

## Vocational Development of Persons with Autism Spectrum Disorder in Switzerland

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### ABSTRACT

*Over the next decade in Switzerland, about 17'000 adolescents with autism will become adults. In the canton of Vaud alone, 1'700 autistic adolescents will arrive on the labor market. We believe it is possible that these individuals will not all need to be financially supported by the community. But for this to happen, their unique qualities need to be considered and there should be support for their professional insertion. The medical, economic, and social issues surrounding autism are numerous and there are many resources focused around the early detection, something which works to the detriment of support in adulthood. The Swiss Federal Council adopted a strategy spell "health 2020" in order to better integrate adults with autism which aims to grant health care system access to this population since the current care situation of adolescents and adults with ASD is insufficient. Continuity of care and longer appointment times are important potential improvements in primary care.*

*We inform you in this article some problems of the care situation for patients with ASD in Switzerland, the treatments, measures and support team at different life stage to inform clinical practice. In our society, work is the fundamental value by which we present ourselves to others and individuals with autism need to be recognized within the framework of their difference, otherwise there is a high risk of developing symptoms that are incompatible with social and professional integration. Obviously, a natural balance exists between one's personal profile, one's profession, and the suitability of the work environment.*

### Keywords

Autism Spectrum Disorders, Asperger's Syndrome, Vocational Development.

### Definition

Autism is a neurodevelopmental disorder characterized by deficits in social cognition, interpersonal interaction, and reciprocal communication, as well as repetitive behaviors and narrow interests.

In its neuropsychological aspect, this disorder involves the functioning of perception as well as the cognitive processing of information that is singularly complicated by the inability to understand and embrace the thoughts and behaviors of others [1], this in a context where the processing and integration of dynamic information is lacking [2-7].

This great difficulty in understanding the complexity of the dynamic environment in its entirety leads to emotional, cognitive, and behavioral maladjustment, which makes it an important handicap in terms of social integration [2,8,9]. These individuals have, on the one hand, an inability to see the world from many perspectives and, on the other hand, to recognize in this process the implication of emotions and intentions. Such a representation seems to be biased by hemispheric dominance. Thus, context blindness, or caetextia, would explain dichotomous thinking, stereotyped behaviors, sensory hypersensitivity, as well as difficulties in abstract thought, social relationships, and coping with unexpected events [10].

The DSM V [11] now links Asperger's syndrome to the category of Autism Spectrum Disorders (ASD) and no longer defines it as a specific category but places it on the extreme positive pole of a continuum encompassing all ASDs. It is therefore a question of

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targeting which alterations of functioning - light versus severe - would handicap the patient, on a scale of severity elaborated according to the need of support that would have to be mobilized to achieve an optimal functioning of the person. Several authors therefore speak of a constellation of disorders and unequal competencies [12-14] with a strong intra-individual variability [15]. The latest large-scale studies have estimated the epidemiology of ASDs from 1% to 2% of the general population [16-18]. Men are two to three times more likely to have ASD than women, indicating the crucial impact of genetics, endocrine, epigenetic, and environmental factors in the pathophysiology of ASD [17]. However, the precise etiology of ASD remains uncertain [19].

Autism spectrum disorders (ASD) have been widely researched in children; however, the quantity and quality of adult research, including research with those diagnosed as adults, lags behind research conducted with autistic children [20,21]. Much of the current research evidence concerning autistic adults is limited by small sample sizes and most participants being “high functioning” [22].

If we take the lowest estimate, namely 1% of the population under 20, in Switzerland [23] according to the Federal Statistical Office [24], over the next decade, about 17'000 adolescents with autism will go on to adulthood. And then, in the canton of Vaud alone, 1'700 autistic adolescents will arrive on the labor market. It is difficult to predict the professional autonomy of these 17,000 individuals.

### **Towards social acceptance and self-representation**

It is often expected that the person with Asperger's will gain full autonomy because of the absence of intellectual deficiency. Because of this, it is crucial to note that the notion of autonomy tends to be confused with the concept of fulfillment for the non-autistic population. Indeed, if an access to autonomy represents an end in and of itself, a happiness, for the civilized human being, it is perhaps different for the autistic person, for whom that autonomy will not necessarily be synonymous with quality of life.

Thus, rather than expecting the autistic person to live a normal life, it would more be a question of thinking through with him what the essential elements would be to ensure a life of quality according to the criteria that only he can define in an optimal way. Rather than hope for a life within the norm for him, i.e. a normal life, it might make more sense to wish him an enviable, happy and optimal life.

Research with adults on the autism spectrum is as yet limited in scope and quality [25,26]. The study of Mason & et al. [27] is important because it shows that using the World Health Organization quality of life measure, it found that autistic people (370) in the UK reported their quality of life to be lower than that of the general population. Better quality of life was associated with being in a relationship and work; those with a mental health condition had poorer quality of life. This research suggests some ways in which autistic people can be helped to improve their quality of life.

### **Social belonging and professional identity**

The person with Asperger is also faced with the difficult question of having to choose, at a very young age, a suitable profession in order to achieve financial and social autonomy, participate in society, and ideally flourish there. But the peculiarities of Asperger syndrome are like a double-sided coin. They represent performances and peculiarities all at the same time; some abilities may be sought by the employer but a certain functioning that is uncomfortable in some contexts may prevent it. Certainly, it is a question of developing the natural talents of the person so that they become professional skills, and to better develop the workstation to reduce any aspects that could cause concern and hinder the exploitation of said skills.

It is sometimes said that Asperger's syndrome is a mild form of autism, the end of the autistic continuum "dissolving into" in normality, and "that no profession is a priori impossible for a person with autism without intellectual disability [28], the situation is more nuanced when the syndrome and real-life interact, and we would rather say that no profession is a priori unthinkable for a person with autism to the extent that his motivation is real and to the extent that a natural fit obviously exists between his personal profile, his profession, and his work environment. In this, the individual with Asperger's is in the same situation as any other young person of his age—that of having to make an informed choice.

Even if each person with Asperger's is unique in their autistic functioning, general trends can still be noted with regard to the professional aspects, and this is what we will try to explain most clearly, in a comparative approach that is intended to be constructive and positive at the same time, and for the autistic people concerned, and for their non-autistic environment, colleagues, and employer. Because we think that an upstream reflection in a young person with Asperger's can drastically reduce the risk of failure and of course especially favor his professional success.

It is also a reminder that the suicide rate among people with Asperger's syndrome is high. Storch et al. [29] reported that 11% of people with autism studied had suicidal thoughts and behaviors that were associated with the presence of depression [17,30]. Cassidy et al. [31] found that people with autism were more likely to have suicidal ideation than people in a general sample of the UK population (the ratio is a 9.6 higher risk than in the general population). In the Chen et al. [17], which is a longitudinal study of a large sample, there is a high likelihood of suicide later in life with the onset of psychiatric co-morbidities.

Also, different authors [32,33] have noted that ‘camouflaging’ by autistic people is described as exhausting, and in the long term can be a threat to self-perception. These findings suggest that females may have an advantage in social situations, and males may find social and professional situations more challenging.

Ignorance about the syndrome is a challenge, because of the mistaken choices that it often involves, and the ill-founded

attitudes of rejection or misunderstanding that it generates around the Asperger's individual. A well-designed professional training perspective should enable him to rely on his qualities, to share them, to make them fruitful, and render inoperative his hypersensitivities, his social withdrawal. It is thus a question of distinguishing normalization and quality of life, for example with the acceptance of the peculiarities of visual contact [34], the motor mannerisms [35,36], the hypersensitivities. Accepting these differences can help improve quality of life and furthermore, exploiting the autistic person's specificities such as specific interests, rigor, and perfectionism can increase his / her potential for integration into the labor market [37-39].

Finally, it would be important to use additional resources for the support of young adults with autism. Currently, most efforts are put into early detection. This means that resources and focus diminish over the years, and eventually disappear once the individual reaches adulthood, implying that the work is done. Yes, the early detection of autism is essential because it will allow the child to reduce his suffering, but we must not believe that early detection will allow individuals with autism to "normalize" through to the approaches used to support it. Autism is an irreversible neurobiological condition that cannot be cured and will be present throughout the life of the person concerned.

In adulthood, three main characteristics are predictive of lower quality of life in almost all domains [27]: being female, having a current mental health diagnosis and higher severity of autism symptoms. A number of factors positively predict quality of life: better physical quality of life is predicted by being employed, greater social quality of life is predicted by being in a relationship and receiving support, and environment quality of life is also predicted by receiving support. These results provide evidence-based indications of specific potential targets for interventions and services to improve quality of life for autistic people; for example, older autistic women with mental health conditions are one group particularly likely to need support through services.

### What strengths and pitfalls to avoid for a person with Asperger's job search or training?

Here is a non-exhaustive chart listing the main qualities and weaknesses of a person with the Asperger's Syndrome. Taking into account these particular aspects could help facilitate his or her career path, for the benefit of all.

Assets to value, qualities to favor	Pitfalls to avoid, fragilities to spare
Needs discipline	Give clear direction
Needs routine	The work to be done should be vague (avoid the phrases: do as you like, it doesn't matter, that isn't important)
Transparent communication	Implied Communication
Organization	Do not disturb the individual, do not give the person work at the last minute, Do not change his or her habits
Specific interests	Think carefully before making a choice

A constancy of quality and fulfillment on the long term	A need for non-stressful breaks and deadlines, well thought out schedules
Care and attention to detail	Overinvestment
A very great sensitivity	A need for sensory fittings, soundproofing, solitary work, no open space
Seriousness to the task	Social withdrawal
Perfectionism, discipline	Rigidity, lack of flexibility
The desire to do well in all circumstances	Over-adaptation and exhaustion
Sincerity	Excessive candor
Loyalty	The need for equity and justice
Honesty, respect for the rules	The need for meaning, frame, coherence
Punctuality, reliability	Anxiety about change, the need for regularity, trust
Originality	A creativity needing guidance

**Table 1:** list of the main qualities and weaknesses of an autistic person.

### Intervention in Switzerland

In 2009, the Swiss Conference of Cantonal Ministers of Education (EDK) ratified an agreement which included three valid legal tools: 1) a standardized procedure of educational needs, 2) a standardized terminology, 3) quality standards for providers. The agreement's provisions clearly position education according to conceptual foundations as well as on tools coming from the International Classification of Functioning, Disability and Health [40]. The ICF is a bio-psycho-social model that doesn't consider disability as a damage to health and/or development, but as the result of interactions between anatomical, organic, and environmental systems. It is thus vital to intervene in the individual's environment by introducing facilitators, as well as work with the individuals involved by developing their skills according to their own resources. This agreement emphasizes each time that an integrative education solution is possible compared to a solution that separates the individual in question. Educating young people with autism is less about their diagnosis as it is about their training projects. The idea is to evaluate the particularities and individual uniqueness, no matter the diagnosis or level of development. Interventions are not based on deficiencies, impairment, or disorder but on the emerging skills of the individual. Since then, the Swiss Federal Council adopted a report from 17.10.2018 [41] in order to better integrate adults with autism. The report indicates that Swiss health policy is to decisively contribute to the improvement of quality of life, especially by promoting the quality of the care offer. But this is a major challenge because there is wide inequality across Switzerland in this domain. Permeability and collaboration between the different sectors are problems that must be dealt with (p.8). The Swiss Federal Council notes that inpatient, intermediate, and outpatient care structures need to be developed. Furthermore, numerous studies show that there is a lack of programs facilitating the transition to adulthood [33,42,43]. The Federal Council developed a "Health 2020" strategy which aims to grant health care system access to this population since the current care situation of adolescents and adults with ASD is insufficient [43]. Unfortunately, between 2009, the date the Cantonal Education

Ministers first ratified the agreement, and today, the date the Federal Council approved its “Health 2020” strategy, the measures have not yet been implemented. The Council estimates the costs for the program as between 20-25 million francs per year and per canton (p. 23).

### **Problem of the care situation for patients with autism in Switzerland**

In its 17.10.2018 report, the Federal Council made recommendations (4, 5, 6, and 7a) for a disability policy targeting treatment equality for all individuals affected and with the goal of promoting their participation in society. This goal should be achieved through better professional integration (p. 31). Unfortunately, today, the existing measures of professional integration are not specific to individuals with autism. The OECD [44] report « mental health and employment – Switzerland concludes that the transition from school to professional training proves problematic for adolescents and young adults with autism. The same applies to the professional world in terms of stable job retention [45].

The Federal Council’s “Health 2020” program is meant to encourage access to further offers to promote integration (p. 39). A survey held in the canton of Vaud shows that specific offers can reduce the need for support [46].

The report concludes [46] that only the targeted qualification of specialists will enable them to appropriately and professionally provide support to adolescents and adults with autism. Which is why the recommendation for different specialists and for acquiring specific expertise on autism.

On page 42, the report deplors the lack of available data and research in the field of autism in Switzerland. The WHO [40] also mentioned this situation and recommended that Switzerland hurriedly improve its system of data collection. There is no current data on the number of individuals with autism in Switzerland, the type of ASD involved, and the care they receive. And yet this information is vital for planning at both the cantonal and federal level (p. 43). The proposed measures include conducting epidemiological studies.

### **Why Invest?**

It is necessary to insist upon the fact that investments lead to savings. Indeed, financing targeted interventions for individuals with autism translates into achievable savings in the long term [47-49]. In England, for example, the National Autistic Society estimates that if the national services manage to diagnose and then support the 4% of adults with Asperger’s who are not yet receiving care, then cost neutrality for the public authorities can be guaranteed in the long-term. If these services identify and support 8% of these individuals, the government can save 67 million pounds per year [50]. The Swiss Federal Council has estimated the average cost of support for an individual with autism in a care center at 15 million for the life of the individual. The creation of new professional training offers but also support (lodging, work) is part of the Council’s 6th and 7th recommendation in order to

cover existing needs.

### **Treatments, measures, and support team at different life stages**

What follows is a proposal inspired by the Federal Council’s report [41] that specifies actions throughout the life of a person with autism during their transition into adulthood.

Development of actions must be founded on the following areas of focus:

- Recognize autism in the sense of the CIF or the DSM-V: that autism is a situational disability and that it requires an adaptation of the working environment.
- Offer each young adult a customized program that considers his or her emerging skills, resources, and potential.
- Encourage vocational schools to base their action on an individualized program.

### **How to intervene in real terms?**

The March 2018 HAS [51] published recommendations and its Part 2 focuses on professional insertion. Page 48 mentions conventionally believed but false ideas, such as, “...that people with autism are more intelligent than the general population; that a person with autism cannot work; that employment will aggravate the difficulties related to autism.” Certain adults with autism do have particular skills in certain areas. The initial evaluation is fundamental to determine their specific interests, the means and rhythm with which they learn, their knowledge and general capacity to work. If there are learning difficulties, it is important to know whether its better to do re-training or correct the issues. Retraining involves specific training programs in certain areas like skills related to professional stance, while correcting the issues is more about finding a way around a problem by using the individual’s other emerging skills to achieve the desired result.

The intervention must also pay special attention to the compatibility of the adult with autism and the profile of the position. For example, it isn’t appropriate to place an individual with autism in a receptionist position that involves multi-tasking (answering phones, welcoming clients, making phone calls). It is also important to provide guidance to the employer both before and after the individual begins a position. For example, we provided assistance to an employer who was not aware that the employee had autism, even if she had worked for the company for several years. The situation had become difficult and the employer was interpreting the behaviors of the employee as an opposition to authority. Although the employee’s work was impeccable, the employer informed us that it was too late, the woman with autism had isolated herself and was no longer integrated in the group. The manager could not take any more. She had been dismissed.

Guidance provided to the employer should focus on a knowledge of autism, the availability of a separate space to be apart, the spatial-temporal structuring of the activity, the professional environment must be calm and without open-space, and with suitable lighting, and instructions given in a determined period of time. Most of the time the individual with Asperger’s isn’t able to express what he

Stage / Procedures	Treatments / Procedures / Measures	Services and support team involved	Overall conditions
Transitions throughout schooling	Ergotherapy Speech therapy at school Psychomotor skills Curative education Psychotherapy Social skills training, individually or in groups TEACCH PECS ABA	School based psychological services Experts in curative education School administration School inspectorate, school-based social workers Parents Department of education Disability insurance (medical treatments)	Parental guidance (administrative and organizational) Parental involvement Involvement / Guidance for teachers Coordination Early planning Specific preparation Detailed follow-up of the transition Direct collaboration (round table) Information to classmates and their parents
Transition I	Social skills training Ergotherapy Curative education Psychotherapy Public vocational guidance Vocational guidance services from disability insurance Years of preparation in selection of profession Transitional training offers Motivation semesters	School administration School-based social workers Parents School-based psychological services Experts in curative education Vocational guidance Unemployment insurance Disability insurance (re-training) Retraining centers	Parental guidance (administrative and organizational) Parental involvement Involvement of future employer Coordination Early planning Specific preparation Detailed follow-up of the transition
Dual training system	Social skills training Training assistance Coaching (in case of training for primary job market) TEACCH PECS ABA Ergotherapy Speech therapy Psychotherapy Psychomotor skills	Retraining centers Disability insurance (re-training and medical re-training measures) Employer Vocational school	Compensation for disadvantages Requisite educational measures for vocational training Guidance for employers Guidance for the vocational school (teachers) Information to classmates and working colleagues Parental involvement
School training (high school, specialized school, etc.)	Social skills training Ergotherapy Speech therapy Psychotherapy Psychomotor skills	Disability insurance (re-training and medical re-training measures) School administration	Compensation for disadvantages Requisite educational measures for vocational training Guidance for teachers Parental involvement Information to classmates
Transition toward studies	Vocational guidance	Disability insurance (re-training) Specialized services "Studies and Disabilities" at the university	Introduction, follow-up and support
Transition II	Coaching Follow-up by a re-training center Trial placement Initial allocation to work	Disability insurance (re-training)	Coordination Early planning Specific preparation Detailed follow-up of the transition
Work in sheltered workspace	TEACCH ABA PECS	Workshops Cantonal office for the elderly and people with disabilities	Individual programs including individual goals
Employment on the primary job market	Coaching Guidance and follow-up Job retention measures	Disability insurance (re-training) Employer	Coaching, guidance, and follow-up of individuals involved and employers Information to work colleagues

**Table 2:** The table demonstrates some of the complexity of the situations, of the number of individuals and organizations involved, and the importance of overall coordination.

or she needs. They would like to be a part of the group, to be like everyone else. The individual's uniqueness's catch them out, and their hypovigilance becomes a source of exhaustion. This is why strong lighting should be avoided, as well as individuals who arrive unexpectedly who might surprise the individual with Asperger's. Also to be avoided are people coming to talk to the individual during their work, because this will mean the person must begin a task all over again as well as experience strong physiological reactions like shortness of breath, perspiration, and pain in the ears

and eyes. Here is an example of an ideal office for someone with Asperger's: "Something soft like cotton underfoot, and so walking on it would be soft and wouldn't hurt my feet. The walls would be covered with a large, thick wall hanging, in wool, and so it would be warm and soft at the same time. The furniture would be rounded so that it doesn't hurt if one bumps up against something." Also, break times should be avoided because although this is a restful and convivial place for neurotypical individuals, it is actually a form of extra work for the individual with Asperger's. For them,

pauses are actually mathematical equations that must be solved. Often the room is loud, there is an echo, and it's warm inside; the people are noisy while they drink and eat. Furthermore, the person with autism must follow several conversations at once and they do not know what to say or when to say it. So the individual with autism should not be required to take breaks with the group. He or she still needs breaks but should be able to take them alone in order to confront any hyperstimulation.

### Work problem

In our society, work is the fundamental value by which we present ourselves to others and is related to the issue of belonging. The person with Asperger's needs to be recognized in his difference and also in his or her particular talents. She also feels the need to be able to give something to the society and not just to be beholden, a feeling which is often experienced in Switzerland by those individuals who receive a disability pension.

A recent systematic review of studies of adult found that fewer than 20% of autistic people enjoy 'good' quality of life defined objectively as independent living, with friendships, and employment and almost 50% have poor or very poor quality of life by these criteria [52].

As we have said in the introduction, in Switzerland over the next decade, around 17'000 autistic teenagers will reach adulthood and enter the labor market. The Minister of Health and Social Action of the Canton of Vaud, Pierre-Yves Maillard, speaks of an amount of support for the supervision of a person with autism at around CHF 300'000.- per year and per individual (TSR "tuning" program of 8.4.2018 containing comments from the Forum interview of 28.3.18 [53]) Is it possible to prevent these 1'700 Vaudois people from being dependent upon the community?

It is therefore necessary to give them an important role in our society, but this can only be done if we allow training that takes into account their particularities because the need for framework and benchmarks is important for the autistic person.

It is therefore also necessary to favor the adaptation of the professional environment of the individual with Asperger's because autism is not a disease, it is a handicap of situation.

Finally, suicide-related symptoms and psychopathologies should be monitored more closely than is currently the case in people with autism. Switzerland may have a role to play around this issue. While the medical, economic, and social challenges around autism are numerous, Switzerland's small size as well as its high standard of living could foster some pioneering work if it would open up the philosophical element and participate in some civilizational soul-searching.

### Financial Sources

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