

Building health system capacity to support people living with intellectual disability

Key messages

- People living with intellectual disability have diverse and complex needs and can require different healthcare services than the general population.
- Health systems need to be responsive to these complex needs. However, there is very little high-quality research about how to build capacity in the system and in individuals to achieve this.
- Available research suggests that a systems approach to capacity building should consider organisational structures, roles, communication and the healthcare environment to improve access, use, quality and safety of services.
- Broad areas for consideration include:
 - Map patient journeys of people with intellectual disability to develop a more detailed understanding of the differences within, as well as across, this population group
 - Respond to the attitudes and capabilities of clinicians to improve their knowledge, skills and confidence. This may include increasing opportunities for clinicians to interact with people with intellectual disability, ensuring they are aware of the specialist and support services available and promoting familiarity with issues faced by people with intellectual disability
 - Create liaison roles to support patients to navigate complex healthcare systems and to support, upskill and interact with mainstream providers
 - Include people with intellectual disability and their carers in research, policy, service design and evaluation
 - Develop strategies to assess the quality and safety of healthcare delivered to people with intellectual disability.



Issue?

How can we build capacity to improve healthcare for people with intellectual disability?



What did we do?

We examined and synthesised the published and grey literature



What did we find?

Approaches should focus on creating environments that bring clinicians and patients together

What is the issue and why is it important?

There is abundant evidence that people living with intellectual disability have higher health risks and receive lower quality care.¹ They are more likely to have multiple health conditions, health issues that have not been identified or addressed, and to die earlier than the general population.^{1,2} Provision of care is complex and the health system has not yet adequately met the needs of this population group.

Capacity building, defined as “interventions which have made ongoing sustainable changes to an organisation’s ability to address health issues by creating new structures, approaches and/or values”,³ has been identified as an important component of the public health system response.

What did the researchers do?

The review explored strategies, approaches or interventions used to build health system capacity to improve healthcare delivery to people living with intellectual disability. The researchers reviewed the published literature about intellectual disability for references to capacity building, organisational development, policy, or quality improvement. A total of 105 articles were included and analysed to inform the findings.

What did the review find?

- There is very limited evidence about the organisation of healthcare services for people living with intellectual disability.⁴
- The evidence that is available points to several areas where capacity can be developed to better respond to the distinct needs of people living with intellectual disability.
- There is a need to recognise that people living with intellectual disability are a diverse group whose needs vary by age⁵, gender^{6,7}, ethnicity⁸ and condition.^{9,10}
- An important first step involves studying the whole health system, examining touchpoints where interactions occur, and identifying opportunities for improvement.
- Healthcare should be delivered through a mix of generalist and specialist services, with specialist services accessible across the life course, including paediatrics, sexual and reproductive health, mental health and palliative care.
- Little is known about the safety and quality of care for people with intellectual disability in Australia. Systems that capture data on the incidence of adverse events are needed.
- Nursing management support, leadership and direction is essential to the provision of adequate services.¹¹

How can we build capacity across the health system?



Structures

Develop structures, policies and guidelines to ensure people living with intellectual disability receive optimal care, including:

- Creating specific teams to improve access to healthcare¹²
- Adopting intensive case management⁵ and integrated care models¹³
- Establishing mechanisms to reduce delays in service provision.¹⁴

Leadership has a key role to play in supporting these structural responses.¹¹



Roles

Consider using specialist liaison staff, as well as carers and families, to improve healthcare delivery:

- A specialist liaison person can provide direct patient care, support carers, and facilitate information provision to clinicians and other providers^{12, 15-17}
- Carers can foster trusting relationships with healthcare staff¹² and alleviate stress for people living with intellectual disability.¹⁷



Communication and information

Ensure effective communication and information provision by:

- Improving information collection and dissemination¹¹
- Using referral forms and pre-admission assessments to both improve information gathering and prepare patients for the healthcare journey^{15, 18}
- Using communication tools such as books, pictures and symbols.^{12, 18}



Clinical interactions

Empower clinicians to provide optimal care by:

- Reducing anxiety and uncertainty about the needs and experiences of people with intellectual disability¹⁸
- Increasing opportunities for mainstream clinicians to interact with people with intellectual disability and their carers¹⁹
- Improving clarity of roles and responsibilities for service staff¹⁹
- Supporting clinicians to respond to organisational structures and processes for example to make reasonable adjustments.²⁰



Healthcare environments

Redesign healthcare to improve access to and use of services by people living with intellectual disability. This includes:

- Improving physical spaces, e.g. access to facilities including toilets, and layouts that are clear and easy to navigate²¹
- Creating relaxed environments¹⁸ that are appropriately resourced¹¹
- Using appropriate signage.¹⁸



Ethics and research

Include people living with intellectual disability and their carers in research, policy, service design and evaluation.²²

References

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