Care pathways for people with intellectual disability

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Executive summary

Service provision for people with intellectual disability varies widely across the UK. A care-pathway approach, providing an outline of care linked to evidence-based interventions and clear time frames, could reduce unacceptable variations in the quality of care and minimise the risk of the so-called 'postcode lottery'. Although care pathways have been developed and used in mental health services for people with intellectual disability for some time, they seem to vary widely in quality. There is also some confusion about what should be included in a care pathway and how that could be used to improve the quality of care. By reviewing the current evidence available from the literature, as well as through the evaluation of the existing pathways, this report provides good practice guidance for clinicians as well as service providers in the development and implementation of care pathways in the area of intellectual disability.

The Faculty of Psychiatry of Intellectual Disability recommends adopting the standards for the development and implementation of care pathways that are outlined in this report. However, care pathways should always be developed with local needs and resources in mind. They need the active involvement of professionals, patients and carers in their development and implementation. The sustainability of care pathways depends on the translation of care-pathway requirements into service specifications by commissioners and the implementation of a skills-development framework by the provider organisations. In addition, local leadership in change management and the identification of innovative solutions are necessary for maximising the benefits of care pathways.

Introduction

A care pathway describes the steps in the care of patients with a specific condition or need. In the USA, the initial focus of pathways was on improving cost-efficiency, whereas in the UK, care pathways have been used mainly for the implementation of evidence-based practice and improving the quality of care. Ideally, care pathways try to bring together evidence-based best practice and local service provision. The difficulty of achieving this aim has been highlighted in an analysis of the pathways in mental health, which revealed that, while there is abundance of assessments and administration processes in these pathways, there is a paucity of details on interventions (Hall, 2004). That review concluded that further guidance is required to align evidence-based practice with the realities of local service providers.

Map of Medicine is a web platform that can be used to develop care pathways (www.mapofmedicine.com). It provides a standardised visualisation of care pathways and aids sharing of information on care processes. The National Health Service (NHS) Connecting for Health service successfully supported a number of early adopters during the initial implementation of Map of Medicine. The Map is now widely used across the NHS in England.

For people with intellectual disability, where the service provision varies widely across the country, care pathways could provide a model of care with certain basic standards, such as evidence-based assessments and treatments, routine and thorough risk management, and patient and carer involvement in care, while continuing to accommodate local variation in the provision of care. In addition, a 'payment by results' model for services for people with intellectual disability is in development and, to develop valid currencies for this model, service provision will need to be based on care pathways (Bhaumik *et al*, 2009, 2011; Roy & Bhaumik, 2012).

Why should care pathways be developed?

The purpose of care pathways is to ensure we provide the right support for patients, delivered by the right person at the right time and place, and to achieve the best outcome in the most cost-effective manner. By providing an outline of care linked to evidence-based interventions and clear timeframes, care pathways could reduce unacceptable variations in the quality of care and minimise the risk of the so-called 'postcode lottery'. Improving the quality of care, efficiency, patient safety and patient experience are the central principles.

Improving quality

Improving the quality of care can be achieved by integrating evidence-based standards (such as National Institute for Health and Care Excellence (NICE) guidelines) with the regular use of outcome measures and patient and carer satisfaction measures.

Improving efficiency

Through process mapping, pathways provide a framework for all the processes involved in the delivery of care. This will allow the service provider an opportunity to review their processes, minimise duplication and provide effective coordination of care.

Breaking barriers to care

It is well known that patients and carers currently face obstacles to the smooth and timely delivery of care. This is largely because service providers tend to work in isolation. If service providers worked in a coordinated manner using a care pathway, they would be better able to meet patient and carer needs.

Transparency of outcomes

Transparency of outcomes is a key recommendation in the Health and Social Care Act 2012, and could be achieved by including routine recording of outcome measures as part of a pathway framework.

Improving personalisation

Overall, the care-pathway framework should provide a clear direction and supporting tools for professionals to provide personalised care. The personalisation of care can be improved by using the following measures in the care pathway:

- routine recording of the treatment goals and outcomes that the patients/carers want to achieve from the service
- development of a personalised and accessible care plan (e.g. health action plan)
- provision of accessible information to enhance the patient's ability to make decisions regarding his or her care
- routine assessment of patient satisfaction to provide valuable information to inform service improvements.

Care pathways in intellectual disability services: survey

Although some care pathways have been developed in mental health services for people with intellectual disability, there seem to be wide variations in their quality. There is also confusion about what should be in a care pathway and how it could be used to improve the quality of care. To understand the position of services across the country with regard to pathway development and implementation, the Faculty of Psychiatry of Intellectual Disability conducted a survey of all intellectual disability service providers in England.

Only 14 service providers out of over 50 contacted responded to the survey. This low response rate suggests that either many trusts have not yet implemented pathway-based service redesigns, or they are at an early stage of development and hence cannot yet be shared. In addition, there might be an issue of sharing of intellectual property that sometimes might contain commercially sensitive information.

The following clinical conditions/needs had existing care pathways:

- acute care (developed regionally)
- attention–deficit hyperactivity disorder (ADHD)
- anger management
- anxiety
- autism
- bereavement
- challenging behaviour
- dementia
- dysphagia (eating and drinking)
- epilepsy
- forensic/offender pathway/secure unit
- hearing impairment
- in-patient
- low mood
- mental health
- physical disability/posture pathway/complex physical disability
- physical health/well-being
- transition.

The range and usefulness of pathways

Using the information collected through the survey, the working group discussed the range of pathways that currently exist and identified groups that have no dedicated pathways. For example, people with both personality disorder and intellectual disability have unique needs and often make intensive use of resources, but do not seem to have a dedicated pathway of care.

Different approaches have been taken to developing care pathways in the area of the mental health of people with intellectual disability. While some trusts are developing a generic pathway for all patients with mental health problems, others are developing specific pathways for specific conditions. This raises an important question about how best-practice guidelines for specific conditions can be applied in a generic pathway.

As evidence on pathway implementation is currently lacking, it is difficult to comment on the utility of pathway guidance in actual practice. This is an area that needs further research.

The fit of pathways with the payment by results model

The payment by results model for services for people with intellectual disability is in development, so we considered the potential effects of linking pathways to this model. The model does not seem to take a diagnostic approach; instead, it is predominantly needs based. In adult mental health, the payment by results model groups conditions into care clusters. However, as each cluster will involve more than one condition, or one condition might be split over more than one cluster, linking the evidence base and guidance (such as NICE guidelines) could be difficult in this context. Care pathways specific to a diagnosis will often overlap multiple care clusters in the payment by results model.

Qualitative feedback from the analysis of pathways

It is evident that there is wide variation in what are labelled ‘care pathways’. While some pathways provide a clear framework for care, others are more focused on best-practice guidance, which makes them similar to guidelines.

Therefore, it was felt that all care pathways for services for people with intellectual disability should be based on explicit standards that would allow them to be assessed. To develop these standards, we reviewed the existing care-pathway literature for information on quality standards and outcomes, sought expert opinion and had a focused discussion on this theme. The resulting standards are described in the next chapter.

Standards for developing and implementing care pathways

While it is important that care pathways should have minimum standards, the standards should not result in a prescriptive approach being taken. When developing a pathway, it is important to take into account variations in local needs and resources and changing best-practice guidance.

Standards for development and implementation

1. Development of care pathways

The process of developing a care pathway is as important as the final product. Patients and their carers should be involved in pathway development in a meaningful way. Patient involvement in particular should be carefully thought through. The following are two examples of good patient and carer involvement:

- focus groups of patients and carers to discuss what does and does not work well and to identify priorities for service development from their perspective
- considering patient and carer expectations of personalised care and how that could be achieved using pathways during consultation.

2. Multidisciplinary clinical involvement

Pathway development almost always needs to be a multidisciplinary exercise. Unless a pathway is developed with the involvement of all relevant stakeholders, it is unlikely to succeed. In services for people with intellectual disability, the following stakeholders should be involved in pathway development:

- clinical and operational managers
- social services (when the social service team is not part of the multidisciplinary team)
- commissioners
- primary care staff (general practitioners, community nurses, etc.)

- relevant mainstream secondary-care professionals
- voluntary sector organisations.

3. The pathway should illustrate a process of anticipated care

The roles and responsibilities of the professionals should be made explicit. It is possible that the actual roles and responsibilities attached to professional groups might vary in different services. The focus should be on meeting the needs of the individual. Triggers for the involvement of services and teams (e.g. when a specialist behavioural intervention team should become involved) should be listed. There should also be clear timelines (days, hours, stages) for access to these interventions, as well as for completion of assessments and interventions.

4. Stepped-care model should be made explicit

There should be clear definitions of the thresholds for specialist referral or a higher level of intervention, starting from primary care. This will enable the service providers and commissioners to decide together the best deployment of resources to maximise efficiency and health outcomes.

5. Interface issues between service providers should be addressed

Interface issues can arise in relation to degree of intellectual disability (specialist intellectual disability service *v.* adult mental health service), nature of the diagnosed clinical conditions (community intellectual disability service *v.* forensic service) or age (adult intellectual disability service *v.* child and adolescent mental health service). It is important for the relevant service providers to work together in the pathway development and make a patient's transfer between services as seamless as possible. Use of mutually agreed transition protocols, as well as setting up dispute resolution arrangements, would be valuable. A pathway's framework could be used to explore the range of interface issues evident locally and find solutions.

6. The staff skills required should be clearly outlined

Skills should be mapped to stages of the pathway and interventions. Doing this would give service providers a guide for workforce development and commissioners a guide for service specifications.

7. The role of care coordination should be made explicit

Every patient on a pathway should have an identified care coordinator; this role is best taken by the 'best fit professional'. The care coordinator ensures that all interventions are delivered by the appropriate professional in a timely manner (the medical professionals are accountable to the care coordinator in this regard). He or she becomes the face of the organisation for that particular patient.

8. Pathway documentation should be included in clinical records

Key information regarding pathway and episodes of care should be routinely provided in clinical records. Duplication of clinical records should be minimised, if possible through the use of electronic patient record systems.

9. Evidence-based guidelines and practice should be integrated into the pathway

There should be clear evidence that links assessments and interventions to best-practice guidelines, such as NICE guidance or other evidence-based or consensus guidelines.

10. Robust risk assessment throughout the duration of care should be included

Risk assessments should be evidence based and linked to effective management of risk through appropriate care planning.

11. Personalised care plan should be used

Routine use of a personalised care plan with multidisciplinary input should be promoted, using pathways to improve quality of care as well as personalisation.

12. Several types of outcomes should be routinely measured

These are:

- process outcomes (such as waiting time, joint assessment rather than separate assessments)
- clinical outcome measurements aimed at improving clinical efficiency (e.g. depression rating scale, Health of the Nation Outcome Scales)
- Patient-reported outcome measures.

13. The pathway should facilitate the involvement of patients in their own care

This can be achieved by:

- providing patients with accessible information
- agreeing and recording the outcomes that patients/carers want to achieve
- checking the progress towards these outcomes at appropriate stages
- recording satisfaction with the care provided at appropriate stages.

14. Variance tracking should be used to monitor performance

Variation from the pathway guidance (e.g. long waiting times, lack of adherence to evidence-based interventions, non-adherence of professionals to pathway triggers) should be routinely recorded and analysed by the care pathway leads. This could be managed through audit programmes. This ongoing analysis would enable the

service provider to improve their practice where faults are discovered, as well as to change the pathway itself where a real problem with it being applied in practice is identified.

15. Clinical governance framework should cover all aspects of a pathway

Following implementation, there needs to be a clear clinical governance framework for the evaluation and audit of the processes and outcomes related to the pathway. This would need a robust IT system that can record and analyse high-quality data.

16. Local commissioning bodies should be actively involved

Local commissioning bodies should be involved from the beginning of a care pathway's development and this involvement is crucial for successful implementation. Care pathways need to be seen as a blueprint for strategic commissioning. Commissioning the pathway would involve working with service providers on a viable implementation plan using a number of delivery methods such as commissioning intents, service developmental initiatives, commissioning for quality and innovations, and transformational funding.

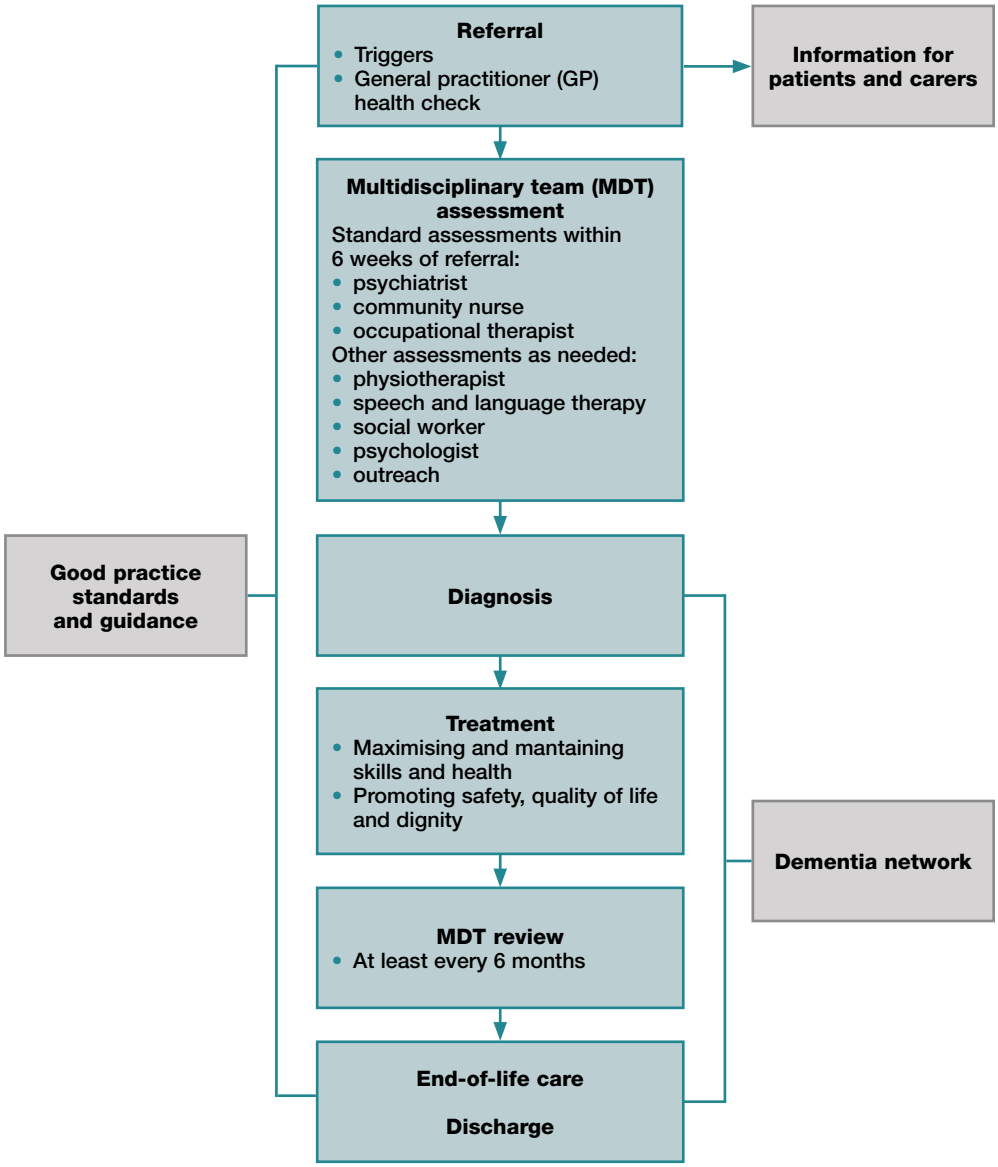
Role of core service pathway

It is clear from the clinician's experience so far in developing and implementing pathways that a stand-alone care pathway – one that does not connect to other pathways or interface with other care providers – is not sustainable. Pathways are better sustained when the entire provision of a service, from receiving a referral to discharge, is structured to facilitate a pathway-based approach. This will become all the more relevant when the payment by results model is implemented.

A proposed solution is to develop a core/service pathway, which might include the following components.

1. Triage-based referral system to ensure referrals are appropriate for the service.
2. A multidisciplinary forum in which a referral could be discussed to identify the best professional(s) for the assessment.
3. Waiting time managed to ensure a first assessment as early as possible.
4. First assessment gathers a core set of information to facilitate identification of the most appropriate pathway(s).
5. A multidisciplinary meeting to discuss and allocate a pathway, nominate the care coordinator and decide professional involvement.
6. Pathway-based specialist assessments/interventions. (This stage is where all condition-specific pathways would be relevant.)
7. Standards for the involvement of patients in care. This might include prompting staff to use accessible information, a personalised care plan and patient-reported outcome measures.
8. Timely and safe discharge.
9. Enable staff to consider measures to prevent deterioration/relapses as well as potential safeguarding issues that are likely to emerge in future and advise the patient, carer and primary care on how best to manage these.

Appendix 1. Example: dementia in intellectual disabilities care pathway



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