

**A SOCIAL SCIENCE PERSPECTIVE ON CARE FOR CHRONICALLY ILL PEOPLE:  
RELEVANCE FOR PUBLIC HEALTH AND HEALTHCARE POLICY MAKING**

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**Policy brief**

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**Scope of this contribution**

This policy brief shows how social sciences offer relevant insights to develop innovative health care policy and public health approaches for people with chronic conditions.

This report summarizes general traits of social science perspectives on chronic illness. It does not sketch all potential nuances, differences and criticisms on the several approaches and theories.

## Key messages

- *Social sciences contribute useful knowledge to develop innovative policy frameworks and visions on health services innovation for people with long term conditions. Social scientists have demonstrated that the interpretation of disease, symptoms or illness is very much affected by cultural values, social norms and culturally shared rules of interpretation, which also shapes the provision of care and policies.*
- *Care and support for a wide range of long term conditions should be organized using a different approach than is generally put forward in acute and post acute health care*
- *Chronic conditions and diseases impact on different life spheres: An innovative policy should consider the management of overall lives of people rather than solely managing the condition. Putting the diagnosis and treatment central will reinforce a medicalised approach of chronic illness and hamper more integrated models of chronic care enabling social participation.*
- *A framework taking into account the time factor helps to outline different stages in a disease and life course, documenting continuities and discontinuities in long term trajectories of illness.*
- *Labeling theory helps to understand on how social processes have an impact on social participation but also on the development of personal identity.*
- *How people manage their chronic illness is not solely an individual issue, it is also affected by cultural and socio-economic differences.*
- *An explicit focus on the body incorporating social and biological facts allows for a more societal perspective on chronic illness.*
- *Managing peoples' long term conditions is not a sole issue for the professional care sector but also for the patients and their partners, children and close friends, in multiple domains of life:*
- *Patients with chronic diseases need not be mere recipients of care but should become key decision makers in the process of cure and care. The patient as an expert is to be recognised, without putting the entire responsibility for the management of the chronic disease course to the individual.*
- *Patient participation is a key issue to be developed on different levels of the health and social care spectrum*
- *The chronic care model is an example of a conceptualization enabling a broader perspective on health service and health policy approaches related to chronic conditions*
- *Care for chronically ill people is not only an issue for the healthcare policy domains, but should integrate with social policy. Patients seek the active responses and strategies to achieve the best possible outcomes in the different stages of their condition. Engaging in relationships with the health and social care sector is crucial in this process*

## Introduction

Chronic illness is emerging as a crucial societal, health service and health policy issue. The caring for chronically ill persons is expected to place an increasing burden on health care expenditures, professional care provision, informal care and on issues related to labor market participation and social allowances or benefits, mainly because people with chronic illness need support in a number of life domains.

Scientific arguments show that care and support for a wide range of long term conditions should be organized using a different approach than is generally put forward in acute and post acute health care. Social sciences contribute useful knowledge to develop policy frameworks and visions on health services innovation for people with long term conditions. Chronic illness is actually socially constructed through underlying ideas. Social scientists have demonstrated that the interpretation of disease, symptoms or illness is very much affected by cultural values, social norms and culturally shared rules of interpretation, which also shapes the provision of care and policies.

This paper gives a short and very general overview on how a more social or societal perspective on the issue of chronic illness could contribute to the policy debate to develop more innovative approaches aiming at social participation and inclusion of persons with chronic illness in society. The scientific field of studies on chronic illness is evolving and different streams of ideas are intertwined.

Readers should remain aware that we present a very general overview and that the structuring of emerging ideas is in a way artificial, as very much overlap of ideas exist between the different sections below.

## The starting point: Disease, sickness, illness and health

During the second half of the 20<sup>th</sup> century it was mainly the framework of medicine, focusing on acute problems and cure that dominated the underlying models of organization of health care. However, the growing numbers of people with a wide range of long-term conditions (and the aging population) required developing a more complex worldview on chronic illness. Some key concepts used in social sciences can offer stepping stones in developing a changing perspective.

The social sciences consider differences between the biomedical condition, the impact of this condition on the person and social participation in society by using separate concepts: illness, disease, and sickness.

- Disease is defined as a condition or disorder that is diagnosed by a physician or other medical expert, which in most cases means that the condition has a known biomedical cause and is often related with known treatments.

- Illness is used to refer specifically to patient's personal experiences and feelings. Illness is defined as the ill health the person identifies themselves with, often based on self reported mental or physical symptoms. It is e.g. possible for a person to be diseased without being ill, and to be ill without being diseased
- Sickness refers to the social role a person with illness or disease takes or is given in society in different areas of life

These three concepts are interrelated, but do not connect on a one to one basis. The most general logic used in society is that a person who does not feel well is diagnosed by a physician. If the problems are serious and affect the person's possibilities to take up specific roles (mainly school and work) the person is liberated to perform expected tasks. However, not all illness is connected to disease; in many cases of experienced illness the person never bothers to have the condition confirmed by a physician. Illnesses and diseases do not lead to sickness either because some of them do not hamper social participation e.g. because a person deliberately chooses not to be identified as a sick person.

Particularly relevant for the field of chronic illness, is the analytical distinction between related trajectories: disease course, the healthcare trajectory and sickness trajectory (Strauss & Glazer, 1975) (Corbin, 1998; Corbin & Strauss, 1991). A chronic disease should be understood as a trajectory evolving over time. It consists of a number of analytical "subtrajectories". (a) the biomedical condition (disease course), (b) the type of actions, interactions taken to control the disease course (healthcare trajectory) and (c) the emotional state (sickness trajectory).

Social scientists have also written a lot about the related health concept. Internationally accepted definitions of health (e.g. World health organization (WHO)) focus a lot on wellbeing, or capacity to act to reach vital goals and the possibility of experiencing meaningful life. It has been documented in research that most people do not see health only as a state where they are free of serious illness and disease.

Blaxter (Blaxter, 2010) summarized ideas concerning health and identified the use of many concepts: more biomedical oriented conceptualizations refer to health as "normality" or health as "absence of disease" and ill health or "disease as deviance". Other concepts see health as "the ability to function". The main message is that different conceptualizations have many implications for clinical practice, health service organization and policy perspectives, as meanings given to a topic has major impact on the social construction of health services and policies. Anthropological literature also offers many insights on how "health beliefs" affect individuals' and societies' cultural construction of health problems and solutions (Kleinman, 1978, 1983).

### **Chronic illness: Life course disruption or continuity of life**

Many authors have described for a wide range of diseases and conditions how people's trajectories are influenced by experiences related to the disease but also to personal life expectations, demands from

society and available resources. Chronic illness, can occur in any stage of life course and people have to come to terms with managing a (life-)long course of illness (Martin & Peterson, 2009)

Early sociological studies were written on the experience of tuberculosis (Roth, 1963) or polio (Holdsworth, 1965) but the major influential work was Glazer and Strauss' analysis of the dying process (Glazer & Strauss, 1965). The pioneering work of Strauss on the experience of trajectories of care were the vanguard of many studies on processes of giving meaning (by metaphors, images and cognitive representations) to a condition or disease. Strauss also emphasized the public health impact of chronic conditions and its implications for the development of health services (Strauss et al., 1975). Many of these studies also connect with approaches on labeling and stigma and the body, issues we will discuss in the next sections.

The particular issue of experience in chronic illness is strongly influenced by the writings of Michael Bury (Bury, 1982, 1991, 1994, 2001, 2010a, b; Bury & Holloway, 2009; Conrad & Bury, 1997; Gabe, Bury, & Ramsay, 2002; Taylor & Bury, 2007) and authors such as Conrad (Conrad, 1990; Conrad et al., 1997) and Charmaz (Charmaz, 1990, 1994, 1995, 1999, 2002)). This stream of literature developed many arguments against a biomedical model because it is inadequate to develop a multidimensional view on chronic illness. The person with chronic illness experiences physiological symptoms but also disruption in work and family relationships and future plans, which can lead to a loss of self

Bury (Bury, 1982) outlines different stages in a disease and life course documenting continuities and discontinuities in long term trajectories of illness. He examined in particular the 'biographical disruption'. He also showed how people with chronic illness develop cultural repertoires (styles) which they can draw upon to represent their changed life (and physical or mental problems) (see also (Williams, 2000)). A disruption takes place of taken for granted assumptions in a personal life, especially for young people and in middle adulthood. The disruption mainly manifests as feelings of "loss of control over life" and a "loss of identity" as persons affected cannot meet societal expectations in different societal roles (work, family, friends, ...). Bury emphasizes on the active responses and the strategies people employ to achieve the best possible outcomes (in terms of quality of life and functioning) in the different stages of their condition. Engaging in relationships with the health and social care sector is a crucial component in giving meaning to their condition. Expectations for treatment and care or support change over the trajectory, very much affected by the uncertainty which they are confronted with.

The biographical disruption emerges thus as an evolving and continuous process manifesting in the different stages of a biography. Chronically ill people engage in a continuous "negotiation process" with the social world in order to maintain "normal" relationships as much as possible. Legitimation to find an acceptable place for the condition and its consequences forms the basis for managing their illness within their personal life and to position them into society.

## **Social roles, deviant behavior, identity and stigma**

Chronic illness is also studied from the deviance perspective. This stream of literature is closely related to the notion of health as "normality". In social science terms deviance is defined by people as a failure

to conform to the expectations, norms and values core to particular reference groups. People can be graded according to how 'normal' they are. Sickness has been conceptualized as a particular form of deviant behavior because of the "exceptional" social roles a person in ill-health takes up or is attributed. Furthermore, people start to change behavior or develop other identities as a result of this external labeling. The stigma of having a chronic illness affects for instance the person's self-concept, capacity to adapt to the illness and the quality of his/her social networks.

The "sick role" developed by Talcott Parsons (Parsons, 1951) is an early but pervading sociological approach aiming to explain on how society deals with sick people. 'Being Sick' is not simply a 'state of fact' or 'condition', it contains a number of expectations expressed as rights and obligations. The rights are that a sick person is not responsible for their condition and therefore exempt from normal social roles. However the role also holds obligations, namely that the sick person is expected to seek competent help and cooperate with the medical professional in an effort to get well. The medical profession can then legitimize the deviant behavior of the sick person.

This early approach has been criticized because of its conceptualization of the "passive" patient, legitimized in its social functioning by medical practitioners. Moreover the sick role does not explain on how people with chronic conditions manage their lives, as is discussed in previous section.

"Labeling theory" introduced the dynamics of "deviance" and stigma. "Labeling theory"(Becker, 1963; Mead, 1934) analyses how people obtain labels from other people in society and how this process affects the development of the 'self', of identity. Labels reflect categories attributed to people by their visible or invisible characteristics. The advantage of a label is that helps to identify people and develop adapted policy and health care programs for particular groups. Labeling theory also helps to understand on how a chronic condition subjects a person to possible stigmatization by those who do not have the illness. Stigma becomes an attribute that discredits an individual in the eyes of society and results in the person being labeled as deviant, devalued and even discriminated(Goffman, 1963). Labeling implicitly suggests that people acting according to the norms and expectations of "normal" people feel morally superior. As such labeling can become the basis for discrimination (compare homosexuality, ethnicity etc) or social isolation. (Scambler, 2009). Goffman laid the foundations to explain on how stigma is an element in the social processes creating and recreating of the human 'self'. He argues that persons often recreate new selves or identities adapting themselves to changed circumstances to meet the changed demands or expectations. In reaction to 'normal others', who unintentionally or deliberately erode the independence and personal competencies of persons with chronic illness, people with chronic conditions develop an identity and manage their illness.

In the health sciences, labeling theory is particularly used for people with mental illness and people with disabilities. Research suggests that people labeled mentally ill regardless of the specific psychiatric diagnosis or level of disability, are stigmatized more severely than those with other health conditions. It has been described on how people with mental illness are labeled as unpredictable, dangerous, and unable to care for themselves, affecting the way on how they are isolated from society. Other studies suggest the public discriminates among psychiatric groups based on the labeled psychiatric disorder (psychotic disorder versus depression or anxiety disorders) (Corrigan, 2004; Corrigan, 2007; Corrigan,

Markowitz, & Watson, 2004; Corrigan & Wassel, 2008; Corrigan & Watson, 2002, 2007a, b; Corrigan, Watson, Byrne, & Davis, 2005; Rao, Feinglass, & Corrigan, 2007; Rusch, Angermeyer, & Corrigan, 2005) Recent studies collecting experiences of people with mental illness demonstrate on how stigma persists in their personal lives. People suffering from long term mental illness describe the efforts needed to cope with labels even to point that it could result in further social isolation and reinforce negative self-concepts. (Larson & Corrigan, 2008) Disability studies have developed many arguments that treating non-disabled individuals as the standard of 'normal living' is a source of discrimination (Albrecht, Seelman, & Bury, 2001). Public and private places and services, education, social work, health care etc are socially constructed to serve 'standard' people, excluding persons with various disabilities. Disability studies have reacted fiercely on the fact that many of the strategies of rehabilitation are very much oriented on restoring disabled persons towards "normal" standard rather than dealing with disorders or conditions.

Labeling theory and the problem of stigmatization has been used to discuss many other chronic conditions demonstrating the complexity of labeling and stigmatizing processes. Especially those diseases or conditions that are associated with non responsible behavior or sexual differences, when the disease is associated with the possible transmission to vulnerable people or those that are associated with criminality, promiscuity, untrustworthiness, noncompliance (cfr hepatitis C AIDS/HIV) are subject to stigmatization (Sandelowski, Lambe, & Barroso, 2004). So it is not the disease as such but the social world associated with the disease that explains the stigmatization process. Other studies describe how the differences between visible and invisible chronic conditions can impact on stigmatizing processes (Joachim & Acorn, 2000).

Closely related to the issue of medicalization of society, social scientist warned against the impact of the "diagnosis" (a label) on the illness construction, because it becomes part of the legitimating process of behavior related to a disease (Brown, 1995; Jutel, 2009). Early work of Freidson (Freidson, 1972) on professional dominance already focuses on the important role of diagnosis in reinforcing medical authority. Diagnosis provides a cultural label of what society is prepared to accept as normal. The label is the anchor point to set the standards for treatment, support but also for acceptable behavior. A diagnosis designates a specific condition and becomes the crucial label that organizes illness: it identifies treatment options and enables access to services and status, from insurance reimbursement to sick leave and support group membership and so on. Diagnosis underlines the authoritative role of medicine, the doctor and the medical sector in policy making. A further understanding of the social impact of "diagnosis" could be a relevant step to explore further and to develop a broader view on chronic illness.

Stigmatisation can also, although not intended, occur at service provision and policy level. Discourses on the policy level and health services level implicitly label a chronic illness or disease being expensive and a burden on society, because it is incurable or because the person is dependent.

A great threat to people with chronic illness comes from self-labeling, induced by confrontations with the "external" world. 'Internalisations' of stigma are derived from the 'negative' perceptions from others; mostly from strangers (often professionals) but also from the social environment and family. Self-labeling develops, often also a result of the grief and loss of self esteem over time, because of social

isolation. The construction of a negative self-image becomes the justification and basis for exclusion from a range of 'normal' social interactions.

Theories and researchers focusing on stigma have been criticized because people with chronic illness are conceptualized far too much as being passive, solely determined by labels and inflexible (Charmaz, 1990, 1994, 1995, 1999, 2002; Williams, 2000, 2006). The previous paragraph introduced evidence on how people with chronic illness do not passively accept a less legitimate status in society; people find strategies to adapt to it during a chronic illness trajectory. Many studies showed how people develop identities to fully participate in society after an initial period of readjustment. Chronically ill people learn ways to handle their symptoms and dependencies through various strategies. Differences have been observed on how young and middle age adults manage their illness in a way to continue to make plans, develop activities and take up responsible roles. It are often these groups that create or participate in self help groups, provide and organize information. In this way, aspects of labeling and stigmatizing became closely connected. Studying the experience and trajectories of people with chronic illness: culture (norms, values and expectations related to social roles) affect the way people deal with and manage their illness, but not in a deterministic way.

### **Social variables and chronic illness**

Several studies have added arguments that social variables, such as gender, socio-economic status or class, culture, family structures, are important intermediate variables to understand the complexity of chronic illness. A range of qualitative studies illustrate that variables such as age, culture, ethnicity, class do impact on how people experience their illness and on their perceived needs. Needs in a chronic illness trajectory do not solely depend of the disease or conditions, but also on position, role and integration in different levels of society. A better understanding of this complexity could eventually support the development of more targeted policies in that area of chronic illness.

### **The Body and chronic illness**

Sociology of the body studies how the social world affects our bodies and how representations and social use of the human body in modern societies occurs. A number of insights are developed concerning the production, regulation and representation of bodies within the context of disciplinary surveillance and the medical regimen (Williams, 2006). The roots of this perspective are found in the writings of Foucault. He described on how the enlightenment period introduced a radical shift in western medicine, introducing a "clinical gaze" (le regard médical) (Foucault, 1973). The clinical gaze gives the medical professional an enormous power to define reality (see also previous section on the role of diagnosis). Foucault's concept denotes the dehumanizing medical separation of the patient's body from the patient's person (identity), which has had many consequences for clinical practice, organizing cure and care and societal perspectives on medical phenomena, including power processes. He identified on how power relations are exercised on an individual level in medical encounters (through the medical gaze), but also on how this medical gaze is part of regulating the public health of populations (see (Lupton, 2003)). Through the development of scientific medicine and the biomedical model attention



shifted from the “person” to the biomedical object carrying a disease: health was therefore increasingly valued as a state of absence of disease or disorders in the body. The main critique is that the person was substituted by the disease in the person: persons became “cases”: showing “objective” signs of a disease or disorder, and the body is treated in a way as a mechanical model. Feminist writings also highlighted the construction and regulation of women’s bodies in and through medical discourse and in various health care settings (Annandale, 2000; Wilson, 2001)

The growing number of chronic diseases and an ageing population urges the health care sector back into developing perspectives of the “person as a whole” dealing with a range of problems beyond bodily problems. A particular stream of literature on the body connects here to the literature of experiencing disease or a (chronic) condition: it focuses on the lived body as a site of on-going experience (Williams, 2006). The biological bases of experience, as perceived both by the person and others have very important effects on the construction of self and identity (Kelly & Field, 1996) (Williams, 2006) Authors such as Williams and Shilling (Shilling, 1999, 2002, 2005, 2007) therefore plead for a corporal realism, acknowledging biological constraints as well as possibilities; but also the development of peoples lives with different stages and phases.

## Expert patients

Health care professionals are important in the process of managing an illness, but it has been demonstrated that especially for chronically ill people, many phases and many aspects of their lives are managed by the individual. The main work of managing their lives is not done by the professional care sector but by the patients and their partners, children and close friends, in multiple domains of life (emotional, social, financial, work housing etc.) (Coulter, 2002; Martin et al., 2009)

Ongoing sociological work discusses issues of 'expert patients'. (eg. (Greenhalgh, 2009; Lindsay & Vrijhoef, 2009)). The work on expert patients builds on the knowledge showing that the management of chronic illness is not in direct control of (health) professionals, but very much in the hands of the patients themselves. Patients with long term conditions become “experts” as they develop and acquire skills to cope with a chronic condition. Moreover, patients manage their conditions according to social circumstances and personal characteristics. Sociologic studies have described the development of a new social context enabling service providers to work in closer partnership with health service users and thus de facto reforming paternalistic relationships. Patients with chronic diseases therefore need not be mere recipients of care but should become key decision-makers in the process of cure and care.

User-led self-management programs have been developed over the last twenty years, building on this knowledge. Certain policy programs see the expert patient as part of prevention strategies and encourage patients to become experts in the self-management of their condition and engage them actively in decisions concerning their care (e.g. UK) These programs assume that this policy would reduce health care utilization because patients will engage more in their health. However, this policy is currently subject to many scientific debates and criticisms (see (Greenhalgh, 2009; Taylor et al., 2007)), mainly debating that the effectiveness of self-management programs is not necessarily proven, and that

many unwanted effects could potentially be the result of these strategies mainly because of issues of social capital impacting on vulnerable people to be their own managers.

## **Chronic illness and socio-economic inequalities**

The research on socio-economic differences related to chronic illness has developed on two major axes.

On the one hand there is the issue of personal expenditures and cost that are not falling under reinsurance or reimbursement rules, putting a particular burden on people lacking sufficient resources to cover all direct and indirect costs (and loss of income) because of their condition.

Another stream of research focuses on the prevalence of chronic diseases and their risk factors in different socioeconomic groups in the population. This stream of literature is closely connected to the general health care insights on the social gradient. In developed countries, there is a negative association between socioeconomic status, social capital and a variety of health outcomes. It has been documented that at different life stages, different risk factors and determinants (eg. stress, violence and traumatic experiences; educational disadvantage; inadequate living environments poor diet, lack of exercise; alcohol and tobacco misuse and tobacco smoking) are also increasingly more prevalent in groups of low socioeconomic status (measured as lower schooling levels, high levels of unemployment; substantial levels of discrimination, interpersonal violence and exclusion; and poverty).

Arguments have been developed that especially higher educated people have a better social capital in the self-management of their illness leading to a steep gradient in outcomes (Goldman & Smith, 2002)

## **Some reflections for (European) policy initiatives**

Chronic conditions go hand in hand with complex and evolving needs. This requires an approach that goes beyond the acute and post-acute oriented policy approaches. A variety of changes for the management of chronic disease care have been advocated in more theoretical models ((Wagner, Austin, & Von Korff, 1996); (WHO, 2003), mainly because of the experienced mismatch between needs of people with chronic illness and care delivery, as the latter is historically largely designed for acute illness. Many reviews conclude that the most effective interventions for improvements in chronic disease care include the combination of multiple strategies in an integrated approach (eg (Armitage, Suter, Oelke, & Adair, 2009; Nolte & McKee, 2008; Ouwens, Wollersheim, Hermens, Hulscher, & Grol, 2005; Singh, 2005).

The Chronic Care Model (Bodenheimer, Wagner, & Grumbach, 2002a, b; Coleman, Austin, Brach, & Wagner, 2009; Coleman, Mattke, Perrault, & Wagner, 2009; Wagner et al., 2001; Wagner et al., 1996) offers a framework that re-orientes healthcare services to effectively deal with the needs and concerns of individuals with chronic disease. It acknowledges that a substantial portion of chronic care takes place outside formal healthcare settings and that the development of a new approach requires intervening on different levels. Six interrelated elements are considered of central importance: patient self-management (Empower and prepare patients to manage their health and health care) community

resources (promote formal and informal community services in health and social care that support and meet patients' needs); decision support (Promote clinical care that is consistent with scientific evidence and patient preferences); delivery system redesign (Define roles and distribute tasks among actors involved adapted to the needs and cultural backgrounds of groups); the healthcare system (Create a culture, organization and mechanisms that promote safe, high quality care) and clinical information systems (Organize patient and population data to facilitate efficient and effective care).

The WHO adapted the chronic care model to focus more on community and policy aspects. The Innovative Care for Chronic Conditions Model (WHO, 2003) focuses on improving care at three levels: micro level (individual and family), meso level (healthcare organization and community), and macro level (policy). The centre of the Framework is the micro level, consisting of people with long-term conditions, families, community partners, and the healthcare team. The micro level should be supported by healthcare organizations and teams and the broader community. Community resources are vital to health care systems and to the management of chronic problems because people with chronic conditions spend the vast majority of their time outside the walls of a health care clinic, living within their communities. Community resources can also fill an important gap in services that are not provided by the health care organization. The policy level is considered as an important tool for organizing the values, principles, and general strategies of governments or administrative divisions to reduce the burden of chronic conditions. The policy environment creates the framework to inspire, advocate and integrate policies that span different disease types; consistent financing; developing human resources; legislative frameworks; and partnership working.

Canadian experiences lead to the introduction of the “Expanded Chronic Care Model” which includes population health promotion components and enhanced community participation(Barr et al., 2003)

Many countries are experimenting with new models of health care delivery aimed at better addressing the (complex) needs of people with chronic health problems, and aimed at a better coordination or integration of services. Case studies on organisational innovations indicate that there is considerable variation in approaches used on chronic disease management (McKee & Nolte, 2008; Singh & Ham, 2006), and that many countries are still working on experimental basis (Nolte, Knai, & McKee, 2008). The introduction of new modes of services delivery seems to be much affected by the local models of health and social service delivery. It also shows that on a policy level an integrated vision, including aspects of social care, health care (and other policy domains) supports the implementation of innovative practices.

At this stage, very little evaluative work is available on these very complex intervention strategies related to health services and systems organization for people with chronic conditions. It would be a suggestion to develop methods to share experiences and develop incentives on the European and international level to develop innovative health services approaches taking into account the social sciences insights. Better insight is needed on effectiveness and efficiency of policy programs aiming at supporting the often needs in different life spheres of people with chronic conditions. An agenda of comparative evaluation research to support innovative policies seems required. Effectiveness should not only be evaluated based on narrow medical aspects as needs are not solely disease or condition specific. Using the social sciences insight it can be discussed whether policy frameworks that are limited to the

development and implementation of disease specific approaches, without integrating them into an overall societal perspective, are accurate strategies. We expect that approaches only focusing on conditions can lead to an unnecessary segmentation and differentiation as well as the loss of insight in transversal needs. Moreover, as many people with long term conditions suffer from the co-existence of multiple disorders this issue of integration of different societal domains will become apparent. Future policy programmes in Europe should focus on the question whether an adequate support system enables social integration and participation of people with long term conditions, taking into account the transversal aspects. Current national experiences seem to learn that especially competing policy frameworks and regulations hamper a coordinated way of implementing approaches.

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