

Advances in Psychology

On Reaching Adulthood

Beatriz Garvía Peñuelas

Psychologist at the Down Medical Centre. Coordinator of the FCSD Therapeutic Care Service (SAT).

Correspondence:

Sra. Beatriz Garvía
Fundació Catalana Síndrome de Down
c/ Comte Borrell, 201-203, entresòl
08029 Barcelona (Spain)

Article received: 05.06.07

Abstract

To let the intellectually handicapped people to get into society and become part of it, they need to have a life project, a concept of themselves, and a clear identity. It will make possible to accept the difficulties, to discover their potentials and reinforce their self-esteem. Building identity does not end in adolescence, it lasts for the whole life.

Adulthood has more external demands, particularly if the person is working in ordinary jobs, and it gets less internal support. In adulthood, persons with intellectual handicaps still need to know themselves, to be satisfied with what they are doing, to be able to choose, and feel socially valued.

Keywords: Adulthood. Disability. Identity building. Mental representation. Social integration.

Over the course of life, the social integration of people with intellectual disabilities (ID) varies according to times and circumstances, not all of which are easy to cope with. This is largely because the process is imbalanced – integration is more of a goal for the individual than for society. The first step towards socialization begins in day care, where caring for a child with special needs is usually fairly straightforward. Schooling, however, even after several years of mainstreaming experience, is fraught with problems and difficulties. School is not just about the children's learning (which is aided through special curricula, support staff and other facilities provided by the school), but about their building their own identity, finding out their limitations and learning to accept them. Likewise, they must also start discovering their own potential so as not to solely identify with what they cannot do. Nevertheless, the overriding aim at this point must be handling of emotional issues, acceptance of the

disability and identity construction, an area where much progress has yet to be made.

Arguably, adolescence is the most problematic stage of life in terms of social integration because the stumbling-blocks stretch beyond the classroom: the teenage crisis is, for all of us, an identity crisis. Not only does personality change and become more vulnerable, but the teen with a disability, on top of this, experiences a growing distance from classmates with greater independence – they start going out on their own, having other interests, getting girlfriends and boyfriends, and enjoying greater freedom.

Although society does provide some specific resources at this stage in terms of leisure, hobbies, and training aimed at social integration, they are fewer than in childhood and we are still failing to tackle the identity crisis, acceptance of disability, and awareness of growth and the transition to adulthood. Because we fear adolescence, instead of encouraging independence (going out, relationships, love interests), we place tighter restrictions and controls on teens. We demand good behavior at the cost of sidestepping their emotions.

And then, after adolescence, comes adulthood. Entry into the adult world takes place with a person's first job. This step, this transition, is extremely complicated for people with a disability.

Programs known as 'transition to adulthood' do exist to prepare students on how to cope with and behave in the workplace and the adult world. They teach social skills, personal skills, domestic tasks, independent travel and a whole host of very important activities and situations. But are we really preparing people with disabilities to become part of the adult world?

The image or idea that society has of individuals with mental disabilities (and more specifically of

those with Down syndrome [DS]) is that of the child who needs round-the-clock protection: “these children are...”. We tell them what they have to do, how they have to do it, and when they have to do it, preventing them from ever being active players in their own life, preventing them from becoming adults. We work on habits, attitudes, rules, and learning without stopping to think that by making these actions automatic and placing such demands, we may end up stifling their own desires and severing them from their emotions. In our quest to make them conform, adapt, and obey we forget to listen, to care about their concerns, feelings, and emotions. It is quite common for a young person with ID in a restaurant not to order their own food, or not to choose what they actually prefer in a clothes shop, when their taste differs from their mother's. Similarly, they do not decorate their own bedroom, choose the furniture, or have a say on family matters that also affect them.

Being an adult does not mean being intelligent or moving out, getting married and having children. Being an adult means being responsible, and we can only be responsible when we have been taught how to acquire responsibilities. Obvious as this may seem, it is extremely challenging when it comes to people with disabilities. While a child of 8 or 9 can shower alone, for example, for a child with a disability it is more problematic: he might burn himself because he cannot regulate the water temperature, she may not dry herself properly and get sore skin, he might not rinse his hair fully and leave it looking dirty... Arguments will always abound for this child to be showered in order to avoid putting him or her at risk – a risk that we do let other children run. There is no need to say that a DS child cannot get showered alone, and yet many never manage it. The same can be said of crossing the road; lighting the kitchen hob; using a knife; being in charge of buying small, everyday items; preparing their sports kit, and so on. We seem only to care about their learning to read and doing manual tasks and risk-free activities. We choose their clothes, we do their hair... they are the focal point of our care and attention, and this preparation does not give them entry into the adult world. Moreover, these restraints chip away at their independence and foster a culture of dependency and disability. Learning difficulties undeniably do entail a series of handicaps, but it is fear and a reluctance to take risks that sometimes magnifies these challenges and leads us to deprive the person with ID by curtailing their social, working and even intimate relationships (countless couples have been split up and relationships prevented for fear of sexuality, pregnancy, and problems).

It is crucial for us to understand that overprotection invalidates, prevents human beings from taking charge of their own actions, and

alienates. It is crucial that children with a disability are not looked on with pity, fear or as being incapable. It is crucial that they learn to deal with frustration, that they are not excluded from situations in which they have to make a choice or take sides. They have to learn from the good *and* the bad; learn to make mistakes, to put up with things they do not like. Equally, they must be allowed to take control of little things that relate to their life. Unless we give them these foundations, we are not helping them to become adults.

For people with ID, as for anyone else, work as a human activity is a means of fulfilling personal, financial and relationship needs. Working does not just mean doing a job, but taking on a role, acknowledging its power and accepting the responsibilities and rights that come with it. This role also entails accepting the roles of others; in other words, being a part of society. Work is not just a place where we carry out a series of functions (for which the person may well be highly equipped). Work is a place of relationships, communication and, at times, conflict, and a person needs resources to solve the minor issues that can arise. They need to be able to take small responsibilities, accept a timetable and cope with at least the basic aspects of the adult world. Unless we provide the right support and guidance in this process, tricky situations can develop as a result of the stress the person is under. Failure to provide this basic grounding can mean that ‘placing’ a disabled person in an adult context – such as the workplace – is very much a risk.

Work may be the first place where a person with special needs goes from having a passive role (others teach and care for me) to being a proactive player (I produce). And this brings about change, both in activities (learning, relationship shifts, techniques, vocabulary, and habits) and in psychological makeup (largely in terms of self-esteem). In turn, mental changes generate other shifts. Becoming an adult means being able to tolerate limits and our own and others' difficulties, cope with frustration, and believe we have access to social functions.

Building an adult identity is a continuum with other stages of life; it does not happen spontaneously nor is it ever definitively resolved. To see how tightly work is bound up with identity we need look no further than the answer to the question “What do you do?” – I’m a plumber, doctor, farmer, lawyer... I am. In *Civilization and its Discontents* Freud maintains that nothing links an individual more to reality than work, which attaches him to a part of reality, to the human community. People with special needs often build their identity at a distinct pace and the identity itself may be partial and at times incomplete. Society has clearly to change dramatically before people with disabilities can develop and grow according to their own potential.

Although the teenage crisis is accepted and

recognized to some extent by us all, childlike or dissonant behavior in adulthood, particularly in the workplace, is not seen as acceptable, which means it is rejected. Furthermore, when a syndrome or learning difficulty is part of the equation, any psychological or psychiatric problems, drops in performance, withdrawals or changes in behavior can be mistakenly linked to the learning difficulty itself, with the result that they are neither diagnosed nor treated. One of the ramifications is the burgeoning rate of depression among adults with DS.

Today, families and professionals are focusing our care and effort on the elderly. Life expectancy has risen across the board, including people with ID and DS. This issue is being tackled fundamentally from the medical point of view, from a health perspective. Integration in social and leisure activities will not be very challenging for the elderly because, like in childhood, their active role diminishes. Senior citizens need support again, they become more reliant on others and decisions are made for them.

Nevertheless, we are still unable to create an image in our minds of the person with ID as an adult entitled to hold a job, have a partner, manage their life and make choices. We cannot overlook the longest stage of life, the most rewarding. We cannot forget that human beings, with or without ID, have to

establish themselves as the subject, build an identity and know, accept and love themselves if they are to live life to the full both emotionally and socially. Focusing on learning and training is only doing half the job. We need to trust.

People with a disability need to have a life plan. Our challenge now is to acknowledge and respect growth times and to accept the adult condition rather than lifelong childhood. If we firmly believe that people with disabilities have the potential to grow and be part of our society, they are bound to respond to our plans. If there are no future plans for them, they will grow up without hope, without cherishing their own achievements, and remain entrenched in the rut of childhood forever.

References

- Freud S. El malestar en la cultura y otros ensayos. Madrid: Alianza; 1999.
- Montobbio E. La identidad difícil. El falso yo en la persona con discapacidad psíquica. Barcelona: Masson, Fundació Catalana Síndrome de Down; 1995.

News

On the occasion of World Red Cross and Red Crescent Day, the Spanish Red Cross has awarded the Gold Medal to the Catalan Down Syndrome Foundation. This award has previously been given to 17 people and institutions that have stood out for their commitment to society and hard work. The prize-giving ceremony was held on 8 May 2007 at the National Theatre of Catalonia, where the Foundation's

President, Montserrat Trueta, received the award from HRH the Infanta Cristina.

Federico Mayor Zaragoza (President of the Foundation for a Culture of Peace and former Director General of UNESCO) is, as of 24 May 2007, a new Honorary Trustee of the Catalan Down Syndrome Foundation.