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Complex continuing care for people with Intellectual Disability and/or NDD

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What is Rehabilitation?

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"a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment".
(WHO 2021)

Rehabilitation in the context of Mental illness is defined as "A whole systems approach to recovery from mental illness that maximises an individual's quality of life and social inclusion by encouraging their skills, promoting independence and autonomy in order to give them hope for the future and leads to successful community living through appropriate support" *(Killaspy et al 2005)*

The need for rehabilitation services for people with ID is particularly under-recognised and under researched *(Morissey et al 2017)*

Rehabilitation services for people with complex mental health needs

(Joint Commissioning Panel for Mental Health, 2016).

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- People with especially complex mental health needs cannot be adequately managed by general adult mental health services, since their particular needs require specialist assessment and treatment.
- This group often require lengthy admissions and ongoing intensive support from rehabilitation and other mental health services to live in the community successfully after discharge. (Killaspy et al. 2016)
- Despite being a relatively small group, they absorb around 25-50% of the total health and social care budget for people with mental health problems. (Killaspy et al. 2016)
- People with complex mental health needs were eight times more likely to achieve and/or sustain successful community living if they were supported by mental health rehabilitation services as compared to general adult mental health services. (Killaspy & Zis 2013)

Rehabilitation services for people with complex mental health needs (Joint Commissioning Panel for Mental Health, 2016).

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Helping people acquire/regain skills and confidence;

Minimising symptoms and functional impairment;

Promoting individual autonomy and independence;

Promotion of activities of daily living and meaningful occupation;

Screening for physical health problems; Promoting healthy living;

Providing evidence-based interventions to support carers.

Differing Models of Care MH vs ID

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Mainstream MH

Guidance for commissioners of rehabilitation services for people with complex mental health needs

Joint Commissioning Panel for Mental Health Nov 2016

Services that refer to rehabilitation services

- Secure forensic units (regional)
- Psychiatric Intensive Care Units (local)
- Acute mental health inpatient units (local)

Services that provide inpatient mental health rehabilitation services

- Low secure rehabilitation unit (30% local)
- High dependency rehabilitation unit (hospital-based)
- Community-based 'inpatient' rehabilitation unit
- Longer-term high dependency rehabilitation unit (hospital-based)
- Longer-term complex care unit (hospital or community-based)

Specialist ID Rehabilitation

People with learning disability and mental health, behavioural or forensic problems: the role of in-patient services

Royal College of Psychiatrists' Faculty of Psychiatry of Intellectual Disability 2013

Faculty Report FR/ID/03 July 2013

Category 1 - Secure forensic beds

Category 2 – Acute admission beds within specialised learning disability Units

Category 3 – acute admission beds within generic mental health services

Category 4 - Forensic rehabilitation beds

Category 5 - Complex continuing care and rehabilitation beds

Category 6 – Other beds including those for specialist neuropsychiatric conditions

Complex continuing care or Rehabilitation pathway

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- A hospital rehabilitation unit will usually provide part of a pathway from specialist acute and forensic services (including acute and longer-term secure services) to a community residence of some kind or from an unsuccessful community placement to a successful placement

- It is vital that the hospital based model is robustly supported with the development of a community complex continuing care/rehabilitation pathway within the Community teams.

- This would enable consistent, long term, intense supervision and support to service users and care providers

Purpose of the NW/CNE/YH ODNs Complex Continuing Care workstream

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Work together and support development of a robust description of the key functions of "rehabilitation" as part of the whole model of care for people with ID, autism or both

Understand where "rehabilitation" functions could and should be included within broader care models and the development of a range of appropriate support and services nationally

Develop quality standards as well as outcomes framework through co-production

Provide advice to commissioners to develop sustainable and robust care for the future, with greater consistency and improved quality of care across TCPs

Project cover 3 areas/5 work streams

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Literature review and Review existing data

Development of quality standards and Outcomes Framework

Development of commissioning guidelines

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Literature review

Dr. Jonathan Williams

Dr. Saman Shahzad

Prof. Mahesh Odiyoor

Prof. Sujeet Jaydeokar

Dr. Tom Jackson

Aim of the Literature Review

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- Identify the “best” model of care for non- forensic inpatient services for people with LD and/or Autism
- Identify significant contributing factors to successful treatment
- Identify significant contributing characteristics of the inpatient service which support timely and effective discharge
- Identify various models of inpatient support for people with learning disabilities from countries with a similar economic, cultural and demographic (broadly) as the UK with priority being on studies within GB.
- To outline the strengths and weaknesses of available models and the population they were examined on

Aim of the Literature Review

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In addition

- Understand the reason why people with Intellectual disabilities end up in long stay hospitals.
- Any literature on rehabilitation/complex care services for people with Intellectual disabilities, focussing on their demographics, the individual diagnosis, any associated mental health and challenging behaviour issues, model of care and other therapeutic approaches used. We also need
- Any literature on outcome measures,

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Service User Profile

3 main areas of needs

- Forensic – arson, sexual offences, severe harm towards others
- Severe challenging behaviours and significant vulnerability with NDD
- Mental health needs and personality disorders

- Issues pertaining to response to treatment

  - Poorer response

  - Longer duration of treatment

  - Protracted time to assess response to treatment and rehabilitation

- Challenging behaviours profile complicated
- Complicated family dynamics and higher prevalence of trauma

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Factors impacting length of stay

Average length of stay ranged from 0.2 to 4.9 year (Devapriam et al. (2018)

Factors in the context of rehabilitation patients include

- psychiatric comorbidity and behavioural problems remaining persistent despite adequate treatment,
- a societal aversion to any form of risk
- certain offence histories, such as arson or sexual offending, affect the likelihood of a community placement accepting a patient from forensic services
- a lack of specialist skills within community teams.

Alexander et al. (2011).

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Environment & Clinical factors

Pursued Clinical model should consider

Professional flexibility to accommodate for clinical inflexibility in service users as well as service user-specific unique needs

Person characteristics

- Service user number and mix
- Behaviour types

Physical environment characteristics

- Fewer sensory destabilisers

Practice characteristics

- Consistency;
- Reliability;
- Predictable structure

Existing data about people

Prof. Sujeet Jaydeokar

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Data review

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Purpose: To understand the characteristics of adults with intellectual disability and/or autism spectrum disorders who are currently in inpatient settings across north of England and the factors contributing to their on-going inpatient stay

Objectives:

- To describe the demographic and clinical characteristics of the inpatient population of learning disability/autism spectrum disorder patients
- To understand the reasons leading to admission
- To explore the clinical and demographic factors that might have an impact on the length of inpatient stay
- To explore relationship, if any, between types of inpatient services, length of stay, and clinical and demographic characteristics of the cohort
- To inform strategies for commissioning and future research

Data review

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Cross sectional study using already collected demographic and clinical data of current inpatients in the North as on 30th January 2022.

Data variables looked up include

- Age
- Gender
- Hospital admission date &total length of stay
- Reason for Admission
- Provider organisation type
- Ward security & Bed type
- Status under MHA
- Number of changes in hospital during stay
- Outcome of CTR

Challenges and next steps

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Cross-sectional data

Difficulty in establishing relative risks and trends

New set of data

Inform deep dive focus and parameters

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Development of outcomes framework

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Christine Hutchinson

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Why do we measure outcomes?

- Achieving good patient health outcomes is fundamental purpose of healthcare
- Measuring, reporting, and comparing outcomes is an important step towards
  - Rapid outcome improvements
  - Making good choices
  - Reduce variation
- True measure of quality
- Ensures that cost reductions are value enhancing

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Current issues with outcome measurements

- Organisational structures and information systems
- Organisations tend to measure only what they could directly control or easily measured than what matters for outcome
- Tend to measure outcomes for interventions and treatments provided rather than outcome relevant for patient
- Outcome measured for intervention units rather than full care cycle

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Outcome measure hierarchy

1

Tier 1 – Health status achieved or retained

- Survival
- Degree of health / recovery

2

Tier 2 – Process of recovery

- Time to recovery and return to normal activities
- Disutility of treatment or care process

3

Tier 3 – Sustainability of health

- Sustainability of health / recovery and nature of recurrence
- Long term consequences of therapy

RC PSYCH
ROYAL COLLEGE OF PSYCHIATRISTS

QNLD
QUALITY NETWORK FOR FOR LEARNING DISABILITY SERVICES

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Development of Quality Standards

Chris Hutchinson

Amy Colwill

Aims of the QNLD

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- Provide a framework for learning disability teams to assess and improve the quality of care they provide
- Help support services develop by benchmarking against agreed criteria
- Engage directly with front line staff, managers, patients and their carers in the quality improvement process
- Aim to provide a Network for all staff from all disciplines add value through **continuity, connection, support, solutions & reflection**

Current membership:

- 36 Inpatient units
- 11 Community teams

- Membership is across the UK, both NHS and independent sector

- Offer both accreditation and developmental membership options

Types of Standards

Robust process of revision, consultation with a wide range of stakeholders ranging from representatives of carer groups, members of various professional Colleges, NHS England, the Learning Disability Senate, the third sector and the services themselves

- Mapped against the College Core Standards with the inclusion of new specialist standards relating to learning disability services

- Standards are revised every 2 years through co-production process

    - **Type 1:** failure to meet these standards would result in a significant threat to patient safety, rights or dignity and/or would breach the law. These standards also include the fundamentals of care, including the provision of evidence-based care and treatment

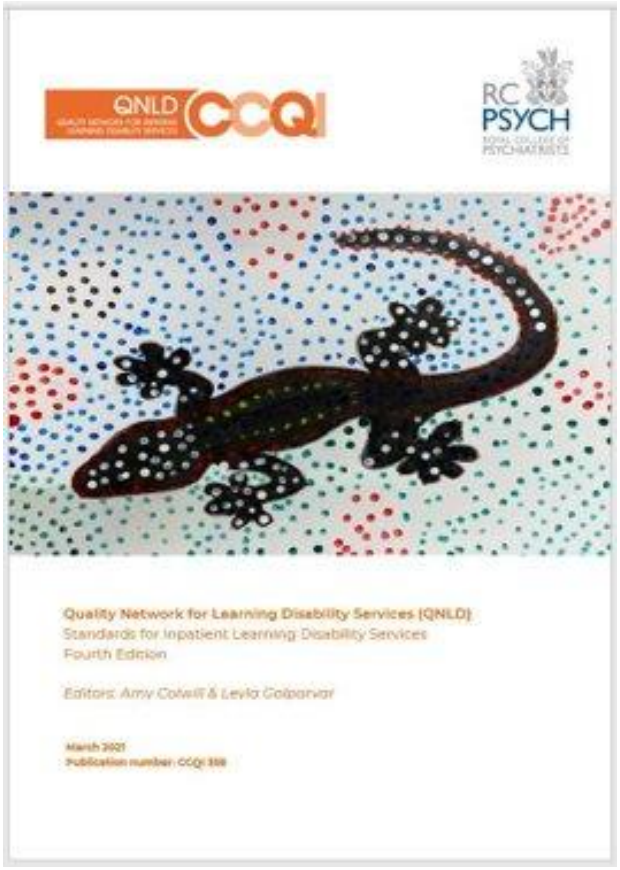
    - **Type 2:** standards that a service would be expected to meet.

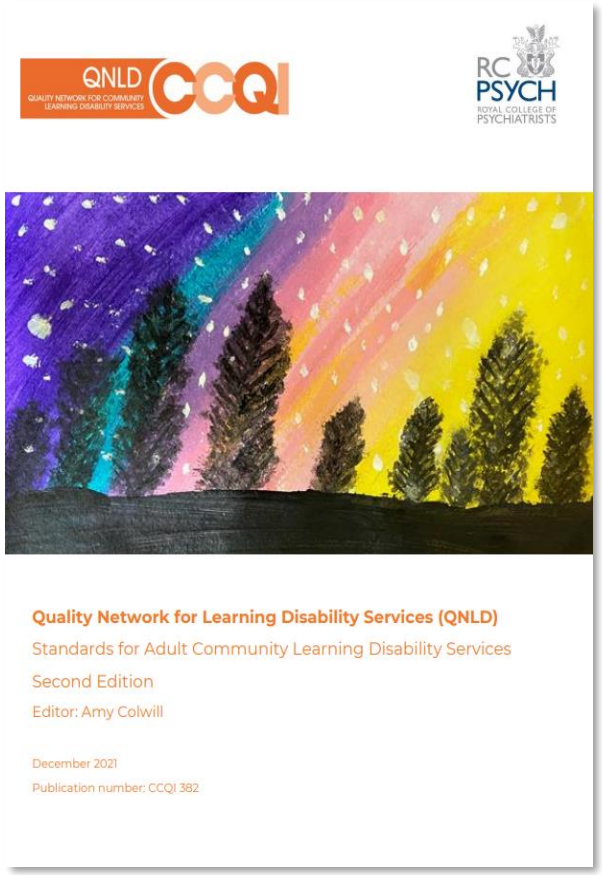
    - **Type 3:** standards that are desirable or out of direct control of the unit.

QNLD Standards

- 7 Sections within the document reflecting a person's journey

- 180 standards (inpatient)
- 138 standards (community)





Objectives - complex continuing care (rehabilitation) services

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- To develop standards for inpatient rehabilitation services for people with learning disability.
- To improve the quality of inpatient rehabilitation service provision for people with learning disabilities, provide consistency across services and create a forum where professionals working in inpatient rehabilitation services for people with learning disabilities can share learning and best practice.
- Project would sit within the well established Quality Network for Learning Disability Services (QNLD) alongside the inpatient and community members

Standards development process

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April/May 2022 – review of current standards & literature search

- Review and incorporation of updated core standards, QNLD & AIMS-Rehab
- Review of any new research, guidance, frameworks or legislation
- Standard consultation document has been sent round – deadline for comments is **Wednesday 1st June**

6th June 2022 - Standards Development Consultation / Workshop

- Attended by Key Stakeholders and experts in the field of LD and Rehab
- Aim is to keep standards up to date, take onboard stakeholder feedback on content, wording and rating of each standard and make them more concise where possible
- Add new standards based on the speciality and remove standards that are not relevant

July & August 2022 - Draft Standards out for e-consultation

- Feedback from the workshop is incorporated into the standards document by the project team.
- Feedback on draft standards is then sought from wider stakeholders

October 2022 -Publish Final Version

The review cycle

Selected teams will be supported in year 1 and year 2

Teams will complete at least one year **developmental cycle**

Teams may then consider going through the accreditation process

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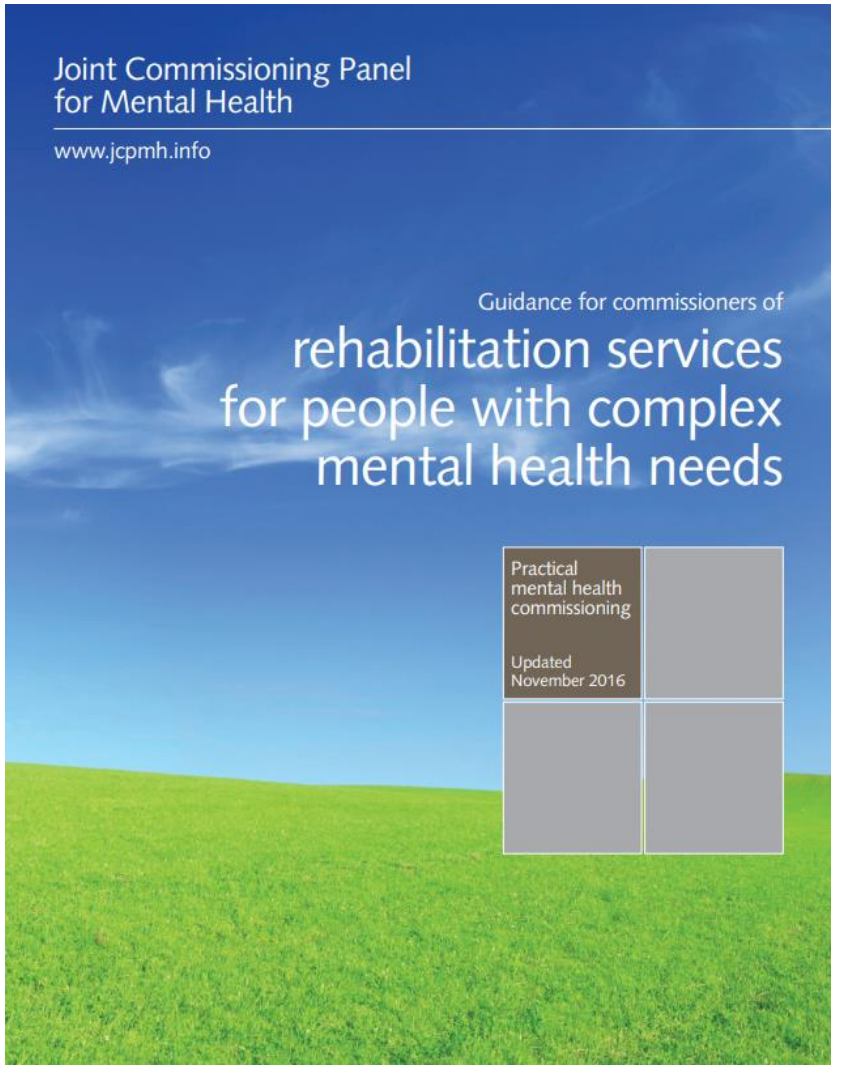
Commissioning Guidance

Claire Swithenbank

Kevin Elliott



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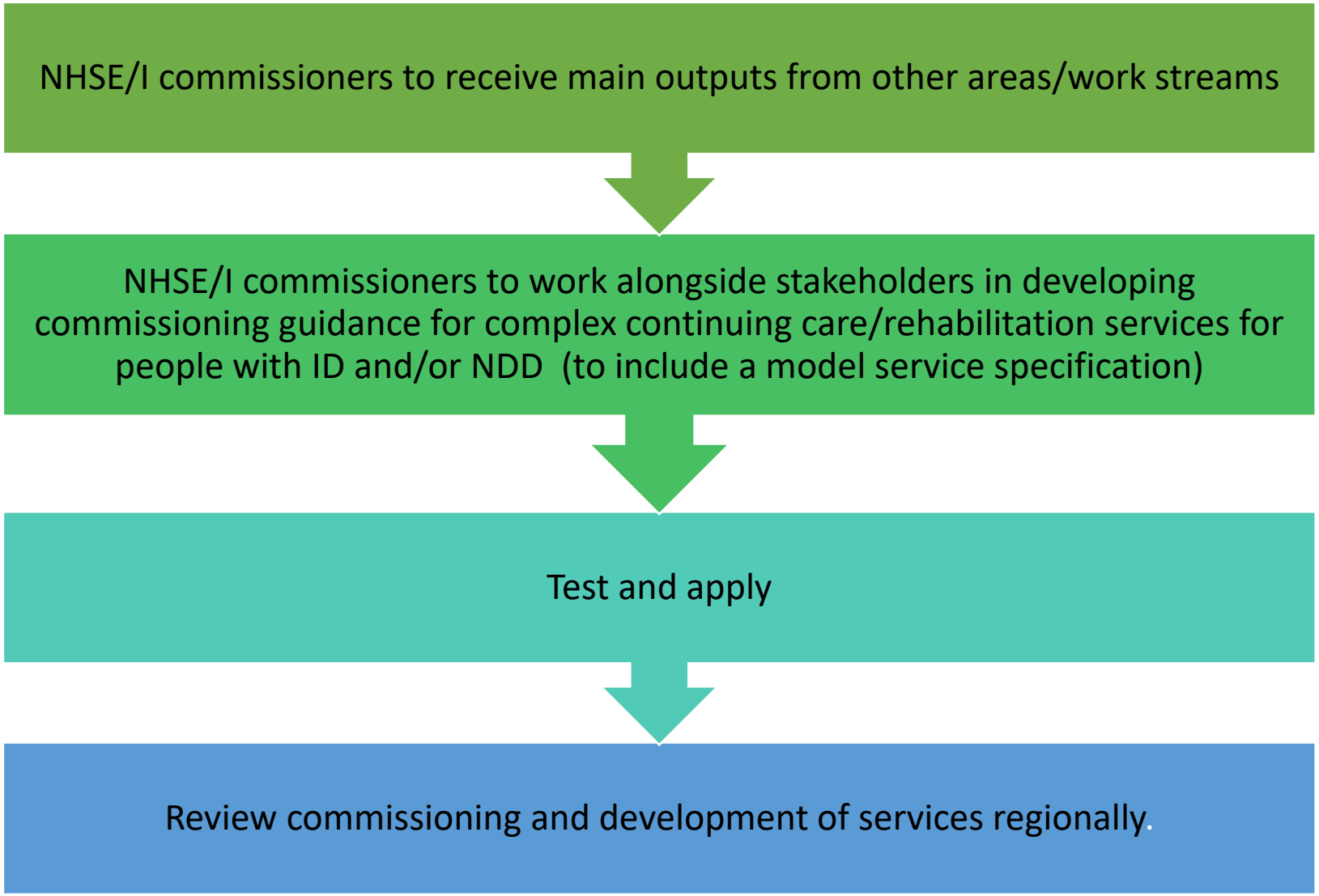
Commissioning Guidance Next steps



Lots of questions..

Potential solutions..