

Multidisciplinary call for contributions on

“Handicap, age, and dependence: which populations are affected?”

For the October-December 2016 issue

This call for contributions is addressed to researchers in sociology, philosophy, geography, history, economics, anthropology, and demographics, as well as to stakeholders in the social and medico-social fields.

Articles should be submitted before **1 April 2016**.

Context

Since 2009, a partnership between the *Direction de la Recherche, des Études, de l'Évaluation et des Statistiques* (DREES - Directorate for Research, Studies, Assessment, and Statistics) and the *Caisse Nationale de Solidarité pour l'Autonomie* (CNSA – National Solidarity Fund for Independence) has supported research into the loss of independence at all ages under the title “Handicap and loss of independence”. The call for research encourages consideration and analyses (especially on a multidisciplinary basis) of the needs of people experiencing a loss of independence, help and helpers, the living environment, institutional reception, academic and professional integration, and the rights of individuals, as well as social representation of disability and dependence. As well as showcasing research, there is annual renewal of support for research-network development.

Changes in public policies over the last decade are significant from a legislative point of view. Various laws now present a certain number of *acquis*, especially in understanding the notion of disability and dependence situations involving older people. In particular, there is law 2002-2 of 2 January, which renews social and medical-social action; law 2005-102 of 11 February on equal rights, opportunities, participation, and citizenship involving disabled people; law 2007-308 of 5 March on reforming legal protection for adults; and the bill on “adapting society to ageing”, which is being prepared.

The issue concentrates on the disciplines of the social sciences, especially sociology, philosophy, geography, history, economics, and demographics. Nonetheless, interdisciplinary approaches would be appreciated, such as those involving the medical sciences (diagnosis and treatments), engineering sciences (equipment and home automation), and the social sciences (origin, standards, stakeholders, and territories).

This issue has a dual aim. It should, in the main, be the opportunity for showcasing research work carried out over the last several years in the field of disability, dependence, and loss of independence more generally. With that in mind, the articles expected will highlight analysis frameworks developed, data used, and new knowledge produced. In that way, this issue of the RFAS will be an original contribution by the scientific community to the review of the research work. In addition, contributions are also expected that present technological and social innovations that have been put in place and experiments that are in hand, especially when they flow from research work or form part of a current analysis approach.

Four main strands are offered as part of the thematic dossier.

1. *Category definitions: “disability”, “dependence”, and “loss of independence”*

The disability field covers multiple realities: motor, sensory, mental, and intellectual disabilities. Mental handicap in turn refers to a set of pathologies of psychiatric origin (bipolarity, depression, schizophrenia, etc.) that are increasingly better identified and measured. Finally, the chronic nature of certain illnesses (food and environmental allergies, diabetes, cancers, etc.) means that they now are part (sometimes controversially) of the field of disability. The border between disability and social maladjustment, as well as between what is normal and what is pathological, is now more fluid than ever.

For its part, dependence is mainly associated with loss of skills linked to ageing. It can vary in severity and be different in nature, whether cognitive or physical; their cumulative effect is to give rise to situations of strong dependence.

Understood from the perspective of loss of independence, dependence and disability are assessed in terms of degree. That suggests at least two dimensions that add to the complexity

of the approach. Firstly, the characteristics of the physical environment (physical, social, medical, etc.) more or less deeply modify the experience of the reality of states of disability and dependence. Those states cannot be understood only in terms of a general index of standardised defects. The interaction between the two dimensions (defects and environment) leads to an initial reworking of the analysis framework. Secondly, disability and dependence cannot be understood as intangible states of which the description at a given moment would be enough to point up the main characteristics. On the contrary, their dynamic character involves working to specify the origin and development. In that sense, taking account of the way in which the corresponding states are built up over time may usefully shed light on the phenomena of loss of independence and their processes. The combination of criteria that are different in nature (medical and social) as well as taking account of individual situations (trajectories and perceptions) and territories' resources (financial and institutional) take the form of a certain elasticity of those notions in space and time.

It may be of interest to analyse changes that are beginning to emerge at European level. Over the last few years, the European Union has sought to understand the “disabled person” category in amongst the categories of people who are most excluded from society. That denotes a dual trend. On the one hand, it induces treatment based on the inclusion of disabled people in the “highly excluded” category, for whom the market cannot be a solution. On the other hand, that links the question to the most fundamental “human rights”, compared with integration “under common law” based on citizenship alone.

Through this strand, the contributions submitted may revisit categories and analysis models relating to “disability” and “dependence”, in order to specify their strict meaning, the various dimensions, and the dynamics in a context marked by an ageing population – which, up to a certain point, contribute to their overlapping. Moreover, there is a constant questioning of the distinction between disability and dependence, which is given expression by the administrative “age barrier” of 60.

For each of those categories, that re-examination may aim at retracing their origins as well as understanding usages and recent changes. From that point of view, the links between “normal and pathological”, “protection and independence”, “health and social”, “statuses and perceptions”, amongst others, may be re-examined. That can lead to a refining of the population groups concerned.

2. Public policies: changes and implementation

In France, policies on disability are distinct from policies on the dependence of elderly people. Each field has undergone its own changes. It is often the case that each field's laws, institutional arrangements, and arrangements in terms of help and benefits meet needs that are themselves assessed according to different scales. Today, the question of the convergence of the two fields is regularly raised; certain arrangements cover both disabled populations and age-related-dependent populations (e.g. *Services des Soins Infirmiers à Domicile* (SSIAD) - home nursing-care services), whereas others remain very specific (e.g. reception establishments for disabled adults, and *Établissements d'Hébergement pour Personnes Âgées Dépendantes* (EHPAD) – Accommodation Establishments for Dependent Elderly Persons). Work on the origin and the principles of current policies, as well as their implementation at local level will bring matters for consideration of the current situation and of the future. A subject of particular significance could be the analysis of the contribution made by institutions that are “points of entry” to the arrangement (*Maisons Départementales des Personnes Handicapées* (MDPH – Departmental Homes for Disabled People) or departmental councils), and the difficulties they encounter in turning into reality the main guidelines of public policies that have been in place for ten years.

The components of those public policies include the importance given to relatives acting as helpers, the dignity of the dependent or disabled person, prevention, maintaining independence, and supporting the person who is beginning a process of loss of independence or who is suffering from dependence.

The user's place and participation in social life are two determining elements of social policies. They include several formats, ranging from family and neighbourhood relationships to involvement in the voluntary sector and in public action. The question of mediation procedures that help avoid marked isolation, which is often linked to being disabled and dependent, could be dealt with in the form of reports based on experiences, or on a more analytical manner based on sociological work done as part of research programmes during the last few years. The work presented can also cover institutional life from a dual perspective. On the one hand, examining the involvement of residents in establishment / user committees and equivalent structures would offer the opportunity to take stock of the situation, from the

point of view of the internal functioning of organisations as well as of re-acquiring identity by people who are no longer able to live independently. Moreover, taking part in social life can also lead to an opening up to the outside world through entertainment activities organised by professional teams, involvement in voluntary work, and the involvement of volunteers.

One of the characteristics of that field of public action is the place taken by associations in drawing up policies and operational arrangements, as well as implementing them through arrangements similar to public-service delegations. Retracing the way in which the most emblematic texts of recent years have been jointly drawn up would enable light to be shed on advances made and commitments given.

From the point of view of regulating professional arrangements, detailed presentations on the method of drawing up scales and implementing them locally would be useful to shed light on the excess that must be borne by people who are in a situation of dependence and their desire to remain at home. From the point of view of quality standards, the difficult link between social, health, and medical logic could be the subject of interesting presentations.

From the point of view of social protection, the question that appears to be raised is that of a contrast between a principle of universality and territorial inequality of access to corresponding protections and services. Moreover, one can raise the question of seeking out a new balance between cover provided by an individual (or asset) contingency and cover provided by collective solidarity bodies, of which some come under the heading of assistance.

Including disabled people in the professional environment is a goal that has been aimed at by a range of mechanisms. The effectiveness of those mechanisms remains limited when judged by the chronic difficulty faced by that population in accessing employment, whether in a protected setting or an ordinary one. On that subject, shedding light on ESATs (*Établissements et Services d'Aide par le Travail* – Establishments and Services providing Help through Work) would be particularly welcome: the legal and financial status of people working therein; an assessment of their needs and expectations; responses to population ageing; and taking account of life choices.

Furthermore, an analysis of strategies followed by businesses to comply with their legal obligations would be of interest, from the point of view of forms of productive organisation

that emerge from those strategies (sub-contracting, etc.) as well as in terms of labour management (outsourcing, etc.)

3. The therapeutic relationship: multiple, complex interactions

The therapeutic relationship that is established to deal with loss of independence takes a range of forms, depending on the nature and degree of disabilities, the characteristics of the close environment, and the institutional resources that can be mobilised. It is doubtless fairly sharply differentiated, depending on whether the disabled or dependent person lives at home or in an institution. However, in those two situations, it would be of interest for the matter of the therapeutic relationship to be approached, from the perspective of relationships between helpers and recipients, and from that of interaction between intervention professionals and the relatives of help recipients.

Firstly, daily care work, dealing with and providing help to disabled people and dependent people is based on multiple legislative and institutional frameworks that combine health-related, medical, and social dimensions as well as social and economic ones. Beyond the rules thus defined, the work presented could look at their effective implementation. Doing so highlights the ways of adjusting the general intervention framework to specific needs; it also highlights the negotiation processes that bring them forth. What can be deduced from that gap between theory and practice, from the point of view of the professionalism of intervenors as well as the welfare of help recipients?

Secondly, it seems interesting to better characterise relationships that develop between professionals and relatives (e.g. in terms of delegation, co-operation, and control), relationships that can develop from professionals to relatives as well as *vice versa*. At the heart of the questioning process is the underlying question of trust, of the conditions under which trust is built up, and of the resources mobilised to that end. There again, beyond the quality of care given, what is involved is the welfare of people, their dignity, and their independence.

4. Innovations and experiments

The question of various technical aids that provide compensation to a greater or lesser degree for loss of independence of different types is a long-standing one. However, it has found fresh relevance with the rise in home automation in various forms. The various types of home automation seem likely to overcome disabilities of different types and multiple dependence situations, with, in addition, an ability to adapt to a wide range of individual needs. The technological aspects are often highlighted because of the possibilities they offer; however, the question of real use by real beneficiaries is worth examining. The presentation of experiments or policies that are applied on a wider scale in the field may bring elements of analysis of interest regarding economic, social, and even psychological conditions of access to home automation and its consequences for people's living conditions and independence. Reference to foreign experience would be particularly valuable in presenting the manner in which public interventions have supported access to home automation and possible difficulties of individual appropriation.

Feedback from professionals in the field, as well as revealing new professional practices (whether in supporting disabled people or dependent elderly people living at home, or those people who live in medical-social institutions), would be appreciated. The opinions and points of view of professionals in the sector are particularly welcome, if they lead to new openings or considerations on the populations studied.

Additional information on the content of this call for contributions can be obtained from Yara Makdessi and Jean-Luc Outin, who are tasked with preparing the issue. They can be reached at:

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