Integrated Care

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Learning Objectives

- To achieve a holistic consideration of physical, behavioural and mental health issues related to persons with intellectual and developmental disabilities, involving in their care a range of disciplines and health professionals.
- Integration across care may have many real and potential advantages, including identification of mental health issues, increased accessibility to mental health services, reduced costs and better outcomes.
- Integration requires the adoption of a person-focused approach which in turn is defined by a bio-psycho-social model.
- Given the high prevalence of physical and mental disorders in persons with intellectual and developmental disabilities and the high rates of physical–mental comorbidity, integrated care and approaches based on inter-disciplinarily input are urgently needed.

13.1 Introduction

Guaranteeing effective and appropriate integrated assistance for people with complex social and health needs represents one of the major challenges of healthcare systems. In Western countries, we are witnessing an increasing ageing of the population and a growing increase in the costs of services. The interest of researchers, service providers and policy makers in integration is not only limited to the elderly, but also to those who simultaneously use services deriving from multiple assistance systems, such as individuals with physical and intellectual disabilities or mental illnesses.

People with intellectual and developmental disabilities (IDD) are more vulnerable to physical and mental health problems than the general population. Besides this higher predisposition, they are often confronted with fragmented healthcare systems in which primary and specialty care is unable to meet their needs. Traditionally, healthcare for these persons has been parsed out to multiple providers and/or agencies and their physical and mental health are managed by different entities.

This lack of integration is made worse by a range of complicating factors, including barriers to the access and healthcare professionals who have received limited trainings about the peculiarities of these disabilities. Furthermore, several disparities emerge between the health sector and the social and education sectors which have significant implications for service planning and delivery. Changes need to be made in order to improve accessibility and integration of services necessary to meet the complex health needs of this population.

The development of integrated care pathways involving different professionals, family and life environments will help ensure that the needs of people with IDD are met. The necessity to address individual needs considering them in their entirety requires a planning of interventions which must take in account the principles of coordination, integration and cooperation between the various institutional levels that participate in the implementation of healthcare and social services. Integration allows the connection between healthcare (including acute care, primary and specialist care) and other assistance systems, improving outcomes both in terms of clinical results and quality of life. Identifying the links between different systems requires the adoption of a holistic approach which considers all major aspects of a person's life interrelated.

To date, the promotion of integrated and person-centred care represents an obligatory step for the improvement of public health policies outcomes. In order to achieve this goal, general understandings about integrated care should be converted into practical terms, in order to make available more effective health services able to improve quality of care and quality of life for the individuals. In this chapter, we discuss the notion of 'integrated care' and its features, exploring the many advantages deriving from its adoption in the field of IDD.

13.2 Integrated Care and Person-Centred Approach in Intellectual and Developmental Disabilities

Integrated care has more than one meaning and it is often used by different people to mean different things. The word 'integration' comes directly to us from the Latin verb 'integer', which means 'to complete'. Consequently, the definition of the adjective 'integrated' is 'combining or coordinating separate elements so as to provide a harmonious, interrelated whole'. It is mostly used to express the bringing together or merging of elements that were formerly separated [1].

The notion of integration in the fields of physical and mental health was first introduced more than a century ago by psychologist Alfred Adler (1870–1937) who codified concepts at the basis of individual psychology. According to this theoretical framework, the relationship between physical health and mental health is inextricable. The adoption of this concept in healthcare allows professionals to examine health status as a whole.

In its joint position statement on health, mental health, vision and dental care (as adopted in February 2013), the American Association on Intellectual and Developmental Disabilities has declared that 'all people, including people with IDD, should have timely access to high quality, comprehensive, accessible, affordable, appropriate healthcare that meets their individual needs, maximizes health, well-being and function, and increases independence and community participation'. Healthcare and social services face patients who have composite problems and this holds particularly true for people with IDD who are far more likely to have multiple comorbidities. People with IDD represent a vulnerable group of patients requiring well-timed, adequate and sensitive care interventions but actually, in several European countries, healthcare does not succeed in providing adequate services for them. Major difficulties refer to access to primary care, medical prescriptions, return of information, treatments for serious mental illnesses, communication between health and social services, lack of clear lines of responsibility and accountability for implementing care, and shortage of financial supports and resources [2, 3].

In the last two decades, the average life expectancy for persons with IDD living in high-income countries has increased, due to the improvement of life conditions and healthcare practices, although it remains lower than in the general population [4–6]. According to some studies, average age of death for persons with IDD is now 63.3 years for males and 69.9 years for females [7, 8]. Simultaneously, a rise of ageing-related diseases has been recorded [9]. These demographic trends suggest that the need for healthcare delivery systems and approaches should be able to coordinate primary, mental and behavioural care in order to address a variety of complex healthcare needs [10]. Nevertheless, people with IDD are still frequently confronted with fragmented healthcare in which primary and specialty care are unable to meet their peculiar needs [11, 12]. In fact, there are very few systems in which different components are integrated and this lack of integration is made worse by a number of complicating factors, such as the limited training received by healthcare providers about issues related to IDD [10, 13]. As a result, unmet physical and mental health needs are common across the lifespan of persons with IDD, and the challenges arise accordingly with increased severity levels of the impairments [14].

To date, the scientific evidence suggests that integration across care may have many real and potential advantages [15, 16]. Integrating primary healthcare with mental and behavioural healthcare entails a number of benefits which includes identification of mental health issues, increased accessibility to mental health services, reduced costs and better outcomes [17–20]. Integrated care was described by

Leutz as a broad inter-sectorial system approach that aims to connect the healthcare system with other human service systems in order to improve outcomes (clinical, satisfaction and efficiency) [21]. Over the last few years, the concept seems to have received attention in the field of IDD and now it is widely supported for improving accessibility and quality of healthcare. Nevertheless, a comprehensive shared knowledge about issues related to integrated care is still lacking. According to Dowling and collaborators, the barriers perceived to prevent its successful implementation could be due to philosophy or culture of care, power and funding structures, high levels of staff turnover and lack of training, lack of experience among service management, inadequate staff supervision and ambiguity among some stakeholders [22].

From a clinical point of view, integration requires the adoption of a person-focused approach rather than a disease-focused one. The main characteristic of person-focused care is defined by a bio-psycho-social approach applied to health which is aimed at comprehending the personal meaning of a disease attempting to comply with individual needs and preferences. From this point of view, diseases are simultaneously a medical, psychological and social problem [23]. Focusing on the disease reveals a clinical perspective that links the specific needs of an individual to separated biological entities [24, 25]. Commonly, health systems in Western countries adopt this perspective which often disregards the implicit reasons of illness. Nevertheless, a disease-focused approach seems to be inappropriate for patients with chronic and overlapping diseases [26]; in these cases, adopting a person-focused approach is more functional as it allows a holistic vision where most health and social issues are interrelated and the identification of the links. Integration is also required to supply an ongoing and comprehensive provision of services matched to the needs of the users. The major challenge is to convert general understanding about integrated care into practical terms to make available more effective health services able to improve quality of care and quality of life for the individuals [27].

An important contribution has been made by the International College of Person-centred Medicine (ICPCM) and the Person-centred Integrative Diagnosis (PID) multi-dimensional matrix [28]. The PID focuses the attention to the importance of involvement and partnership in the clinical care process and supports the patients' autonomy, responsibility and dignity while advancing the recovery and promotion of well-being. The construction of this theoretical model has been carried out by the World Psychiatric Association (WPA) through an Institutional Program on Psychiatry for the Person (IPPP) [29, 30]. Emerging features of the PID model include them being a diagnosis of health (of both illness and positive aspects of health), involving collaborative and empowering engagement of patients and serving as informational basis for prevention, treatment, rehabilitation and health promotion [31]. PID uses descriptive categories, dimensions and narratives, to manage patient-family-clinician partnerships for achieving shared diagnostic understanding and shared commitment to care. The application of this model to the assessment of personal well-being, experiences, satisfaction and aspirations of persons with IDD faces significant challenges as the self-reported assessment of these complex concepts is limited due to the cognitive and communication impairments which frequently occur in persons with IDD [32].

IDD may be a good example of how the holistic and comprehensive approach is useful for comprehending these complex constructs in healthcare. Integrated care and person-centred approach lay on the same conceptual frame of practice-based research. What is effective in evidence-based studies, including first-level studies, does not always have the same efficacy in the real world of everyday practice [33, 34]. The same applies to the relationship between costs and benefits of interventions: the dynamic interaction of the many factors conditioning the psychic state of persons with IDD and those who implement professional interventions can substantially change what is indicated by evidence-based studies. Moreover, some researchers have identified that even in organic medicine – in which the variables involved in the genesis and in the

resolution of the disorders are lower than those of the psychological and psychiatric clinic – the portion of patients to whom evidence-based guidelines are applicable without major adaptations often remains below 50% [35, 36].

An attempt to overcome these limitations is represented by research based on practice (practice-based research (PBR)), or by a collection and analysis of data derived from daily clinical practice and aimed directly at improving it. PBR is applied to professional studies, in outpatient clinics, in schools, in rehabilitation centres and in all other contexts in which people with IDD actually receive the interventions they need, becoming themselves an active part of the research process [37, 38]. The application of PBR can identify and solve the problems of applicability of the evidence from the scientific literature to the practices in various care settings [39, 40].

Integrated care promotes a holistic vision in which health and social problems are interconnected, allowing the identification of links between the different systems. Multiple perspectives may lead to the development of new intervention models based on person-oriented approaches to address individual characteristics and needs.

Tip

- Integrated care may be defined as a coherent set of methods and models regarding the provision of administrative-organizational and clinical services designed to create connectivity and collaboration within the healthcare contexts.
- From a clinical point of view, integrated care models require the adoption of a person-focused approach, in order to improve the patient's general well-being and take into account his/her needs.
- The integration of different health disciplines in the treatment of persons with IDD is increasingly indicated as a useful method, which may result in improved accessibility, appropriate use of healthcare services and higher quality of healthcare.

13.3 Integrated Care and Physical Ill-Health

It is widely proven that persons with IDD present a higher vulnerability to mental and physical health problems [41] (see ▶ Chap. 3) and face a much greater burden and earlier onset of physical ill-health than the general adult population [42, 43]. Given the high prevalence of physical and mental disorders in persons with IDD, they often tend to coexist. According to the findings of the Adult Psychiatric Morbidity Survey 2014 [44], chronic physical conditions such as asthma, cardiovascular disease, epilepsy and diabetes seem to be associated with common mental disorders (e.g. anxiety and depression) and poorer mental well-being in the general adult population. Barnett and colleagues [45] found the prevalence of physical–mental comorbidity to be 8.3% in the general population, and the likelihood of presenting mental disorders seemed to go up as the number of physical illnesses increased. It is widely known that physical–mental comorbidity is associated with poorer outcomes compared with the presence of either physical or psychiatric conditions alone [46, 47]. These high rates of comorbidity have some serious consequences, such as higher mortality [48], increased risk of suicide [47], functional impairments [49], poorer quality of life [50] and higher medical care costs [48].

To date, only few researches have examined the relationship between physical and mental ill-health in adults with IDD and those which have been identified have some limitations. Three studies have examined this relation focusing on older adults with IDD [51–53]. Cooper [52] observed a positive association between physical ill-health and dementia in a sample of 134 of older adults (aged 65 or over) but her study did not show further connections with other mental disorders. A complex relationship between the presence of epilepsy and mental health among adults with intellectual disabilities has been described [54], while McCarron and collaborators [53] have identified a significant

association between gastrointestinal disease – but no other physical conditions – and mental ill-health in a sample of 753 adults with IDD over the age of 40. More recently, Dunham and colleagues have found no significant correlations between physical multimorbidity and mental ill-health in adults with intellectual disability [55]. Nevertheless, this result could be due to the width of physical multi-morbidity (99.2% of the sample had physical conditions), which was so high to compromise the chance to identify associations.

Findings of some recent studies have shown that obesity is associated with mental ill-health and aggression [56–58]. Endocrine disorders were found to increase the risk of having problem behaviours by 22.4%; in particular, hyperthyroidism has been shown to be associated with psychosis, irritability/behaviour changes, restlessness and hyperkinesis [59]. Respiratory disorders have been identified as protective factors against problem behaviours and every type of mental disorders; this finding could be attributed to the ease of detection of symptoms (e.g. cough, breathlessness and wheeze), resulting in more attention by family members and/or carers which in turn produces a positive psychosocial effect [55].

Another significant association was found with reference to musculoskeletal problems. Actually, their presence seems to reduce the risk of mental disorders of any kind by 15.8%; this may be due to the anti-inflammatory effect of the drugs prescribed to treat these conditions. Some researchers have suggested that inflammation can induce depression. Makhija and Karunakaran have demonstrated that increased inflammatory cytokines are mechanistically linked to a number of interacting neural pathways that may contribute to the onset of depressive symptoms [60]. Other important findings concern ischaemic heart disease that has been found to increase the risk for the onset of problem behaviours by three-fold. Thombs and colleagues have shown that depression is around three times more common in patients after an acute myocardial infarction than in the general population [61]. The authors have also suggested that the mechanisms behind these associations in adults with IDD may be similar to those seen in adults who do not have IDD.

Given the high prevalence of physical and mental disorders in persons with IDD and the high rates of physical–mental comorbidity, integrated care and approaches based on interdisciplinarily input are urgently needed. The collaboration between psychiatrists and other professionals such as general practitioners, family doctors, neurologists, dental practitioners or orthopaedic surgeons [62–64] is, therefore, recommended. Good interdisciplinary communication seems to be associated with improvements in personal outcomes and in diagnostic and prognostic abilities of health professionals [65]. Providing specific trainings in the field of IDD for all health professionals seems to be fundamental in order to achieve a better knowledge of issues related to the identification and treatment for chronic health conditions which affect people with these conditions. Moreover, greater efforts should be made in order to improve the understanding of how to monitor mental and physical health among ageing IDD population.

13.4 Integrated Care and Mental Ill-Health

Diagnosing psychiatric symptoms in persons with IDD faces several difficulties, particularly in evaluating the impact of the specific symptoms on daily functioning. Assessment, diagnosis and treatment of mental problems in this group of patients demand specific adjustments due to the cognitive impairment, limited communication, sensory impairments, skill deficits, difficulties in adaptation and other disabilities [66]. Despite their complex and specific general health and mental health needs, people with IDD continue to experience disparities in healthcare provision. Unmet mental health needs are common across the lifespan of IDD, and the challenges increase accordingly with increased severity levels of the condition [14]. Particularly, the most urgent intervention required is the reduction of health

disparities, addressing to those issues which represent barriers to their access to services and appropriate treatments. Adopting adequate strategies is necessary to include people with IDD in health prevention programs, through an early identification of such problems, and to develop structured assessment tools coupled with tailored interventions [27].

As mentioned above, IDD presents several positive implications for psychiatry, such as providing assessment models, support system and diagnostic frameworks in severe mental and cognitive disorders. As suggested by Bertelli and colleagues, models of care – such as residential care, respite care and multi-disciplinary approach to care – as well as social issues of health – such as stigma and labelling and self-advocacy – were developed first in the IDD field, and now they are widely used in general psychiatry [27]. The usefulness of an integrated psychiatric assessment results from the consideration of several factors. Taking into account the high vulnerability of persons with IDD and the significant prevalence of mental health problems in this population, the adoption of a holistic approach that comprehends as many points of views as possible seems to be the most appropriate in their assessment.

Problem behaviours may be a significant example of the usefulness of an integrated assessment. In persons with IDD, the first choice treatment for problem behaviours is often pharmacotherapy and the search for a non-pharmacological therapy which considers the individual-specific conditions and individual quality of life as an outcome is often ignored. Actually, clinical practice suggests that an effective intervention of problem behaviours should be characterized by a simultaneous consideration of organic, psychiatric and socio-functional aspects and their pathogenetic contribution, on the basis of a multimodal analytical approach [27]. According to NICE guidelines [67], assessment on problem behaviours should be integrated into a comprehensive assessment for adults with autism. When assessing problem behaviours, practitioners should undertake a functional analysis in order to identify and evaluate any factors that may trigger or maintain the behaviour, including any physical health problems, the social environment (including relationships with friends, families and carers), the physical environment, coexisting mental health disorders, communication problems, changes to routine or personal circumstances.

The involvement of various disciplines in an integrated assessment might be useful in the identification of problems in the classification systems, strictly connected to clinical practices, and in identifying more and more sensitive diagnostic tools, instead of starting from very generic symptoms in assessing skills and performances [27]. Persons with IDD are uniquely positioned to benefit from the coordination of care that originates from integrated medical and mental and behavioural healthcare [10]. In fact, more than any other mental health condition, IDD provides opportunities to explore the clinical expression of the body-mind link. In order to have a clear understanding of it, all parameters of a quality mental healthcare such as holistic consideration of individual and sensitive diagnostic methods are highly relevant [32]. Multiple perspectives may lead to the development of new intervention models based on person-oriented approaches to address individual characteristics and needs.

The adoption of Patient-Reported Outcomes (PROs) is widely encouraged in assessing patients' performances and evaluating the efficacy of the treatments. These measures include the model of Quality of Life, widely applied in the field of IDD. In the field of IDD, since it is difficult to think about rehabilitative, educational and medical objectives that restore functional capabilities similar to those of most people, Quality of Life becomes a fundamental reference. It allows the assessment of the distance between individual expectations in the different areas of life and the results that are actually achievable; it helps to identify the most important and satisfying areas among the various interests and capabilities of individuals. Thus, a contextualized multi-modal assessment and a multi-disciplinary integrated intervention, involving different professionals, family and life environments, have several positive implications in achieving a comprehensive consideration of physical, behavioural and mental health issues related to persons with IDD, involving in their care a range of disciplines and

health professionals [27]. ► Box 13.1 summarizes the main factors supporting the relevance of an integrated care in psychiatry for IDD.

Tip

- Compared to the general population, persons with intellectual and developmental disabilities show a higher prevalence rate of both mental disorders and physical disorders.
- Due to their clinical peculiarities, persons with intellectual and developmental disabilities could particularly benefit from the coordination of multiple interventions deriving from the involvement of several specialists in the medical, mental and behavioural fields, as well as from different disciplines, services and supports for health promotion.

People with intellectual and developmental disabilities have complicated and ongoing needs and require a mix of services delivered by multiple providers. Integrated care improves mental and physical health treatments for people with intellectual and developmental disabilities establishing a comprehensive approach to patient, which enhances both quality of healthcare and quality of life.

Box 13.1: Reasons for Integrated Psychiatric Care in Persons with IDD Experiencing Mental Disorders

- Higher prevalence of psychiatric disorders than in the general population
- Identification of problems in the classification systems (i.e. ICD)
- New understanding for intelligence
- Models for the assessment of problem behaviours in severe mental disorders and cognitive deficit
- Genetic models for psychiatric disorders
- Direct clinical expression of the body-mind link
- Changes and adaptation of diagnostic criteria and diagnostic process for psychiatric disorders
- Sensitive diagnostic skills and tools (one often has to start from very generic symptoms, like behavioural changes or problems)
- Models for the assessment of adaptive skills as well as supports
- Life-span approach
- Holistic consideration of the person which requires multi-disciplinary intervention
- Model for high vulnerability to distress
- Person-related outcome measures, like generic quality of life

Bertelli et al. [27]

13.5 Conclusion

IDD represents an interesting area for the exploration and the understanding of the implementation of person-centred integrated care in classification, assessment, interventions, care delivery and policy planning [27]. In recent years, interest in healthcare integration has grown, with increasing evidence of its role in achieving better outcomes for mental health services' users. Nevertheless, reliable models and guidelines for daily practice still seem unclear, although persons with IDD, their families and an increasing number of healthcare providers are demanding them. To this purpose, health, social and educational professionals should collaborate to produce or enhance inter-disciplinary model of intervention and support, as well as to prove them through research trials and include them in the training curricula. This should be addressed also to primary care [10]. The necessity to encompass the existing models developed for the general population with the specific characteristics of IDD needs immediate attention [68].

Key Points

- Integrating primary healthcare with mental and behavioural healthcare entails a number of benefits.

- The early development of strategies of both person-centred care and integrated care in the field of intellectual disability and autism spectrum disorder may contribute to a better knowledge of the challenges of developing integrated care both in the interaction between primary care and secondary care and in the integration of health and social care.

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