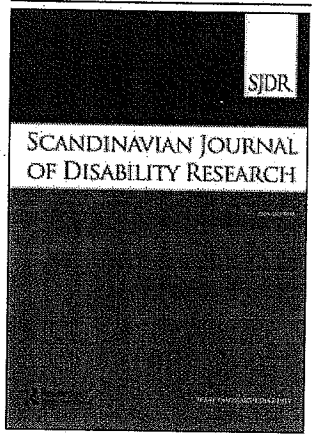


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# Affiliating Participation for Active Citizenship

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# Affiliating Participation for Active Citizenship

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ABSTRACT *This article relates the participative model to the consecration of a citizen-centred individualism based upon an experiential conception of citizenship. Inspired by theories of recognition, it examines the affiliation effect of the components of social participation. It looks at the identity-based impact of involvement in social processes, of the links created with family and friends. Above and beyond the possibilities of participation, it thus links citizenship with the possibilities of participating on an equal basis, i.e. the possibility of interacting with others as an equal. In this way it offers an identity-based approach to disability which takes into consideration the relationships of inter-dependency that unite disabled persons with able-bodied persons, and relates the understanding of the phenomenon of disability to the forms of invisibilization which erode one's positive relationship with oneself and which distance people from the demands of participation.*

The concept of participation was given some importance from the early 1980s onwards (see the World Programme of Action for People with Disabilities; UN 1983) and today participation in the life of the community is at the heart of public policies. Following the United Nations (UN) *Standard Rules for the Equalization of Opportunities for Persons with Disabilities*, which were adopted in December 1993 at UN level (UN 1994), over the last decade the European Union has been trying to promote the participation of the most vulnerable groups of the population, especially people with disabilities. The revision process of the International Classification of Disability, which was initiated in 1997, has developed the concept of disability as a restriction in social participation rooted in societies' inability to allow for disabled people's full involvement therein (WHO 2001). The *Convention on the Rights of Persons with Disabilities*, which was recently adopted by the UN General Assembly, urges the States to recognize the rights of people with disabilities and to promote their full participation in economic, political and social life (UN 2006).

This link between disability and participation shows the shift from an integrative model that has been in place since the end of the 19th century towards a participatory model. This participatory model was initiated by a movement that began in the 1960s to fight for a society that would respect differences and welcome individuals' contributions and choices (Barnes 1991,

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Bickenbach 1993, Goode 1994, Oliver 1990). It reflects a new social featuring of impairment that aims to overcome the difficulties encountered by the integrative model. Indeed, integration was not enough to achieve the recognition of people with disabilities as people with full rights and, in particular, the right to be involved in their state's economic, political and social life. It was felt that the framework of bodies that had been set up to achieve integration had proven itself unable to promote people's full citizenship. Furthermore, this new social featuring of impairment also aims to overcome difficulties faced by the concept of handicap to separate disability from impairment: the situational perspective aims, just as the integrative model did in the 1930s in France by promoting the concept of handicap, to separate disability from impairment and to get away from the medical aspects of disability by looking primarily at its social aspects (Stiker 1999, Ebersold 1992).

Now, beyond these aspects, the participatory model shows a shift in economic, political, ethical and social stakes which are at the root of social treatment of disability. It is organized around a new concept of society: society is no longer perceived as the result of a dialectic between social body and individuals, but is built upon a system of cooperation which will move forward according to each individual's involvement and which will find cohesion in its own strategies (Rawls 1971). This new position given to disability also results from a new concept of inequalities. Inequalities are no longer produced by a society generating social insecurity; they are now considered to be the product of a society that is limiting individual freedom of action because of a lack of accessibility. This means that the relation to diversity and difference has changed: diversity has lost its reference to marginality and has become a source of social vitality and of increasing collective wealth. Disability is no longer seen as a disadvantage created by a precise impairment but as a result of an environment that is a barrier to free participation.

This participatory model discloses a new concept of citizenship. A civic individualism is growing, replacing the form of citizenship produced by the industrial wage society (Bourque, Duchastel & Pineault 1999). This civic individualism is distancing itself from the passive and delegation-based concept of integration (Boltanski & Chiapello 1999). It aims at a model of active citizenship based on the effective achievement of people's expectations and wishes. Instead of a theoretical citizenship promoted by a social state, it prefers an effective citizenship supported by bodies and institutions respecting people's real concerns and trying to make them aware of their position as citizens in the most efficient way by involving them in all processes as well as by avoiding feelings of categorization and labelling (Fraser & Labbé 1993, Rawls 1999). In so doing, this civic individualism promotes a concept of experienced citizenship that places symbolic dimensions and subjectivity at the heart of social belonging: it expects institutions to be affiliation bodies allowing persons with disabilities and their families to experience forms of social recognition, to consider themselves as people enjoying full citizenship (Rawls 1971, Sen 1992).

This paper will therefore connect the different dimensions of participation in social life with the identity factors that underpin access to leisure, sport or cultural activities and that can also be found in access to employment or to school (Ravaud & Ville 1986). Drawing inspiration in particular from the theories of recognition (Honneth 1995, Renault 2004, Ricoeur 1992), we consider in this paper that access to leisure, employment and school is not just a matter of opportunities that an individual is given, but constitute real social markers that have a very important impact on people's identity. It is also assumed that help and support act as basic elements for this identification upon which people build their own representation of themselves and their possible belonging (Ville, Crost, Ravaud & Tetrafigap Group 2003): lack of or limited support, choices that are not always allowed, intimacy that is not always respected are all factors which can affect the image that people with disabilities and their families have of themselves. This is why this paper links the participation opportunities people with disabilities and their families have with their affiliation effect, that is to say with the identity-based impact of involvement in social activities, involvement in social processes, the links developed with family and friends. It thus links citizenship with the various aspects that allow people to legitimately consider themselves to be respectable and respected, and to have positive relationships with themselves.

The paper is initially based on research done on the living conditions of parents with a disabled child (Ebersold 2005a, Ebersold 2007) as well as on the works carried out by the Organization of Economic Cooperation and Development on inclusive education (OECD 1999) to describe the conceptual framework that served as a basis for action-research on the participation of people with mobility impairments. It then draws upon research carried out on the living conditions of people with mobility impairments in order to establish a link between participation and an identity-based approach to disability linking citizenship to the feeling of existing (Flahaut 2002), which disabled people and their families acquire through social participation (Ebersold 2006).

This research is based on 45 interviews given in 2003 to gather the data. Of these, 15 were with adults with a motor impairment, and 15 with children presenting a motor impairment and their parents. Questionnaires were also sent to adults, children and their parents and professionals who worked with them. In 2004–2005 the questionnaire was given to 300 people in the Loir et Cher and Nord et Seine Maritime regions, 60% of whom were over 25 years old, 20% of whom were aged 16–25 and 20% were between 12 and 15 years old. Both interviews and questionnaires looked at opportunities for choice, the relational environment, access opportunities to community and to provision as well as to social activities. Questions also covered the work done by professionals. The present paper refers only to the interviews given. The conceptual and methodological framework of the research was published in a paper called "The affiliation effect of participation into community" (Ebersold 2004). The results of the research were published in the form of a report entitled *La participation à l'aune de l'affiliation* (Ebersold 2006).

**From Social Participation as Functioning ...**

*Access as a Vector of Social Participation*

Social participation has an affiliating effect through access to various areas of social life, providing disabled people with the same opportunities as those who have no disabilities. Access to education and training allows people to acquire knowledge that is crucial for their development. It is also a way to be professionally armed and protected against social risks such as unemployment, an ever more precarious labour market, and a continued increase in part-time work (OECD 2003a). Access to employment provides economic autonomy in as much as a working person's income is generally higher than that of a person who does not work. Employment also gives access to the forms of social recognition that are linked to it; having a professional life is a strong means of social integration. Access to leisure activities, to social and political involvement is a clear source of citizenship. It allows people to share activities and experiences and thus challenge preconceived ideas about disability. It creates relationships of mutual assistance and promotes friendship based on reciprocal recognition so that exchanges between people with disabilities and people without disabilities become more and more natural. Disabled people can use such moments as "times to catch their breath", moments in which they can forget the weight of their bodies (Ebersold 2006).

However, the very fact of doing an activity does not per se mean social belonging. Access rates to employment, school or leisure activities, etc., do, of course, show the level of inclusion of people with disabilities and/or their families or, on the contrary, their level of exclusion. Their professional marginality becomes clear with their rate of unemployment, which is double that of the general population of people of working age (Amar & Samira 2003); their lack of qualification is the sign of marginalization during their education that can have a disastrous effect on employment (OECD 2003a); by showing that 29% of persons with an impairment belong to an association, whereas associative involvement concerns 45% of French people over the age of 15, the HID survey (Handicap, Incapacités, Dépendance) reveals difficulties in accessing an active political citizenship (Roussel 2004). But these rates say very little about either the social consequences of the performed activities or about the meaning that they are given by people with disabilities. They reveal very little about the possible personal development acquired by the individuals or about the forms of social belonging they experience. Although access is a sign of the right to citizenship, it does not guarantee full enjoyment of this right. Access to employment does not mean equal treatment: in most countries the incomes of people with disabilities are lower than those of the population as a whole (Burchardt 2005, Lueking & Mooney 2002, OECD 2003a, Wagner & Blackorby 1996). Workplaces can be places where people with disabilities face intolerant or discriminatory attitudes especially when they have poor qualifications or when they are given unqualified jobs (Algava & Beque 2004). A low salary or such attitudes are not, in isolation, barriers to employment. They nevertheless highlight the prejudices relating to bodies which are different, and in this way they remind

disabled persons and their families of a blameworthy difference which cannot leave them indifferent to the representations that they might have of their roles and places in society.

In the same way, having access to schools does not mean having high-quality schooling. Untrained teachers and poorly prepared curricula are not an obstacle to having access to school. But they make going to school a permanent struggle for students and parents. Many a parent uses words like "struggle" or "battle" when describing the difficulties encountered when searching for a school near their home, when convincing hesitant teachers to accept their child, when attempting to ensure proper progress in their child's education and acquiring the help of a school assistant. Furthermore, the lack of any precise assessment of the student's educational needs is not as such a barrier to the child's access to school. It does, however, make it difficult to provide individualized teaching and the necessary flexible support (OECD 1999). The whole process is anchored in a dynamic of failure that is particularly hard to bear, for both the student and the parents. Parents mention their ceaseless anxiety due to the lack of any pedagogical project. This lack increases the difficulties the teacher encounters when adapting his/her practice to the student's rhythms and, where necessary, when trying to find the support, at the risk of restricting the possibilities of the child's education. Some parents say that it could prompt some teachers "to desert the most disabled children", or to lack pedagogical imagination. One parent said that "they used exactly the same teaching materials for six years," for his child "but with no success".

By reducing social belonging to physical access one neglects the fact that citizenship is not a destination that can be determined in advance, with a final objective that an institution must achieve. Schools and institutions are areas of coexistence in which people experience this self-consciousness that makes individuals feel that they are actors of their future (Ville, Ravaud, Diard & Paicheler 1994). In the same way, reducing social belonging to physical access dictates a vision of citizenship that still has an allusive attitude to the impact of environmental factors by avoiding linking participation opportunities to collective well-being and to the transformation of the system. Participation becomes a norm and disability is then defined as a restriction in participation, the severity of which is measured according to the distance to access, or according to the absence of social function. The basic mechanisms of schools and institutions that condition the acceptance of difference, the individualization of practices, and more generally, a way of living together that respects differences, are thus neglected. This utilitarian approach forgets, for instance, that schools which do not include diversity issues in a global strategy involving all staff members are laying the coherence of the school process solely on the shoulders of those teachers or other professionals who commit themselves on an individual and often philanthropic basis (OECD 2003b). Instead of being synonymous with social recognition, access to schools and services may become the factor that reveals the disability: the difficulties experienced by the person are a sign of the distance that is separating him/her from the requirements of life within society, whereas the many measures that

might facilitate his/her success are not always available. Difficulties in accessing schools or bodies thus appear to be a strong "evidence" of a person's functional limitation. The difficulties and barriers that are at the root of disability are still an ontologically personal characteristic of the individual.

*A Needs-Based Approach as a Means of Social Participation*

The affiliating effect of social participation must therefore be linked to the different factors assuring that people with disabilities and their families receive equal treatment. The basis for equal treatment is to be found in a developmental vision of the person, aiming to adapt laws and practice to the individual's rhythms of development so as to best meet his/her needs. The International Classification of Education (ISCED) adopted in 1997 by UNESCO refused to continue to consider that difficulties encountered in school by students are due to an inability or a disadvantage. It roots these problems in the inability of school systems to adapt their organization and their pedagogy to the students' educational needs and to gather the human and technical resources that might stimulate their learning and promote their success (UNESCO 1997). This classification thus admits that a student, whatever his/her particular features may be, is able to acquire knowledge and skills if he/she is stimulated by ambitious individual education plans which are put into practice, as far as possible, in regular schools and meeting his/her needs (Büchel *et al.* 1995, Paour 1995).

Instead of normalizing the person with disability, this needs-based approach aims to achieve his/her valorization. Individualized practice then becomes a means for supporting people in their development and is no longer a compensation of incapacities or inabilities. Educational practices are understood as strategies[1] that have to take into account people's evolution in expectations and needs in time and space, and that, in order to do so, must maintain focus on a continuous and appropriate mobilization of the resources required by the process. Such a needs-based approach requires bodies and services to identify each individual's specific needs and expectations and to translate them into an individual education plan that sets out the goals, and that states the technical, pedagogical and human resources that are to be mobilized in order to build pathways facilitating both the person's progress and his/her inclusion (circular no. 2001–104/21–2–2001 on the education of students with disabilities in high school and on the development of individualized pedagogical units). It also requires schools and bodies to consider the whole process of intervention as a series of interactive and dynamic events that will be combined according to their capacity to be as creative and proactive as possible. This approach asks teachers (as well as all the stakeholders involved in the process) to be flexible so as to adapt themselves to the person's changing needs and to develop strategies which suit the children's different abilities and rhythms.

This needs-based approach considers the unforeseeable as a source of energy, dynamism, efficiency and innovation and therefore strengthens the opportunities for putting disabled children into school. The countries that

have adopted it (such as Italy and Canada) have generalized education in regular schools and, as a result, only very few children are attending special schools. On the other hand, countries linking a person's difficulties to an incapacity (such as Belgium, Germany or the Netherlands) tend to place students with special needs into special schools (OECD 2007). Because the resources required are related to the identification of people's needs, such an approach probably also contributes towards raising the schools' awareness of the diversity of students attending schools. Indeed, in the UK, the growing number of students in higher education seems to be closely connected to a better identification of those students who need additional resources in order to succeed in their curriculum. The number of students whose disability was not clearly identified decreased from 33.9% of all students in 1995 to 2.2% in 2004; the number of students with learning difficulties increased nearly three-fold between 1994 and 2003, with an increase from 15.5% of the whole population of students with disabilities to 41.2%; the number of disabled students with an intellectual impairment has nearly doubled during the same period of time and so has the number of students with multiple impairments.

However, this shift should not lead us to think that having one's needs answered does, as such, mean citizenship (Elliot & Sherrard Sherraden 2005, Topping & Maloney 2005, Veit-Wilson 2004). Rates of satisfaction, of graduating or of well-being demonstrate the ability of educational settings to reach the goals that were part of the individual education plan. But they do not allow us to qualify the service with regard to the practices and mechanisms that have contributed to this achievement nor do they give any information on the impact of the service on the person. They do not tell us anything about the conditions for people's involvement, about the way in which the individualized plan has been implemented, about the modalities used for defining the contract, whereas these different dimensions are crucial for an effective citizenship (Evers, Haverinen, Leichsenring & Wistow 1997). Educational settings have some difficulties in considering (in the light of the very philosophy of the project) that a project is the result of an action that has been jointly defined and carried out by all of the stakeholders. They see it more as a tool that defines the deliverable they have to offer. They may regret, in some cases, that people or their representatives are not very aware of their needs and that their project is not precise enough for them to do anything about education or inclusion. In addition, neither achievement rates nor satisfaction rates allow one to know whether the adaptation of practice and means to the person's needs and path has been made by professionals or delegated to the family who was then required to do whatever was necessary for the child to be successful. Now, while recognizing the merits of the educational staff, nearly all parents stress their own active role in their child's achievements at school. They mention that they had to take holiday leave in order to replace their child's classroom assistant for some school trips and also how in the evenings they help their child to catch up in academic areas that he/she did not really understand during the school day. They also say that they are obliged to ensure that there are coherent links between professionals. They think that without their active involvement in the process

"there would be no coherence between the professionals who care for the child and the parents".

The need is also more than one of providing a deliverable to meet expectations which are not necessarily clearly expressed (Goffman 1963). Studies made on the conditions for including disabled children in a classroom show that such inclusion is the result of a real work where professionals, people with disabilities and families are trying to achieve mutual understanding, and develop a dynamic of co-construction that involves all stakeholders in a logic of common action (Bonjour & Lapeyre 2000, Ebersold 2003). These studies allow one to think, as Goffman does (Goffman 1961), that the service in practice reflects the relationship that resulted from the stakeholders' exchanges with a view to defining and implementing the rules of common action, for combining their different rationalities and for building the necessary coherence between individuals as well as between bodies. These rules provide the process with an inter-individual and an inter-institutional coherence and help make it so admission to a school is not an end in itself but a means for the student to become a stakeholder in society (Ebersold 2003). They make it possible to avoid a mere integrative organization of the student's school time that would require the student to comply with standards that will allow him/her to be accepted by the teachers. These rules also make it possible to avoid a mere socio-educational approach where social skills are given more importance than academic skills, which would result in separating school achievements from the student's future.

Finally, a needs-based approach is not a finality per se but a means of action for supporting people. Considering needs as the only goal would contribute towards making needs the qualifiers defining the person's problem and particularity. Far from being abolished, the process of labelling surrounding the bodily difference is shifted: the difficulties that persons experience are no longer related to body defects but to the many requirements of a service, as for example, the ability to identify one's needs, to formulate a project, to accept being involved in it and to meet the requirements for participation. Labelling thus moves away from the body and its social impact and finds a new place in the degree of dependency that is shown by the need for a service or by a difficulty in complying with the requirements. This approach therefore opposes people who are resilient and need only little support to those who, on the contrary, appear to be dependent because they do not have the resources they need to overcome the difficulties they face and/or to cope with the requirements for participation and they therefore need support from services (Ebersold 2001, 2005a). It replaces the figure of the "disabled person" whose stigma depends on impairment with the figure of the "needy person" who is stigmatized because he/she requires a support to fulfil his/her needs.

Satisfaction of one's needs – just as is the case for access – is not enough to qualify for citizenship. In both approaches people with disabilities are only seen in the light of their social functioning, which preserves an allusive focus on environmental factors. Such an approach anchors citizenship in the precarious timing of projects and plans, in the individual's ability to legitimize

their existence by transforming the various dimensions of life in society into movable resources with which to implement a project and become involved in the process to the detriment of all the dimensions that make up human and social interdependency (Elias 1991a). The long-lasting status of citizen is replaced by the far more ephemeral one, of user, a status that only exists in a haphazard way, according to the relations that may be established with public bodies and/or schools. Because it steadily urges people with disabilities and their families to build up the sense of their existence, such an approach imposes an ephemeral and precarious citizenship (Arendt 1968), making it difficult to consider oneself as a citizen with social respect and esteem. People with disabilities are thus deprived of the poles of security that allow for a vision of their future. Their own continuity and consistency is questioned (Elias 1984, Zawadszki 2002).

### ... To Social Participation as Parity into Participation

*Participation as Social Recognition*

Relating the concept of participation to its affiliating effect requires an identity-based approach, caring for the bond between citizenship and social recognition. The obstacles to access and progress are not just barriers showing the restriction in social participation that are more or less bearable and/ more or less accepted by the individuals. They reflect the institutionalized forms of recognition that people with disabilities and their family are entitled to be given. Parents of a disabled child unanimously agree that the practice of professionals and bodies or services cannot be reduced just to its technical aspect of relations, information, care and therapy. They consider that this practice is an act of solidarity that reveals their degree of social integrity, or else of social abnormality. They expect institutions and bodies to be able to consider themselves as people with qualities, people who are precious elements of society, recognized in their rights and in the significant input they can bring to the collective well-being. Access to rights and implementation of these rights are dimensions showing the degree of social respect that society gives to these members (Honneth 1995). The steady struggle that parents mention so often tells them that their access to rights, to community, is a very special form of social belonging because it has to be conquered again and again, which is not the case of parents who don't have a disabled child. This steady struggle also shows that the support that their child needs, the adaptations that their situation requires, will only be available if they comply with the requirements or if they are able to fulfil the conditions making society and its bodies accessible. It symbolizes a model of society that only accepts to recognize them as citizens with rights in a special context and that anchors social belonging in very precarious forms of recognition. People with mobility impairments might then say that travelling sometimes makes them feel "like cattle to be loaded", like they are superfluous and aware that they are rejected. Some parents feel that they have a child "that is rejected

everywhere" and they say that this makes it "difficult to imagine how to help parents".

Considering institutional practices as acts of solidarity also leads parents to relate their citizenship opportunities to their social value as is shown by professionals' attitudes and practices. Exchanges between parents and professionals challenge the identity of both parties. They are the place where possibilities of the subjective recognition that is essential to social esteem are at stake (Honneth 1995). Being given the opportunity to speak, having access to explanations that allow for action, answering positive attitudes, all these are marks of esteem indicating to the parents that they have the qualities and capacities to be precious to the community. They are comforted in their dignity when they are shown that there is no difference "between the one who is disabled and the one who is not", that they are not living "on another planet", that they are not "plague-stricken persons", that what they are experiencing can be shared, is sharable. On the other hand, the impersonal nature of the exchanges and the lack of empathy highlight the asymmetry of the relationships between parents and professionals. They reveal that society does not hold them in social esteem, that they do not have the same social value as others and that they are not in a position to speak as equals with the professionals who are the representatives of this society. This lack of esteem is symbolic of the distance separating them from other people; it is a label reminding them that they are not only parents but "disabled" parents, standing out by their sufferings and difficulties.

For parents, bodies and institutions are vectors of recognition, and practices and attitudes are therefore markers that they use to assess the level of social respectability and esteem given to them. The many barriers and obstacles become trials which prove the denial of recognition surrounding the impaired and different body and which reveal the distance that separates them from the social standard. They reveal their lesser social visibility that is demonstrated by a daily experience that is difficult to share with others who do not have to cope with similar situations. Differences in timing and in practices, "telling looks" transform life within the community into a series of events through which disability reveals itself by emphasizing the social implication of an impairment or illness. Just like a rasp, the denial of recognition changes social contacts into a series of moments which can erode the social bond that makes up citizenship, with which it may be possible to consider oneself as a being of the same value as other human beings, with the same right to esteem and respect. To the strength and self esteem of the citizen, the denial of recognition opposes the social vulnerability and the lack of self-esteem of the person who is assisted and whose social and personal integrity is steadily questioned by a quest for meaning.

Denying recognition is consequently part of the process that produces disability. It brings about a social invisibility, transforming the sense of belonging and becoming into a feeling of social inexistence that may convert participation in community into a source of disillusion and of challenged self becoming that deprives people with disabilities and their families of the possibility of considering that they have the same value as others.

Furthermore, this denial of recognition makes them vulnerable in their attitudes to themselves and is a barrier to their self-confidence and self-respect that are crucial for their own image as responsible subjects, able to contribute actively in the development of the society. Some parents say, in this context, that they are "limiting themselves to projects that are essential and unquestionably possible", that they avoid making "projects that take place outside of holiday periods" because they think that it could make "things more difficult". They live from day to day, sometimes to such an extent that they are no longer aware of what is happening around them, believing in nothing, their child's disability becoming the only axis around which they can build up their identity and on the basis of which signs of social recognition can be organized without too great a risk (Ebersold 2005a). Thus by linking disability to the forms of respectability and social esteem shown by institutions and the professionals working there, parents invite the linking of citizenship with their opportunities to enjoy parity of participation, which means being able to participate equally in esteem and respect with others (Fraser 2005).

### *The Sense of Existing as Form of Recognition*

Relating the affiliating effect of the concept of participation to parity in participation places the possibilities of citizenship in the dimensions which provide individuals with equal opportunities in their quest for social esteem. According to this approach, social participation is not an aim as such, but a source of social linking, allowing people to think of themselves as individuals with capacities who are inhabited by a sense of existence. This approach, in line with that of Elias (Elias 1991b), avoids opposing individuals to their environment: it considers that individuals are a full part of environments and that environments are all made up by individuals challenged in their identity and in their relations to institutions. The emphasis is put on the forms of interdependency where those signs of recognition that are crucial to citizenship are built, in particular the components of identity that are to be found in the sources of economic, physical and social independence and that make it possible for people with disabilities and their families to consider that they are entitled to the same respect and esteem as non-disabled persons. Relating the affiliating effect of participation to the opportunities that people with disabilities may be given to feel that they are in parity in participation with anybody else, leads one to examine this sense of existing (Flahaut 2002) that is brought about by public policies, by institutional practices as well as by the attitudes of professionals.

This perspective leads one to consider the poles of conviction that people may have, so as to be able to look at their future and their moral responsibility. These poles of conviction are, of course, built around the autonomy in decision making that is given when there are possibilities of choice. To choose means saying what one wants or wishes, what one is thinking, in a sense it is acting with words (Austin 1962). When they were interviewed on this topic, some people with disabilities said that to them it

means "being proud of doing things by themselves" and that it is the main source of autonomy making it possible "to be free in one's behaviour and thoughts", "to be given several possibilities so as not to be obliged to rely (too much) on friends or family". But being able to choose is not social recognition as such. People with disabilities link possibilities to choose with their ability to make decisions and with the responsibilities that they can assume. They say that making own choices "means deciding by oneself" or also "being responsible for what one is doing and deciding". By insisting on these elements, they are reminding us that making choices allows one to show one's values and commitments and to be recognized for these values and commitments. For them, choosing is more than just opting for one possibility among several, more than being given the necessary information. For them choosing means taking the responsibilities they can afford to take, towards themselves and towards others. This means that it is not enough to be able to live in the community or to attend a normal school for this choice to be synonymous with social recognition: when such a choice is not accompanied by human, technical and financial support, access to school or to independent living may become a trial showing how little interest is given to the dimensions that make people want to live in the community or to attend a regular school. In addition, information is not enough for decision making and action. This information has to be relevant and allow for knowledge-based action. Indeed, when for example documents which are supposed to help people find aid in fact contain no useful information (nothing about professional know-how, methods or aims) on which to base a decision, they may appear to be useless because it is not possible to plan for the future. Where information is wrong or provided in a too impersonal way it may appear to be irrelevant or even misleading because it cannot lead to decision making.

This approach also invites one to look at the relationships of recognition that are formed during social exchanges. Social isolation is a source of deep suffering (Pan Ké Son 2003) because living in a community is not possible without friends, without a relationship with one's neighbours, without being accepted by one's family. For a young disabled lady participating means "being with the others, eating with all the others, it is not being separated. It is mixing with others, being with the others". Having a network of relations makes it easier to have access to the public area: it is easier to go out with friends, to participate in sport or cultural activities. With such a network one has more chances to make many different friends and the more friends one has, the greater are the opportunities to meet with other people and make more friends. This is particularly true for young people. Relationships are also a means of conciliating social rhythms, of facilitating access to employment, getting support in difficult times or when certain institutional dysfunctions so require. People with disabilities all say that they are helped by their friends and underline the role of helpers that these friends have to play when the environment is not accessible. Some of them say that their friends help them to go to the toilet, others say that having a drink together may mean that their friends have to carry them, others say that their friends have to compensate for

the absence of human support. As one of them says: "At school, because there is no helper, it's difficult. But it's always the same, I always find somebody who helps me, a friend who writes for me and things like that". Of course, such help may be considered as a sign of the level of solidarity that characterizes a society. However, people with disabilities see it as forced solidarity and consider that it is not "up to the friends to be the helpers". They may also consider that such forced help creates an unbalanced relationship that reveals their own physical dependence and may lead to a painful feeling of inferiority. They feel that this obligation of mutual aid can bring to the fore an impairment the impact of which had gradually faded as relationships and exchanges developed. As this interviewee says: "My disability, they don't see it. Sometimes even they are forgetting that I am disabled. They say 'let's go there' and I say, 'but I can't' and then they say 'ah, yes, it's true'. I have already spoken with them, they say that for them I am normal; the only thing is that I am in a wheelchair. But they don't see that. One more friend came yesterday evening with his brother and said 'Oh, I had forgotten that you are in a wheelchair' and so on. 'Well,' I said, 'it's sometimes difficult, but ...'".

By insisting on these dimensions, people with disabilities are reminding us that relationships do not automatically create social recognition. They think that relationships become a source of recognition when they incite people with disabilities and their families to consider that they have an independent link to other people, so that they can tell what they are doing and who they are. They then underline, in particular, how difficult it is for them not to feel dependent on their families and this is even more important inasmuch as this feeling of dependence makes it difficult for their parents to see them in the light of their capacities; they insist on how important it is to have a relationship with friends that is built upon a level of reciprocity that pushes all disability-related matters into the background. They consider that the fact of not being "obliged to ask for help to climb the stairs", gives them the feeling that they are "not a burden on society". People with disabilities remind us that mobility, the ability to share activities with others and to be connected with others are all social signs upon which they can build their feeling of being people who are precious to society. This leads them to measure access (physical, social, psychological access) in terms of the forms of social symmetry of their relationships as well as in terms of the possibility of thinking that they are in parity of participation. The interpersonal links are then considered as links that generate a feeling of recognition and belonging so that they may think that they are like everybody else. Such links provide the evidence that "one does exist, one is like others, one is not rejected by society".

This sense of existing is however also built upon the symbolic mediation made by the different social activities in social life. The disabled interviewees all say that sharing activities with others anchors access to the public space in a common action that generates recognition and social belonging. Doing sport is a symbol of the capacity to show one's body, to show one's abilities and in so doing, as one person said "to face the way other people look at you". It is also another way to experience their bodies and, in so doing, as one interviewee says, to "feel you are like the others" whilst still being different. People with

disabilities also consider that going to the theatre, doing leisure activities and travelling are opportunities for dreaming, speaking and for having exchanges with others. By underlining these dimensions people with disabilities not only consider these activities as an opportunity for well-being, relaxing and having another environment. They also see in them an opportunity to have adventures with their friends and to have exchanges that are located in a dynamic of reciprocity where words, representations and practices can be shared and discussed. They provide them with a narrative capacity, an ability to share with others and to be like others while still not having the same physical, sensory or mental capacities. In this way they acquire the possibility to portray themselves differently than by just referring to their bodies which are different and to think of themselves as being like the others. This means that the possibilities given by social exchanges to consider oneself as being able, as being "just like the others" (Ricoeur 1992) are considered by people with disabilities as a means of transforming that unbalanced relationship generated by disability into a mutual recognition built upon reciprocity. They relate social belonging to the intersubjective acceptance of a positive relation to oneself and they suggest that the different dimensions of access cannot be separated from the capacities that people acquire to think of themselves as having a future and being able to cope with changes and developments.

This linking of social belonging to parity of participation refers the affiliation effect of participation to an identity-based approach to disability, understanding the relationship between people with disabilities and people who are not disabled as a relationship of interdependence built on the mutual recognition of citizens with an ethical right to be recognized, with the advantages that are attached to this right. The phenomenon of disability is explained and understood in relation to the forms of invisibilization with which people with disabilities are confronted and which erodes the relationship that persons with disabilities have with themselves. This identity-based approach subordinates individual responsibility to the responsibility of those primary vectors of social injustice that are institutions and bodies. It highlights the disabling effect of policies and practices weakening people in their identities or, on the contrary, their enabling effect. The capacity to think of oneself as being able, as having a narrative identity and the different dimensions of individual well-being, become parts of social participation in their own right. This identity-based approach to disability may help fight prejudice and discrimination by highlighting the dimensions that strengthen the visibility of disabled people.

**Elements of Conclusion**

Whilst the participatory model has the same aim as the integrative model, it differs from it by focusing on an experience-based approach to citizenship caused by an interactionist vision of the social world destroying social relations. This experienced-based approach relates social belonging to the subjective components of citizenship as seen by people with disabilities, taking into account the way in which they may consider themselves, their role in

society and their future. The vulnerabilities that they experience are rooted in the denial of recognition, making them transparent for themselves and for others, and, because of that, at a distance from the forms of participation upon which citizenship is built. This suggests that, whereas from a historical point of view participation replaces integration, in fact they are linked together because one defines the other. Contrary to the position taken by the managing approach, society is not limited to an addition of interactions and the individual does not make society even if he/she contributes to it. All forms of individualization suppose that exchanges between individuals are rooted in a collective dynamic. In the same way as there is no "user" without the organization of a service and no organization of a service without "users", no recognition is possible between individuals if there is no collective recognition. By relating social belonging to equal participation it becomes obvious to consider society as a dialectic which mixes together exclusively social factors with individual factors and this in turn requires one to consider the different forms of interdependence that make society.

Not complying with this requirement would mean that the medical approach that characterizes integration would be replaced by a managerial approach, reducing the act of living together to a management problem (Ebersold 2005b). The functional inabilities generated by a particular biological feature would then be replaced by an inability to participate, shown in the difficulties in developing a realistic life plan, to find the psychological, social and financial resources that are necessary for being the hero of one's own daily life. To the inequalities linked to the economical and social consequences of impairment would be added those due to the requirements made by a type of society asking its members to transform all resources which make up life in society, into *capitalizable* resources. All those who do not have the social, cultural, economical, symbolic, etc., capital that allows them to be proactive would be made vulnerable. The participatory model would then not reduce inequalities but increase them; instead of being a source of active citizenship and inclusion, it would be a vector of invisibility and, therefore, of exclusion.

### Disclaimer

The approach developed in this article reflects the author's point of view and not that of OECD.

## Notes

[1] The circular from the French government of 19 May 2002 says that pedagogical strategies have to be included in a collective dynamic and written into the school project.

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