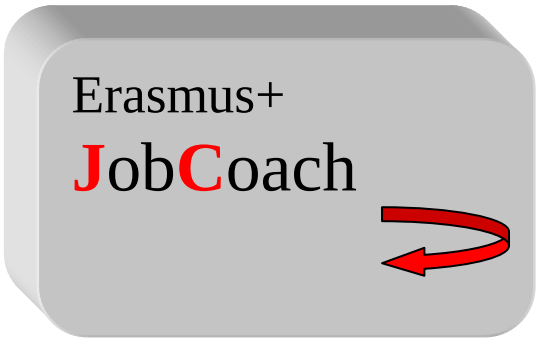
Erasmus+ Project

„Job coach for persons with disabilities”



Guideline for handling specific disabilities

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These Guidelines for the employment and support of persons with specific disabilities summarizes the necessary condition-specific knowledge for Job Coaches and was developed by an international partnership led by Fachhochschule Münster. The following project partners directly supported the development of the product:

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The following partners also contributed to the development of these Guidelines:	
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	Les Genêts d'Or France
	Stowarzyszenie Wsparcie Spoleczne Ja Ty My Poland
	Stowarzyszenie Niepelnosprawni dla Srodowiska EKON Poland
	Cordaan Netherlands

Introduction

These guidelines are intended to be used in a European framework for qualification and professional standards of a Job Coach specializing in the support of persons with disabilities (JC/D).

In the long term, full professionalization with unified education standards and curricular content for JC/D should be developed.

However, for now the (yet to be fully established) profession of a JC/D comprises experts from different disciplines, including education, social work, occupational science, administration, and health care.

A qualified JC/D requires a common knowledge base about individuals who are in need of a JC/D.

In this handbook we decided to focus on three major clinical presentations: autism spectrum disorder, intellectual disabilities, and psychicatric disorders. The activities of a specialized JC/D are especially crucial for integration and success in the labour market for persons with these diagnoses.

1. Autism spectrum disorders

Authors: Lyn McKerr & Karola Dillenburger

1.1 What is Autism?

Autism Spectrum Disorder (ASD) is the label applied to persons who experience pervasive developmental delays and specific, atypical patterns in social communication and repetitive/restricted behaviours (American Psychiatric Association, 2013). There are two main diagnostic systems that both recognize ASD as a diagnostic category: The International Classification of Diseases (e.g., ICD-10; World Health Organization, 1992), and the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013); note that the ICD-11 was released for approval in 2018 and will replace ICD-10 in due course (World Health Organisation 2018). Although the ICD-10 is the instrument most widely used in European countries, internationally, most published research is based on the DSM (Dillenburger, Jordan, McKerr & Keenan, 2015). Table 1 shows examples of behaviours relevant to a diagnosis of ASD.

Table 1: Examples of behaviours observed for ASD diagnosis

Social interaction and Communication Difficulties	*Restricted and repetitive behaviours*
Initiating or sustaining a conversation Reading facial expressions accurately Building and maintaining peer relations Developmental delay in language	Repetitive behaviours Restricted interests (and in some cases, special abilities) Inflexible adherence to routines Sensory issues e.g., sensory overload or distortion

ASD is diagnosed according to three levels of support needs (DSM-5; American Psychiatric Association, 2013):

- Level 1: Requiring Support
- Level 2: Requiring Substantial Support
- Level 3: Requiring Very Substantial Support.

Asperger's Syndrome is characterized by average or above average intellectual ability usually with significant social and communication difficulties and restricted/repetitive behaviours. Asperger's Syndrome was used as a diagnostic category in the ICD-10 and the DSM-IV, however it is subsumed in the ASD diagnostic category in the DMS-5 and the proposed ICD-11 (Autism Europe 2018, p.1).

At present, there are no reliable biological or neurological indicators for ASD (American Psychiatric Association, 2013). A diagnosis of autism therefore is confirmed directly through behavioural observations of child's behaviours by the diagnosing clinicians and indirectly through reports from parents/caregivers and other family members.

Advances in recent genetic and neurobiological research support the existence of 'multiple impairment models of ASD' (Bedford et al. 2014, p.612) and it seems increasingly unlikely that any single factor underlies the condition (Boucher, 2012). There is some evidence that autism may have a genetic origin (Szatmari et al., 2007), although a large range of environmental factors also impact on pre- and post-natal development (Medical Research Council, 2001; Rutter 2011). At present, an association between autism and vaccinations remains unconfirmed (DeStefano, Bhasin, Thompson, Yeargin-Allsopp, & Boyle, 2004; Rutter 2011), although the presence of industrial chemicals in the environment have been linked with developmental neurotoxicity (Rutter 2011) and, consequently, neurodevelopmental disorders such as autism (Grandjean & Landrigan 2014).

Individuals with autism commonly have a number of co-occurring conditions (Kielinen, Rantala, Timonen, Linna, & Moilanen, 2004). For example, epilepsy has been reported to

affect between 5%-38% of people with ASD (Mannion, Leader, & Healy, 2013; Tuchman & Rapin, 2002). Other frequently co-occurring medical conditions include motor difficulties, sensory impairment, Down syndrome, and cerebral palsy (Kielinen et al., 2004; Office for National Statistics, 2005). There is evidence that gastro-intestinal problems are relatively common among individuals who have autism (Mouridsen, Rich & Isager, 2010); it is possibility that there is an association with harmful gut bacteria, such as *Clostridium bolteae*, which has been found in greater numbers in children with autism than others (Pequegnat et al. 2013). However, a causal relationship between non-neurodevelopmental factors and autism remains highly speculative.

Mental health problems such as depression and anxiety also frequently co-occur with autism (Stewart, 2008; Matson & Shoemaker, 2009). Although intellectual disability is not a diagnostic feature of autism, this is probably the most common co-occurring diagnosis (Matson & Shoemaker, 2009), and has been reported to affect between 50-70% of individuals diagnosed with autism (ibid.). While the figures are variable, individuals with a more severe intellectual disability (i.e., a reported IQ of <70) are thought to comprise fewer than half of those diagnosed with autism (Baio, 2012).

1.2. Epidemiology

The global prevalence for ASD was estimated to be 0.62% with an overall variability from 0.30%-1.16% (Elsabbagh et al., 2012). There is no evidence of geographic, ethnic or socioeconomic differences, although existing data sets are limited, particularly in developing countries (ibid.). The Centers for Disease Control and Prevention found prevalence rates in children in the United States have risen from 1 in 110 in 2006 (Centers for Disease Control and Prevention, 2009) to 1 in 59 in 2014 (Centers for Disease Control and Prevention, 2016). The estimated prevalence rate in South Korea has been reported to be 1 in 38 (Kim et al. 2011)

In the United Kingdom, a secondary data analysis of the Millennium Cohort Study that

included more than 18,000 children born in 2000 indicated rising prevalence rates over time. Reported autism prevalence was 0.9% when the children were aged 5 years rising to 3.5% when the children were aged 11 years (Dillenburger, Jordan, & McKerr, 2014). Within Northern Ireland, the annual School Census revealed rates of school-aged children diagnosed with ASD are rising by approx. 0.2% per year (ibid.) The most recent figures indicate that the estimated prevalence among school-aged children in Northern Ireland is 2.9% (Department of Health 2018)

Prevalence studies indicate that at present, males outnumber females by a ratio of approximately 1 to 4, although there are increasing concerns about inaccurate diagnosis for girls; current diagnostic tools may miss the presentation in females, who are likely to be diagnosed later, and generally only when more severe impairments are identified (Gould & Ashton-Smith, 2011; Dworzynski, Ronald, Bolton & Happe, 2012).

1.3 The cost of autism

The most recent study of the economic costs of autism in the UK and the USA (Buescher, Cidav, Knapp & Mandell, 2014) indicated that overall, the lifetime expenditure in supporting an individual with an autism spectrum condition without intellectual disability is £920,000 (€1.067million), and for those with a co-occurring intellectual disability it is £1.5 million (€1.74 million).Overall, the annual cost of autism provision and loss of productivity for adults is estimated to be £29-31 billion (€33.6-35.9 billion)[1] in the UK; 42% of this cost is due to lost employment opportunities for adults with autism (Buescher, et al., 2014, p.724-725).

With regards to the cost of autism in Europe, *Autism Spectrum Disorders in the European*

[1] Dependent upon the variation in estimated prevalence figures for co-occurring intellectual disability (40-60% respectively); the figure does not include social security benefits, which the authors deem 'transfer payments and not real societal costs', see Buescher et al. (2014, p. 724)

Union (ASDEU)[2] are conducting a wide-ranging study which includes prevalence and economic cost within 12 European countries (2015-2018). This study will provide the most up-to-date figures for adult employment loss; it will also consider quality of life issues. Although there is no centralised database in Europe, some European countries have collected cost of autism data. For example, in Germany, the economic cost is thought to be around 70% of that in the UK, with a lifetime costs for a person with autism without intellectual disability around €766,865 (Bachmann, 2013). A study from the Netherlands estimated that €109.2–€182 billion are spent on autism annually (Peters-Scheffer, Didden, Korzilius, & Matson, 2012), including education, (supported) work and (sheltered) living and concluded that this could be off-set by approx. €1,103,067 per child, if Early Intensive Behavioural Interventions (EIBI) were put in place (Reichow, Barton, Boyd, & Hume, 2014; Reichow, Hume, Barton & Boyd 2018).

1.4 Autism and the working environment

Given the characteristics commonly associated with a diagnosis of autism outlined in Table 1, such as repetitive behaviours, inflexible adherence to routines, sensory issues and difficulties with perspective taking, it is not surprising that these individuals may find challenges in obtaining and maintaining employment (Rosenblatt, 2008). Some may be unable to interpret colleagues' feelings or expressions, and thus appear insensitive or are thought to behave inappropriately, others may have difficulty coping with change to routine or environment, organising work and planning or predicting outcomes of their actions (National Autistic Society, 2011, p.3)[3].

[2] See http://www.autismeurope.org/files/files/09h35-joaquin-fuentes.pdf for details of the programmes and funding

[3] For a more detailed view of the potential impact in the workplace, and means to address this, see http://www.disabilityaction.org/fs/doc/publications/employing-people-with-autism-a-brief-guide-for-employers-external-publication.pdf

> *…[name] was stacking shelves somewhere and halfway through the job someone asked him to change and wipe the floor, and that was just a nightmare. In the work placements I think there could have been better autism awareness training around what stresses out people on the spectrum.'* [Parent of a young adult with autism and intellectual disabilities] (Dillenburger, McKerr & Jordan, 2015, p. 88)

Others may find that employers underestimate their capabilities and do not offer employment that makes full use of their abilities because of misconceptions about autism.

> *… [I was working in] a laptop repair shop, because one of my interests was IT, computers … I'm very interested in the technical spec of things … I like to work with an open source system, something called Linux [but] …people see computers like a black box… they just want to push the buttons … and the way they speak to me… 'No [name]... brush the floor'… I'm probably exaggerating, but…'* [Adult with autism who was holding a Master's degree] (Dillenburger et al., 2015, p. 101)

Employers can make reasonable adjustments for the needs of individuals on the autism spectrum to enable them to become 'effective and highly valued employees' (National Autistic Society, 2011, p. 5). For example, in food production, work-related activity is seasonal and weather dependent and there is no guarantee of a fixed daily routine. An employer will need to enable the employee with autism to adjust to frequent changes in routine or allocate duties that require adjustments less frequently. Advance planning (including for 'unplanned' activities that could arise) and well-developed communication strategies need to be in place as business owners recognise individuals with autism may need extra time or additional instruction.

> *And in the morning too, to help the people with autism, we'd have a white board, so you would write down, structure… what they're doing today... you know, in this climate*

sometimes it rains and all … You can clearly score it out, 'we are unable to do that because of the weather' and if they can't read you can draw wee symbols, it's raining, cloud, and that helps to de-stress ... because things do change. [Business owners offering work placements] (Dillenburger et al., 2015, p. 145-6)

For some adults with autism, the need for a more predictable or solitary environment with fewer workplace distractions may be met by self–employment.

'*I basically found a job where people would tell me what they want … and then they would leave me alone… and I could get on with it [laughs]. So, doing [craft] is very good, you know, I'm an expert in it… it's all controlled and I don't get any paradoxical situations… I like the fact that I'm in control, with it, and it's definable, and then occasionally there's… you get a moment where what you do far surpasses what people expect, and they come in and go 'Wow' and then, that's great.* ' [Self-employed craftsman and artist]. (Dillenburger et al., 2015, p. 102)

1.5 Employment statistics

Accurate employment figures for adults with autism in the UK are presently not available. The most comprehensive information to date is derived from a survey of 1,179 adults with autism in England which suggested that only 15% of adults with autism were in full-time employment (Rosenblatt, 2008).

A small German survey of 125 adults with Aspergers' Syndrome suggests a similar situation Despite average or above average formal school and professional qualifications, only a minority - fewer than 20% - was in full-time jobs, and many individuals were without any employment (Nedjat, Röttgers & Croissant 2011).

Clearly, many adults on the autism spectrum are not fulfilling their employment potential. However, public opinion is very positive regarding individuals with an autism spectrum condition in employment. The Northern Ireland Life and Times Survey included a designated autism module in 2012 (total of n=1209 respondents). Very positive views were expressed about working together with adults with autism in a variety of job positions, and for individuals without intellectual disabilities it was felt that there were very few job-related boundaries. In fact, 12% of respondents indicated that they would give more business to firms with an active policy of employing adults with an autism spectrum condition (Dillenburger, Jordan, McKerr, Devine, & Keenan 2013).

Some employers are already aware of the advantages of employing people with autism. The German Information Technology firm Systems Applications Products (SAP) introduced a scheme to specifically recruit adults with ASD (Guardian, 2013). The company valued the potentially enhanced abilities of employees with autism regarding to attention to detail and accuracy in data analysis. In Ireland, SAP has entered into partnership with the Danish organisation, Specialisterne[4], who select and train adults with ASD for employment in the technology sector in 17 countries worldwide.

1.6 Intervention

Interventions for most adults with autism focus on adaptive behaviour and are based on assistive technology, augmentative communication, or behavioural programmes (e.g., Applied Behaviour Analysis-based interventions (Anderson, Furlonger, Moore, Sullivan, & White, 2018) to enhance skills and reduce maladaptive behaviours (Research Autism, 2016). The National Institute for Health and Care Excellence (NICE, 2012) in the UK produced clinical guidance and recommended a number of interventions, including psychosocial (e.g., adaptive/lifeskills, anger management and job support) and ‘bio-medical‘

[4] http://specialisternefoundation.com/

(pharmacological, physical and dietary) therapies.

There is a statistically significant relationship between early intensive applied behaviour analysis (ABA)-based interventions and ‘optimal outcomes‘ for children with autism, including a significant reduction in symptoms such as restricted and repetitive behaviours (MacDonald, Parry-Cruwys, Dupere, & Ahearn, 2014; Troyb et al., 2014); in turn, this can lead to improved chances of employment and reduced care needs for adults (Fein et al., 2013; Orinstein et al., 2014).Conversely, a lack of appropriate early intensive behavioural interventions has been linked with extremely poor long-term outcomes (Howlin, Goode, Hutton, & Rutter, 2004; Howlin, Savage, Moss, Tempier, & Rutter, 2014) and some parents have successfully sued for damages, citing lack of these kinds of intervention (Kelly, 2014). ABA-based interventions are considered ‘treatment as usual’ in most of North America and Canada (Keenan et al., 2014) and have been linked to significant cost savings (Motiwala, Gupta, Lilly, Ungar, & Coyte, 2006).

1.7 Conclusion

Low employment rates of adults with autism do not reflect a lack of willingness to work. In general, adults with autism want to work, however, once employment is obtained they can face additional challenges, including discrimination and/or bullying in the workplace. Consequently, after having found a job, an estimated 43% of adults with autism resign or are made redundant (Bancroft et al., 2012). Factors that can determine success in the workplace include higher IQ and competency in language (Holwerda, van der Klink, Groothoff & Brouwer 2012, p. 340). However, co-occurring mental health problems, other medical conditions, maladaptive behaviours, or intellectual disabilities can pose significant barriers to gaining and maintaining employment (Baio, 2012; Kielinen, Rantala, Timonen, Linna, & Moilanen, 2004; Matson & Shoemaker 2009; Stewart, 2008). Guidelines related to these issues should be considered in conjunction with the autism guidelines (Dillenburger, Matuska, de Bruijn, & Röttgers, 2019).

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2. Intellectual disability

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2.1 What is Intellectual Disability?

Intellectual disability is a term generally used when a person has certain limitations in cognitive functioning and deficits in adaptive functioning. The onset of intellectual disability can happen any time during the developmental period, even before birth, and influences overall psychical, social and economic functioning in adult life. The definitions of intellectual disability and related terminology have evolved over time to reflect the legal and social gains made by individuals with such a disability and their families.

The term of ‘intellectual disability’ is used in two main classifications of mental diseases: The World Health Organization’s ICD-10 (World Health Organisation, 1992) and the American Psychiatric Association’s DSM-5 (American Psychiatric Association, 2013). However, while the DSM-5 uses the term ‘disorders of intellectual development’, he ICD-10 still uses the old-fashioned term "mental retardation” and incudes a section entitled "Mental Retardation" (codes F70–F79). The revision, the ICD-11, is expected to replace these terms with ‘disorders of intellectual development’ (World Health Organization 2018, 6A00; Salvador-Carulla, Reed, Vaez-Azizi, et al. 2011). Across most of Europe, the term ‘intellectual disability’ predominates, however, in the United Kingdom the term ‘learning disability’ is used more frequently.

DSM-5 details three types of neurodevelopmental disorders:

(1) *Intellectual Disabilities,*
(2) *Intellectual Disability* (Intellectual Developmental Disorder) and
(3) *Global Developmental Delay. Unspecified Intellectual Disability* (Intellectual Developmental Disorder).

For the purposes of this paper we use the general category of the DSM-5 ‘intellectual disability’, which focuses on levels of support necessary to maximize an individual's skills

rather than strictly on deficits in functioning. According to the American Association on Intellectual and Developmental Disabilities (AAIDD, 2013), intellectual disability is characterized by three diagnostic criteria:

- significant limitations in intellectual functioning - e.g., reasoning, learning, and problem solving;
- significant limitations in adaptive behaviour - i.e., conceptual, social, and practical skills in everyday life); and
- onset in childhood - before the age of 18 years.

Severity levels of intellectual disability as defined in *DSM-5*:

- mild (IQ scores between 55 and 70),
- moderate (IQ scores between 30 and 55),
- severe and profound (IQ scores that fall below 30),

When diagnosing intellectual disability, usually the clinical assessment of adaptive functioning is considered primarily with the IQ test score considered secondary. Limitations in adaptive functioning in specific skill areas are a necessary criterion for diagnosis under the American Association on Intellectual and Developmental Disabilities intellectual disability and DSM-5 definitions (American Psychiatric Association, 2013). The severity categories are based on evaluation of adaptive functioning in the conceptual, social, and practical domains.

The conceptual domain includes skills in language, reading, writing, mathematics, reasoning, knowledge, and memory. Possible clinical signs and symptoms in this domain include slow language development (children learn to talk later, if at all), slow development of pre-academic skills, difficulties in academic learning (reading, writing, mathematics), difficulty understanding concepts of time and money, problems with abstract thinking (concrete approach to problem solving), difficulties in executive function (i.e., planning, strategizing, priority setting, cognitive flexibility), problems with short-term memory,

difficulties with functional use of academic skills such as money management and time management.

The social domain refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities. Clinical signs and symptoms in this domain, especially speech and communication, may include for example limitations in language and communication skills, more concrete and less complex spoken language (if used), compared with peers, limited vocabulary and grammatical skills, receptive language that may be limited to comprehension of simple speech and gestures, communication that may occur through non-spoken means only, such as gestures, signs, facial expressions, and other forms of augmentative and alternative communication (AAC). Clinical signs and symptoms deficits in the area of social skills may include: immature social judgment and decision making, difficulty understanding peer social cues and social rules, emotional and behavioural regulation difficulties that may adversely affect social interactions.

The practical domain centres on self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks. Clinical signs and symptoms in this domain demonstrate that the person with intellectual disability requires sigificant levels of support for daily life activities such as personal care, more complex tasks (e.g., shopping, transportation, care organization, meals, money management), employment, health care and legal decisions, household tasks, recreational skills.

Functioning in all three domains (conceptual, social, and practical) is important in coping with everyday tasks, but the practical domain in particular is used to assess the severity level of the intellectual disability. Intellectual disability is usually readily diagnosable, yet, cross-cultural attitudes and beliefs may influence the process of identification in particular cases (Allison & Strydom, 2009; Scior, 2011).

Individuals with intellectual disability are a very heterogeneous group and their communication skills can vary according to the severity level, co-occurring conditions, and other behavioural, emotional, and social factors. There are common syndromes of intellectual disability depending on specific aetiological factors. Generally, there are prenatal, perinatal, and postnatal causes of intellectual disability:

Prenatal causes of intellectual disability represent for example, genetic syndromes (e.g., Down syndrome and Fragile X syndrome); inborn problems with metabolism; brain malformation (e.g., microcephaly); maternal disease (e.g., placental disease); and environmental influences (e.g., alcohol, other drugs, toxins, teratogens).

Perinatal causes of intellectual disability include for example, labour and delivery-related events leading to neonatal encephalopathy (complications during labour and birth, such as a baby not getting enough oxygen, etc.); and anoxia at birth.

Postnatal causes of intellectual disability are for example, hypoxic ischemic injury; traumatic brain injury; infections; demyelinating disorders; seizure disorders (e.g., infantile spasms); severe and chronic social deprivation; toxic metabolic syndromes; and intoxications (e.g., lead, mercury).

Genetic causes are responsible for approximately 45% of intellectual disability (Batshaw, Roizen, & Lotrecchiano, 2013). Down syndrome is the largest diagnostic category with a genetic cause of intellectual disability and Fragile X syndrome is the largest category with an inherited cause of intellectual disability. Fetal alcohol syndrome is the largest diagnostic category with an environmental cause of intellectual disability. Some prenatal causes (e.g., environmental influences) are preventable.

Intellectual disability is considered life-long and often co-occurs with other mental conditions like depression, attention-deficit/hyperactivity disorder, and autism spectrum disorder (American Psychiatric Association, 2013). Persons with intellectual disability may have more

health problems than the general population. Usually this is a result of inadequate health care, limited access to quality services (Krahn, Hammond, & Turner, 2006), and communication limitations (Gentile, Cowan, & Smith, 2015). Associated health conditions include anxiety disorders, hearing loss, heart conditions, obesity-related problems, seizure activity, and visual impairment. Addressing health inequalities and providing adequate health care and medical training can significantly improve quality of life and increase longevity for individuals with intellectual disability.

2.2 Epidemiology

Intellectual disability is the most common developmental disability. The determination of incidence and prevalence is quite complicated because researchers do not use the same operational definition when identifying individuals with intellectual disability[5]. Overall estimates consider that approximately 1-3 percent of the global population have an intellectual disability, i.e., appox. 200 million people worldwide. A meta-analysis of international studies published in 2011 found that the prevalence of intellectual disability across the life span is 10.37/1000 or 1.04% (Maulik et al., 2011; 2013). More recent data found prevalence of intellectual disability in children/adolescents and adults to range from .05 to 1.55% (McKenzie, Milton, Smith & Ouellette-Kuntz, 2016). Intellectual disability is significantly more common in low-income countries with an estimated 16.41 in every 1,000 people.

For Europe, the average estimate of intellectual disability (Wittchen et al., 2011, p.664-5) was assumed to be 10/1000 with a higher prevalence for middle-income countries (15.94 compared with 7.86 for western Europe), and a total of 4,2 million persons with intellectual

[5] Some authors use the terms intellectual disability and developmental disability interchangeably, but the latter can also include conditions like ASD and developmental language disorder. In some cases, an IQ cut-off score is used (e.g., <70) as a criterion for diagnosis, whereas in other cases, the diagnostic criteria are more qualitative in nature (e.g., onset in childhood with limitations in adaptive behaviour and intellectual functioning).

disability. The higher estimation for lower income countries was influenced by lack of sufficiently reliable studies from those countries and the suggestion about possible influence of environmental/ social risk factors on the causes of intellectual disability. Such factors as alcoholism, lead exposure, iron deficiency, malnutrition, perinatal problems and many other non-genetic conditions play a major role in higher prevalence rates of people with intellectual disability in less economically developed countries (CRPD, 2006).

2.3 The cost of intellectual disability

The estimated cost of disorders of the brain in Europe has been rising. In 2004 it was estimated to be €386 billion, distributed over 12 diagnostic groups affecting 127 million adult Europeans (Andlin-Sobocki et al., 2005). In 2010, the total European cost of brain disorders was already €798 billion, of which direct health care costs were 37%, direct non-medical cost 23%, and indirect cost 40% (Olesen et al., 2012). In this study the total annual cost in case of intellectual disability ("mental retardation" in ICD -10) was estimated on 43.3 million €. A 2010 benchmark European study showed similar results for "mental retardation" (Wittchen et al., 2011, p.736).

Cost type	2010 annual costs per person (in €)	2010 total costs (in milion €)
Direct healthcare costs	6970	29,204
Direct non-medical costs	3364	14,097
Total costs	10,334	43,301

The above calculation of costs did not include most direct non-medical costs attributable to the intellectual disabilities, such as the extra resources needed in the educational and social service sectors. Neither does it include indirect costs in terms of lost productivity. Considering that the employment rate is very low among individuals with intellectual disability and that this diagnosis is usually associated with significant health problems, such

as multiple disabilities and other medical conditions, the total economic cost of intellectual disability is even higher.

2.4 Intellectual disability and the working environment

Individuals with a diagnosis of mild level intellectual disability usually attend special schools, which commonly have educational programmes at pre-primary school level, while some continue education at a low vocational levels. The highest level of education or training attained by individuals with intellectual disability is ISCED 0, 1 or 2[6]. The level of education generally determines a person's opportunities for employment, but there are other important individual characteristics, such as communication and adaptive skills as well as the individual's health status.

Individuals with intellectual disability can work in a supported employment environment or in supported work in the open markets, usually carrying out relatively simple tasks under the supervision of a job coach. Sheltered workplaces, including copy centres or packing facilities, often focus on simple product assembly or the performance of a few easy tasks, such as bulk mailing, etc. Such work can even be undertaken by individuals with moderate levels of intellectual disability. In the open market, grocery stores, garden centres and small businesses tend to hire people with mild intellectual disability. Persons with intellectual disability usually provide cleaning or landscape services, commercial services to businesses, or include production, packaging and distribution and at times care sector services. Employers recognise the advantage of employing people with intellectual disability, such as they tend to be stable and consistent in their performance and work with a high level of motivation (BASE, 2018).

2.5 Employment statistics

[6] International Standard Classification of Education (ISCED) Level 0 - pre-primary education, L1 - primary education, L2 lower secondary education (see http://www.uis.unesco.org/Education/Documents/isced-2011-en.pdf)

Employment rates of people with disabilities are generally low in Europe and the situation for people with intellectual disabilities is even worse. Overall rates of employment for people with mental health problems in Europe vary from 18% to 30%. Figures from EU Member States suggest that in some countries more than 80% of people with intellectual disabilities remain unemployed[7]. In other countries, the employment rate is higher due to the provision of sheltered workplaces where the majority of workers have no employee status. The employment rate of people with intellectual disabilities in the open labour market is extremely low in all EU countries. The main barriers in access of people with intellectual disability to employability are connected with a number of issues [8]:

- *Outdated legal capacity legislation* in many European countries. Without the capacity to sign work contracts, people with intellectual disabilities cannot legally work. If they live in residential institutions or work in sheltered workplaces, they often do not earn a real salary or their salary is kept by the institution;
- *Common indirect discrimination* against people with intellectual disabilities in recruitment. School leaving certificates are requested even if there is little or no connection to the job in question. Thus, people with intellectual disabilities are excluded from jobs they could perform with little or no support. This is increased by the lack of knowledge about reasonable adjustment measures and a lack of support services. Even where job coaches or other support services exist, they are mostly unknown to potential employers;
- *The pitfall of the 'benefit trap'*. The legislation on social benefits in most Member States does not allow people to return to a disability benefits scheme after they have worked in open employment. This creates a huge barrier for persons with intellectual disabilities who may want to work in the open labour market;

[7] For example: of the 26.786 adults with a Learning Disability known to local authorities in Scotland in 2014 only 1.782 were listed as in employment with only 875 listed as being in open, paid employment. The majority of adults with intellectual disabilities in Cyprus are either unemployed (84%) or underemployed (I suggest you provide a reference for these statistics) .

[8] *Inclusion Europe's contribution to the mid-term review of the European Disability Strategy*, online: http://inclusion-europe.eu/wp-content/uploads/2015/03/IE_submission_EDS_final1.pdf, p.8-9.

- *Lack of appropriate skills of people with intellectual disability* hinders the smooth transition from school to working life. Weaknesses exist in relation to the acquisition of professional and social skills that are mainly due to lack of appropriate training.
- *Not enough accessible work places. E*mployers are reluctant to employ people with intellectual disability, even if they are offered the benefits of a supported employment policy.
- *Pay gap* is still significant between persons with intellectual disabilities and other workers.

2.6 Intervention

The adequate psychological assessment across the three domains, conceptual, social, and practical, is especially important in the development of a skills development plan for individuals diagnosed with intellectual disability.

The goal of intervention in support of persons with intellectual disability is to minimize the potential debilitating effects of disabilities on clients and their families and to maximize the likelihood of desirable outcomes which may improve the client's adaptive behaviour. As indicated by the American Association on Intellectual and Developmental Disabilities (AAIDD, 2013), a person's level of life functioning may improve only if appropriate personalized support is provided.

Communication interventions are widely supported for individuals with intellectual disabilities (Sevcik & Romski, 2016; Snell et al., 2010). Because of the variety of unique profiles of persons with intellectual disabilities, it is necessary to conduct individual assessments of the initial level of language functioning as well as functioning in areas related to communication more generally, including hearing, cognitive level, speech production skills, and emotional status. In all cases intervention considers coexisting strengths and needs to ensure treatment and support is individualized. Communication interventions focus on the context of

interactions and includes individuals that persons with intellectual disability encounter in their natural environments. Speech and language pathologists (SLPs) ensure that intervention provides ample opportunities for communication and incorporates a variety of language functions (e.g., greeting, commenting, requesting); multiple partners; different forms and modalities of speech and varied communication contexts (e.g., home, educational, recreational, vocational, and community settings).

Various treatment options use *technology and support systems* in conjunction with functional training of communication/social skills and other target behaviours. For example:

- *Augmentative and alternative communication (AAC)* offers supplementing, or using in the absence of, natural speech and/or writing with aided (e.g., picture communication symbols, line drawings, Blissymbols, and tangible objects) (Beukelman & Mirenda, 2013);
- *Activity schedules/visual supports* include objects, photographs, drawings, or written words that act as cues or prompts to help individuals complete a sequence of tasks/activities, attend to tasks, transit from one task to another, or behave appropriately in various settings and tinitiate or sustain interactions which are called *scripts.* Scripts promote social interaction and can be used in a classroom setting to facilitate academic interactions and engagement (Hart & Whalon, 2008);
- *Computer-based instruction* include the use of computer technology (e.g., iPad) and/or computerized programs to teach communication and social skills (Neely, Rispoli, Camargo, Davis, & Boles, 2013);
- *Video modelling* is based on video recordings of desired behaviours that are observed and then imitated by the individual. The learner's self-modelling can be videotaped for later review (Rausa, Moore, & Anderson, 2016).

Behavioural interventions and techniques (e.g., different reinforcement, prompting, fading, and modelling) are designed to reduce problem behaviours and teach functional alternative behaviours using the basic principles of behaviour change. Most common interventions useful both for children as for adults with intellectual disability include:

- *Applied behaviour analysis (ABA*) is the science that uses principles of behaviour analysis to bring about meaningful and socially relevant change in behaviour. ABA techniques help build a wide variety of skills including communication, social skills, self-control, and self-monitoring (Spreckley & Boyd, 2009).
- *Functional communication training (FCT)* combines the assessment of the communicative functions of problem behaviour with ABA-based procedures to teach alternative responses. FCT is used across a range of ages regardless of cognitive level or expressive communication abilities (Carr & Durand, 1985).
- *Incidental teaching* focusses on naturally occurring teaching opportunities that are provided based on the individual's interests; attempts to communicate are reinforced as these attempts get closer to the desired communication behaviour (McGee, Morrier, & Daly, 1999).
- *Time delay* mean that the time between initial instruction and additional instruction or prompting is gradually increased as the individual becomes more proficient at the skill being taught. This method can be used with individuals regardless of cognitive level or expressive communication abilities (Liber, Frea, & Symon, 2008).

A special kind of approach is used for youth and adults with intellectual disability who are being prepared to acquire the skills necessary for independent living and achieving success in postsecondary education/training programmes, employment settings, and variable social situations. They need continued support to facilitate a successful transition to adulthood. Therapists are involved in their transition planning and may also be involved to varying

degrees in other support services beyond high school. This special kind of support is offered to aging adults to maximize their independent functioning. The aging process may be premature in adults with intellectual disability as compared with the general population (Lin, Wu, Lin, Lin, & Chu, 2011); for example, individuals with Down syndrome are more likely to experience early onset of dementia than the general population (Burt et al., 2005). For others, speech and language skills may begin to decline, often as early as 50 years of age (Roberts et al., 2007). Some adults with intellectual disability, particularly those with psychomotor impairments or other co-morbid conditions that affect feeding and swallowing, may experience dysphagia-related problems as they age (Lazenby-Paterson & Crawford, 2014). General rules for interventions to support persons with intellectual disability include:

- Using family-centred and culturally appropriate practises.
- Forming collaborative teams.
- Following a strength-based perspective.
- Maximizing self-sufficiency.
- Recognizing individual variability.
- Fostering a community environment of respect and inclusion.
- Using natural environments.
- Involving peers as communication partners.

Interventions designed to enhance peer interactions in the settings in which adults live, work, or socialize have shown that continued support can lead to enriched social functioning. For example, job coaching, partner training, and social facilitation can improve interactions of these individuals in the workplace (Mautz, Storey, & Certo, 2001).

2.7 Conclusions

'Enable many more people with disabilities to earn their living on the open labour market' (European Union, 2010, p.7)

Low employment rates of persons with intellectual disability usually are due to inefficient support systems and not to obstacles on the side of employers and employees. Lack of sufficient communication skills and adaptive skills connected with different health complications are the main reasons why persons with intellectual disability have limited chances for employment in the open labour market. However, those with a less severe levels of disability have a significant potential to work that can be utilised by employers. There is a variety of tasks that individuals with intellectual disability are able to undertake and that they can perform with high levels of engagement. Supported employment and the assistance of job coaches is necessary and welcome. Employers should develop non-discriminatory recruitment methods so as to be more open to the possibility of employing this group of potential workers and engage with external services to support employees with intellectual disabilities. In the current labour market, where it is increasingly difficult to find dedicated workers to perform basic tasks such a measure seems to be quite obvious and beneficial for business. It is also essential to recognise capacity legislation that hinders access to employment as direct discrimination against people with intellectual disabilities.

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3. Psychiatric disorders

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3.1 What are psychicatric disorders

Psychiatric disorders are defined by the International Classification of Diseases (ICD)[9] (World Health Organization, 1992). There are many psychicatric disorders and the influence of these on the health, wellbeing and occupational situation of people should not be underestimated.

Job coaches for persons with disabilities (JC/D) may support persons with long-term recurrent and/or chronic condition, like Schizophrenia and affective disorders, as well as more frequent disorders, like anxiety and OCD. All of these conditions have a siginficant impact on the occupational situation and profound and sound knowledge on the part of a JC/D should contribute to successful placements and well-adapted workplaces for important periods of the clients' lifespans. There are common misunderstandings about treatment and outcome and scientifically sound knowledge will not only be in the best interests of the employee, but also of colleagues and employers.

A JC/D is no psychiatrist, so, of course, they should not be expected to act as such. The information given here focusses on general knowledge and on symptoms and behaviours that

a) have a direct impact on the job situation and/or employability,
b) need specific support and/or intervention in a workplace situation, and
c) may indicate a change in the course of the psychiatric condition so that, among others, an employer, colleagues or a JC/D may refer the client to his

[9] The current edition (ICD-10) will be replaced by ICD-11 as the diagnostic manual once approval is granted (World Health Organisation 2018).

or her psychiatrist or take emergency measures according to the respective national laws.

A JC/D should know the exact diagnosis and medical background of the employee they support, in order to be able to individualize and customize personalized support. In reality, the availability of information will depend on data protection regulation and above all on the quality of the personal relationship between the JC/D and client. Under all circumstances, the autonomy of the client and data protection laws have to be respected. Only as long as a client views the support of the JC/D as an important positive element in their employment situation, will they agree to sharing confidential personal information (Lauber & Kawohl, 2013).

In this chapter we focus on the four most common psychicatric disorders. Prevalence, epidemiology and diagnosis specific intervention are detailed under each of the headings:

- schizophrenia
- affective disorders
- anxiety disorders
- obsessive-compulsive disorders (OCD)

3.2 Schizophrenia

With a lifetime prevalence of approximately 1%, schizophrenia is one of the most common mental illnesses. With symptoms that are often difficult to understand for those unaffected schizophrenia tends to shape the image of mental illnesses in general. Schizophrenic disorders affect persons in all cultures and geographic regions; the risk of developing this condition is mainly genetically determined. That means certain families have a very pronounced risk of the condition. If the genetic disposition is a given, external external stress factors then lead to the condition; the typical age of onset is between 20 and 30 years, men

are likely to be on the younger end of the spectrum and a key factor for initial manifestation and relapse is cannabis use (Schöler et al 2016). Thus, the condition tends to affect people at the beginning of their vocational training, university studies or career, and has a long-term impact on their working life.

According to the criteria outlined in ICD-10, schizophrenic disorders are mainly characterized by thought and sensory disorders. Dramatic symptoms are hallucinations in the form of hearing voices, delusional misinterpretation of reality, and a thought process that is difficult or impossible for outsiders to understand.

Schizophrenic disorders can be limited to a single episode, but in the majority of cases further episodes occur. Clinical experience indicates that in many cases each further episode progressively limits skills, including those needed for employment.

Treatment is predominantly based on pharmacotherapy with so-called neuroleptics which should be continued in most cases for 1-2 years after initial manifestation and for several years in cases of recurrent episodes. However, the medication is accompanied by individually varying, sometimes cumbersome, adverse effects so that compliance is rather volatile.

Key risk factors for a relapse are unilateral discontinuation of neuroleptic medication, however, others include the continued use of psychoactive substances. This is the focus of care, mainly for the attending psychiatrist. However, given that workplace-related influences can also be risk factors psychiatrists ideally cooperate closely with the JC/D. For example, most persons diagnosed with schizophrenia benefit from a regular day/night rhythm, so that (alternating) shift work should be avoided. Social stress factors can play a role, too and open-space offices contain the risk of becoming a stressor. Individual workstations and possibilities to retreat for privacy should be provided as an option.

It is above all the chronic aspects of schizophrenic disorders, often continuing after the acute symptoms have subsided, that have an impact on working life. They are called negative symptoms (as opposed to the “positive symptoms” like delusion and hallucinations that do not occur in the thought processes of healthy persons). Negative symptoms include a lack of, or problems with, motivation, as well as neuropsychological deficits in the so-called executive functions (planning, initiating and executing actions and reviewing the results). A skills assessment prior to commencement of employment or change in the requirement profile helps to avoid situations that would overwhelm the employee’s coping strategies. Therefore, for job coaches supporting employees with schizophrena, the following factors are particularly important:

Regarding the disorder:

- is it a recurring disorder?
- is the person in their care undergoing psychiatric treatment?
- is the prescribed medication taken regularly?
- are there typical early or preliminary symptoms that preceeded a relapse or recurrence in the past?
- is there a “contingency plan” for such events?

Regarding the work routine:

- what was the level of performance prior to the condition?
- how pronounced are the above mentioned “negative symptoms”?
- are there any of neuropsychological deficits?
- are there additional stress factors like changing work hours, loud/disturbing environments, night or shift work?
- are employer, supervisors, occupational health service and co-workers informed about the condition and if so, to what extent?

3.3. Affective disorders

Affective disorders, also known as “affective psychoses” or “manic-depressive disorders”, are associated with emotion, mood and motivation disorders and manifest in polarly opposed changes of the affect. They are distinguished by high and low affect, into the manic and the depressive/melancholic symptoms. Motivation changes parallel to the mood and affect., i.e., it is reduced during depression and enhanced during mania when the general level of activity is elevated. Affective disorders progress in phases, with complete remission common (i.e., there can be decade-long “healthy” intervals without any symptoms), and are prone to recurrences without causing any significant personality changes or deficits. In this respect, they differ significantly from schizophrenic disorders.

The term affective disorder was coined to avoid the negative connotations of the older term “manic-depressive illness”. It is also more precise as “manic-depressive illness” implies that every person experiences both, manic and depressive symptoms. However, this is not true. Rather, in the majority of cases there is a “unipolar” progression, i.e., all phases of the condition experienced by a person are either depressive (quite common) or manic (much less common). Accordingly, a condition progression with both manifestations is referred to as “bipolar” disorder or as “affective psychosis”.

Different severity levels are distinguished in the depressive and in the manic phases (“mild”, “moderate”, “severe” episode). If delusions co-occur, the phase is referred to as an “episode with psychotic symptoms”. While during mild and, depending on motivation and environmental factors, also during moderare episodes, the ability to work is essentially preserved, a severe episode is not compatible with a working life and often needs to be treated in an in-patient setting. For persons in a depressive phase, the immediate cause for hospitalization is often suicidal tendencies. Persons with manic disorders usually do not perceive themselves as “ill”, but rather as particularly active, creative and productive, even though this is objectively not the case and the condition leads to serious financial and

personal mistakes. However, without the person's consent treatment is legally not possible or only possible under certain circumstances, which can lead to extreme stress situations for families, as well as work co-workers. After the symptoms have subsided, it is important to remember that the behaviors were caused by the condition and the person cannot be held accountable for them.

Affective psychoses occur at about similar rates in all ethnical groups and societies. The prevalence is about 0.5% to 2%, and the lifetime risk is at approximately 1%. In general, more women are affected. This overbalance is due to the more frequent depressive phases while manic phases are as frequent in men as they are in women. The onset of condition is usually in the third or fourth decade of life. If the first phase is a manic phase, the onset usually is earlier. Bipolar disorders have a tendency of an earlier onset and can occur before the person is 20 years of age. In some cases, trigger events can be identified for a relapse.

Treatment for mild to moderate depressive episodes is mainly psychotherapy. The best results are achieved with cognitive behavioural therapy (CBT). During moderate episodes, antidepressive medication can be helpful and is usually prescribed during severe depression. As motivation and mood are disturbed, family physicians and general practitioners tend to issue sick notes quite readily, even for mild and moderate forms. Although the notion of “rest” is commendable, it risks isolation and withdrawal, furthermore, the persons miss out on social contact, and the feeling of purpose and achievement in the workplace. After severe episodes during which the person is unable to work, an individualized return-to-work plan with gradually increasing demands (“progressive reintegration”) can be helpful.

Acute manic phases are mainly treated pharmacologically with neuroleptics; there is no rationale for offering psychotherapy in the narrow sense during acute manic phases.

Since both depressive and manic disorders are prone to recurrence, “phase prophylaxis” (medication with substances from the “mood stabilizers” group) is recommended in addition to the acute treatment after recurring episodes, depending on the individual progression, and has proven to be of value in many cases. It is important to note that none of the medication groups mentioned, antidepressants, neuroleptics or mood stabilizers/phase prophylaxis,

This Erasmus+-project product was supported by the funds of the European commission

create addiction. This understandable but unfounded concern occasionally leads to discontinuation of treatment; all professionals should work as trustworthy advisors in this field.

The following aspects are important for job coaches supporting persons with an affective disorder:

Regarding the disorder:

- is it a recurring disorder?
- were there depressive, manic or both manifestations in the past?
- is the person in their care undergoing psychiatric treatment?
- is the prescribed medication taken regularly?
- are there typical early or preliminary symptoms that preceeded a relapse or recurrence in the past?
- is there a “contingency plan” for such events?

Regarding the work routine:

- what was the level of performance prior to the condition?
- how can progressive reintegration be structured after an acute episode has subsided?
- are there any neuropsychological deficits?
- are there additional stress factors like changing work hours, loud/disturbing environments, night or shift work?
- are there hazardous situations specific in the work routine to the disorder (e.g., regarding suicidal tendencies or risks during a manic episode)?
- are employer, supervisors, occupational health service and co-workers informed about the condition and if so, to what extent?

3.4. Anxiety disorders

Together with addiction and affective disorders, anxiety disorders are the most common psychological disorders. Three main types of anxiety disorder are distinguished:

a) Phobias are object-related or situational anxieties. Well-known phobias are phobias of certain animals (dogs, spiders) or situations (social phobias).
b) Generalized anxiety disorder have no specific triggers that can be identified; the person experiences fear “of everything”, which can also present as “fear of fear itself”.
c) Panic disorders are diagnosed when the acute onset of anxiety leads to attack-like situations during which the person feels as if they are dying. Prior to identifying these attacks as psychological, suspicions of possible cardiovascular or metabolic conditions must be excluded.

Persons with anxiety disorders typically react with avoidance behaviour, i.e., they try to avoid situations where they have experienced anxiety in the past. This avoidance behavior can expand to complete isolation and withdrawal. Another risk is that of developing an addiction when the person with undiagnosed and/or untreated anxiety may try to numb or prevent the unpleasant or unbearable sensations with either legal (alcohol, tranquilizers) or illegal drugs.

All anxiety disorders are essentially treatable with no long-term impairments after successful treatment. In the majority of cases, psychotherapy in the form of CBT, psychoeducation, and confrontation exercises are useful. Therefore, in an ideal world, a JC/D should not be necessary for a person suffering with anxiety.

A number of maintenance factors abet a chronification and expansion of anxiety disorders. Apart from deficiencies in the care system (lack of qualified psychotherapists, uncritical prescription of tranquilizers with risk of addiction) these factors also often occur in the personal life wwhen families try to relieve the person by taking over their obligations and

responsibilities. This understandable reaction, however, is more likely to cause chronification and expansion of avoidance behaviour. In extreme cases, the person will no longer leave the family circle, subjectively perceived as “safe”, in order to avoid anxiety-inducing situations. Thus, they lose the opportunity of corrective experiences and to find out that allegedly dangerous objects and/or situations are not actually a hazard.

In the working life, anxiety disorders can lead to long periods of absence and work interruptions in severe cases. Here again, co-workers can unwittingly encourage the disorder. When persons with long-term anxiety disorders return to the workplace, the underlying principle should be that of normality. Anxiety disorders do not cause long-term damage or limitations of capability and there are no particular professional activities that are excluded for employees that were formerly diagnosed with anxiety disorders. If a job coach is working as a personal assistant, they should therefore strive to make themselves “redundant”, as permanent assistance on the grounds of an anxiety disorder is counterproductive.

A job coach can, however, play an important role for both employers and co-workers by pointing out the pitfalls of “good intentions”, such as overprotection to relief the symptoms of the disorder. Instead the job coach should actively support the person in finding therapeutic help. Therefore, for job coaches supporting an employee with anxiety disorder the following aspects are important:

Regarding the disorder:

- is it a recurring disorder?
- were there complicating factors in the past like, for example, substance addiction?
- is the person in their care undergoing psychiatric or psychotherapeutic treatment?
- are there typical avoidance behaviours?

Regarding the work routine:

- are there factors at the workplace that have triggered anxiety in the past? They could have been car journeys or certain customer contact events.
- are employer, supervisors, occupational health service and co-workers informed about the condition and if so, to what extent?

3.5. Obsessive compulsive disorders

Obsessive compulsive disorders (OCD) are among the more common mental disorders. They have many parallels to the anxiety disorders discussed in 3.4. A common feature of all OCDs is that the persons are aware of the nonsensical nature of the content and yet the compulsions are upheld by a fear that is perceived as irrational. Typical are cleanliness (for example fear of disease and infection) and control (for example the notion of endangering things by untidiness or risking a break-in by leaving the door open).

Three main types of OCDs are distinguished:

a) *Compulsive thoughts* only contain phenomena taking place in the person's imagination, such as obsessive counting and magical thoughts that are difficult to let go, and therefore impact, for example, on work productivity or processes.
b) *Compulsive impulses* have an imperative component, for example, the person can suffer from feeling compelled to perform aggressive actions against members of their families. This goes against their better judgement and usually, these impulses are not realized such that a bystander cannot see anything "objectively".
c) *Compulsive acts* can be noted externally. They can be anything from short tic-like movements to extensive rituals. Most of all, compulsive acts that are motivated by issues of cleanliness and fear of contamination/infection can have dire consequences on structuring every-day activities and quality of life. A persons may shower for hours and perform their personal hygiene in a strictly set routine; even the slightest

deviation forces them to start over again. Similarly, extensive and time-consuming rituals can occur around the issue of “safety and security”. These can encompass repeated checks of all doors and windows up to repeated checks of all heat sources and electrical appliances; such compulsive acts usually delay leaving the house in the morning and have an adverse effect on punctuallity of arriving at work.

Persons with OCD are usually embarrassed by their own actions, because they are aware that “it’s nonsense”, although they are unable to abolish them. Therefore, the problems are often kept secret or “covered up” with great effort.

OCDs are essentially well treatable. As with anxiety disorders, there are no deficits or long-term impairments after successful treatment. However, even after years, there can be relapses, possibly with a obsessons or complusions of a different new “topic”. Psychotherapy treatment, similar to that for anxiety disorders in the form of CBT, is successful in most cases. The most effective method is exposure, for example with a “contamination stimulus” or desensitisation regarding leaving the house. With the help of a well-trained therapist the (pathological) reaction is preventable. Therapy encourages persons to resist the impulse to engage in excessive washing and disinfection after touching a door knob or using a public toilet or being able to take the bus from their home to work without repeated checks of the stove. Typically, the anxiety and its physical symptoms subside, so that the expectations of looming disaster lose their influence. Certain antidepressants have been successful for people with a more chronic or very severe obsessive- compulsive perception or behaviour.

However, there are factors that abet a chronification or expansion of the symptoms. Apart from deficiencies in the care system (lack of qualified psychotherapists, use of unsuitable forms of therapy), these maintenance factors often occur in personal life. Since the OCD symptoms are “controlled by fear”, therapy is not attractive for every person and treatment

offers are often foregone or discontinued. Unlike anxiety, persons with OCD usually hide their problems and often drift into isolation.

Clearly, OCD can lead to long periods of absence and work interruptions, especially in severe cases. Simply “sitting out” a leave of absence does not lead to an improvement of the situation. When persons with OCDs return to the workplace the underlying principle, as with anxiety disorders, is that of normality. OCDs do not cause long-term damage or limitations of capability; there are no particular professional activities that are excluded for persons formally diagnosed with OCD.

A job coach can play an important role for the employer and the co-workers by identifying workplace-related factors and specific needs for assistance. If the employee has trouble completing a work process, it can be helpful to have external limits on the processing time or an active “intervention” taking the process out of the person’s responsibility.

Therefore, for job coaches supporting employees with OCD the following aspects are important:

Regarding the disorder:

- is it a recurring disorder?
- is the person in their care undergoing psychiatric or psychotherapeutic treatment?

Regarding the work routine:

- are there factors at the workplace that caused or triggered compulsive thoughts, impulses or acts in the past? They could be sanitary facilities.
- do OCD symptoms impact on the work routine; e.g., is the person unable to complete a process because they have to check repeatedly for errors and mistakes?

- are employer, supervisors, occupational health service and co-workers informed about the condition and if so, to what extent?

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4. Best practice examples

This section outlines some best practice examples of employees and employers (all names have been changed).

Mark started working at a furniture shop. Together with the employer we talked about the possibilities for Mark within the existing jobs. Mark liked the early morning shifts, emptying the trucks, and best for him was working 5 days from 7am until 12 noon. At first the employer did not want him to do so because workers on the morning shift needed to perform other

functions. But, while he learned that Mark was best at this work and when his workdays were predictable and structured in some way. So, the employer created work responsibilities around Mark. While working here, doing the same thing every day, Mark learned to work independently. He learned about the store and all the items it sold, and after several years, the employer was able to ask him to carry out different work in the store, working other shifts for example at the weekend and he even felt secure enough to help customers. After ten years he is still working there even with some managerial changes. (Mark has a diagnosis of Autism co-occuring with intellectual disability).

Doreen is a well educated woman who works for ten hours a week in a big company. Although she would like to work more hours it is to hard for her. Her job coach mediates between Doreen and her colleagues, especially her manager. For example, her manager says that she is fully capable of keeping an overview of her work. Doreen does not understand why he is saying this, because she does not feel capable of doing this. She is, however very capable at seeing every detail and found a way to keep all the details well organised together in an Excel sheet. Therefore, when the manager asks her for particular information about tasks that she is working on, she knows exactly where to find the details he is asking for. Her job coach played a significant role in mediating between Doreen and her manager in order that they learn to understand each other better. With the right questions Doreen was capable of organising her work tasks in a way that works for her. Just thinking that it would be good to structure every working day from minute to minute would not help her. It would make her really inflexible and give her more stress if it turned out that she could not finish all of her tasks for the day. She needed a global overview of the tasks she needs to complete in a day, with priorities given by her manager. This gave enough structure and provided sifficient flexibility for any adjustmenst that needed to be made during the day. Ideally the tasks Doreen was required to complete are so clear that she knows were to start and when the work is good enough. If the result is uncleair it makers it harder for her to work on the task and her feelings of stress wil increase. Her job coach needed to be fully

present to give her the best support. It means that she asked questions to help Doreen organise her thoughts, making tasks clear to her, sometimes making decisions for her and being as expliciet as possible. At the start of the coaching relationship the job coach thought she was being sufficiently explicit but it turned out not to be that way. Because she could not talk about her feelings easily, Doreen wrote a letter. She was quite explicit and direct. Because the job coach learned about the disability she knew where this behaviour was coming from and so it did not scare her of. Instead, she learned more about this employee and what was important for her in our coaching relationship. As a result the job coach could support her even better until she trusted her and the coaching got easier and easier. (Doreen has a diagnosis of autism spectrum disorder).

Sonia learned that she needed to be honest about your compulsive thoughts. That required a lot of courage. A mother of two children, she knows what she is talking about. She was raised in a stongly Christian environment. Over the years the fear grew that God would let her "bad" thoughts come true. With every bad thought she prayed to God. It became a ritual that she performed endlessly and everywhere. Sonia expressed this: "Every person has bad thoughts, but most realize that you are not yet a bad person. I started thinking about that." Cognitive behavioural therapy showed her eventually that bad thoughts do not make her a bad person. She explained, "I have learned to let the fear be there, to endure it, no more reassurance." It would have been better if the diagnosis had been made earlier, then she would have benefited from this therapy at a much younger age. Besides the therapy, she also had a lot of support from her husband. "His love, patience and relativity helped me so ... If you have not experienced it yourself, it is very difficult to understand, to feel what it does to you ..." The same empathy had been missing with her colleagues and she feels that therefore she has become an expert for experiences with other people with OCD. "I am committed, come closer than the therapists." Sonia now has a paid job for 14 hours per week and she also studies. "Work is healing, with me it could go hand in hand with the treatment. Work distracts, there is less room for obsessive thoughts. Because of my work I

gained more confidence again, I am proud of myself, I am more among the people. I feel more powerful." (Sonia has a diagnosis of OCD)[10]

Geoff is young man who worked as a runner at a bank. He wanted to be the best, wanting to earn the most money for the bank. It brought a lot of stress. This was too much for his girlfriend and she left him. He started taking drugs and ended up with a severe psychosis. "A psychosis is a kind of allergic reaction to circumstances that are not really there," he explains. When he wanted to return to work with his former employer, his manager advised him to talk to colleagues about his psychosis. The questions that were posed to him and the stories that did the rounds, however, created a lot of tension for him. Eventually he chose to confide in a number of colleagues. "I could no longer keep it to myself ... I do not want to hide." However, this trust was violated and the entire department knew about his diagnosis in no time. And instead of leading to more understanding, colleagues distanced themselves further from him. The word 'psychotic' evokes fear among many people. Nevertheless, according to Geoff, the attitude of others was not the most important obstacle. Recovery started with a more positive self-image. "You have to discover where the light comes from, and move there ... If you cannot see the light, listen to what other experience experts can tell you about it." He reinvented himself. He now speaks of his 'old me' and his 'new self'. An important step in this process was his choice to no longer want to be a runner. Following consultation with him, a suitable job was created at another bank where he could work at his own pace. Eventually, he left the banking world completely. He now works in the non-profit sector. "I am much happier now ... Free from the stress of the bank."
About his psychosis he says, "It was horrible. I really never want to experience that again." Protecting boundaries and preventing stress was of great importance to Geoff, as were a good night's sleep. Sleep deprivation increases vulnerability. Geoff now works now as an

[10] cf., http://www.mmm-mensenmetmogelijkheden.nl/download/?id=1446&download=1

expert in experience in his new life and plans to write a collection of stories about his experiences. (Geoff had been diagnosed with psychosis)[11]

Sean is a director of a company. The company is doing well, clients are very satisfied. Several people with psychological vulnerabilities work within the company. "That's fine", he says very down-to-earth. "The most important thing is that they are motivated. As an employer, you need to know what motivates your people, offer them perspective, give them appreciation." Providing space is also reflected in his story. "A new job can be very exciting, especially if people have not worked for a long time. Give them time and space to grow. Be flexible, for example when it comes to the number of working hours." But also: "In the room of one of my employees it is 28 degrees, I do not have to think about that, but if he works well with it, that's fine". Sean requires openness and honesty from his employees, but also from supervisors. He likes to know what is happening to his staff so that he can take this into account. "Epilepsy? Just tell. But without problematizing ... It sometimes helps to make a joke about it. Reassurance is important, but do not be too careful either". Finally, Sean has a clear message for the group, "The biggest problem lies with policy makers and supervisors. They do not really believe in the possibilities of these people. That has to change first". He ends his story with a quote from Albert Schweizer[12], "I am the life that wants life, in the midst of life that wants life". (Sean is an employer who succesfully employed several people with psychiatric disorders)[13].

5. Summary

Job coaches for persons with dissabilities will be needed for as long as there are adults with disabilities. However, the role of the job coach has changed over time. In the past, the main emphasis of their role was to support the person with disability towards securing and

[11] cf., http://www.mmm-mensenmetmogelijkheden.nl/download/?id=1446&download=1
[12] https://www.goodreads.com/quotes/31219-i-am-life-that-wants-to-live-in-the-midst
[13] cf., http://www.mmm-mensenmetmogelijkheden.nl/download/?id=1446&download=1

retaining a job. Nowadays, employers expect the job coach to offer more of a consultant role. The job coach is becoming more and more a strategic partner of the employer in addition to their coaching role for the person with disabilities.

This change in role requires different skills from job coaches and appropriate training is important. Of course, the organisational perspective needs to be taken into account in the training of job coaches, for example, adding more skills regarding jobcrafting and team effectiveness. However, knowledge about the different types of disabilities with which a job coach is working, as illustrated here, is vitally important and helps to understand the individual employee's needs. If more people with disabilities participate in the open labour market, because a more inclusive work environment is created, than the skills of job coaches have to include improved knowledge about the different types of disabilities of the persons they support.

Like Sean, the employer, pointed out, people need to be honest about their disability. Job coaches can support honesty by helping the employee, the employer and the job coach to talk openly about the disability. This will lead to a situation where the employee, the employer and their colleagues can perform well. Everyone will learn what works well for the employee with disabilities and what circumstances are best avoided because they increase stress and negatively affect productivity. Job coaches need to promote equality and support the employer to adjust work conditions in order to enable people with disabilities to fully participate.

Job coaching is about creating an inclusive work environment for the employee. To be able to do that, job coaches need to influence various stakeholders. This includes advocacy to ensure that policy and finance as well as adequate social networks are in place. It also includes a sufficient level of knowledge about the diagnosis of the employee.

These guidelines describe a number of disabilities that may be encountered by employees who have a job coach. The focus was first on autism spectrum disorder and a number of co-occuring conditions. It described the costs for society, optimal conditions for the work environment for a person with autism and effective interventions that can help a person with autism in their work environment.

This is followed by a section about intellectual disability, a term generally used when a person has certain limitations in cognitive and adaptive functioning. Optimal conditions for the work environment and effective interventions related to work were identified.

The section about psychiatric disorders described schizophrenia, affective disorders, anxiety disorders and obsessive-compulsive disorders. It outlined how these conditions manifest themselves and what it means for the daily lives or persons who have one of these disorders.

Finaly, these guidelines highlighted a number of examples of best practice in job coaching with people with different disabilities. With the appropriate knowledge of particular disabilities and effective interventions, job coaches can effectively people with disabilities to participate productively in the open labour market.