

Employment and Adults with PWS in France

This text is a short and incomplete survey of the situation of adults with PWS in France regarding employment - the possibilities and the challenges.

Firstly, it is necessary to understand how disability is managed in France.

When a situation of disability is identified, the family may make a submission to be considered by a departmental commission for disability. This multidisciplinary commission is composed of local civil servants, the family, social workers, representative and experts in disability. The commission will set a "disability rate", and develop a care-plan.

This plan may include:

- access to various supports either in the ordinary environment, in protected work or in specialised workshops;
- a place in a residential home with or without medical support.

This system has many drawbacks including:

- delays - in certain departments, families may wait a long time for their file to be evaluated;
- lack of knowledge - the members of the commission, in the majority of cases, do not know anything about PWS;
- focus - the assessment is based on criteria where autonomy in daily life is dominant. It was designed for physical disabilities and is not well suited for conditions such as PWS.

In 2016, PWF surveyed its membership; the results indicated:

- 2% were directed towards the ordinary environment, 1% for adapted environments 34% for specialised workshops (ESAT), and 66% for residential homes.

However, in practice, the person may not accept the assessment, may not find a job nor a place in a residential home.

The real situation was as follows:

- 58% had no employment, 1% were students, 34% were in specialised workshops and 7% in protected employment or in the ordinary environment.

For most families, a specialised workshop (ESAT) is the goal for their child. ESAT workers are people with disabilities with a special status. They are paid and may work full or part-time. The instructors and professional do not have knowledge in PWS and PWF is sometimes asked to provide specific training for challenging behaviours. The types of jobs proposed are often repetitive, such as packaging, however, sometimes open-air activities relating to animal welfare or gardening is offered. People with PWS are proud of being paid and recognised as workers. Behavioral problems are, however, frequent and can lead to dismissal.

This system faces many criticisms. It is not open and reserved for people with disabilities. There is no training for neurodevelopmental disease and there is a lack of understanding around food security. Moreover, workers in ESAT live either in their families or in residential facilities where they have a great deal of autonomy. Access to food is not controlled and personal hygiene is often problematic.

ESATs are managed by non-profit private associations. Their business model is fragile drawing upon public funding and subcontracted work, which is becoming more difficult to secure and sustain.

With regard to protected employment or employment in the ordinary environment, companies with more than 20 employees must employ a minimum of 6% of people with disabled worker status. Failure to do so incurs a penalty proportional to the missing number of disabled employees of between 400 to 500 times the minimum salary. Many companies prefer to pay this fee as in reality the rate is not 6% but 3 or 4%.

The employment problem for people with disabilities is the subject of very active debate between two extreme positions:

- a preference to facilitate employment in the ordinary environment, which raises the question of necessary supports, and, with high unemployment rates, available places are hard to find.
- the need to create more places in specialised workshops, with the drawbacks mentioned earlier:

In fact, the fundamental question is about social inclusion. In our societies, paid employment is a privilege, but there are other solutions which could expand inclusivity and increase recognition.

Sadly, the problem of global support and coordination is not really addressed and positive solutions can rapidly turn to severe failures.

Training, for everyone involved in managing people with disabilities and people with PWS in the working environment, is the key to success; in reality, however, such training is unfortunately lacking.