the ‘problem’ on by referring Yusuf to another professional or healthcare system without taking full responsibility for communicating what his needs were. She was left feeling confused about what to do and anxious about her son’s health. However, with a little communication and planning, much of what she and Yusuf experienced was avoidable.

The events detailed in this study are consistent with the findings of previous research in this area (e.g. Michael 2008). While not complete, the current research literature provides a good starting point for how healthcare services should be organised to meet the needs of people with learning disabilities. Yet in spite of this, some of the most basic factors, such as good communication, are still not taking place. The challenge is how what is already known can be implemented to help people with learning disabilities access healthcare systems. This is essentially about organisational culture and attitudes towards learning disabled people.

While it is accepted that healthcare systems are complex and busy environments, more priority needs to be given to the needs of people with learning disabilities to enable them to access the care they need. There is no single process or system that will work for everyone. Rather professionals need to ensure they consider the individuals needs and adapt existing systems to meet them. In particular, professionals need to take time to plan and prepare how to do this.
References


