

Challenge of transition in the socio-professional insertion of youngsters with neurodisabilities

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Pascale Baumann (corresponding authors), phone number 0041786594727,
Pascale.Baumann@unil.ch

Christopher Newman, Senior Lecturer, Paediatric Neurology and Neurorehabilitation Unit, CHUV,
Lausanne

Karin Diserens, MER, Transition consultation of young adults, Department of Clinical Neurosciences,
CHUV, Lausanne

Keywords: neuromuscular, neurodevelopmental disorders, young adults, transition, rehabilitation, studies, employments

Abstract

Patients with neurodisabilities require early management, continuing into adulthood. Thus, transition services were implemented in hospitals. To have a better support when they enter into adult life, it is useful to know the problems that they could face. The aim of this study is to evaluate their activities and to assess their insertion problems in the professional world. It is based on medical records of patients, aged 16 to 25 years, followed in the transition clinic of young adults in the Neurorehabilitation services of a tertiary centre. From 387 patients of the paediatric consultation, there are 267 patients (69%), included 224 with neurodevelopmental diseases and 43 with neuromuscular diseases. Nearly half of them (46.8%) were in a protected environment, 37.08% studied and 3.4% worked. Paradoxically, only 29.2% reported work problems. These results highlight the need to increase the integration of young adults with neuromotor disorders in the labor market.

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Introduction

Adolescence is a critical period for anyone. Each young adult has to adapt to changes in their body, develop an identity and detach from the family life to make new experiences with people of their age. Patients with neurodisabilities (ND) have to face additional challenges in connection with the developmental disorder and all the co-morbidities. According to Roebroek et al. [1], people with ND have “less experience with teenage activities such as mixed peer contacts and small jobs. These restrictions in participation could come from the critical period of transition from childhood to adulthood”. Presently, “an increasing numbers of them are living into adulthood, thus the focus of the healthcare has to moved from survival to understanding how to support them to make the transition into adult world, be independent, successful and contributing adults society” as expressed

by Donkervoort et al [2]. Thus, transition units were created in hospitals. They provided continuity of care and allowed adolescents to engage more autonomously in their own health-care, as described in several studies [3,4,5]. In addition, these services use a multidisciplinary approach to surround the patients in their social and professional life [1,6].

During adolescence, all young people have to think about their future. The same questions arise for people with ND. At this age, they usually attend a mainstream or special needs school, with adapted teaching. Mesterman et al. [7] explored the state of education of 163 Israeli individuals affected by cerebral palsy (CP) aged from 8 to 30 years. Seventy-nine percent reported having completed 12 years of schooling or longer. Among them, more than half attended a segregated class, a part of them having been diagnosed with attention-deficit hyperactivity disorder or specific learning difficulties. Thus, the majority followed schooling. However, in the study by Darrah et al. [8] educational programs were mainly designed to enrich the social experiences of young people with CP and dysgraphism in Canada. Some of them explained that they could pass the year, not according to their results, but to maintain friendships. Therefore, there is a lag between graduation and their actual knowledge. Paradoxically, several studies [9,10,11,12,13] have reported that the level of education was a predictive factor for getting a job on the labor market. This factor is particularly important if a person has a physical disability without mental retardation, in this case, an intellectual work will be more suitable than a physical job. Previous studies [8,9,10,11,14,15,16], that examined the employment rate in patients with ND, found results ranging from 29% to 56.7%. There was a huge gap between these two results. Pathologies of participants (some of them studied patients with dysgraphism, some others with CP and the last both disabilities), inclusion or exclusion of patients with mental retardation, age of participants are several factors that may explain this discrepancy.

In Switzerland, the difficulty for people with disabilities to find an employment in the competitive labor market is increased by the fact that Swiss companies are not under any incentive to employ them. There is no proactive attitude towards the employment of disabled people, unlike

other European countries. For example, French companies that have more than twenty employees must have 6% of disabled people, for German companies the figure is 5%. If this criteria is not respected, companies are fined.

The purpose of this study is to evaluate the activity rate of adolescents and young adults with ND entering or about to enter professional life, assess the distribution between education and employment, whether in public or protected environments and identify the problems that they might encounter. For all these points, the results were compared between two groups of patients divided by age: 16-20 and 21-25 years old. In Switzerland, people under 21 years old (the younger group) are supported for their medical care by the national disability insurance (AI). Their medical and psychiatric care, their aids (wheelchair for example), obligatory school and professional formation were supported for all of them. At 21 years old (the older group), they needed to apply to receive money: AI will calculate a degree of disability, according to that, they will receive a specific amount to support them. But the annuity did not always equivalent to what they received before. It is necessary for transition services in neurorehabilitation to know these results in order to adapt the support as required.

Methods

This is a retrospective study based on patient records of the Neurorehabilitation services of Lausanne University hospital, Switzerland. In total, there were 387 patients aged 16 to 25 age. 267 patients, all originally from the French part of the country, were transferred from the paediatric neurorehabilitation consultation to the young adult transition consultation. Patients suffered of neurodisabilities, divided into neuromuscular disorders (NMD) and neurodevelopmental disabilities (NDD). Part of them had mental retardation (MR), that is mean an intellectual quotient under 70. Secondly, subjects had between 16 to 25 years old with a median age of 19.1, divided into two age classes: 16-20 (73.8%, N=197) and 21-25 (26.2%, N=70) years old. The patients who were transferred

to the young adult transition consultation were the patients with a disability diminishing their cognitive or physical autonomy. The others had no medical follow up of a specialist.

Data was collected in medical records by the transition medical team. Furthermore, a social worker has developed a questionnaire to assess social and professional situations of patients. They were asked about their studies (in public school, private school or sheltered school), level of education (there were three levels in public school), their work (in open or sheltered employment, activity rate), problems at work or to find a job, their financial status (if they had financial assistance) and their leisure. Results were summarized using descriptive statistics. Associations were made between professional activities and personal characteristics (age, type of disability, with or without mental retardation, motor ability). To perform comparisons, X^2 tests were used, with $p < 0.05$ considered statistically significant. Finally, the rate of participants in training was compared to rate in the population for the same age, according to the Swiss Federal Statistic Office.

Results

Forty-three (16.1%) patients had NMD, which included: progressive muscular dystrophy, myotonic dystrophy, mitochondrial myopathy and Charcot-Marie-Tooth neuropathy. The NDD group included 224 (83.9%) patients, who had: CP, dysraphism, dysmorphogenetic syndromes (Angelman, Rett, trisomy 21), hereditary degenerative disease and traumatic brain injury. Patients with MR were 99 (35.6%).

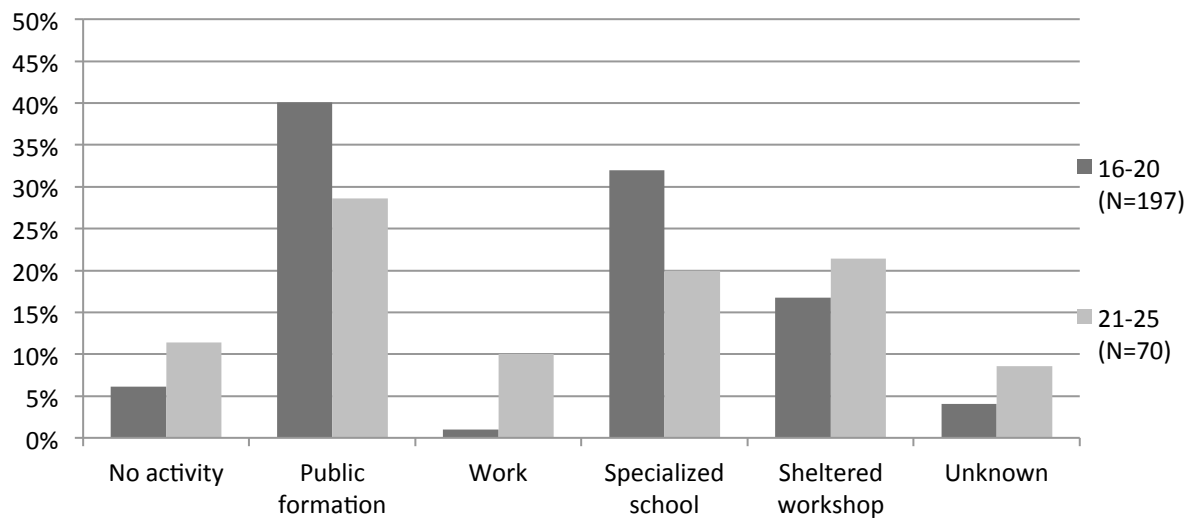
Table 1 : Distribution of participants in education (N=176), n(%)

Specialized	77 (43.75)
Normal education	99 (56.25)
Secondary school	38 (21.59)
Lower level	16 (09.09)
Middle level	9 (05.11)
Higher level	2 (01.14)
Other	11 (06.25)
Learning at work	33 (18.75)
High school	20 (11.37)
University	8 (04.54)

Taking into account all the participants with all ages, the distribution of their academic or professional projects are as follows: most young adults (46.8%, N=125) were in a protected environment. Indeed, 28.8%(N=77) of them were in a special needs school, where classes are smaller and the level of education adapted to each, and 18% (N=48) spent time in sheltered workshop. 37.1% (N=99) of the participants were in education, whose distribution is shown in table 1. People who worked represented 3.4% (N=9) and only two of them had a full-time employment. Regarding the other participants, 7.5% (N=20) were inactive and for 5.2% (N=14) their activity was not known.

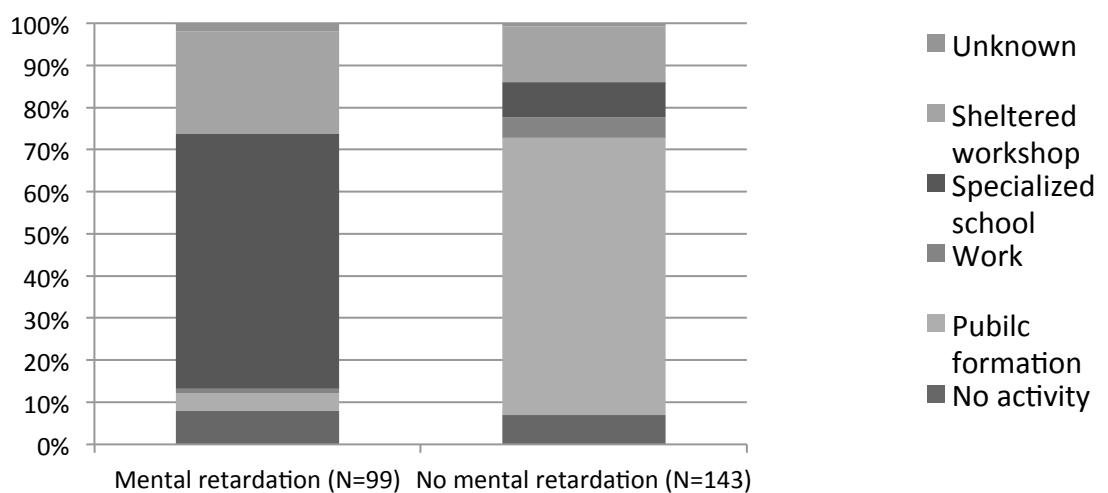
In figure 1, the distribution of professional projects is shown by age. As expected, older participants attended less public or specialized schools. However they were not significantly more in protected environments (41.4%, N=29, against 48.7%, N=96, for the youngsters; $p=0.937$); it showed an increased rate of work and unfortunately an increase of inactivity for the older group.

Figure 1 : Distribution of types of professional activities by age group (N=267)



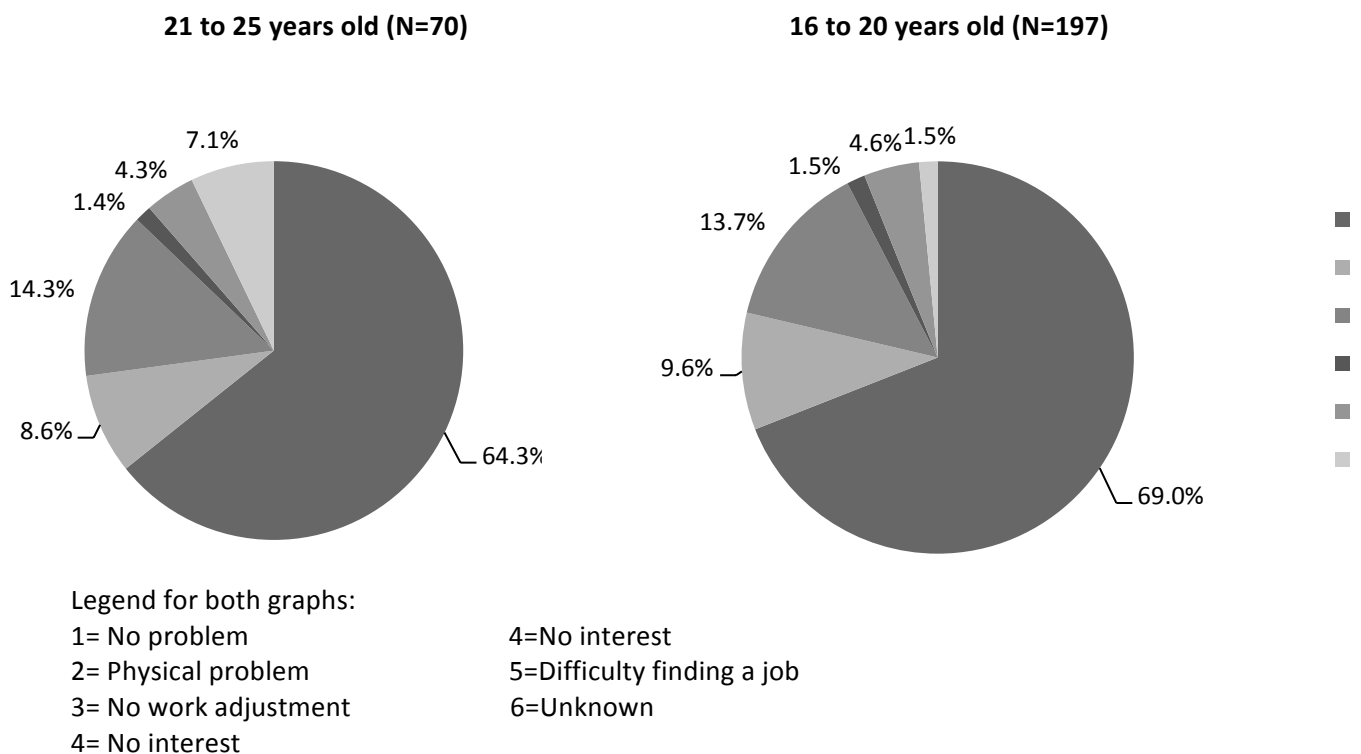
Other points were that attendance in protected environments was significantly higher for patients with MR (85%, N=84) than for patients with a normal intellectual function (21.7%, N=31) ($p=0.0059$) as represented in figure 2, but not significantly higher for patients with NDD (48.5%, N=111) than for patients with NMD (37.2%, N=16) ($p=0.323$).

Figure 2 : Distribution of types of professional activities by mental retardation (N=242)



During the transition consultation of young adults, 29.2%(N=78) of patients spoke about problems related to their professional activity. These problems have been identified and classified in figure 3, with patients separated into two age groups. Firstly, about 13% found that adaptation to disability in the workplace or at school was insufficient. Physical problems came second and included: fatigability, pain, planning and concentration disorders, slowness and difficulty to carry loads. Complaints may come from the patient himself or complaints of his employer reported by the patient. They also spoke about difficulties to find an internship or a work place. A minority expressed a lack of interest for their employment. Despite financial difficulties, patients over 21 years old did not complain of more problems than the younger group. Finally, patients who could walk complained significantly more about problems (39.3%, N=70) than the ones having to use a wheelchair (8.9%, N=6) ($p=0.03$).

Figure 3 : Distribution of types of problems by age groups (N=267)



Discussion

The majority (65.9%) of young adults from 16 to 25 years old, who had passed through the transition clinic in neurorehabilitation, were still in training. Participants were divided into two classes: the youth group (from 16 to 20 years old) and the older group (from 21 to 25 years old). Taking into account mainstream and special needs schools, 72.1% of participants in the youth group were in training. According to the Swiss Federal Statistic Office, 74% of young Swiss people of the same age were still students. The proportion was close, but the distribution was different: 20% of patients were still in obligatory school against only 3% in the population and 9% studied in university, but this number was doubled in the standard population. In the older group, 49% were in training, but only 35% in Swiss young people for the same age. Thus, studies were longer for patients with ND and the rate of people at university was reduced. This could be a problem, since some previous studies [9,10,11,12,13] have highlighted the fact that the level of education is a predictive factor for getting a job on the labor market.

Only 3.4% (N=9) of patients worked. Of these nine, two participants had a full-time employment, four had a part-time employment, one was waiting on a vocational rehabilitation and the last two worked in a family business. The observed factors that promoted a position on the labour market were: “to have no mental retardation” and “to be completely autonomous”. Especially if they had mobility limitations, finding a job was more difficult as reflected in previous studies [17,18] and like it was seen in this study (only one person in a wheelchair among the 9 who worked), because they were more in protected environments. Their jobs were preferentially in offices, except for patients with more severe disorders (cerebral palsy with cognitive impairments or serious sequelae of traumatic brain injury) who worked for the family business.

The work participation rate of 3.4% found in this study was lower than the percentages reported in earlier studies, which went from 19% to 56.7% [8,9,10,11,14,15,16]. But these studies took participants of all ages. Patients from the study of Barf et al. [18] were same ages as this study,

but all of them had spina bifida and persons with serious physical or mental impairments were excluded. In the group of participants who had finished their study, 47% worked and 38% had no activity against 11.7% and 26% for the present study. This difference may partly be explained by more severe disorders affecting patients with NDD, especially 41% of them had MR. That was why they were more in sheltered workshop (62.3%) than the other study (15%).

Approximately, the same proportion of people with NDD and NMD studied, particularly at the University. Paradoxically, patients with NMD were less represented in labour market. Indeed, the only one patient with NMD who worked, had to ask for a professional rehabilitation, because of the evolution of his disorder. Thus, they complained more about insufficient adaptation to disability in the workplace. Adjustment problems and lack of financial support could explain a decrease in competitiveness at work. This hypothesis could explain a very small number of employees, thus these patients should go in sheltered workshops. Another point was that the walking patients complained more about problems, it was probably related to less attendance protected environments by patients who walked (40.4%, N=72) than patients in wheelchair (71.6%, N=48).

Results were based on patient's records. Therefore, data were from the last consultation of patient, that might be from several months up to a year ago. Thus, information might have changed or evolved since that time. Moreover, information was not always in the records, gaps could appear in the data of certain patients. Another point was that the population of patients younger than 21 years old (N= 197) was 2.8 times larger than the older group (N=70). From the 387 paediatric patients only 69% (N= 267) were transferred to the young adult transition consultation as their symptoms interfered with their daily life. The others had probably stopped their medical follow-up before or during the transition time to the adult unit and seven of them stopped because they died. This loss of follow-up could explain in part the very low percentage of work participation in this study compared with others studies. Mentioned items can be sources of bias in this study.

Conclusion

The majority of these young adults with NDD were still students. Overall, their studies were longer and they were less at university than Swiss people at same ages. The most important finding of this study was the small number of people professionally independent. They were 9 out of 267 patients to work and only two of them had a full-time employment. The criteria to be competitive were: no MR and to be completely independent. Patients with NMD worked less and it was harder for them to keep their job if there was a progression of the disease. The main problem related to work was the lack of adaptation of the workplace and some physical problems like fatigability. Knowing these problems, a transition team could adapt its help, its support to patients and to find solutions to increase their competitiveness in the workplace.

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Declaration of Interest Statement

The authors report no conflicts of interest.

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