CHALLENGES OF PSYCHOLOGICAL THERAPY WORK WITH AUTISTIC ADULTS

**Ewa Dobiała**
MD, psychotherapist & supervisor-trainee in Polish Psychiatric Association, Basic Trainer on PPT, Mental Health Center in Leszno, Positive Psychotherapy Center in Leszno, Institutum Investigationis Scovorodianum at the Autism Team Foundation (Head of the Psychiatric Section, Poland), Prodeste Foundation (Poland)

Email: edobiala@gmail.com

**Renata Stefańska-Klar**
MA, PhD, counseling psychologist, therapist State Higher Vocational School in Racibórz, Institute of Educational Studies, Institutum Investigationis Scovorodianum at the Autism Team Foundation (Head of the Psychological Section, Poland)

Email: renata.stefanska-klar@wp.pl

**Aleksandra Rumińska**
MA, Doctoral School of the University of Silesia in Katowice, Institutum Investigationis Scovorodianum at the Autism Team Foundation (coordinator of interdisciplinary research, Pedagogical Section, Poland)

Email: aleksandra.ruminska@us.edu.pl

**Paulina Gołaska-Ciesielska**
MA, PhD, psychologist, therapist Centre for Supporting Relationships in Poznań, Institutum Investigationis Scovorodianum at the Autism Team Foundation (Psychotherapeutic Section, Poland)

Email: kontakt@wspieranierelacji.pl

**Maciej Duras**
MA, Pedagogue, therapist Centre for Supporting Relationships in Poznań

Email: maciej@wspieranierelacji.pl

**Weronika Janiak**
MA, journalist, politologist, activist and volunteer FIONA Foundation, Active Foundation FURIA in Poznań

Email: wejaniak@gmail.com
Received 19.03.2021  
Accepted for publication 28.06.2021  
Published 07.07.2021

Abstract

Autism spectrum disorder (ASD), as a neurodiverse developmental pattern, affects between one and two individuals in every 100 people. Autistic individuals experience different challenges in every decade of their lives. The difficulties in sensorimotor functioning, emotional codes, communication and cognition, albeit causing emotional distress, form a basis for developing a unique culture. Knowledge, understanding, respect and openness to neurodiversity are the fundamental prerequisites for Transcultural and Positive Psychotherapists and any professional who intends to deliver psychological therapy to autistic individuals. In this paper, we discuss the medical, psychological and sociocultural aspects of the autistic spectrum and present the basic goals of therapeutic work with autistic adults.

Keywords: adults, autism spectrum disorder, recommendations, Positive Psychotherapy

Introduction

Due to their different developmental pattern, autistic individuals often experience lack of understanding of their unique needs by others, including psychological therapists. In the current medical and psychological sciences, there is no “gold standard” for therapeutic intervention in autistic individuals. At the same time, our understanding of the autistic spectrum changes and becomes outdated very quickly. Whereas there is a plethora of therapeutic interventions intended for autistic children and adolescents (Greenspan & Wieder, 2014), there are only a few interventions intended for autistic adults, making the available assistance on offer insufficient. The number of autistic adults worldwide is difficult to estimate. Epidemiological studies are usually conducted in children and their results are extrapolated onto the general population, which does not seem entirely legitimate. One of the few studies conducted in adults (Brugha et al., 2007) showed that in the UK, the prevalence of autism spectrum disorder was 1%. Clinical experience suggests that the number of autistic adults, who receive their diagnosis of autism very late, e.g. after a long-term search and numerous visits to different professionals, or having discovered their own neurodiversity through the diagnosis of their own children, increases every year. This increase is particularly noticeable in women whose diagnostic assessment requires distinct knowledge and attention from professionals who are only beginning to learn how to effectively recognise the subtle manifestations of the female autism phenotype (Rynkiewicz et al., 2019). As shown later in this paper, the need for psychological and therapeutic support is already great in the autistic population for a number of reasons, and it will become even greater with the growth of that population. Where professionals are not sensitive to the specificity of the autism spectrum, this work may, however, be ineffective and a source of frustration for all parties involved.

1.1 General overview of adulthood

Adulthood is the longest developmental stage in human life, spanning across several decades between adolescence and old age, the boundaries of which are determined by biological, demographic, social and cultural factors. This is because the lifespan itself as well as the ageing rate and legal norms and regulations of different age-related matters affect who is considered to be at the age of consent to e.g. a marriage, who is subject to criminal liability or who is entitled to retire. Developmental psychology has come up with many developmental stage classifications, which are often discrepant in age range boundaries of adulthood. For instance, E. Erikson or R. Havighurst considered the age of 18 as the beginning of adulthood, further subdivided into: early adulthood (18-35 years of age), middle adulthood (aka midlife, 35-60 years of age), and late adulthood (over 60 years of age). D. Levinson considerably extends early adulthood, placing it between 17 and 45 years of age, within which five-year period marking its respective beginning and end seen as a transitional phase (Brzezińska et al., 2015).

Contemporary research data indicates the increasingly “delayed onset of adulthood” in modern young people, which is reflected by their staying in full time education for longer, having a full time, permanent career later, as well as starting a family or giving birth to the first child after the age of 30 years (Brzezińska &
Syska, 2016). Therefore, the divisions of adulthood proposed by contemporary authors need to account for it, although it is not clear whether the key issue should be termed the ‘postponement’ of adulthood rather than its ‘delayed onset’. Accordingly, Bee (2004) suggests that early adulthood begins at the age of 20 and lasts until the age of 40, midlife falls between 40 and 60 years of age, after which the late adulthood follows. This shift of the age at onset affects subsequent age ranges, blurring their limits. In line with the above, Brzezińska et al. (2015) divide human life into 4 distinct stages: early and late childhood (from birth to 10-12 years of age), adolescence (from 10-12 to 20-25 years of age) and adulthood (from 20-25 years of age to the end of life).

Oleś (2015), on the other hand, postulated four criteria which - if met - confirm that an individual progressed to adulthood. The first criterion (1) is accepting and carrying out adult life tasks. Traditionally, those would include having a job and starting a family. Nowadays, however, the extent of social and mental transformations within our culture, as well as changes to the conditions in which those life roles are fulfilled, warrant a revision of adult-like life roles and tasks. Hence, at the moment, adults would be persons who have determined the directions of their life pursuits, have chosen their predominant activity (not necessarily of a professional nature), have identified their aspirations for the subsequent 10-20 years and are capable of active and persistent attempt to live their chosen lives. Regarding starting a family, this expectation is increasingly more often replaced now by considering themselves ready and able to build long-term relationships or abide by their choice to live alone. The second criterion (2) is the ability to take responsibility for oneself and others. The third criterion (3) is achieving independence, in particular emotional independence, from one’s parents (carers/ protectors). This does not necessarily mean leaving the family home, which - Oleś postulates - is not the most important thing. Instead, he argues, the ability to make autonomous choices and decisions without the need for the decision-making process to be supported or approved by “an adult”. The fourth criterion (4) is the freedom of choice and the accompanying drive to fulfill one’s desires and aspirations. This takes courage (to live an independent life), perseverance (to tackle adult life roles), and endurance (in the face of hardships and obstacles) to continuously strive to achieve one’s goals despite difficulties and setbacks.

Thinking of these criteria, it becomes clear that adulthood is not about one’s age. Instead, the factors related to individuals and the degree of their personal development, as well as contextual factors creating the field of possibility, necessity and acceptability of one’s actions play the key role.

1.2. Adulthood on the autistic spectrum

When assessing psychosocial function of autistic adults with the view to determine their needs in order to provide sufficient support, a number of factors which affect their daily lives, beyond those typically associated with their current stage of life, need to be considered. These are all biological/ medical, psychological and social consequences of neurodiversity, that is, of the autistic pattern of development, which need to be explored beyond the usual psychopathological perspective (Stefańska-Klar, 2017a; Stefańska-Klar, 2017b).

1.3 Medical aspects of autism

Contemporary understanding of the autism spectrum assumes its neurobiological nature, underpinned by both genetic (Sandin et al., 2014; Risch et al., 2014) and environmental factors, which affect both prenatal and postnatal brain development. The research to date failed to identify any isolated causal factors. Hence, autism spectrum disorder is considered one of the most heterogeneous neuropsychiatric disorders. Numerous cohort studies (e.g. Hviid et al., 2019) have excluded the link between autism and vaccinations, which was suggested in 1998 and has since become popular. On the other hand, variations in over 700 genes have been confirmed in autistic individuals. However, these include only few de novo mutations (Ruzzo et al., 2019). Hence, even though the genes clearly play a role in autism, their phenotypic expression in autistic individuals remains highly variable (Veenstra-Vanderweele et al., 2004), affected by a number of prenatal, perinatal and postnatal factors (Wang et al., 2017). The specificity of autistic cognition, sensory and motor function as well as communication pose a medical challenge throughout the lifespan of an autistic adult alongside comorbidities, both physical and mental, including primary and secondary disorders. Highly prevalent, those comorbidities contribute to the
high variability of clinical presentations in autistic adults.

Recent studies show that 50% of autistic individuals have at least four confirmed comorbidities (psychiatric, neurological, endocrine, rheumatologic, gastrointestinal, etc.) and that over 95% of autistic children have at least one additional diagnosed condition (Baron-Cohen, 2020). In clinical practice, 83% of autistic children have another neurodevelopmental condition, 10% have at least one mental health condition (anxiety disorder, depressive disorder, eating disorder, etc.), and 16% have a concomitant neurological disorder. Sleep problems affect 50% to 73% of autistic individuals, with prevalence depending on the assumed definition of sleep or the assessment tool used in a study (Hodges et al., 2020).

The prevalence of mental illness and disorder increases significantly with age in the autistic population, which is believed to be attributable to childhood and adolescence microtraumas and traumas. Approximately 50-70% of autistic adults have at least one diagnosed mental health condition. The risks of depression and schizophrenia in autistic individuals are 3 times and 22 times higher than in the non-autistic population, respectively. Even though the risk of a suicidal attempt is 5-fold higher in autistic individuals, only 50% of those who attempt suicide have been previously diagnosed with depression. The prevalence of autoimmune, endocrine or rheumatologic diseases is also significantly higher in autistic individuals compared to the general population. A single population-based prospective study indicated that the mortality risk in autistic population is nearly twice that of the general population (Mouridsen et al., 2008).

1.4 Psychological difficulties of autistic adults

Individuals with autistic traits (whether formally diagnosed or not) experience a range of psychological difficulties, both specific to their condition and those commonly affecting other adults for a number of reasons. The developmental, clinical and health psychology provides tools to group those difficulties translating into different counselling approaches (Czabała & Kluczyńska, 2020). Some of those problems result from internal and external barriers to one’s progression through consecutive developmental stages and/ or fulfilling their respective developmental tasks, positive resolution of normative life crises. These may as well be difficulties in maintaining optimum mental health and associated psychological wellbeing, which stems from satisfaction from a life which one perceives as meaningful, fruitful and conducive to their further personal development.

The World Health Organisation (2004) defines mental health as “a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community”. Therefore, from a psychological perspective, mental health is a by-product of reaching one’s full potential in terms of meeting one’s needs, achieving one’s aspirations, plans and goals, undertaking tasks which mobilise one’s internal and external resources, as well as positive coping with stress and difficult life events. What follows is acknowledgement of mental health as a sine qua non prerequisite for achieving everything that wellbeing depends upon i.e. good and fruitful human functioning, positive adjustment to life changes and self-fulfilment in terms of achieving one’s aspirations.

Research into psychological functioning of autistic adults supports the conclusion that it is a group particularly vulnerable to stress and its consequences, as well as to experiencing emotional crises of various origins. Environmental maladjustment, related to the situational stimuli or challenges and difficulties of social life, seems an important factor (Hirvikoski & Blomqvist, 2015). The inherent autistic specificity of receiving and processing sensory and semantic information, as well as interpersonal and social difficulties (encompassing cognitive, emotional and practical aspects), means that many situations that most neurotypical people find to be usual and manageable become considerably difficult to cope with for the autistic individual. Some situations may even put one on the verge of mental and physical safety, being exceptionally energy-consuming and demanding significantly intense activity across different domains, in order to meet the expectations, achieve the goal or just survive until the conclusion of a situation. It should be noted that the emotional and energy expenditures in question are considerably higher compared to those of a neurotypical individual. When such experience becomes regular or even permanent, one lives in a state of chronic fatigue, leading to periods of exhaustion and even a subjective sense of ‘life burnout’ (Stefanińska-Klar, 2020). One’s inability to cope with the situation may lead to atypical consequences, sometimes perceived as shocking by the environment.
These can be sudden affective-behavioural outbursts (meltdowns) or energetic breakdown, manifesting as a prolonged inability to move, detachment from the stimuli, or even falling into a deep sleep, regardless of one’s physical location (shutdown). In the absence of support and access to personal resources, exhaustion results in what has been termed ‘autistic burnout’, which is a state threatening to health or even life itself.

A distinctive group of psychological difficulties experienced by autistic individuals are those resulting from the untimely (i.e. accelerated or delayed) achievement of subsequent stages of psychosocial and personality development. They stem from the mismatch between one’s intellectual ability, readiness to undertake specific developmental tasks, and one’s social, communication or emotional skills. Alternatively, they may originate from one’s not being ready to assume certain roles, despite societal norms and expectations expressed, explicitly or implicitly, by those important to an individual (Stefańska-Klar, 2017). The society may "push" an autistic person to assume roles and tasks considered age-appropriate, status-appropriate, or expected by socio-cultural norms. Alternatively, fuelled by fear, concern or prejudice, it may create barriers, hinder his/her activity or prevent him/her from taking certain actions. What follows, as psychological consequence, is the lack or loss of autonomy, emotional crises, depression and/or learned helplessness. On the other hand, the effect of autism may cause difficulties in achieving one’s goals and meeting one’s own needs even for an individual who is successfully fulfilling his/her personal life plan, in the absence of, or despite barriers or obstacles. Whereas such effect may be confined to an individual (personal problems, personality difficulties, etc.), it often affects the person’s closer and more distant social environment, such as relationships with loved ones, within the family system, workplace, neighbourhood etc. The autistic individuals who are in relationships, have started families and have children, experience problems typical of couples or families where a member of a family is autistic, be it an adult, a child/children or both. In these circumstances, the autistic traits of one or both spouses/ partners affect the issues typically addressed in couple counselling, family therapy and psychological support for parents of autistic children, which should always be taken into account when working with this client group. For example, autistic parents may fear that they are not competent enough to raise their non-autistic child, feeling unable to understand the child or to appropriately respond to the child’s needs.

Another group of psychological difficulties is linked to self-image and self-acceptance, the subjective meaning of life and perceived life satisfaction, which form the basis of psychological wellbeing across the lifespan. This includes all issues associated with autism awareness, understanding its impact, accepting the diagnosis, self-contentment as well as a positive appraisal of one’s place in the world and the quality of their relationships with others. As reasonably expected, the needs of young adults will differ from the needs of those in their midlife or old age. Hence, it is important to identify the stage of adult life affected by the personality and existential difficulties of an autistic person (Stefańska-Klar, 2017).

1.5 Social and cultural dimensions of autism: the issue of autistic self-identity

Autistic self-identity, defined as a cognitive self-perception of an autistic individual in all possible relationships with oneself and the outside world, can only start to develop once autism has become known. Building self-identity requires grounding in society and culture, followed by a construct of awareness and self-awareness, the ability to identify oneself with others and compare one’s own traits with those of others. A. Giddens (2012) defines self-identity as “a reflexive project of the self, which consists in sustaining consistent, yet continuously revised, biographical narratives, and takes place in the context of multiple choice as filtered through abstract systems”. Autistic self-identity, as the collective identity of a social movement, cognitive self-perception common to and shared by groups of people with similar characteristics, defined as autistic traits, is a new and dynamic reality, yet deeply rooted in culture, created by, and typical of, society. It fits into the model of resistance identity with projective characteristics, as defined by Bokszanski (2005), because the social actors are marginalised by the logic of domination, which leaves them feeling stigmatised. They are often excluded from full participation in social life, which additionally grounds them in resistance leading to adopting rules different from those upheld by the part of the society which is excluding them. The activities aimed at a comprehensive transformation of the social structure and its underpinning principles (Bokszanski, 2005),
being one of the key objectives of autistic self-advocacy, demonstrate features in keeping with the projective model of identity. Such activities bring about qualitative changes in the level of autism awareness and understanding. Thus, as such, they are significant from the praxeology perspective. This is largely a credit to self-advocacy movements, which aim to empower groups and individuals, help them regain their agency, and ensure that human and civil rights are duly granted. Self-advocacy is therefore centred on such sociological categories as trust, agency, social identity, care, dignity and respect, representation, cooperation, and subjectivity (Raclaw & Trawkowska, 2017).

The history of autistic self-advocacy movements dates back to 1990, when the first such identity movement of individuals diagnosed with autism, the Autism National Committee (AUTCOM), was founded “... to protect and advance the human rights and civil rights of all persons with autism and related differences of communication and behaviour. In the face of social policies of devaluation, which are expressed in the practices of segregation, medicalization, and aversive conditioning, we assert that all individuals are created equal and endowed with certain inalienable rights, and that among these are life, liberty, and the pursuit of happiness” (https://www.autcom.org/about.html [accessed on: 30.08.2020]).

Another such organisation, the Autism Network International (ANI) is an autistic-run self-help and advocacy organization for autistic people created in 1992 by Jim Sinclair, Kathy Grant and Donna Williams. The organisation objectives are to help autistic people identify positive ways of living with autism and about functioning as autistic people in a neurotypical world, to give them a sense of belonging to the shared autistic culture and, since 1996, to share and expand knowledge based on first-hand accounts of autistic people during Autreat conferences (https://www.autreat.com/History_ofANI.html [accessed on: 30.08.2020]).

In 2006, Ari Ne’eman and Scott Michael Robertson founded the Autistic Self Advocacy Network (ASAN), an international organisation whose motto is: Nothing about us without us. It was founded in response to the US legislation as well as inaccurate media portrayals of autistic people as lacking independence, dangerous and in need of intensive aversion therapy. ASAN voiced their opposition to Autism Speaks - an organisation claiming to support autistic people and their families, on the grounds of their systemic, strategic disregard of autistic people their contribution to autistic stigmatisation and excluding autistic people from the public debate on issues which directly affected them. The ASAN initiated the campaign to introduce legal changes in a bid to prevent the Judge Rotenberg Educational Center from using the graduated electronic decelerator (GED), an electrical stimulation device designed by the centre’s founder, Matthew Israel. The American Food and Drug Administration (FDA) only banned the GED in 2020, after the United Nations had twice condemned the device as torture. However, the IRC still use other aversive treatments on their students and residents (https://www.masslive.com/news/2020/03/after-fda-bans-judge-rotenberg-center-from-using-electric-shock-devices-advocates-seek-public-apology-reparations.html [accessed on: 01.09.2020]).

The grassroot initiatives appear essential for the discourse on the place of autistic individuals in the society. Therefore, such autistic self-advocacy movements and third sector organisations working with and on behalf of autistic people and their allies have been set up in Poland, too. These are the Bright Side of the Spectrum [Polish: Jasna Strona Spektrum] autistic self-advocacy organisation and autistic self-advocates centred around the Mary and Max Association [Polish: Stowarzyszenie Mary i Max]. Furthermore, the Autism Team Foundation, an organisation for autistic people, their families, friends and allies, has the “Conscious Youth Club”, a grassroot initiative started by Jan Gawroński, a young autistic self-advocate. All these groups provide psychoeducation for autistic people, their families, teachers/educators and other professionals. Some of those initiatives additionally aim at promoting positive changes in law and infrastructure in order to reduce social disability of autistic individuals.

The ASAN website reads: *Autism (...) is not a disease. It is a neurological, developmental condition; it is considered a disorder, and it is disabling in many and varied ways. It is lifelong. It does not harm or kill of its own accord. It is an edifying and meaningful component of a person’s identity, and it defines the ways in which an individual experiences and understands the world around him or her. It is all-pervasive* (https://autisticadvocacy.org/about-asan/identity-first-language/ [accessed on: 04.09.2020]). This definition is quintessential for autistic self-advocacy. While it does not rule out the coexistence of autism and disability, it points out that such coexistence is not a
commonplace. Autism is not a functional deficit or deficiency, which can and should be corrected. An autistic individual growing and developing in a friendly environment will build his/her self-identity based on their personal resources and those obtained from the environment; hence autism cannot be seen as an “addition” to an individual. Furthermore, as Sabina Pawlik points out, autistic self-advocates, whose activity contributes to shaping the autism discourse in a public domain, win increasingly more control of categories that they are defined by, exposing such dark sides as eugenics, institutional abuse and stigmatisation that have been an experience of many autistic individuals (Pawlik, 2015). A pursuit to define normality based on what is common, homogeneous and uniform by means of rejecting what is different, is deeply rooted in our culture. Whatever causes upset, anxiety or surprise should be investigated and explained (Brauner & Brauner, 1988). As the investigation is limited by the resources and tools, uneducated communities developed their own folk stories, myths and legends. In those, developmentally different individuals were labelled as “foundlings” (in Polish: podrzutki, podciepy, niańduchy, zamienoki, znajdy, cf. Kojder-Demska, 2020), that is, children dropped off in their families by goddesses, elves, good people or other characters of the world of magic. This emic notion of disability still significantly affects the level of social acceptance of disability or developmental differences. It is reflected in numerous superstitions regarding, for instance, pregnant women and babies. Babies still wear red ribbons as a protection against evil and the motif of a “bad eye” is omnipresent across cultures. Some people still believe that disability can be a punishment from God for the sins of one’s ancestors, or a result of substandard upbringing.

The perception of autism has also been affected by the development of social sciences, starting from L. Kanner and H. Asperger whose work encompassed the concept and diagnostic criteria of autism. Later, Bettelheim’s psychogenic theory of autism with its central ‘refrigerator mother’ concept caused significant irreversible harm to autistic people and their families (Rosmalen & Veer, 2020). Unfortunately, that is also true about the applied behavioural analysis using aversive treatments developed by Lovaas (Kirkham, 2017). Finally, contemporary authors such as T. Attwood, T. Gątkowski or S. Baron-Cohen, undisputed autism research experts, have also contributed to the current perception and understanding of the autistic spectrum.

In the project discussed, we have been guided by the motto: “The person comes first” from the inception of our work, with the primary aim of putting the patient/client, his/her emotions and needs first in all therapeutic support, regardless of his/her cognitive and social potential, self-awareness, emotional regulation, health or independence. Hence, the humanistic therapy paradigm, in which the perception of a person as a subject rather than object is central to all activities building on one’s strengths and protecting their vulnerabilities, regardless of one’s (neuro)diversity or disability, has become central to the recommendations postulated herein. This paradigm is consistent with the social definition of disability, and the perception of disability in terms of normalisation, integration and emancipation (Krauze, 2010). Defining autism as neurodiversity rather than a disorder is a significant aspect of autistic self-identity and a factor in promoting and maintaining good mental health of autistic individuals.

**Methodology**

These recommendations were written as part of the "Awareness and Relationships. Improving Access to Psychological Therapies for Adults on the Autism Spectrum" project carried out by the Centre for Supporting Relationships as a part of the “Accessibility Generator: Social Innovation Incubator” under the Operational Programme “Knowledge Education Development”, Priority Axis IV Social Innovation and Transnational Cooperation, Action 4.1 Social Innovation, co-financed by the European Union under the European Social Fund. The aim was to inspire reflection on the specificity and distinctness of (psycho)therapeutic work with neurodiverse persons. The author team, all being members of the project working team, represent various domains of science and clinical practice. We decided to present different perspectives on and modes of understanding of the autism spectrum in adulthood. The descriptive language of this paper was intended to be supraparadigmatic, hence the terms patient/client were used interchangeably to denote an autistic individual seeking therapeutic support, leaving behind the discussion of the meanings attached to those terms. We firmly believe that, whether termed a client or a patient, individuals and their needs should always be at
the heart of design and delivery of any support services. Accordingly, the overarching aim of such services should always be to promote their optimum wellbeing - both physical and mental - with the possibility of achieving their full potential in good relationships with their important ones. The target audience of this paper are researchers and clinicians of various professions, who encounter or may encounter neurodiverse adults as a part of their respective roles. We are convinced that therapeutic encounter of an autistic individual differs from that of a neurotypical individual and, as such, it requires a separate, in-depth discussion. In line with project limitations, an autistic person is denoted herein as an autistic adult without concomitant intellectual disability (aka learning disability, LD). The issues of psychological therapy with autistic adults with concomitant LD are relevant and significant enough to warrant a separate project followed by a separate article or even a book. Being aware of the need for such recommendations, it is our intention to develop them as a part of subsequent social innovation projects.

Results

The following recommendations are the sum of the conclusions of the working team and then of three groups of reviewers:

- three independent psychotherapists experienced in working with autistic patients
- three independent autistic people with experience of psychotherapeutical process
- three independent psychotherapists implementing the developed by authors recommendations in daily psychotherapeutical work within three months.

3.1 Therapy goals in autistic adults

Highly vulnerable and with a unique psychosocial profile, autistic adults and children can undoubtedly benefit from therapeutic support, which should aim at:

1. identification of one’s own physiological and emotional states with their subsequent self-regulation,
2. increasing self-awareness,
3. understanding one’s own needs and wellbeing and learning how to meet/ promote them,
4. coping with sensory hypersensitivities, and
5. acceptance of one’s neurodiversity. Autistic people are at high risk of developing mental health problems - depression, anxiety, strong psychosomatic response to stress - which are typically secondary to their needs being unmet throughout the lifetime, as they are exposed to high levels of stress from an early age - in education, peer relationships, developmental crises, professional career and/or family life (if one chooses to have a family). This highlights the urgent and vital need to build awareness and broaden the understanding of unique cognitive, emotional and social aspects of autism in professionals (including therapists) and to teach them how to effectively support autistic adults. Whatever shape or form such awareness-building takes, it is always worth the effort.

The “Awareness and Relationships: Improving Access to Psychological Therapies for Adults on the Autism Spectrum” project carried out by the Centre for Supporting Relationships as a part of the “Accessibility Generator: Social Innovation Incubator” under the Operational Programme “Knowledge Education Development”, Priority Axis IV Social Innovation and Transnational Cooperation, Action 4.1 Social Innovation, co-financed by the European Union under the European Social Fund was an attempt to fill the gap in the support offered to autistic adults. The aim of the project was to draw particular attention to the psychosocial situation of autistic adults without learning disability and to inspire debate and reflection on the quality of available support. The outcomes of the project included, alongside the current article, an educational brochure containing detailed clinical recommendations for professionals working with autistic adults, as well as an instructional video which present the recommendations in an enriched, more dynamic manner (all resources will be available at www.wspieranielerlacj.pl and can be directly requested from the authors). Using the opportunities of the social innovation projects, the resources developed by the project working group were reviewed by both experts according to knowledge (psychological therapists) and experts according to experience (autistic patients/clients). This ensured that the developed content was evidence-based and well-suited to the needs of its recipients, both direct (therapists) and indirect (autistic adults). The project was carried out between September 2020 and May 2021.

The project working group developed a number of recommendations for professionals who work (or intend to work) with autistic patients/ clients. One of those recommendations includes primary therapeutic goals which can/ should be considered when working
with autistic adults in an effective, respectful and dignified manner. These goals can specifically include:

- Developing the SELF, that is improving one’s awareness, building identity, strengthening self-esteem, developing the philosophy of acceptance and/or affirmation of their autism spectrum condition whilst developing acceptance (and/or affirmation) or other people’s uniqueness, thus promoting positive regard for human diversity.

  These four elements (self-awareness, coherent self-identity, healthy self-esteem regardless of one’s ability levels, and accepting neurodiversity, both one’s own and that of other people) are the most important therapeutic goals when working with autistic people of any age - children, adolescents, and adults.

- Enhancing self-regulation and coping skills, especially in highly emotive situations or during a sensory overload;

- Developing emotional literacy and awareness (starting from identifying emotions based on bodily symptoms) and working towards emotional maturity;

- Building understanding of one’s own needs followed by understanding the needs and emotions of others;

- Identifying relaxation techniques and activities (massage, osteopathy, manual therapy, medication, physical activity - individual or in a group setting), as well as self-regulation and self-soothing strategies (stimming, acupressure mat, weighted blanket, etc.);

- Developing the ability to maintain a dynamic psychoemotional balance and to return to it following the short-term highs/ lows;

- Developing the motivation and competence to build relationships, become a part of a wider community and positively contribute to it in a number of accessible and mutually beneficial ways, while feeling the satisfaction from said contribution and attending to the emotional needs of others;

- Building on one’s strengths - exploring their special interests and passions, while moving away from a harmful, negative view of autistic special interests/ passions as manifestations of disorder (“fixations” or “stereotyped behaviours”);

- Supporting individuals to identify their strengths and talents and to set suitable SMART goals.

- Building assertiveness, especially in those who have been exposed to ‘therapeutic interventions’ which disregarded their needs and their right to autonomy (such individuals are exceptional patients; sometimes a professional can also encounter an adult completely dependent on other adults - their carers - despite a clear potential and capacity for more independent living).

We emphasize those particular goals, as they have been disregarded in many other proposed interventions for autistic people (despite having a clear role in promoting and maintaining optimum mental health) in favour of interventions focused on eliminating autism or fixing what is “autistically broken”. Supported by the reasoning of Polish and international researchers and organisations, we encourage the shift of perspective towards a more humanistically-oriented view based on respect for each person’s uniqueness.

The strategies that may help achieve the goals described earlier which can be used by professionals, include primarily

1) a therapeutic relationship based on trust and positive regard,

2) creating the sense of safety, by means of understanding and acceptance shown to the client by the therapist, their consistent responses, attitude, and a stable, predictable setting, that a client considers important.

For many autistic people, this will also include the therapist’s appearance (e.g. hairstyle, hair colour, attire, etc.), the therapy room layout (also important in online therapy). Any significant changes may cause upset, uncertainty or distraction causing difficulty focusing on the actual conversation;

3) session continuity and regularity (session frequency can be changed as long as regular intervals are kept) avoiding sudden, abrupt changes.

Most autistic patients prefer more frequent sessions to discuss ongoing changes in themselves, their environment and the relationship between themselves and the environment, especially if these discussions seem to be helping in their daily lives. However, where the therapy is not a part of the public healthcare system or subsidized by external funding with the third sector provider, financial constraints will likely determine therapy duration and session frequency;

4) therapists’ open-mindedness and willingness to explore new ideas, solutions, and techniques to meet
the needs of a patient whose needs evolve throughout the relationship and who may need different activities or challenges.

This requires flexibility and creativity, but also the therapists’ ability to learn from their patients, their motivation to be led by their clients and accompany them, while encouraging changes;

(5) providing ample opportunities for the client to test out the newly acquired skills and to put them into practice, first in the therapy room and then in life;

(6) considering one’s personal development as the overarching principle for everything that takes place as a part of therapy.

This means that, alongside the immediate or short-term goals, there should be some long-term goals which determine the direction of change in the clients’ behaviour and personality as well as provide the general direction in their ongoing work on their own lives. Obviously, the clients still remain the principal architects and creators of themselves and their lives. The therapist is their conscious companion, sometimes taking on the role of a guide or adviser, but never making the choices/decisions for an individual.

Conclusions

The growing awareness of neurodiversity in society creates the need to be both attentive in a diagnostic setting and aware of potential challenges in a therapeutic setting when working with autistic people.

Positive Psychotherapy (PPT after Peseschkian, since 1977), owing to its humanistic-psychodynamic nature and a deep reflection on transcultural dynamics (Dobiała & Winkler, 2016), is one of the promising approaches in psychological therapy for autistic individuals (Dobiała, 2020). We remain aware of the need for further research and publications to enable a debate and reflection on the neurodiverse specificity across various aspects of psychological therapy for autistic people, including the therapeutic covenant, relationship and process.

It should also be noted that being an autistic adult is not a condition which requires an urgent psychological or psychiatric intervention per se, as autism itself is not a condition to be treated or fixed. However, psychological therapy, especially for those who have grown in an environment not embracing their neurodiversity and not promoting their autonomy and independence, can prove an important, powerful driver for a change understood as developing a good, healthy autistic life. This paper is one of the outcomes of the “Awareness and Relationships: Improving Access to Psychological Therapies for Adults on the Autism Spectrum” project carried out by the Centre for Supporting Relationships as a part of the “Accessibility Generator: Social Innovation Incubator” under the Operational Programme “Knowledge Education Development”, Priority Axis IV Social Innovation and Transnational Cooperation, Action 4.1 Social Innovation, co-financed by the European Union under the European Social Fund. As the project team members we hope that the content of this publication, the brochure and the instructional video, which aim at changing the perception of autism and improving the quality and relevance of support services to enable comprehensive, holistic development of autistic people will inspire reflection, promoting updated and improved understanding of autism by researchers and practitioners working with autistic adults.

References


[22] Koider-Demska, K. (2020). Bohynie, dziwożon, mamuny, czyli skąd się biorą niepełnosprawne dzieci [Bohynie, goblins, moms, or where the disabled children come from]. URL: https://www.academia.edu/35760453/Kaja_Koider_Demska_Bohynie_dziwo%C5%82Cony_mamuny_cyli_sk%C4%85d_si%C4%99_bior%C4%85_niepe%C5%82nosprowane_dzieci, p. 4 [accessed: 14.03.2021]


Acknowledgements

The authors gratefully acknowledge the assistance of Karolina Kalisz in translating the manuscript.

Author contributions

Ewa Dobiala - coordinator of work on a scientific article, member of the project working team, author of an abstract, subsection No. 1.2., co-author of subsection No. 2, 3 and 4, additionally substantive correction and consolidation of individual fragments of the text.

Renata Stefańska-Klar - member of the working team, author of sub-chapters: 1.1, 1.12, 1. co-author of subsection No. 3, additionally of a substantive correction and consolidation of individual fragments of the text.

Aleksandra Rumińska - member of the working team, author of subsection 1.4, co-author of subsection No. 3, additionally of substantive correction of the text;

Paulina Gołaska-Ciesielska - project manager, author of the section 1. and 2. , co-author of subsection No. 3 and 4, additionally of a substantive correction and consolidation of individual fragments of the text.

Maciej Duras - member of the project’s working team, correction of the text.

Weronika Janiak - member of the project’s working team, correction of the text.

Competing interests

This article was written as part of the "Awareness and Relationships. Improving Access to Psychological Therapies for Adults on the Autism Spectrum" project carried out by the Centre for Supporting Relationships as a part of the “Accessibility Generator: Social Innovation Incubator” under the Operational Programme “Knowledge Education Development”, Priority Axis IV Social Innovation and Transnational Cooperation, Action 4.1 Social Innovation, co-financed by the European Union under the European Social Fund.