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Intellectual Disability Psychiatry

A practical handbook

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Contents

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Foreword

People with intellectual disabilities are among the most complex and most rewarding of people to work with and the changes in attitudes, in services and in working practices that have occurred in this field in the UK and in some other parts of the world have been truly remarkable. Central to such changes has been the recognition of the importance of respect for the human rights of people with intellectual disabilities, as exemplified by the recent UN Convention on the Rights of Persons with Disabilities, together with an understanding that people with intellectual disabilities vary considerably in the nature and extent of their needs and in their strengths and vulnerabilities. The skills necessary to meet such needs are diverse and require collaborative work across disciplines and between staff from different agencies, including education, health, social services and different service providers.

Achieving much of what people with intellectual disabilities, their families, support workers and others working with people with intellectual disabilities might aspire to, in terms of social inclusion, choice and participation, will depend not just on the opportunities available to people with intellectual disabilities. Also central is ensuring, as far as is possible, sound physical and mental health, and the provision of support and communication strategies that are based on an understanding of individual need. This approach requires a clear understanding of the responsibilities of all those concerned with respect to the prevention, detection and treatment of ill health and ready access to primary and secondary health services and to specialist services as and when required. The extent of health inequalities and the attitudinal and practical barriers to primary, secondary and specialist health care services

are increasingly acknowledged, if not, as yet, exactly resolved.

This book is a very welcome contribution to the literature with its specific focus on the mental health of people with intellectual disabilities. As exemplified by the different chapters, this has been an area of substantial development over the last few years. Clinicians and researchers have gained a much better recognition of the relevance of different conceptual models of understanding of the various developmental, biological, psychological and social factors that might predispose to, precipitate and/or maintain the occurrence of particular behaviours and/or abnormal mental states affecting people with intellectual disabilities, and of the range of interventions that should be considered. The focus for the early chapters is on assessment and on the complex issues that can arise with respect to consent and the capacity of individuals to consent to interventions. The subsequent chapters address various aspects of psychiatric comorbidity and focus on specific issues that are becoming increasingly relevant, particularly with respect to people with mild intellectual disabilities, such as substance misuse and the needs of those arrested, charged with and/or convicted of offences. Other chapters focus on challenging behaviour and also on the mental health needs of older people with intellectual disabilities – perhaps best exemplified by the age-related needs of people with Down's syndrome. The final chapters are on interventions and on services.

This book brings together under one cover present-day knowledge and through its very publication makes a clear statement about the importance of these issues and of what can be done. This book is fundamentally optimistic in that its emphasis is on the benefits of sound assessment and informed intervention, yet it also brings to our attention the limitations of our knowledge and the complexity of the field.

Tony Holland
April 2009

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Introduction

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Clinical involvement with, and awareness of, disability is a core component of the current undergraduate medical curriculum. It is one of eight key themes recommended by the General Medical Council which run through the entire five-year medical programme. Despite this, the majority of clinicians who only meet individuals with intellectual disabilities occasionally, often only have limited experience or training in how to work with this group where communication difficulties and variable symptom presentation create particular challenges in the consulting room.

Intellectual Disability Psychiatry: A Practical Handbook has been written and edited by working clinicians and academics in intellectual disabilities with the aim of creating a concise and practical text that addresses the clinical uncertainties that we face in everyday practice.

Working with people with intellectual disability is intellectually stimulating and professionally rewarding. All contributors have day-to-day clinical contact with people with intellectual disabilities, run diverse and innovative

services and train undergraduate medical students and psychiatrists in training.

The complex clinical case work and emerging advances in epidemiological and health services research make this an exciting and interesting field. Recent government policy guidance provides an impetus for service innovation and the results of public enquiries help to prioritize initiatives to combat discrimination that people with intellectual disabilities can be subjected to when accessing health services.

People with intellectual disabilities experience high rates of mental disorders especially if problem behaviours are included in the prevalence rates. They are more likely to have associated physical health problems particularly people with more severe intellectual disabilities. There are many challenges in supporting people with intellectual disabilities overcome mental health problems. The ascertainment of mental disorders in this population is far from straightforward: the existing major classification systems, ICD-10 and DSM-IV-TR, are difficult to apply because the criteria for many mental disorders assume a level of ability and development that is lacking in our population. Furthermore, onset or relapse of a mental disorder may be unrecognized because of assumptions that people with intellectual disabilities behave in a certain way. Conditions that are treatable may therefore remain untreated and consequently the individual's needs are not met and their quality of life is reduced. *Intellectual Disability Psychiatry* will enable readers to effectively challenge this diagnostic overshadowing.

Chapters cover the key topics in the psychiatry of intellectual disability and include illustrative cases and examples of good practice. Communication is the topic of our first main chapter, and returned to many times in *Intellectual Disability Psychiatry* because it is so essential.

Good communication skills can make all the difference for a clinician to be able to identify mental health problems in people with intellectual disabilities, and deliver treatment interventions.

In many parts of the world, there are no specific mental health services for people with intellectual disabilities. In other places, people with intellectual disabilities use a combination of specialist and mainstream services. We hope *Intellectual Disability Psychiatry*, written from a practice perspective, will help enable all psychiatrists to have the confidence and skills to work with people with intellectual disabilities. We have designed it to be an invaluable aid in achieving professional competencies and passing professional exams such as the MRCPsych. It is also highly relevant to other health professionals and social workers working with this client group.

We have deliberately avoided making *Intellectual Disability Psychiatry* an exhaustive research guide, though references to important papers are included as well as suggestions for further reading.

Psychiatry for people with intellectual disabilities is a very well established specialty in the United Kingdom, and several of our contributors use UK legislation and services to illustrate important principles. However, the content and information presented in *Intellectual Disability Psychiatry* can be adapted and applied in other settings outside the UK. We have intentionally adopted an international perspective in our community care chapter, and solicited contributions from three continents to help ensure an outward looking, forward thinking focus.

2

Effective Communication

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2.1 Introduction

This chapter aims to give some good practice points to facilitate communication with people with intellectual disability. In reality very few practitioners will have any training specific to the communication needs of this group of people. *Our Health, Our Care, Our Say: A New Direction For Community Services* [1] drew attention to the lack of skills and training; stating that there is a need to build up skills, especially in basic communication, in social care settings where only 25% of employees have a qualification. Healthcare for All [2] recommends that training for all health care professionals at undergraduate and postgraduate level must include intellectual disabilities on the curriculum.

People communicate in a variety of different ways and all have a right to communicate. A simple definition of communication is dependent upon three things:

1. a message to communicate
2. people who need to communicate with each other

3. a shared way of communicating.

This simple definition applies to everyone regardless of their age and ability to communicate.

Understanding and improving communication can greatly enhance clinical care and the experience of people with intellectual disabilities and those working with them. Moreover recent changes in UK legislation formalize a duty upon practitioners to strive to communicate effectively with individuals in order to maximize their understanding and ability to make decisions. For this reason we hope that this chapter will be used by the reader to help inform their understanding of many other parts of this textbook.

We discuss the different components of communication and the way that these impact upon the assessment and management of mental health disorders in people with intellectual disabilities. The basis of communication difficulties and their prevalence are outlined.

We also consider the general issues of communication in a clinical setting and the role of communication with others including carers, other disciplines and agencies that are frequently involved in the network working with a person with intellectual disabilities. The chapter is written from the joint perspective of psychiatry of intellectual disabilities and speech and language therapy and includes good practice points and case vignettes that can be used by readers to improve their own communication practices.

2.2 Background

There is a high incidence of communication difficulties in people with intellectual disabilities in comparison to the rest of the population. Research has indicated that anything between 50 and 90% of people with intellectual disabilities have such difficulties [3]. Therefore health professionals

need to modify their communication to accommodate the communication needs of the person with intellectual disabilities. This will include spoken language, non-verbal communication such as facial expression, body language and gestures and any written forms of communication.

An approach that encompasses all the above and values all forms of communication equally is Total Communication. This is the communication approach that we have based the chapter on. The environment plays a key role in promoting effective communication. Considerations should also be made to ensure that communication is culturally appropriate with increased use of interpreters versus reliance on family members.

There is a higher incidence of sensory impairments with people with intellectual disabilities than in the general population. The literature shows that up to 60% of people with intellectual disabilities are likely to have a sensory impairment of some kind. 50% of people with intellectual disabilities were found to have a hearing impairment and between 30 and 70% have visual impairment [4, 5]. This figure can rise to 80% with certain ‘at risk’ groups, such as people with Down’s syndrome.

There is also a higher incidence of physical disability amongst people with intellectual disabilities [2] and this can impact on communication skills. Such people are more likely to be dependent on others, therefore the ability and opportunity to communicate their needs and wishes and to have these acted upon is essential. The communication modes such as speech and signing may be more difficult for people with intellectual and physical disabilities to use easily.

From the speech and language therapist’s perspective the communication skills of people with intellectual disabilities are described as:

1. **Pre-verbal:** This means that people do not have the cognitive abilities to understand words. They have profound and multiple learning disabilities. They can be helped to understand through routines, tone of voice, repetition, the context of the situation, objects and their own experience.
2. **Non-verbal:** This means that people have abilities to understand words but do not have the ability to express themselves using words and will use an alternative means, for example signing, pictures.
3. **Verbal:** People will have a variety of skills in understanding language and expressing themselves, predominantly using speech.

2.3 Professional obligations

Communication with patients, family members, carers and other professionals is an inherent part of everyday practice. There is a general assumption that both doctor and patient are able to understand what is being said and to contribute and respond in a way that is also understood. In clinical practice this assumption often does not hold true particularly in the context people with intellectual disabilities. In these situations doctors have a duty to communicate in a way that is appropriate for the individual.

This duty stems from the doctor's duty to preserve the autonomy of the patient, their right to self-determination and is a cornerstone of medical ethics. Increasingly this ethical principle has become incorporated into the law and has led to legal obligations set out in statute. See Box 2.1 for key statutes and policy applicable in England.

Box 2.1 Key statutes and policy in England

Human Rights Act 2000 [6]

Article 3: Freedom from torture or inhuman or degrading treatment

Article 14: Freedom from discrimination

Mental Capacity Act (MCA) 2005 [7]

Principle 2: 'A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.' (section 1(3))

Mental Capacity Act Code of Practice 2008 [8]

The MCA Code of Practice (chapter 3) provides general guidance for communication and further guidance specific to intellectual disabilities. It emphasizes the importance of doing everything practical to help a person make a decision for themselves before concluding that they lack capacity to do so. It also states that to help someone make a decision for themselves, all possible and appropriate means of communication should be tried.

Mental Health Act 2007 [9]

Section 132B(1) imposes a duty to provide 'help in obtaining information about and understanding, **…** the provisions of this Act' **…** and other issues relevant to the Act.

Mental Health Act 1983 Code of Practice amended 2008 [10]

Chapter 2 outlines the duty to keep patients informed of their rights. Section 2.3 in the same chapter also outlines general guidance for communication with patients and states that everything possible should be

done to overcome barriers to effective communication, which may be caused.

Section 2.4 highlights how communication difficulties affect each patient individually, so that practitioners can assess the needs of each patient and address them in the most appropriate way.

Chapter 34 specifically considers the needs of people with intellectual disabilities and people with autism and highlights the need to set aside sufficient time for preparation of suitable information and for preparation before meetings. Meetings should be held in an environment that is not intimidating, in order to allow the patient every chance to understand the information given.

Valuing People 2001 [11]

In paragraph 4.30 the white paper outlines the government expectation that organizations working with people with intellectual disabilities will develop communication policies and produce and disseminate information in accessible formats. For those with severe disabilities this may require individual communication techniques and effective use of new technology.

Good Medical Practice (2006) [12]

Published by the General Medical Council, this guidance for doctors imposes the duty on doctors to make sure, wherever practical, that arrangements are made to meet patients' language and communication needs.

Seeking Consent: Working with People with Learning Disabilities (2001) [13]

Published by the Department of Health specifically looks at the issue of consent in intellectual disabilities

– both those individuals with and without the capacity to make decisions for themselves.

Beyond the duty to communicate is the therapeutic importance of good communication and its role in developing a therapeutic alliance between the doctor, patient and carers and other professionals around them [14].

2.4 Language skills of people with intellectual disability

Understanding of language

Many people with intellectual disabilities will have difficulties understanding what the health professional says. Some people will have developed good social language which masks their underlying difficulties, and it is important to be aware of this. Also some people will have developed an ability to understand simple abstract questions, for example, ‘What did you do today?’, ‘Where’s so and so?’, but will find it harder to understand more complex abstract questions and concepts such as inference, for example, ‘What would you do if … ?’, emotions and time concepts such as ‘yesterday’, ‘tomorrow’ and ‘twice a day’.

It is useful to think about understanding from a simple developmental perspective while being mindful that the health professional is working with people who are adults and who will have had many life experiences which will increase their abilities. This means that sometimes people will be able to understand at a seemingly higher level