Adolescents with cerebral palsy on the road to adulthood

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Abstract

Transition to adulthood is for adolescents with cerebral palsy even more challenging than for their abled peers. Empowering them gradually as soon as possible by involving them in decisions for issues that affect them, will give them self-esteem and will help them in their evolution to maximal autonomy. It's important to refer children with medical comorbidities in time to adult subspecialists and the general practitioner should be involved to keep an overview. Adolescents with cerebral palsy encounter quite a few obstacles on the way to participation. A counsellor that is familiar with all the possibilities in the "market of care and support" could be an added value to guide parents and children through this period and later on in adult life. Factors that have a negative influence on the quality of life of adults with cerebral palsy are pain, poor physical fitness, non-addressed psychological issues as a child, parental stress and the ability to develop and maintain peer relationships. One should take this into account when dealing with adolescents : prevention and early treatment of pain, leisure time activities with peers (abled and disabled) with physical activity should be encouraged, the use of new technologies could be a strong motivator for movement and therapy, emotional and psychological problems in childhood should be addressed, parents should be supported. A lot of practical obstacles to participation still need to be addressed by society but real inclusion demands a shift in attitude of society towards persons with a disability, embracing diversity.

Introduction

The time that cerebral palsy was a paediatric condition has long gone. It is now in most countries the most common cause of life time physical disability (1). The survival rate of the more affected individuals has improved dramatically the last decades and the number of individuals that need adult care and follow up by specialists has equally increased. About 98% of children aged 4 to 14 years survive to age 20, and of those who survive 20 years, 86% survive to age 50 (comparing to 96% in the general population) (2).

Since cerebral palsy is a very heterogeneous condition, needing personalized treatment, the transition into adulthood also needs to be personalized and well prepared (3). Transition is not an event but a process (4). The goal of a well prepared transition is maximal participation with a good quality of life (5).

This article highlights the main topics to consider during the transition into adulthood and points out possible pitfalls.

From supported and shared decision making towards maximal autonomy

Starting point in the approach of adolescents with cerebral palsy is the way of empowering them towards autonomous decision making in adult life (2,6). The decree on the legal position of minors in Belgium states that every child from the age of 12 years should be involved in decisions concerning all issues that affect them. This decree is based on the WHO declaration of children's rights. It's important that parents as well as caregivers listen to the needs and concerns of the adolescents, taking into account their intellectual ability and realizing the necessary support to speak out for themselves, before starting any kind of care or treatment and that they always try to see decisions from the perspective of the adolescent. In this way the adolescent can gradually learn what the impact of specific decisions is on their daily life, function and participation and can learn to weigh the pros and cons of their decisions (6). It will certainly also motivate them to follow the sometimes very strict protocols of care and treatment they require. For caregivers and especially parents it is an exercise of "letting go" , a process that every parent has to go through but that's even more challenging when facing a child with special needs (2).

Healthcare transition (HCT) : towards a "spoke and wheel" approach in adulthood?

In Belgium, there are five centres of reference for children and adults with cerebral palsy. They go there for follow up and treatment generally two times a year. A multidisciplinary rehab team of paediatric neurologists, orthopaedic surgeons, physiatrists, physiotherapists, occupational therapists, speech therapists, psychologists and social workers can see the children on a regular basis in these centres. Especially children from the higher gross motor function classification system (GMF-CS) levels 4 and 5 can have serious associated health conditions that also need regular referral to other specialists such as ophthalmologists, pneumologists, gastroenterologists, otorhinolagyngologists, psychiatrists.

As children grow into adolescence and adult life, we see that the need for follow up by the reference centres diminishes, mostly because the motor and communication abilities stabilize and because adults, in our experience, don't feel the need as such any more to attend these intense consultations. Many of the health problems also tend to stabilize but still need regular follow up by specialists. During adolescence it is crucial to refer the adolescents timely to the appropriate adult health care specialists including specialists in the field of mental health care (7). This is often challenging because sub specialisms in adult medicine are often not familiar with the specific conditions of individuals with cerebral palsy and the time consuming consultations of people with sometimes severe motor disability and speech problems make that few specialists are available or even accessible (6,8). Nevertheless the reference centre is responsible for the fluent transition to the adult subspecialists and as stated in the literature, meeting the adult subspecialists is crucial before transition is finished (4). Some authors advocate multidisciplinary teams for adults too, but in our opinion, if so, one should in anyway consider another constellation of these teams in adulthood, given the different needs they have, as will be pointed out later (8). Instead of setting up a multidisciplinary team for adults in hospital, we rather think that in this health care transition process, the general practitioner should play a central role. He should be the one that can later in life overview the health condition of the individual with cerebral palsy and refer to the chosen subspecialists when needed. To be able to do that he should timely be involved in the transition period by the centre of reference. He should be the axe of a spoke and wheel approach (2). In this function he could also connect with other professional and personal caregivers around the adolescent or adult with cerebral palsy and fulfil the holistic role that the paediatrician plays in childhood.

From multidisciplinary rehabilitation towards fun and fitness

Rehabilitation of children with cerebral palsy aims at maximal participation. During growth and development physiotherapy (PT), occupational therapy (OT), speech therapy (ST) and feeding therapy can be given according to the individual needs of the child and be adjusted with each milestone the child reaches. Surgery, medication, splinting, tools and technologies further support the given treatments (9). The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) frame of the WHO is the guiding framework throughout childhood to reach the goal of participation (fig 1) (10,11) . According to the study of Majnemer et al., over half of the children with cerebral palsy attend normal schools (53,2% of children, 57,5 % of adolescents) (12). These figures seem comparable with the situation in Belgium although no exact numbers are available. In the same study 85% of the children receive any kind of therapy, in adolescence 68%. The higher affected the children are, the more services of rehabilitation they receive. In special schools where there are more children with more motor limitations, lower IQ and more activity limitations, children are much more likely to receive multidisciplinary therapy, what we see in Belgium too. In our institution, linked to a special school for children with physical disability, from the children to age 6, 100% receive multidisciplinary therapy, from age 6 to 13, 95% and after the age of 13 the percentage drops to 40% of the adolescents who receive monodisciplinary therapy, mostly physiotherapy (table 1). So in adolescence, therapy intensity and frequency drops due to stabilisation of function. However keeping adolescents motivated for therapy and especially movement is a challenge, as also often is the case for their abled peers. Technologies like robotics, virtual reality training and gaming should be considered to keep them motivated, leisure time physical activity should be encouraged too (13-17). This is especially important considering that pain, fatigue and physical fitness are the main factors that have a negative influence on the quality of life of adults with cerebral palsy (18-24). The 6f frame of Rosenbaum (fig 2)should be kept in mind to encourage adolescents to keep moving to be physical fit, to have fun together with friends so they can benefit from it in the future (25-27).

Figure 1: *WHO ICF-CY framework*

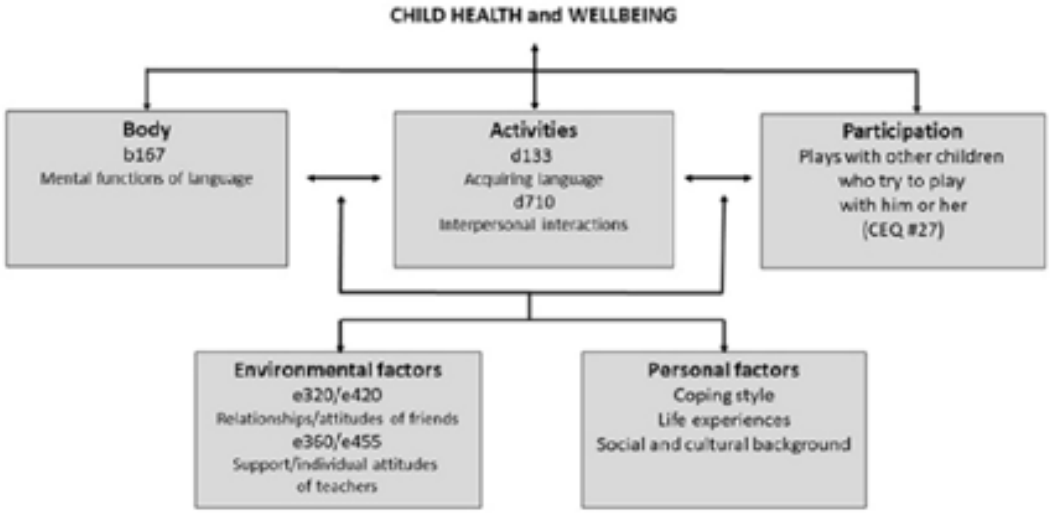

Figure 2: *6f ICF framework (Rosenbaum)*

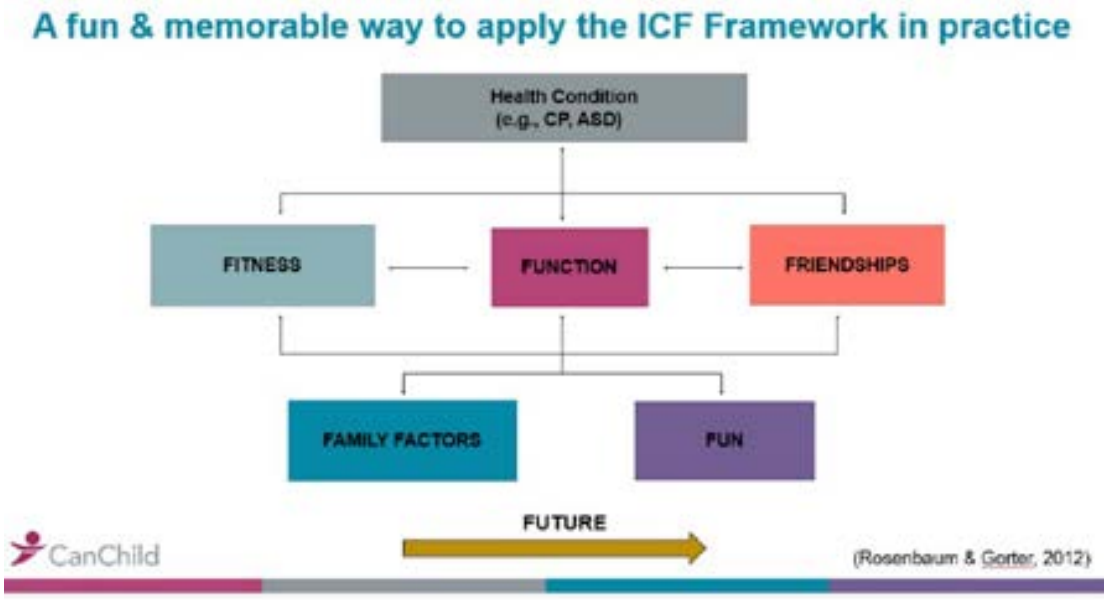

Table 1. amount and percentage of children in Heder following multidisciplinary of monodisciplinary therapy.

Numbers (%)			
age	#CP	#CP/mono disc.	#CP/multi disc.
< 6 y	14 (8%)	0 (0%)	14 (100%)
6-13 y	68 (41%)	4 (6%)	64 (94%)
> 13 y	85 (51%)	51 (60%)	34 (40%)
	167 (100%)		

#CP : number of children or youngsters with cerebral palsy, #CP/mono disc : number or children or youngsters getting monodisciplinary therapy, #CP/multi disc : number or children of youngsters getting multidisciplinary therapy

Towards participation and quality of life

The approach to people with a disability has shifted from a policy of institutionalisation in the previous century to a policy of (re)integration and inclusion of people with a disability in society : efforts are made with mixed success to send children with a disability as long as possible to regular schools. Institutions for children with a disability have developed a more diverse offer including short trajectories of support, short stays for caregiver respite, smaller units and ambulatory care and treatment. This is on the way to inclusion. On the other hand we have to be careful with what kind of inclusion we aim for. Inclusion like in : "everything the same as everyone else, together with the others, in the same way as the others" seems intuitively the best of worlds. This can however lead to a denial of the problem. Behaviour has to be the same as the abled peers, they have to look the same as their friends and the idea is stressed they are just like everyone else. That could isolate them from other children with a disability and give them the feeling of being a lonesome outsider in the world. Children, and certainly adolescents, need role models, need to meet people with the same problems, feel the bonding or simply be the best at something (28). That's what we observe in our institution too, when we organize camps for children that go to regular schools (for instance the camps for upper limb training for children with unilateral cerebral palsy). The recognition of other children having the same problems/splints is reported by parents and children as even more beneficial than the training effects for which these camps are organized for. We observe the same effect when children after a long and difficult trajectory in regular schools, start special education. The feeling of relief of not having to struggle anymore to fit in of to fulfil expectations is sometimes strikingly. Inclusion as in the definition of Cobigo et al. which includes a factor of reciprocity, social role models and being accepted for who one is, is more than just participation (29). It makes that the responsibility of inclusion lies not only with the person with the disability but it embraces diversity in society as an added value instead of aiming for equality (30).

Inclusion and maximal participation according to the ability of the adolescent is still the aim (5). The dreams and aspirations of adolescents on the threshold of adulthood are no other than the dreams of their abled peers. They want to earn their own money with a meaningful job, have an intimate relationship, friends and family, experience a pleasant leisure time, live independently in a nice home without financial troubles. Yet, after a childhood of working hard to achieve maximal function in mobility , activities of daily life, communication and education they face quite a few obstacles (2,32,33).

For a lot of adolescents with cerebral palsy, one of the first disappointments when they finish school is that they can't get a drivers licence. They remain dependent on public transportation, and when they are wheelchair dependent, they always have to plan trips long in advance, and even then cannot always get on every tram/train or bus and still face inaccessibility of some train stations

Accessibility of public buildings for people with a disability is obligatory by law, yet a lot of older buildings and even new constructions are still not fit for entering with a wheelchair

Studies reveal that people with cerebral palsy have more difficulties to find a suitable job and when they eventually get a job, often have a job well under the level of their education of capabilities. We also know that even in sheltered working spaces, meant for people with disabilities, people with motor disabilities and movement disorders often cannot keep up with the pace that is needed for production. They often end up at volunteer jobs (34,35). For more affected people with cerebral palsy, going to a day care centre is a possibility to meet with peers, do all kinds of activities and give respite to their caregivers.

The administrative burden on people with a disability is well known. Endless and repetitive filling in of papers to prove over and over again that they have a motor disability is very frustrating and time consuming. In Belgium the reference centres and private therapy are incorporated in the federal health system, whereas care, multidisciplinary therapy and educational support are regional. In Flanders adults have a personalized financial budget for care since 2017, many adults are still on a waiting list to acquire this budget. Administration to get this budget is an exhausting search for adolescents and their parents on the way to adulthood. Soon this personalized budget will be introduced for children too. Question is whether or not it will make the administrative burden for parents even more complicated. A budget for children will have to be tailored and adjusted constantly during growth and development to the needs of the child. Especially for the more affected children who need multidisciplinary therapy, the risk of gradually wiping out specialisation for therapy exists because these budgets are based on general scores of care and not specific for specific conditions nor for specific care givers or therapists. Almost all political parties in Flanders see this personalized budget as a symbol of autonomy and inclusion, although it's merely a possible aid to get there, and real inclusion is not accomplished by giving disabled persons a budget. There is very little literature about the long term effects of these personal budgets, but experts warn that they will bring more responsibility concerning the outcome to parents, likely along with a feeling of guilt induced by themselves or the outside world when things don't go well with the disabled person

Living independently is not achievable for every person with cerebral palsy, depending on the intellectual capacity and the level of motor impairment (19). There is a tendency that small groups of parents join together to realise a living unit for their disabled children. It's a challenge to make that not only the parents, but also their children have a good match with each other and that enough professional support and equipment is available for sometimes severely disabled people. For adolescents with cerebral palsy, often raised in a protective environment, and their parents, it's not always easy to make the assessment whether or not they can manage to live independently. Projects of "training homes" are a very useful way to learn them gradually how to organize independent living.

Many of the above mentioned obstacles should be addressed by politicians and regulation. Other obstacles come together with the nature of some of the comorbidities of people with cerebral palsy like cognitive impairment, problems with executive functions, behavioural problems, communication disorders, emotional vulnerability or attachment disorders.

A mentor or navigator could be appointed to guide youngsters and their parents around some of the obstacles and to give information (36). This could be a social worker, a specialized counsellor or another caregiver familiar with "the market of care".

Despite all these obstacles, the study of Colver et al., along with other studies on quality of life, reveals that self-reported quality of life of adolescents with cerebral palsy is very similar to that of their abled peers, except for a few factors that can have a negative influence on their well- being : pain (as mentioned before), parenting stress and non-addressed psychological problems as a child (3,33). The most important negative factor however is the ability to develop and maintain peer relationships (24,37). It will certainly help to encourage children and adolescents to join leisure time activities and to go to school together with abled and disabled children (30,38). Developing peer relationships later in life is a difficult issue to address because it has to do with the way society looks at people who are disabled and the way it tends to identify and categorise people by their handicap instead of looking at them as a person with the same aspirations and diversity in personality as everyone else. Only a change of this attitude, embracing diversity, can lead to real inclusion.

Conclusion

During the last decades many efforts have been made to set up multidisciplinary treatment, care and follow up for children with cerebral palsy. During the transition period the needs of adolescents with cerebral palsy gradually shift towards of those of adults, being more focused on participation and quality of life. Already in childhood, and certainly in adolescence, there has to be a proactive policy, addressing issues that can lead to diminished quality of life as an adult.

Transition is not a moment but a period in time and should be tailored together with the adolescent, based on his proper needs. Lots of obstacles for maximal participation can and should be addressed by society, but for real inclusion there also needs to be a shift in attitude towards people with a disability, embracing diversity.

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