

4.2 LEWIS FAMILY CASE STUDY 1: NEURODIVERSITY

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Introduction to case study



Learning Objectives

By the end of this case study you should be able to:

- Articulate what resources are available to support individuals with autism spectrum disorder (ASD) and their families.
- Discuss ways in which nursing practice may need to change to accommodate people with a different style of thinking.
- Define the different style of thinking someone with ASD has compared with someone without ASD.
- Discuss which health professionals may contribute to caring for someone with ASD and how the interprofessional team can collaborate to promote person-centred care and positive outcomes.

Scenario

Sally worries that Luke is lonely without any friends. He was the only child not invited to a birthday party last weekend. Luke's pre-school teachers have discussed with Nigel and Sally how he struggles to build social relationships with his peers. Last week, Luke was playing on the mat with his cars, lining them up in 'car parks' according to their colour. One of the other children (Theo) sat next to Luke and picked up one of the cars and 'parked' it in another area. Luke said "No" and put the car back in its spot. Theo moved it again and Luke got increasingly agitated and upset, pushing Theo away. The teacher came over and suggested Theo play with the diggers in another area. Theo moved away, upset he could not join in Luke's game. Luke continued to place his cars in the coloured car parks, ensuring all of the wheels were aligned. Luke's teacher talked calmly to Luke to explain that Theo wanted to play with him and was now feeling sad. All the time, Luke continued with his cars, not looking at his teacher and not acknowledging Theo or that he was upset.

Sally has bought Luke a Spiderman costume as a surprise for the upcoming book week. On the morning of the parade, Sally surprises Luke with his costume. Luke refuses to wear it saying, "I am Luke, I am not Spiderman". As Luke becomes increasingly upset, Sally puts the costume in his bag, drops him at day-care, telling the teachers where his costume is. When all of the other children are changing into their costumes, ready to go to the 'big school' for the parade, Luke again refuses to dress up, despite the excitement from his peers at being a policeman, a fireman or a nurse. While his teachers try to encourage him, Luke chooses to sit in the corner of the room with his cars. He does not want to leave the pre-school room to go to the parade.

Luke is due to start at the primary school where his sister Ella goes in 5 months' time. Sally is worried how Luke will cope at school. When she tries discussing with Nigel how to plan to help Luke before he starts, Nigel does not feel this is necessary, saying 'he'll be fine once he starts school with all the other kids.'



Case study questions

1. Following Luke's diagnosis of autism spectrum disorder (ASD), how might different members of the interprofessional team work with him and his family to support him?
2. Nigel is struggling with his relationship with Luke following his diagnosis of ASD. Why do you think this may be?
3. In what ways could Nigel and Luke work towards improving their relationship?
4. Drawing on the information in the scenario, how is Luke's style of thinking different from that of a child without ASD?
5. As a nurse, how may your practice need to change to ensure person-centred care if you were looking after Luke in a healthcare setting?

Key information and links to other resources



Australian organisations that support Autism Spectrum

Disorder

The following websites have some excellent resources, including a number of videos and patient stories that you might find valuable to explore:

- [Autism Spectrum Australia](#)
- [Autism Awareness Australia](#)



Reasonable adjustments for people with Autism

Spectrum Disorder

Healthcare systems pose a number of challenges for people with ASD. Some of these challenges are based within systems or organisational structures, while others are created through healthcare professionals' lack of understanding about how to provide person-centred care to someone with ASD (Maloney et al., 2021). This gap in health care provision and the problem of how to address the needs of patients with ASD is significant in the light of increased mortality and morbidity amongst those with ASD (Wilson et al.,

2021; Croen et al., 2015). As healthcare practitioners, we have a responsibility to ensure we understand what reasonable adjustments we can make to assist people with ASD access and use healthcare effectively. Reasonable adjustments are positive measures that can be implemented at a variety of levels within an organisation to ensure equity in healthcare (Maloney et al., 2021).



Thinking points

Read the following paper by Wilson et al., (2022) and reflect on the questions that follow:

- Wilson, N. J., Pracilio, A., Kersten, M., Morphet, J., Buckely, T., Trollor, J. N., Griffin, K., & Cashin, A. (2021). Registered nurses' awareness and implementation of reasonable adjustments for people with intellectual disability and/or autism. *Journal of Advanced Nursing*, 78(8), 2426-2435. <https://doi.org/10.1111/jan.15171>

Questions:

1. Why is it important to adjust our care for patients who have a diverse thinking and information processing style, such as ASD?
2. In what ways, if any, have you applied reasonable adjustments in your practice when you have cared for someone with ASD?
3. What changes would you now make to your practice following reading the article by Wilson et al., (2022)?



Addressing the needs of the whole family

The number of people (children and adults) being diagnosed with ASD is increasing globally (AIHW, 2017, Mullen et al., 2021). In 2015, an estimated 164,000 people had an autism diagnosis in Australia, equating to approximately one in every 150 people (Australian Bureau of Statistics [ABS], 2016). This is up from an estimated 64,400 people in 2009. While it is not clear why prevalence rates are increasing, more acceptance,

awareness and better diagnostic services could contribute to this acceleration (Nyrenius et al., 2022; Davidovitch et al., 2021).

Research shows that having a child with ASD leads to increased stress on families and a poorer quality of life (Bonis, 2016; Vasilopoulou & Nisbet, 2016). The relationships between siblings can also be affected (Coffman et al., 2021; Perlman & Howe, 2023). Despite significant impacts on the entire family, interventions and treatments still focus predominantly on the needs of the child with ASD rather than on the family as a whole. Research also shows that intervention programs with the whole family unit can improve the child's personal care, adaptation to change and decrease anger and meltdowns (Mullen et al., 2021). Parents also report being less stressed, experiencing an improvement in mood, developing an increased confidence and ability to manage their child and having less parental conflict and greater relationship happiness (Mullen et al., 2021; Manohar et al., 2019; Tellegan & Sanders, 2014).



Thinking point

If you were to design a support program for the Lewis family, what would you want to achieve and what would you include in your program? Read one or 2 of the following papers to learn more about some of the intervention programs that have taken place globally. Consider which strategies have worked well, which have limitations, and why this may be.

- Mullen, A., Boyd, K., & McConkey, R. (2021). The impact of a brief home-based intervention on families with a child with Autism Spectrum Disorder. *Journal of Developmental and Physical Disabilities*, 33, 693-708. <https://doi.org/10.1007/s10882-020-09768-4>
- Manohar, H., Kandasamy, P., Chandrasekaran, V., & Rajkumar, R.P. (2019). Brief parent-mediated intervention for children with Autism Spectrum Disorder: A feasibility study from South India. *Journal of Autism and Developmental Disorders*, 49, 3146-3158. <https://doi.org/10.1007/s10803-019-04032-x>
- Tellegen, C. L., & Sanders, M. R. (2014). A randomized controlled trial evaluating a brief parenting program with children with Autism Spectrum Disorders. *Journal of*



Case study 1 summary

This case study has provided you with the opportunity to consider diverse thinking and information processing styles for people with ASD. You have reflected on changes you may need to make to the care you provide to ensure you embed reasonable adjustments and carry out person-centred care when nursing someone who has ASD. You have had the opportunity to consider the needs of the family and family relationships when one (or more) family members have ASD.

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