

# Fostering Local Caring Community Building through Mutual-aid Funding in Accordance with § 20 h SGB V and § 45 d SGB XI, Using the Example of the “Social Network Lausitz”

*anthropology of donation and sociology of reciprocity; Caring Community Building; inclusion; intersectoral networking; mutual aid; services of general public interest; social change management; Social Space Coordination*

*The socio-structural development towards an ever-increasing lifespan (in Germany), predicted by social scientists, implies a growing need of services of general public interest for those in need, especially in the areas of health and care provision. Considering the continuous skills shortage in these areas one can assume that social insurances and the welfare state might become partially incapable to fulfil their obligation to guarantee social security. Innovative alternative approaches of local provision of services of general public interest, especially in rural areas, make use of effective resources of mutual-aid organisation which is efficiently networking with other social institutions, NGOs, local businesses and the citizens. Professional and financial support is ideally given by the local administration/ the municipalities as well as the social insurers according to § 20 h SGB V and § 45 d SGB XI. This article presents and analyses a successful coordination of services of general public interest through a contact office for mutual-aid groups in the Oberlausitz/Saxony, Germany which is mainly operating in the realms of the Third Sector.*

## 1 Introduction

Over the life course human beings are constantly confronted with developmental challenges that require the persons facing them to find solutions to overcome these challenges. That means, persons rely on learned abilities, conveyed by their social environment, and infrastructural capacities, provided by the welfare state, which are combined to a set of so-called capabilities, to cope with existence self-responsibly and as far as possible autonomously. But what if a human being and its social environment is not capable to cope with existence and is overburdened by mental or physical health problems or psychosocial issues? Given the existence of a welfare state, one would argue that the social insurances are responsible to provide health or nursing care benefits that solves individual problems. Although these professional services are indisputable necessary to maintain a society’s health care, there are also other factors that determine a person’s well-being and quality of life. Especially in the case of chronic disease, disabil-

ity and frailty health and nursing care become increasingly difficult to manage, as persons might be stigmatized, lack close social networks, are heavily limited in their mobility, or are ashamed to reach out for help, thus become socially isolated or, even worse, are actively excluded from the societal centre and pushed towards its periphery only to become outsiders. Being cut off from social participation and interacting in the social dialogue by meaningful role-playing in a community violates the human dignity. Thus, social inclusion of outsiders must be lived by local communities to provide equality of living conditions for those who are limited in their capabilities and social participation. One of Burns/Williams/Windebank's (2004: 23) central points of criticism on the status quo of community self-help is that modern welfare regimes have established a culture of dependency for their citizens which is corrosive for society and the collective well-being of and inside communities. I.e. as citizens in welfare states are either dependent on employment or state benefits communities have unlearned how to generate social capital through economic-moral principles of reciprocal self-help as well as mutual-aid activity and social cohesion. Mutual-aid activity in mutual-aid groups has proven itself to be a well-established solution for many of the above-mentioned problems, as it offers supplementary health care through expertise of self-affected group members, reduces social isolation and fosters personal autonomy and self-responsibility. Mutual-aid activity is characterised by autonomous organisation, independence from other health care related institutions and the public sector and the reciprocal, corporative non-economic learning of how to improve the personal state of health through dialogues and common activities between self-affected persons. Many types of health related mutual-aid groups and related support institutions have the option to receive financial support from health and nursing care insurances which helps to keep the group work alive if they fulfil the condition of pursuing health protection and improvement. Although mutual-aid activity offers great improvements of well-being and coping with every-day problems, it is not suitable for everyone who is in need of support. Therefore, it is necessary that municipalities, especially in rural areas, provide a comprehensive and sustainable infrastructure of social services of general interest that fosters social capital generation and networking among the local population. The establishment and maintenance of such infrastructures is called caring community building and evolves around the provision of services of general interest in form of care, capability transfer and inclusion, while taking the existing local sociodemographic and infrastructural conditions into account, thus making it a social space and need oriented approach. Caring community building needs social non-profit institutions that operate and manage local and regional networking, mutual-aid activity and civic involvement embedded in a welfare-mix framework. In combination with the principle of subsidiarity which aims at the promotion of the community's self-determination, self-responsibility and (self-)empowerment through capability development, caring community building is supposed to improve the collective well-being and quality of life in municipalities, neighbourhoods and city districts. But establishing such social infrastructures is by far not an easily achievable task as it requires a social learning process that conveys the importance of lived inclusion of the suffering outsiders as well as a new self-conception of relevant societal actors like social insurances, public authorities on all administrative levels and the market based professionals working in the health care system. To get a deeper insight into the state of research on caring community building in Germany the present thesis will discuss its anthropological foundation and theoretical back-

ground, the use of mutual-aid activity in this context, legally regulated options of financial funding for mutual-aid groups and their related support institutions as well as analyse a case example situated in the East German district of Görlitz in terms of efficacy and beneficial effects for the population.

## 2 Theoretical Background

This chapter is supposed to provide a deeper insight into the theoretical backgrounds of caring community building. The first subsection will present the anthropological foundation of welfare and social space oriented social politics, based on the existential nature of the human being in a perspective of ageing over the life-course. Subsection 2.2 will show the reader why social inclusion, as a process of social learning and change, is necessary for a successful development of caring community building. The last subsection provides an overview of what caring community building is about and how it can be managed by social policies as well as the role of professional (market based) health care and forms of social civic involvement and mutual aid organisation.

### 2.1 Anthropological Foundation of Caring Community and Social Space Building

This subsection is supposed to explain the necessity and importance of local caring community and social space building from an anthropological perspective. Therefore, the complex context and interrelation of human existence, as well as coping with its every day struggles and problematic (chronic) situations over the life-course, social welfare, social policy and public services of general [economic or non-economic] interest (SG[e]I), will be, hopefully sufficiently, explained.

The human as a social being defines him- or herself (in the sense of a narration of the own biography) through diverse social relations which constitute his/her personal identity (Schulz-Nieswandt 2018 a: 7). Social support in a sense of giving and taking, originating from the primordial act of donation, is an essential part of these relations, especially for elderly people and the *homo patiens*<sup>1</sup> (Schulz-Nieswandt 2018 a: 7). I.e. that the orientation of social communities in social political thinking is based anthropologically in the existential condition of the human being and his/her creation and “management” of -and coping with- existence (Schulz-Nieswandt 2018 a: 7). Social politics as an configuration of ageing situated in a generational arrangement of diversity, precarity and marginalisation in a social structure with a centrum-periphery character is supposed to build up social caring communities where “community” is to

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1 The concept of the *homo patiens* refers to the suffering and pain as part of the conditio humana, i.e. suffering results from the diagnosis of a structure of concern of creatureliness and vulnerability (Schulz-Nieswandt 2017 b: 93). The elderly are not inevitably homo patiens just because of a higher age but because the higher age increases the chances of being limited in social participation. General higher frailty and risk of physical and mental illness become more prevalent in higher age groups, the mobility often decreases and the need for care and care might increase.

be understood as a space of possibilities and limitations that is determined by an underlying dynamic of creation (Schulz- Nieswandt 2018a: 7f.). The human being, as a person, is situated and embedded in the centre of his/her social relations<sup>2</sup> where he/she tries to successfully narrate the own personal life (biography), although these relations are often painfully inharmonious and ambivalently tensed while complex developmental problems might cause the human being to fail the narration (Schulz-Nieswandt 2017 b: 88). This potential to fail in life implies a deep existential fear: human existence is a risk; persons are continuously confronted with new development tasks and challenges over the life-course, i.e. they are naturally vulnerable. Existence is considerably a risk every person must face with courage, loving attitude towards the world and self-responsibly using the given (donated) personal abilities and environmental capacities, with reliance on social networks and the solidarity of society. The metaphor of the maze is often used when describing the journey of life, a labyrinth with many possibilities of taking the wrong turn or way, in having to return to a certain point, maybe of starting again at another point, related to confusion, different life choices, not knowing where to go and where the journey (of life) will end and having the requirement of a guide who knows the way and can help finding the right path (Schulz-Nieswandt 2017 b: 79). In his vision of the cultural transformation of social togetherness in social politics and policy in form of a liberating (in the sense of enabling) and at the same time embedding serious care for the homo patiens (as a person which is limited in social participation, thus excluded from society and therefore suffering) in the light of sacral human dignity and the freedom of personalisation, Schulz-Nieswandt's idea (2017 b: 78ff.) of the human being is based on a “theology without (any) god”: salvation in form of the good life is not anymore allegedly given by a personified higher power but comes from the “godly” power inherited in the act of compassionate caring donation which is constituted in the overarching context of the existence of living together in a society/community. I.e. that very love as a source of creative power to cope with existence and its life-affirming extraversion nature that was once believed to be given by god, *can* now be provided by the solidary organized and empathically compassionate members (the so called *homo donans*) of society and community (Schulz-Nieswandt 2017 b: 80ff.). Thus, love is the foundation of an anthropology of solidary reciprocity in the mode of donation and mutual care (Schulz-Nieswandt 2017 b: 85), where suffering and the ability of compassionate empathy are mutually dependent and homo patiens and homo donans create a cooperative community to achieve the common goal of the good life (Schulz-Nieswandt 2017 b: 83). The concept of reciprocally donating care while at the same time being in need of support is an essential part of the every-day solidary life, and, in a more specialized and differently organized from the basic idea of mutual-aid groups, that is able to empower the homo patiens by giving him/her a socially productive task and fosters social embeddedness, participation and personal well-being (BMFSFJ 2017 a: 51). Care means e.g. (medical) health treatment, mentoring, social support, nursing, consultation, etc., usually in a sense of (self-)empowerment and activating work by and for the homo patiens (which corresponds to the idea of mutual aid) (Schulz-Nieswandt 2017 a: 6). This concept of cooperative generation of services of general interest, care and welfare can be found in all types of mutual-aid groups which will be presented in chapter 3 of this thesis. But: Schulz-Nieswandt (2017 b:

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2 Which does not imply that this relational centre is also the societal centre!

83) argues that the diagnosed current state of social reciprocity between homo patiens and homo donans does not meet the above visioned and desired condition in the modern (German) welfare society: the question is how to achieve the transformation from the current state to the desired one, how to achieve social change and progress?<sup>3</sup> Social policies and public SG[e]Is with the welfare state as a legal guarantor of social security together with society as a social space/area in form of a caring community (e.g. through an innovatively developed third sector) could be the driving force in the process of cultural change management (Schulz-Nieswandt 2017 b: 83). Social change management needs to be enabled to progressively change a society's cultural grammar of living together (Schulz-Nieswandt 2017 b: 86 f.), the psychodynamics behind awareness, the attitude towards socio-cultural environments and relations. Persons are embedded in path dependent social structures and normative orders (which refers to the Apollonian characteristic of humanity) but they can also be creatively constructive (which refers to the Dionysian characteristic) (Schulz-Nieswandt (2017 b: 89). Therefore, social networks and caring communities are necessary for social inclusion of outsiders, as those communities can generate social capital in urban and rural districts. Social capital is the benefit of networking and interconnectedness in a local area: e.g. social support, integration, personalizing meaningful role offers in the life-course, etc. (Schulz-Nieswandt 2017 b: 13). Living a successful life, with and especially despite limited chances of participation and existential challenges (also in the perspective of social embeddedness and inclusion), therefore is a question of quality of life and well-being up until old age and death, while quality of life is not a linear function of material wealth but depends on the well-being in the sense of self-esteem, self-efficacy, self-awareness and confidence, as well as resilience and the repertoire of coping strategies (Schulz-Nieswandt 2017 a: 15). Primarily, a human being as a personalized individual is self-responsible for successfully coping with life and existence, but not in a neo-liberal perspective of being entirely responsible for everything that might be happening to him/her over the life-course – *not* every man/woman is the architect of his/her own fortune- thus, society is jointly responsible for guaranteeing equal chances to live life successfully (Schulz-Nieswandt 2017 b: 88) and to provide a minimum level of social security. But often enough, the homo patiens resides in the semi-periphery of society, suffering not only from his/her limited quality of life and participation chances resulting from chronic physical or mental illness, social problems, cultural discrimination or other hindering conditions, the homo patiens also suffers from social exclusion and becoming an outsider for having said condition or for failing existential development challenges. The exclusion of outsiders is based on the deep anxieties that are connected to the relation between the insider and the outsider: the homo patiens represents the unknown, the strange that remains unidentified and is therefore kept out of the inner circle of society, thus, as an analogy to the topography of inside and outside, Schulz-Nieswandt (2016: 6, bold and italic in the original) proposes the following structural equation:

***fear : love = exclusion : inclusion.***

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3 This is of course a very difficult question that has many implications (of political, cultural, social, anthropological, professional nature) and the realization of the transformation might be even more complex and difficult than the answer to this question. Nonetheless, it is a central question of this work and there are different local/ regional approaches already, one of them the "Social Network Lausitz" will be analysed in this thesis.

It refers to the above discussed love and open-minded attitude towards the social environment of the world that is necessary for understanding the *truth* of and behind human existence by questioning the meaning of existence and therefore him/herself existentially, thus being existent becomes a relational structure of reality and ideality which is generated through morality (Schulz-Nieswandt 2017 b: 89 f.). The above described life-course perspective in the context of permanent human vulnerability and social dependency shows that personal autonomy must always be regarded in relation to social networks, communities, the society, 'the others' as absolute autonomy would mean social isolation (an early 'social death') in absence of either receiving or donating love by/to others, without an loving attitude towards others and the world – a self-chosen life of exclusion (Schulz-Nieswandt 2017 b).

Modern societies have mostly grasped the concept of integration that creates a specific space in a community for persons with limited chances of participation but is based on making a clear difference between insiders and outsiders, while inclusion appreciates the diversity and heterogeneity of persons and aims to transform outsiders into insiders by giving them the opportunity to be an equal member of society based on the sacral value of human dignity and a loving open-minded attitude towards the (social) world/environment. Or: "How can autonomy and independency in the mode of participation of the human person in the community be guaranteed?" (Schulz-Nieswandt 2017 b: 12). The next subsection will address the inclusion of the *homo patiens*, the framework of personalization and social policies.

## 2.2 The Inclusion of the *homo patiens*

"... Successful inclusion is a process of social change (...) understood as cultural transformation" (Schulz-Nieswandt 2016: 5) and for this process, respectively this transformation, a society (as a collective) as well as its smallest structural unit (individuals) must recognize the necessity to rethink the collective identity and the inherited self-conception. I.e. a social learning process: that does not mean it needs to be done through social engineering but can be managed and supported by social policies, an innovative approach of developing the deinstitutionalisation of the modern life-course (especially) in its cultural aspects, social participation and civic engagement by living the idea of inclusion. Thus, inclusion questions the way of societal relations, arrangements and the every-day organization of living together in and as a society where everyone has the chance of living the 'good life', regardless of personal socio-economic status, mental and physical health issues, age, gender, sex, ethnicity and all other characteristics that potentially provide any points to attack, discriminate and exclude. "Inclusion (...) as the radical alternative to the cultural reality of social exclusion of the *homo patiens* is an anthropological paradigm of philosophy of law" (Schulz-Nieswandt 2016: 9). It is a permanent matter over the life-course: beginning with childhood (or birth, to be more precise) young children are naturally more vulnerable because they lack self-responsibility and autonomy due to their developmental status, thus they need a strong social environment they can learn from to become an 'independent' person. Then, in the working-age, persons become more self-reliant, go to work, are mostly financially independent, live apart from their parents, create own families but still need reliable social networks that provide social security (e.g. family, friends, colleagues, social

communities: a solidary society). Especially, in case of unforeseen events like arising chronical illness, accidents, disabilities, (long-term) unemployment and other situations of incapability (i.e. when becoming a *homo patiens*). When retiring, persons tend to become more vulnerable again, thus in greater need of existential security, regarding the provision of mobility, age-ad-equate housing, participation as well as health and nursing (BMFSFJ 2017 a: 28): pensions are often lower than once earned salaries (poverty among seniors is a widely discussed phenomenon in Germany), especially elder women are significantly more likely to suffer old-age poverty as they were born in generations when the male bread-winner gender role was predominant (e.g. BMFSFJ 2017 b: 15). The basic needs remain the same over time and overlap across age groups, but differently pronounced and weighted, thus not only the elderly people are supposed to benefit from caring communities (BMFSFJ 2017 b: 14). Illness becomes more prevalent with advancing age: according to meta studies about 35% of seniors aged 90 and older suffer from Alzheimer's dementia, also 80% of all statutory health insurance expenses are invested in only 20% of the insured persons, which are characterized by frailty-syndrome and chronic diseases that become worse over time and not rarely develop into multi-morbidity (Schulz-Nieswandt 2017 a: 9).<sup>4</sup> Approximately 50% (about one trillion €) of the social fund's expenditure is invested in senior citizens (Schulz-Nieswandt 2017 a: 8). As an expression of the ongoing demographic change, the number of dementia patients and care dependent elderly will increase together with the demographic share of old age persons in the German society, constituting an upcoming central social challenge for communal and regional provision of services of public interest (BMFSFJ 2017 a: 22). Another change is observed in the generation of middle-aged persons who are increasingly unable to take care of the older, parental generation, due to spatial mobility (living too far away from their parents) and incapability of taking care of the family and being employed (BMFSFJ 2017 a: 22). Considering these numbers, changes and challenges, it is obvious that a requirement of nurture and health care provision as well as case, care and health management on the local and regional level emerges. As an alternative to family-provided inhouse care, social caring communities, as social spaces or areas of inclusion, can provide *infrastructures* and enable *competences* the human person, especially the *homo patiens*, needs for being able to participate effectively in society and interact with the environment (Schulz-Nieswandt 2016: 10) with less 'hurdles'/'barriers' (not only in a physical way) but also more autonomously and self-responsibly, thus with (more) dignity. Therefore, inclusion might be able to reduce existential fears of the included *homo patiens* as well as the worries of their relatives. The idea of inclusion, based on the sacral character of human dignity is a moral concept that is represented in several treaties of the United Nations (UN), of the European Union (EU), the German Constitution as well as in the German Social Code (Sozialgesetzbücher: SGB) (the relevant articles and laws will be discussed in detail in chapter 4 of this thesis). On the one hand, the social structures of modern societies are bound to the dynamic production of social differences and inequalities that are moderated through social mechanisms of social classes (social milieus/socio-economic status), age, gender, ethnicity and other characteristics

4 Schulz-Nieswandt's (2017 b: 24) discourse on the increased vulnerability of persons of higher age in the context of risk situations (in terms of income, housing, mobility, health, nursing, disability) can be transferred on persons who are affected by precarious life situations (*homo patiens*) (without intending to make a too gross generalisation).

that allow codifying and categorizing of what is normal and abnormal, good and bad – insiders and outsiders (Schulz-Nieswandt 2016: 13). On the other hand, modern societies and welfare states generally embrace the values that originated in the French Revolution: freedom (1), equality (2), solidarity (3) (*liberté, égalité, fraternité*). The freedom (1) of realizing a good life with resources (capacities and abilities) given, i.e. personalisation over the life-course. Personality is the *personalising* individualisation through participation in social networks and by the status of communisation and association (as personal social embeddedness and inclusion) to counteract (or ideally eradicate) exclusion, alienation and the social death (Schulz-Nieswandt 2017b: 47). The equality (2) of developmental chances of the personality (e.g. equal access to education, culture, housing etc.), as well as having the right to benefit from resources of social security (e.g. SG[e]I), provided by the solidarity (3) of the society organised in the social welfare state and the third sector, in case of failing to realise a ‘good life’ (Schulz-Nieswandt 2016: 13). But (this was already discussed in the previous section), there is a disparity between these societal values and our social reality. There are outsiders – the homo patiens who is limited in his/her participation in social life, thus circumscribed in his/her human dignity – living in the periphery of society, while the healthy and successful (or at least not limited and failing) majority of persons spend their lives in the societal centre with an exclusive club character (Schulz-Nieswandt 2016: 13), revealing obvious social inequalities. Thus, the homo patiens is considered to be an outsider: he/she is alienated by the insiders and excluded from the societal centre through the mechanism of cultural stigmatisation, a behaviour that is rooted in affectivities of fear of the otherness, the strange, the unknown (Schulz-Nieswandt 2016: 15). In the ongoing process of developing and becoming a modern society, humanity is challenged with building a functional structure of (social) security that considers the evolutionary, cultural and civic status quo of enlightenment. But deeply entrenched (institutionalised) in this order of security is “(...) a moral order of good and bad and of purity and impurity in a structural relationship with profanity and sacrality (...)” (Schulz-Nieswandt 2016: 16), which is manifested in a social order of two separated groups: the insider ‘vs.’ the outsider, which again is mirrored in a spatial order of both groups (centre and [semi]-periphery). The gap between both groups – socially and spatially – might be bridged by inclusion. Similar imbalances are observable in the professional health care sector: in health and nursing related institutions there is the ambivalence of the moral human-logic of empathy, charity, altruism etc.: the care; and at the same time an attitude of looking down from above that is expressed by a hierarchical structure between patients and professionals, which provokes an information and decision making asymmetry and an establishment of professional supremacy (patriarchalism) (Schulz-Nieswandt 2016: 17). The structural grammar of need and power can explain the structural relation between care and love in this context: care refers to social interaction between persons in the setting of social connectedness and cultural embeddedness in time and space (Schulz-Nieswandt 2016: 18). While love is the care someone donates to the homo patiens, thus reacting to his/her need of care, interacting in a social dialogue in the mode of reciprocity (Schulz-Nieswandt 2016: 18). The question is how to transform the prevalent top-down system in the health care and nursing institutions to a bottom-up approach that enhances the participation of the patient before, during and after the treatment process and leads to a health care provision that inherits less (at best minimal) hierarchical power asymmetries, takes the patient and his/her will serious and is mutually organized and

structured by the four sectors (government, market, private households and the third sector)? Schulz-Nieswandt (2016: 19) sees a possible answer in an innovative setting of collective living with mutual help structures based on reciprocity which provide socio-cultural embeddedness and social inclusion to its members, while the professional sector needs to reconsider its work ethics which integrates a self-conscious understanding of empathic care and health needs based on awareness. The right to inclusion in the light of sacral human dignity is the guiding value that is legally embedded in international and German law.

Inclusion, as the process of transforming outsiders to insiders, is not only an acute challenge for professionals in health care but for society in general. Integration is not enough as it refers to the assimilation of the outsider, meaning they are still considered an abnormal minority that is feared by the norm-conform majority, expecting the outsiders to adapt to their norms. While inclusion refers to being fully aware of individual and personal diversity and heterogeneity, understanding and accepting this fact and creating a social environment (a caring community) in which chances for participation are equal for everyone.<sup>5</sup> It is about a process of collective learning that diversity in whatever form does not need to be feared and excluded (Schulz-Nieswandt 2016: 25) and this challenging process must be implemented by social policies. “Inclusion is a process of community building. Community is a [social] network that generates social capital. Social capital is the outcome of the network (...)" (Schulz-Nieswandt 2016: 25 f.). Social networks may emerge wherever trust capital is generated, which again is the result of successful investment in social networks to build social capital: i.e. there is a circular causality between trust and social capital (Schulz-Nieswandt 2016: 26).

Summarising, inclusion is a key feature and factor for societal progress in terms of health care provision and nursing, social embeddedness and networking. It is based on a loving attitude towards the world and social environment and a mind-set that requires extraversion. Overcoming deeply inherited fears of alienated outsiders (the homo patiens) and reconsidering, rethinking and reinventing a society’s collective identity as a process of social change is therefore inevitable.

### **2.3 Inclusion and Social Capital in the Scope of Caring Community Building**

After providing an anthropological picture of the human being, that is naturally vulnerable in his/her creatureliness and therefore reliant on the identity-establishing social relations in which he/she is embedded, while continuously being challenged by developmental tasks over the life course, thus permanently facing the risk of failing one’s existence, as well as giving an explanation why the inclusion, in the mode of loving empathetic care and open-mindedness, of those who actually are failing in coping with existence, the homo patiens, need to be included into society by donating help, care and support and enable their abilities and enhancing environmental capacities (e.g. through the means of SG[e]Is), this subsection is concerned with giving insight into the including mechanisms of caring community building that generate social capital.

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5 Total social equality will most likely remain a societal dream.

Social caring community building is about fostering an inclusive experience of social coherence for human beings who exist in a cross-linked social environment that can provide SG[e]Is in all required forms. This social space/community is not simply pre-existing or generated out of nowhere but must be shaped and developed through social political actions. Ultimately, caring communities are the capital of social networks: the societal benefit and profit which results from social political investment (Schulz-Nieswandt 2018 a: 8). Social spatial orientation of social politics and policies in this context refers to a sustainable promotion and maintenance of social capital (Schulz-Nieswandt 2017 b: 13). This investment in social communities and networks (or the generation of social capital of social networks) does not refer to a neo-liberal perspective of individual benefits by health or social insurances but in the sense of guaranteeing the provision of public social infrastructures and services of general interest on the national, regional and local level, allowing to transform collaborative aid into mutual aid forms (Schulz-Nieswandt 2017 b: 13). That means also, it is about personal skill development as human beings are continuously in a reciprocal impression-perception cycle with the social environment they must cope with (or fail to do so) (Schulz-Nieswandt 2017 b: 13). The idea of social space in the context of caring community building is based on the moral-economic efficiency of embeddedness that may be provided by social networks, while social capital, the benefit of investing in social networks, is understood to be social support, integration and personalisation (Schulz-Nieswandt 2017 a: 5). Usually, this idea relates to the regional/local locality of physical existence. The goal of caring community building is to establish an infrastructure of SG[e]Is in which the availability, accessibility, awareness and quality related acceptability of social institutions and general services is equal for all persons who are affected by existential difficulties and specific needs (Schulz-Nieswandt 2017 a: 32). I.e. the chances of access to care provision and general public services are of primary importance in the local caring community, as the status of social participation and autonomy of the homo partiens remains deficient. "Services of public interest thus become a task of coordination and management of the range of action in the public respectively municipal responsibility" (BMFSFJ 2017 a: 35).

Social welfare in the sense of an institutionalisation of the life-course eventually is supposed to guarantee the unrestricted possibility of personalisation in society and in the mediate and immediate social environment. The function of social politics is to organize the living standards equally for everyone (Schulz-Nieswandt 2017 b: 18). Living standards or situations are personal and individual resource spaces in the context of the developmental chances of personalisation in relation to participation (Schulz-Nieswandt 2017 b: 18). On the one hand, a human being can take advantage of available personal resources (human capital and existential competences) and on the other hand make use of external (economic, social, legal, infrastructural, housing, etc.) operational capacities provided by the social environment the person is embedded in: both types of resources interact reciprocally (Schulz-Nieswandt 2017 b: 18 f.). "Social services of general interest are *modes of design* of inclusion in the sense of infrastructural capacities combined with personal competences of abilities" (Schulz-Nieswandt 2016: 37). This concept of human scope of action directly relates to Sen's and Nussbaum's Capability Approach.

#### *Digression: Sen's Capability Approach*

The general Capability Approach of Sen (e.g. 1995) is a theory that offers a way to evaluate a person's social position/status in terms of functionings and capabilities given and learned over

the life-course. According to Sen a person's position and status in life can be described by the things he or she manages to *achieve* and the *freedom*, as a real opportunity, to achieve what he or she intrinsically values (Sen 1995: 31). Interpersonal and societal inequalities, thus, can be viewed in the perspective of actual achievements and the freedom of choice what to value and then achieve (Sen 1995: 31), relating to the conversion problem of resources and primary goods where, under equalized ownership distributions the issue of unequal freedom remains unconsidered. E.g. two persons with the same income (financial resources) do not necessarily have the same freedom to achieve the same things, depending on personal factors like physical and mental health, place of residence, gender etc. Freedom can then be characterised as alternative sets of accomplishments (so called functionings) that persons are able to achieve (Sen 1995: 34).

A person's well-being directly relates to his/her quality of life and being. According to Sen's Capability Approach living or 'being' is a set of interrelated functionings (i.e. being and doing itself), thus personal achievement is the vector of these functionings (Sen 1995: 39). Relevant functionings can range from basic factors like good nourishment, being healthy, living in a proper housing, to rather complex achievements like happiness, self-respect, being embedded in a well working social network (Sen 1995: 39), thus functionings constitute a person's being. The *capability* of a person is the set of possible combinations of functionings achievable for him/her, thus "(...) reflecting the person's freedom to lead one type of life or another" (Sen 1995: 40) and depends on personal characteristics and social arrangements (Sen 1995: 33). As the well-being of a person depends on the achieved functionings, the *freedom* to create this well-being depends on the personal capability (Sen 1995: 40). If either the ability of achieving functionings or the interrelated capability of a person is limited, his/her well-being and quality of life will be negatively impacted, which again may lead to increased social inequality. While the achieved well-being is directly dependent on the capability to function as the capability represents the set of achieved functionings that are available to a person (Sen 1995: 41), capability may even contribute directly to the well-being, e.g. in the form of having a real choice between various options in life (Sen 1995: 50; 1993: 39). As Sen (1995: 52) puts it: "..., if choosing is seen as a part of living, and 'doing x' is distinguished from 'choosing to do x and doing it', then even the achievement of well-being must be seen as being influenced by the freedom reflected in the capability set". Which implies that humans cannot simply choose a lifestyle or determine their own life course fully self-responsibly, like neo-liberal ideas of living in modern societies promote (Schulz-Nieswandt 2017 b: 88).

Further, Sen (1993: 35 f.) proposed a four-way classification to assess a person's status of advantage in society. Each point of classification has two different distinctions which are the following:

1. Well-being achievement (as the evaluation of the 'wellness' of the person's state of being):
  - a) Promotion of the person's well-being.
  - b) Pursuit of personal agency goals (as desirable achievements that are not directly related to a person's well-being).
2. Agency achievement:
  - a) Achievement
  - b) Freedom to achieve

3. Well-being freedom
4. Agency freedom

All four concepts of advantage and their function of well-being assessment are interrelated. Their relevance may differ as Sen (1993: 36) makes clear with an example: the well-being achievement and freedom is likely more relevant than the agency achievement for persons living in deprived circumstances, i.e. the social policies and the society should rather focus on promoting the former than the latter to create social welfare and capital. Otherwise, e.g. in very advanced welfare states where basic needs are well covered, well-being achievement becomes less important (as it is highly likely to be accomplished), while well-being freedom becomes increasingly relevant, i.e. the means, alternatives and options as well as their diversity might be promoted (Sen 1993: 36) to foster overall well-being. The Capability Approach proposed by Sen thus is a potent theory to assess personal well-being, the quality of life and even further identify social inequality through concepts of achievement in relation to freedom.

Martha C. Nussbaum's (e.g. 2000: 5; 2006: 70) capabilities approach, which is directly related to many of Sen's ideas, evolves around the concept that basic human capabilities, as a socially acceptable minimum of what people are able to do or to be, enable a life worth living (i.e. the good life) in human dignity. These basic capabilities are valuable and important to and for every human being, thus treating each person as end rather than means to an end, in the sense of Kant, giving a consensual set of ethical values and life goals or achievements among all persons who actually consider different definitions of the good life (Nussbaum 2000: 5). Therefore, Nussbaum (2006: 70) argues that her approach “(...) provides core human entitlements that should be respected and implemented by governments of all nations, as a bare minimum of what respect of human dignity requires”. Other than Sen, Nussbaum introduces the concept of a threshold level of capabilities, beneath which actual functioning (see above) a life in dignity is not possible, thus the goal of each society (further: the welfare state) should be to elevate all citizens above this threshold level rather than focusing on equality of capability (2000: 6 & 12). Further, Nussbaum (2000: 13) made a distinction of three different types of capabilities: *basic*, e.g. human senses or the ability to speak and learn language, *internal*, i.e. abilities learned through education for practical executions and *combined*, which are internal capabilities that are available through the environmental context in which persons are embedded: referring to what social space oriented policy making and community development and building is responsible of. The approach, just like Sen's, recognizes capabilities as actual opportunities of accomplishing beings and doings that citizens should lawfully be entitled to, enabling a life with dignity, while simple access and distribution of resources is considered to be an inadequate indicator of how people can really cope with existence (Nussbaum 2006: 74 f.). Based on this concept Nussbaum (2006: 75-78) presents a list of ten following basic and central capabilities that are at minimum necessary to live a good life: life (being able to avoid premature death and living in dignity), bodily health, bodily integrity, senses as well as imagination and thought (as one capability), emotional freedom, practical reason, affiliation to communities and the self, respecting other species, play and control over one's material and political environment. “The basic idea is that with regard to each of these, we can argue, by imagining a life without the capability in question, that such a life is not a life worthy of human dignity” (Nussbaum 2006: 78). The above presented basic capabilities are generally in line with the UN human rights which are

cross-culturally accepted and agreed on (but not always implemented to the full extent). The homo patiens is usually limited in at least one point of Nussbaum's basic capability list, which does not mean he/she is unable to live a life in human dignity, but that the homo patiens has more complex needs for this certain capability area and is in expanded need of care that is aimed towards him/her. Nussbaum's approach, based on the principle of human dignity and the inviolability of the person, is largely overlapping and in line with the theoretical considerations presented in this chapter, promoting the importance of mutual respect, care, empowerment and social reciprocity.

The human being is dependent on social networks but also able to construct and maintain them, leading to the notion that social policy, as life course policy, needs to be reinvented towards a social space-oriented development and fostering of the good life for a nation's population (Schulz-Nieswandt 2018 c: 228). The realization of this kind of welfare state organisation can be achieved through the interaction of the social state, civil society, markets and the third sector: this is called welfare-mix approach. Therefore, a close coordination of all involved parties as well as the social and health insurance funds, under the consideration of the articulated needs of the local population is necessary to implement a wholistic care system, aimed at autonomy and participation, that can satisfy the demand of health care, mobility, housing and socio-cultural offerings (BMFSFJ 2017 a: 23). The welfare-mix approach thus corresponds largely with the general idea of the principle of subsidiarity which evolves around the responsibility of the state and the municipalities to implement infrastructural and social resources (or capabilities) that enable self-determination, autonomy and participation of the person on the local level as well as the coordination of the political and societal order between all levels of the governmental authorities, individuals, informal social networks and all other forms of communal self-organisation (BMFSFJ 2017 a: 44). The perspective of inclusion plays an important role, as it allows the homo patiens whose institutional requirements in form of SG[e]Is enable social and political participation with dignity (BMFSFJ 2017 a: 35). As mentioned before, the life-course perspective is interwoven with the ageing process of the person, which does not imply that only persons of high age are in need of care or that someone who receives care is incapable of donating and providing such care on the basis of mutual-aid or voluntary commitment (BMFSFJ 2017 a: 23). The role and potential of the local social surrounding and environment (i.e. friends, family, neighbours) is not being exploited to the fullest, especially when this form of informal care networking is considered as a supplement for the provision of health care and nursing by professionals that is guaranteed by the municipal administration. I.e. the municipalities have the responsibility to promote and fund this kind of network structure by guaranteeing the development of a platform that manages the social network and connects relevant cooperation partners that are interested in and capable of creating social capital and building caring communities on the local and regional levels (BMFSFJ 2017 a: 23). Managing the cooperation of network partners is a complex task as different actors and institutions that are supposed to work together have rather different work cultures, professionals are often reluctant to work with volunteers and the municipalities are short on financial resources for network building, which hints to an unfavourable situation of limited options to fund caring community building (BMFSFJ 2017 a: 24). Regarding the difficulties of network management, the gap of financial funding options as well as the mentioned challenges of demographic change, the necessity to provide the municipi-

pal authorities with fundamental competences and financial resources, as they are responsible for the implementation of services of general public interest, becomes obvious. The implementation of enabling the good life through a welfare-mix approach takes place in local/regional municipalities, that can be understood as a cooperative community based on mutual social support and networking (BMFSFJ 2017 a: 24). As stated above, the idea of caring community building is about enabling the good life with dignity over the whole life-course (not only relating to highly vulnerable senior citizens or persons with impairing disabilities), it is about mechanisms of social and cultural embeddedness and acceptance, thus also about emergence and coherence of the personality and ultimately about the free development of human personality based on the sacrality of human dignity (Schulz-Nieswandt 2018 c: 229 f.). “It is about the effective implementation of the obligation of the social welfare state as a guarantor of social infrastructures (Capacities) and the promotion of personal competences (Abilities) to [self]-empowerment (Capabilities), (...)” (Schulz-Nieswandt 2018 c: 231), following Sen’s and Nussbaum’s above described Capability Approach. It is also about personal diversity in the process of self-conceptualisation over the life-course in the context of a successful local and regional daily life in society (Schulz-Nieswandt 2018 c: 231). As described in both succeeding subsections of this chapter, persons tend to continuously strive for meaningful role identities and a task-oriented way of living which results from the human needs for appreciation, acceptance, participation, autonomy and (self-)responsibility. A social environment that can provide services of general public interest through the mode of inclusion and based on a social life-course policy, fostering personal abilities, environmental capacities and social embeddedness is called caring community (Schulz-Nieswandt 2018 c: 232).

Therefore, social policy needs to focus on social space-oriented life course politics that are based on inclusion and human dignity to foster “(...) the relative, relational and context-sensitive autonomy of the human being in the mode of participation in community” (Schulz-Nieswandt 2018 c: 232). The welfare state government as well as the municipalities have the constitutional obligation to guarantee and implement the institutional framework that allows and enables a need-oriented support and the provision of SG[e]Is creating equal opportunities among citizens to live life autonomously in the community (BMFSFJ 2017 a: 28). This becomes especially important in the context of a modern, globalised and digitalised fast paced world. These so-called mega trends<sup>6</sup> have an undeniable impact on the life-course as well as on the structure of interrelated generations in a society, leading to newly arising challenges for modern welfare states (Schulz-Nieswandt 2017 b: 43 f.). Caring community building can only be successfully accomplished and managed in a local social environment that lives the culture of an open municipality, where the sustainable guaranteed provision of a professional care landscape, that is complemented and subsidised by voluntary civic engagement and mutual aid structures, can organically grow and develop (Schulz-Nieswandt 2017 b: 43 f.). Care and Care management without interconnected infrastructures of a guaranteed provision of SG[e]Is embedded in a caring community will remain ineffective (compare Schulz-Nieswandt 2017 a: 27). Of special interest in the inseparable context of physicality of the regional and local level are

6 Other mega trends of social change are e.g. the redistribution of gender roles, supra national regime politics, epidemiologic developments and demographic change.

housing and mobility as they are situated in a transactional reciprocity cycle of human personality and constitute the fundamental living environment, enable an autonomous life and empower the coping with developmental challenges (Schulz-Nieswandt 2018 c: 232), in a social network of cure, care, mutual-aid activity and civic engagement, shaped by a welfare-mix approach. In the course of this, it is important to note the continuous shortage of professionals in nursing and health care, which is, especially in the relation with the phenomenon of the increasing life expectancy (in the sense of a prolonged phase of life after retirement) of the German population and with the corresponding requirement of health care and nursing, becoming a Herculean task of demographic change.

The question is how financial support of mutual aid in accordance to § 20 h SGB V and § 45 d SGB XI can benefit the municipal/local services of general interest (SG[e]Is), thus fostering caring community building. What can be achieved by the organised mutual aid which is supported by contact offices in terms of provision of services of general interest as well as building and shaping social caring communities? The next chapter will sufficiently but not over extensively describe the structural mutual-aid organisation and its benefits in Germany, as well as address the above asked questions.

### 3 The Mutual Aid Landscape Organisation in Germany

The present chapter will introduce the German mutual-aid landscape, describe its organisational structure with all relevant institutional elements which are working on the micro-, meso- and macro-level of mutual-aid activity and operating on the local/regional, the federal state and national level. Further, the actual personal and societal benefits of mutual-aid activity will be presented in more detail, as they can be considered to be SG[e]Is provided by the third sector, fostering the creation of social capital and local caring community building.

The term mutual-aid is not to be understood in the above mentioned neo-liberal idea but in a collective mutual self-help in terms of a self-organised social construct, situated between governmental and privately managed supply structures, as a pro-social moral economy of solidary management of challenges and developmental tasks by transforming capacities and abilities into social resources (see Sen and Nussbaum's Capability-Approach).

#### 3.1 Organisational Structure of the Mutual Aid Movement

The health related mutual-aid movement<sup>7</sup> in Germany has a long tradition and, over the last decades, evolved into a significantly important and indispensable part of the health care system. Rooting in the late 19<sup>th</sup> century, e.g. related to substance addiction issues, the Blaue Kreuz in Deutschland e.V. founded in 1885, self-help and mutual-aid associations and initiatives have become increasingly institutionalised in the 1970s as a response to persistent health care mis-

<sup>7</sup> Mutual-aid movement means every institution that is related to mutual-aid activity and its support that is striving for the improvement of the members and/or societal health and overall well-being.

management, structural dominance of professionals and as a cost-effective alternative for generic health care provision (NAKOS 2017: 20). Until the end of the 70s mutual-aid activity was not accepted in Germany, neither by society, nor by the health care institutions, nor the government (Mazat 2011: 386). The deficiencies of the earlier as well as the modern health and social system regarding the social framework and the institutional organisation structure are of course not the single causing factor of all personal health and social issues. These issues need to be fought by improving the legal situation, as well as the structural framework and process in the individual case management in favour of a sustainable provision of SG[e]Is which would also benefit from an innovative reorientation of its social localisation, according to Engelhardt (2011: 23). The societal process of individualisation in which persons are increasingly set free from traditional social institutions e.g. family and neighbourhood urged those in need without receiving care to organise in mutual-aid groups (MAGs) (Engelhardt 2011: 26). Since then, an astonishing mutual-aid landscape<sup>8</sup> has been established on the micro, meso and macro level including approximately 70,000 – 100,000 mutual-aid groups (two thirds of them are health related while the other third focuses on social issues), with over 3 million affected members (homo patiens) and relatives, almost 300 Selbsthilfekontaktstellen (contact offices that support the mutual aid-organisation on the local and regional level) supporting over 36,000 registered of the above mentioned MAGs as well as 320 mutual-aid initiatives<sup>9</sup> related to rare diseases and four umbrella organisations on the national level (NAKOS 2017). Central overarching goals of the mutual-aid organisation<sup>10</sup> are personal improvement of coping strategies, reciprocal help and support and care as well as social change (NAKOS 2017: 20 f.), e.g. by improving patient involvement as an increasement of participation in decision making during the therapy or by informing patients in hospitals so they can join MAGs after inpatient treatment in so called self-help friendly hospitals (Trojan et al. 2012). The German mutual-aid landscape is organisationally structured on the national level, the federal state level and on the regional/local level (NAKOS 2017: 23, Übersicht 11): the MAGs as well as the contact offices (e.g. Kontakt- und Informationsstelle für Selbsthilfegruppen, short KISS) are organised on the local and regional micro level, being in direct contact with the affected persons and relatives. The contact offices provide information on the benefits of mutual-aid activity and the offer of the local groups that might be suitable for interested persons in need, thus working on the organisational and institutional meso level as they connect local MAGs with mutual-aid initiatives and health care professionals. Additionally, they actively support over 36,000 regional groups independent of their respective health or social indication by networking with professional health care institutions (NAKOS 2017: 21), coordinating funding applications of MAGs according § 20 h SGB V and § 45 d SGB XI, giving professional advice, offering a lobby, help founding groups, provide meeting rooms and representing the interests of mutual-aid initiatives in public on the local and regional level as well as giving training in group organisation (Robert Koch-Institut 2015: 371).

8 Mutual-aid landscape refers to the mutual-aid movement on the micro, meso and macro level of organisation.

9 Mutual-aid initiatives operate similar like MAGs but often on the federal state level or sometimes even on the national level. They tend to have an impact on society by raising awareness for their certain issues and often act in the interest of the affected members.

10 Mutual-aid organisation refers to how the different mutual-aid institutions on the micro, meso and macro level are 'hierarchically' structured and organised in cooperation.

The local/regional framework conditions regarding the contact offices and mutual-aid initiatives are decisively of advantage for the foundation and continued existence of the connected MAGs. Many contact offices emerged out of the national mutual-aid movement, thus being not only professional self-help related service providers but directly connected with the group work (the employees of contact offices work in full- or half-time jobs) (Mazat 2011: 385).

On the federal level there are 49 mutual-aid associations that coordinate group activities, give guidelines and serve as a link between the groups and contact offices on one side and the umbrella organisations on the other side. Also, over 300 mutual-aid unions offer support for members who are affected by rare diseases on the meso level to bridge the lack of local groups for these specific indications (NAKOS 2017: 23, Übersicht 11). These associations and initiatives are also generally autonomous although many of them are represented and guided by one of the umbrella organisations. They may have influence on legislative procedures and cooperate as accepted partners with health- and pension insurances, physicians and rarely with the pharma industry (Mazat 2011: 384). The initiatives are administratively organised, usually as registered associations, take membership fees, vote executive boards and assemblies of delegates, etc. (Mazat 2011: 384). On the national macro level there are about 160 initiatives related to certain chronic diseases and disabilities which take care of representation of interests on the national level as well as the four appointed umbrella associations: BAG SELBSTHILFE, der PARTÄTISCHE, the DAG SHG and the DHS. These four associations are the biggest representatives of mutual aid organisation and activity in Germany that are responsible for the representation and safeguarding of the interest, the support and organisation of contact offices, funding as well as the structural framework construction (NAKOS 2017: 21 f.). The legal notion of mutual-aid organisation is noteworthy as it fulfils functions of social security as well as cure and care (e.g. provision of certain SG[e]Is) that otherwise lies in the responsibilities of health care and social insurances as well as the governmental authorities (Grunow 2011: 174).

### 3.2 The Effects and Social Benefits of Mutual-Aid Groups and Activities

The GKV Spitzerverband (2018: 9) defines health related MAGs as voluntary associations of directly or indirectly (e.g. as partners, family, etc.) affected persons, whose activity aims for the mutual coping with chronic diseases, its consequences and/or mental health issues. Autonomously organised MAGs do not strive for economic benefits but for better situations and coping strategies of their members through regular, mostly weekly, group meetings that focus on equality, group discussion and reciprocal care, offside of health or social related professional monitoring (AOK Bundesverband 2000: 170 f.). As MAGs are self-organised constructs based on the principles of democracy and autonomy which aim for reaching a common goal through reciprocal support, they can be characterized as cooperative communities in the mode of civic involvement (Schulz-Nieswandt 2018 a: 29). Because of the highly complex heterogeneity of mutual-aid groups and initiatives regarding their structure, organisation and indication topic there is no unified systematisation but only general working principles, characteristics and aims reflecting the equally complex and diverse living and problem situations of their members (Engelhardt 2011: 37 f.). Although one could make a differentiation between health, social and psy-

chosocial issue related groups, most groups tend to focus and talk about all issue areas, at least to a certain extent. Engelhardt (2011: 47) notes that the methods and the beneficial effects of mutual-aid activity in groups, whether health or social issue related, have a psychosocial character: exchange of experience, improvement of psychosocial well-being (through experiencing to be understood and empathically understand the other members, social participation), learning coping strategies for the relevant issue as well as capabilities and social activities and activation. Central shared characteristics of MAGs are self-organisation, autonomy, self-affectedness of the members, voluntary participation in group activity/discussions, relative obligation in the sense of commitment to the group and the pursuit of common non-economic goals like the improvement of the quality of life. Especially health related MAGs show the regular characteristic of a positive impact on the emotional well-being of group members, long continued existence and the organisation of social contact and participation in- and outside the group, as well as the issue-orientated exchange of information and knowledge about coping strategies (Engelhardt 2011: 100). One important difference between mutual-aid activity and voluntary engagement is the self-affectedness of the group members (Matzat 2011: 381). Only those who suffer from the same chronic illness or the same physical or mental health issue can genuinely understand and comprehend the specific daily struggle, pain and limitations that are faced by their co-members, thus situating them in the credible position to give actual and individual helpful advice and meaningful care. Burns/Williams/Windebank (2004: 15 f) state that “(...) the relationship between individual self-interest and collective interest is intertwined, and this manifests itself most clearly in various forms of reciprocity”. Thus, MAGs can achieve an improvement of the quality of life of their members which cannot be realised by professional health care (Engelhardt 2011: 26). It is important to recognize mutual help organisation as a significantly meaningful *supplement* to the social and health care system. The work of MAGs is not supposed to *replace* professional health care provision and is of course not capable of monitoring mental and physical health related therapy processes as physicians and therapists can. But mutual-aid activity has played a notable role in overthrowing the decision making dominance of professional health care personnel (Engelhardt 2011: 27), as group members often have more versatile information on their rights and therapy alternatives and is also still engaged in the improvement of patient involvement in the German health care system. This approach of self-organised mutual care has specific trade-offs with the institutionalised health care: institution orientation decreases in favour of a stronger focus on the affected person, administration orientation in favour of coping strategies and expert dominance is balanced in favour of patient empowerment (Engelhardt 2011: 27).

### 3.2.1 What Motivates the homo patiens to Participate in MAGs?

Members participate in MAGS for non-professional follow-up care, in the case of relapse of the issue or for complementary support during the professional therapy (Matzat 2011: 382). The competences in terms of care and cure of autonomous organized self-affected laymen/laywomen in MAGs is especially effective at improving psychosocial related issues (Matzat 2011: 382) But MAGs do not have the universal effectiveness of school medicine. The basic principles of

self-affectedness and reciprocity are the driving force of every mutual-aid group. The voluntary participating members experience through co-members that they are not alone with their specific problems and learn, especially through the group's "veterans", who function as an motivational example of successful coping with the new (worse) living circumstances how to take responsibility for their own recovery and *themselves*, but more importantly *together* with and *through* the other self-affected group members (Matzat 2011: 383). As the social and health care system was only partially able to satisfy the patients' needs, suffering persons were motivated to engage in self-help and mutual-aid by the chronic high degree of the physical or mental strain, by searching and finding answers that contribute to solve their problems or at least to get a permanent grip on them, to handle social isolation and exclusion as well as to gain better information (Engelhardt 2011: 82).

Engelhardt (2011: 28) reports that participating in MAGs offers important impulses in coping with the daily limitations of social participation rooting in chronic illness, disabilities and/or mental and social issues, which may result in an improvement of emotional state and every-day coping in terms of participation, insight, stimulation and empowering activation. Group activity may help reducing social and personal isolation that is caused by the specific issue. First, the benefits of MAGs are outcome-oriented: the positive effect for the individual and the group is paramount, not the effort that is necessary to achieve the improvement. Engelhardt (2011: 115 f.) has systemised the effects of health-related discussion- and contact-groups by differentiating the emerging effects by their social benefit range. The effects primarily reaching the members, not any third parties outside of the group, are e.g. the improvement of confidence, exchange of experience, social contacts, emotional support, improvement of psychosocial well-being, a change of perspective on the issues, empowerment and activation, development of specific issue related capabilities and coping strategies, reciprocal support in problem solving through role model learning, practical help and information exchange, group dynamic development and organisational mutual-aid activity (Engelhardt 2011: 115 f.). The effects that influence not only the members but also their close social environment (family, friends, colleagues) are the improvement of interpersonal relationships, the provision of information and knowledge regarding the specific health issue of the affected person leading to more empathy and cohesion, mutual-aid activity outside the group such as drawing the public's attention to the disease in question, supporting other affected persons outside the group by giving advice, information on the group, etc. (Engelhardt 2011: 115 f.). When groups are increasingly focusing on activities outside their member circle they can effectively impact social grievances through representation of interests, change of professionals' attitudes towards the mutual-aid movement, provoke institutional change, introduce new concepts of problem solving and coping on a large scale, constructive cooperation with professionals and reducing health care treatment costs by improving patients' overall well-being (Engelhardt 2011: 115 f.). Of course, the above-mentioned positive effects are only a representation of what MAGs are capable of. Not every group can provide all the listed benefits and they differ greatly in intensity between groups. Also, some effects are more common among groups than others, e.g. are beneficial effects for relatives and the society way less common than effects concerning the members (Engelhardt 2011: 123). This might be due to the fact that there are mutual-aid organisations already operating on the meso and macro levels trying to have an impact on the societal perception and the system as

well as dedicated groups for relatives that have not been taken into Engelhardt's meta-analysis or lack of research interest by social and health scientists regarding the investigation of these types of effects. Nonetheless, there is considerable empirical evidence on the peripheral social environment of affected persons and the health system in terms of patient participation, their autonomy and contribution. Overall, the state of research on beneficial effects of mutual-aid activity is scarce, not only on personal benefits but also for monetary/economic effects e.g. in form of preventing or at least delaying the need of further professional therapy services (Engelhardt 2011: 125). Summarizing, as the welfare production of MAGs can be considered as social, health and nursing politically relevant services of public interest, they create social benefits, both internally and externally of the group itself (Schulz-Nieswandt 2018 a: 30).

Effects of so-called action groups (i.e. groups that focus on joint activities as their method rather than discussions), self-organised and alternative projects (e.g. senior home sharing projects, resocialisation projects, women's refuges etc.) aim for "(...) protecting the own identity from further damage and alienation and preserving the *personal human dignity through autonomy, codetermination [as participation] and involvement*" (Engelhardt 2011: 126 f., italics in the original). These types of groups have a person-centred problem perspective approach that sets the affected person in a holistic context of his/her (social) environment and treats them as self-responsibly acting and capable subjects (Engelhardt 2011: 127). The groups are collectively able to reciprocally empower the members to cope with their problems while often subsidised by professional treatment, and focusing on the personal capabilities, expert knowledge and experience based on consensus democratic principles of group organisation and structure, decision making and member rights and obligations (Engelhardt 2011: 127, Abbildung 7). The traditional working methods of the professionals in the health care and nursing sector in contrast treat the chronically ill and otherwise suffering patients as deficient and norm divergent social objects that need to be cured and medically treated to transform them into (economically) valuable beings for society while the decision making is dominated by professionals, warranted through their alleged elite academic education and social-professional status (technical competences, organized through hierarchical structures that are designed to fix health issues in a certain time frame or when becoming acute) (Engelhardt 2011: 127). Many of these alternative projects have managed to earn considerable recognition and respect by social and health authorities as well as welfare associations through their innovative action models that were helpful, financially funded and finally long term established in the infrastructure which was sustainably modernised (Engelhardt 2011: 138). According to Engelhardt (2011: 145) MAGs are often reacting to new problematic situations very quickly after they emerge, thus putting themselves years ahead of the professional institutions which take more time to adapt to patients' needs.

If the working ethics of MAGs are transferred to processes and innovative projects of caring community building which are set in a framework of welfare-mix and brought to people who are willing to adapt to these methods in cooperation and coproduction with the professional health care and nursing system in terms of social involvement of third parties, inclusion with human dignity for the homo patients can be realised in local and regional settings of community life. Noteworthy is that this idea is somehow contradictory to the principle of self-affectedness of MAGs as it includes the participation of third-party social involvement of non-affected persons. Second, a high degree of willingness and endurance of all individuals involved is required

for this social learning process, especially by the non-affected as they have not the motivation of chronic strain pressure to fight for this cause.

### **3.2.2 Forms of Cooperation Between MAGs, Professionals and Mutual-aid Organisations**

It is not unusual for professionals to be invited by MAGs to lecture on specific or psychosocial issues the members are affected by. The professionals might discuss their presentation afterwards with the members but will not have any further influence on the groups' work, but in return receive some valuable insight into the problems that are not directly related to medical treatment, allowing to better understand their patients' needs (Engelhardt 2011: 160). The contact offices are also supporting the MAGs by providing knowledge and advise but in terms of group organisation, funding options, meeting room provision, etc. The advice and support can be received on demand and has not to be realised by the groups; thus, they stay somehow independent from the contact offices and their professional employees. Cooperation between health-related MAGs and health care institutions as well as medical specialists have increased over the last decade. Especially hospitals and rehabilitation clinics cooperate more and more with MAGs to provide better follow-up care for their patients and to improve their internal quality management (Trojan et al. 2012), while partnerships with local physicians and specialists remain scarce but are mostly achievable (Engelhardt 2011: 163). The most hindering factors are (Engelhardt 2011: 163): the unalterable otherness of both systems, i.e. the mutual reciprocal support among the MAGs' members that produces personal capabilities and empowerment as well as, to some extent, social welfare follows significantly different principles as the profession health care that follows hierarchical structures, focuses on objective facts in terms of cure and care as well as monetary profit. Also, many professionals still tend to perceive mutual-aid activity as a direct illegitimate competitor, which is not the intended role of mutual aid, as discussed earlier in this chapter. In cases of chronic illness with heavy psychosomatic characteristics cooperation showed to be fruitful where after especially difficult surgeries or other therapeutic interventions mutual-aid experts could serve a role model of successful coping for the new patients, thus directly contributing to professional therapy methods (Engelhardt 2011: 135).

A group's membership of a mutual-aid (umbrella) organisation, which are often run by professionals, can have adverse effects on the group's organisation and development, if they have to bow to the organisation's statutes, hindering an autonomous innovative development and trimming the general values of self-determination, codetermination and involvement, e.g. in the case of statutes with religious guiding principles (Engelhardt 2011: 161). If MAGs are animated to not only cooperate with professional health care and support institutions, but would be also directly supported by member relatives, neighbourhoods and civil initiatives as well as the municipals, new potentials of caring community building could arise and a pathway to innovative social space orientation on the micro, meso and macro level will be paved.

## 4 Legal Background of Mutual-Aid Funding

The following sections will provide an overview of the legal backgrounds that are relevant for caring community building. Starting with UN and EU treaties on fundamental human rights providing the moral-ethical basis for universal social security, over German national law Articles that regulate social service provision responsibilities, to specific paragraphs of the German social code which regulate the funding of mutual-aid activity, this chapter's purpose is to describe the legal foundation that allows the fostering of successful caring community building.

### 4.1 Article 1 UN Universal Declaration of Human Rights

Article 1 of the UN Universal Declaration of Human Rights from 10<sup>th</sup> December 1948, proclaimed by the United Nations General Assembly resolution 217 A, states that all UN member states, their governments and societies recognize that “All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards another in a spirit of brotherhood.” As these statements are relatively clear in their meaning, they might become more *meaningful* in combination with the first sentence of the Preamble of the Declaration that underlines the “(...) recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family [which] is the foundation of freedom, justice and peace in the world”. Obviously, the focus lies on the sacral character of human dignity that is considered to be the most important precondition of modern secular welfare states (and also of other forms of modern state governance). The Declaration states that all human beings equally inhere dignity, i.e. they are born, live and die with it, cannot be taken or legally withdrawn from them, which leads to the statement that it is inalienable. This inalienability as well as the inviolability of the human dignity refers to the moral-ethical commandment that no other human, no government, no legal body, institution, etc. is allowed or should be able to violate or limit a person’s dignity in any way. The modern social welfare state thus has the obligation to guarantee the protection of this precondition for all persons regardless of theirs social, ethnic or cultural origin, their gender, age, sexual orientation, physical and mental constitution etc., which is achievable through social polities and policies that implement equal rights. The inviolability and inalienability of the inherited human dignity is the highest and most important fundamental right for the UN, the EU and all their member states. E.g. Article 1 of the German Constitution is very similar to the first Article of the Human Rights Declaration, considering the human dignity as “untouchable” and recognizing also its inalienability and inviolability.

### 4.2 Article 3, 4 and 5 of the UN Convention on the Rights of Persons with Disabilities

According to Article 1, the purpose of the Convention on the Rights of Persons with Disabilities from 13<sup>th</sup> December 2006 is to promote and protect the full and equal rights and fundamental freedoms of all persons with disabilities, i.e. long-term physical, mental, intellectual and

sensory impairments which limit their social interaction and participation in society in any way, compared to other non-disabled persons. The convention and its articles are based on the principles of respect of human dignity, individual autonomy and independence as well as the freedom of choice and decision as a fundamental necessity of existence with a basic minimum of quality of life, the principle of non-discrimination which refers to the full and equal rights and enables effective participation and inclusion in society, the principle of respect for difference and diversity of the human kind in reference to the abolishment of the alienation and exclusion of persons with disabilities, the principles of equality of opportunity and accessibility which are closely related to the equal chances of participation in social and cultural interaction as well as the equal access to public transportation, housing optimized for special needs, facilities and services of general interest, education etc., the principle of equality of men and women as women still suffer more excessively from social inequality, and lastly, on the principle of respect for the development of children with disabilities as they are especially vulnerable due to the lack of responsibility and autonomy (see chapter 2, section 2).

Article 4 of the Convention declares that all UN member states, their governments and the respective political parties have the quasi legal obligation to realize the human rights and fundamental freedoms of persons with disabilities fully. They are urged to implement the rights recognized in the Convention's 50 articles through legislative measures that enforce the above-mentioned principles and promote and protect the development as well as the identity of persons with disabilities. The Convention's 5<sup>th</sup> Article obliges the states parties to recognize the equality of all persons by law and to protect them from any form of discrimination based on disability and to guarantee the provision of housing and accommodation that is suitable and need-oriented for the specific limitations caused by all types of disabilities.

The UN Convention on the Rights of Persons with Disabilities thus provide the legal foundation through its principles of social inclusion of the homo patiens. Although it refers more directly and explicitly to persons with disabilities, the parallels to all kinds of the homo patiens' limiting sufferings are clear. Also, the convention declares the (social welfare) states and its political parties to be responsible for the legal implementation of the protection and promotion of the human dignity, the personal identity as well as the autonomy and participation of persons with disabilities. I.e. they must guarantee the provision of SG[e]Is, e.g. the mentioned need-oriented housing facilities.

### 4.3 The Charter of Fundamental Rights of the European Union

The Preamble of the Charter of Fundamental Rights of the European Union proclaimed on 7<sup>th</sup> of December 2000 (OJ C 326, 26.10.2012, p. 391-407) mentions that the peoples of Europe share the common universal values of human dignity, freedom, equality and solidarity (the values originating from the French Revolution) on which the Union is founded on, while based on the principles of democracy and rule of law. The Union and its member states are responsible to preserve and further develop the diversity of cultures and national identities and their organisational autonomy of public authorities within the framework of existing EU legislation. The Charter's here relevant articles recognize the inviolability of human dignity, the right to life, to

liberty and security of the person, the universal human equality before the law, the right of the elderly to live with dignity and independence as well as their right to social and cultural participation and the right of persons with disabilities to resources and services of general interest that enable their unlimited self-responsibility, independence and opportunity to participate in communal life, thus being included. Article 34 of the Charter states that the EU in cooperation with its member states needs to grant social security in terms of entitlement to social security benefits such as social housing, (un)employment benefits, child care, health care and social assistance, hence the member states are in charge to establish an infrastructure of social well-being, e.g. hospitals, advisory services, public mobility, energy, communication services, and other types of SG[e]Is that foster capacities and abilities. The EU can handle the financial funding of social security provision on the member states on the national and community level through the European Social Fund (ESF) and the European Regional Development Fund (ERDF). The Co-ordinated social right and the social services of general interest are defined by EU institutions and must be implemented by the member states and their communities. Thus, supranational decisions on the EU-level show their outcomes in federal states and municipalities (vertical political networks). The member states and their communities are obliged to take care of the implementation of the SG[e]Is and social rights, thus national and subnational governments on the federal level are linked to the development of their society.

Further, Article 35 grants, besides the right to preventive health care and medical treatment, the Union's obligation to ensure a high level of health protection for the citizens, which can e.g. be performed by mutual-aid activity and caring community building. Walter/Volkenand (2017) refer to the fact that there are no legal obligations for municipal health protection in Germany, although health protection and promotion should be part of a modern interpretation of SG[e]Is. Therefore, they recommend developing legal regulations that clearly incorporate salutogenic health protection measures as obligatory for the municipal provision of SG[e]Is that fulfil quantifiable quality standards (Walter/Volkenand 2017). Article 36 states the Union's recognition of access to SG[e]Is that are provided by the member states and the respective national laws and practices.

According to Article 14 of the Treaty on the Functioning of the EU, the Union and its member states are responsible within their respective powers of authority and administration that the SG[e]Is can operate in such way that their original purpose can be fulfilled. Further, the member states are responsible for the provision, the commission to (market based) providers and funding of said services. Protocol 26, Article 1 on Services of General Interest highlights the extensive margin of discretion of the national, regional and local authorities in organising the provision and commission in such way that they are as need- and consumer oriented as possible, while considering the necessity of diversity of the offered services which originates from various needs of the potential users. Ideally, these services should bring a high level of quality, safety and affordability, while offering an equal accessibility as well as user rights.

Article 36 of the Charter of Fundamental Rights of the EU essentially recognizes the citizens' right to access to SG[e]Is according to national laws and practices in the framework of EU guidelines.

#### 4.4 Article 28 of the German Constitution

The provision of social services of general interest is a constitutional obligation of the demographic and social federalist Republic of Germany as well as its federal and local administrative authorities (§§ 30(1) & 28(2) German Constitution). These services include for example the population's provision with economic services such as energy, drinking water, waste disposal and road construction, but also with social and cultural services such as social welfare, youth welfare, child care, public schools and housing, health care, disaster control as well as cure and care for dependents and persons with disabilities (LRA Görlitz 2010: 22).

Article 28 of the German Constitution, from the 23<sup>rd</sup> of May 1949 (BGBl. I, p. 1), last amended by Article 1 from the 15<sup>th</sup> of November 2019 (BGBl. I, p. 1546), states that municipalities and local communities have the right to be responsible for all community concerns, i.e. also to take care of public social infrastructures as well as all types of SG[e]Is. Thus, German municipalities must guarantee the provision of public services by commissioning contracts to companies and service providers that are able to fulfil their duties locally. This closely relates to Article 34 of the Charter of fundamental Right of the EU, which states that the member states are responsible for the provision of social services of general interest on the national, regional and local level. The function of the municipality also includes the promotion of personal autonomy and guaranteeing the possibility to social, cultural and political participation independent of the extent of personal limitations (BMFSFJ 2017a: 21). The general idea of the principle of subsidiarity evolves around the responsibility of the state and the municipalities to implement infrastructural and social resources that enable self-determination, autonomy and participation of the person on the local level and the coordination of the political and societal order between all levels of governmental authorities, individuals, informal social networks and all other forms of communal self-organisation, as anchored in Article 28 (2) of the German Constitution (BMFSFJ 2017a: 44). Therefore, the municipalities need to receive the relevant resources and competences to build a local care landscape as well as a mobility and housing infrastructure that allows equal access to quality health care and nursing institutions, thus creating social security through local social space oriented coordination and management of network partners and the participating citizens. Rethinking responsibilities of nursing care insurances on the local level would therefore strengthen caring community building in the sense of a social space oriented and subsidiary welfare-mix policy approach (BMFSFJ 2017a: 50).

The idea of the EU includes the common market with its values of transparency and non-discrimination where contracts of social services are publicly procured. This market-oriented mechanism is supposed to enforce the competition on the European market. The way the EU tries to regulate the distribution of SG[e]Is stands in a tensed ambivalent interdependent relation with the interpretive design development of the social human rights defined in the Charter of Fundamental Rights as well as the German nation law (Schulz-Nieswandt 2016: 31). According to the Treaty of the Functioning of the EU, the European common market (or European Single Market) shall guarantee free movement of goods, persons, services and capital between EU member states for more efficient cooperation, increased competition and optimal redistribution of resources, while the EU declares the member states to be responsible for guaranteeing social services and securities (Schulz-Nieswandt 2016: 31 f.), i.e. the member states and their

municipalities supervise the implementation of SG[e]Is but as the modalities are market oriented they are supposed to be provided through public procurement on the common market. In the case of Germany most social services are procured through an in-house strategy, meaning that the national authorities select their providers on the internal market, leading to the challenge of the quasi-institutional treaties of the common market order on the one hand and the modalities of guaranteeing the provision of SG[e]Is on the nation level on the other hand (Schulz-Nieswandt 2016: 31 f.).

#### 4.5 § 20 h SGB V (German Social Code Book 5: Statutory Health Insurances)

§ 20 h (1) SGB V of the fifth book of the German Social Code, from the 20<sup>th</sup> of December 1988 (BGBl. I, p. 2477), last amended by Article 5 from the 22<sup>nd</sup> of March 2020 (BGBl. I, p. 604), states that the statutory health insurers and their association need to financially fund mutual-aid groups and initiatives as well as the supporting contact offices that aim for the *health related* prevention or rehabilitation of certain listed, mostly chronic, diseases and disabilities (i.e. MAGs concerned with social issues have no legal claim for financial funding in accordance with § 20 h SGB V). The potential recipients have no legal claim to receive the funding *per se*, as the responsible insurances and their associations make funding decisions at their own discretion (GKV-Spitzenverband 2019: 8). A financial funding of mutual-aid activity through the public authority is not provided by law, although municipalities are of course free to provide voluntary benefits to groups and organisations (Thiel 2016: 91). According to the circular letter of the National Health Insurance Association (Verbände der Krankenkassen auf Bundesebene 2018: 5) the amount of 1.13 € per insured person is determined to contribute to the funding pool, which cumulates to the total amount of 82.2 million euro in the year of 2019 (plus potential funds that have not been invested in the previous year). At least 70% of the financial fund have to be made available for lump sum funding to all eligible mutual-aid organisations on all national levels, while the remaining 30% of the pool can be distributed to projects to which the health insurances are directly related (GKV-Spitzenverband 2019: 12). Important eligibility conditions for mutual-aid organisations on the national level are: the organisation is a registered association (eingetragener Verein, short: e.V.) that has a functional organisation structure both internally and externally and as of 1<sup>st</sup> January 2020, the organisations are obliged to raise membership fees (Verbände der Krankenkassen auf Bundesebene 2018: 6). Local MAGs do not have to be registered associations to receive funds in accordance to § 20 h SGB V (Thiel 2016: 92). The insurers provide 80% of the lump sum funds to MAGs and initiatives on the local, regional and national level, while the other 20% of this pool are to be invested into organisations only operating on the national level (GKV-Spitzenverband 2019: 12). The funding of mutual-aid activity and its support in accordance with § 20 h SGB V is the most popular financial source as 82.1% of 296 support facilities used this source, while 63.5% raised own capital resources (e.g. through membership fees) and 61.8% were funded by public authorities in 2017 (NAKOS 2017: 15, Overview 8.2).

Schulz-Nieswandt (2018 a: 26) reports on noteworthy issues of mutual-aid funding in the context of § 20h SGB V. First, there is an ambivalence in general between the need of social insu-

rance funded professional direct or indirect support of mutual-aid activity on the one hand, and its accompanying social control and negative impact on the initiatives' autonomy on the other hand (Schulz-Nieswandt 2018 a: 26). As this ambivalence is inevitable, it needs to be actively minimized by both actors. Second, the continuously increasing need of mutual-aid funding and support through social insurance professionals is limited by the fixed administrative budget of the insurers and the legal regulation that insurance employees are not to be financed through the funds raised in accordance with § 20 h SGV (Schulz-Nieswandt 2018 a: 27), although the funding of a contact office for example on this basis leads to the same outcome, as professionals who promote and support mutual-aid activity are paid indirectly by the insurers (Schulz-Nieswandt 2018 a: 27). I.e. the social insurances finance third party employees who guarantee the provision of SG[e]Is as a form of social welfare production in the context of social space-orientation (Schulz-Nieswandt 2018 a: 27). This also means that the health insurances transfer their responsibility to guarantee a local and regional provision of SG[e]Is to third party contractors (either private or municipal) including the obligation to pursue the social goals determined by the public welfare act (Schulz-Nieswandt 2018 a: 28 f.). This cannot be the true sense and intention of this kind of public welfare management and other, more authority based solutions need to be found to improve the funding situations for health related MAGs that play an important role in social capital creation and SG[e]I provision in the context of caring community building. One prerequisite for generating SG[e]Is and using them in the framework of autonomy and participation is the provision of empowerment structures regarding civic involvement and co-responsibility in the community as well as the acquisition of the needed financial resources (BMFSFJ 2017 a: 22). When developing the local social space, the needs of other generations and cultures must not be neglected or even trimmed.

#### 4.6 § 45 d SGB XI (German Social Code Book 11: Social Nursing Care Insurance)

The § 45 d of the eleventh book of the German Social Code, from the 26<sup>th</sup> of May 1994 (BGBl. I, p. 1014), last amended by Article 10 from 22<sup>nd</sup> of March 2020 (BGBl. I, p. 604), states that the statutory and private nursing care insurances need to financially fund MAGs, organisations and contact offices that aim for the support and empowerment of those in need of care and nursing, their relatives as well as comparably related persons. Since January 2019 the amount of 0.15 € per insured person is determined to contribute to the funding pool. When the federal state or regional authority is willing to contribute 25% of the subsidy amount, the funding request can be successfully approved (i.e. that the ratio for insurances to the contribution is 75%) (NAKOS 2019). This leads to a yearly total budget of 16 million euro that can be invested into nursing care related mutual-aid activity (NAKOS 2019).

### 5 Analysis of the Social Network Lausitz

This chapter will be focused on the analysis of the Social Network Lausitz, (SNL) which will serve as a case example for local caring community building in the context of a welfare-mix

approach. First, the socio-demographic factors in the district of Görlitz will be described, followed by an introduction of the network, its contributions to the local and regional provision of SG[e]Is, a subsection concerned with the impact of digitalisation in this context and an analysis of the social capital and benefits generated by the network. The chapter is largely based on grey literature (mostly annual reports of SNL and KISS) that documents the network's development over the last eight years (from 2011 to 2019), thus progression of concepts, operation, organisation, success, professionalisation, impacting factors, financial requirements, crisis etc. can be captured (Engelhardt 2011: 137).

## 5.1 Introduction of the Network

The Social Network Lausitz gGmbH is a project of caring community building situated in the district of Görlitz/Oberlausitz in the federal state of Saxony, East Germany, funded in accordance with § 20 h SGB V. To better understand the underlying factors interrelated with the local and regional community building, this subsection will give insight into the social demographic structure and the spatial framework conditions of the district of Görlitz<sup>11</sup> and the region of Oberlausitz.<sup>12</sup>

### 5.1.1 Demographic Framework of the District of Görlitz

The district of Görlitz is situated in the very east of Saxony, bordering Poland in the east, the Czech Republic in the South and the German federal state of Brandenburg in the north. In 2015, the district was home to 260,000 inhabitants, which is almost 8,000 people less compared to the year 2011 and the population is continuously decreasing, making the district Saxony's region with the greatest demographic decline since 1990 (Landratsamt (LRA) Görlitz 2017: 16, Table 1.4). Two factors are impacting this decline significantly: the birth and death rates as well as the migration balance. The district has the lowest birth rate of Saxony with less than half as many live births as deaths, accounting for a population decline of 2,686 inhabitants (LRA Görlitz 2017: 17, Tab. 1.7). Since 2011 more people migrate into the district than out of it. But this is due to a strong immigration of foreigners, mainly from Poland and the Czech Republic, as still more German inhabitants chose to leave compared to move to the region (LRA Görlitz 2017: 19ff.). According to forecasts of the German Federal Statistical Office, the demographic change of an ever older becoming society will eventually emerge also in Saxony. While the population will further decrease over the next decades, the largest population share will be the one constituted by persons over the age of 65 by the year of 2030 (LRA Görlitz 2017: 25 f., Figure 1.15). This effect will be even more distinct by 2060. The social charges quotient is a tool that indicates how many persons of the workforce population (i.e. persons between the age of 19 and 65) must pay through taxes for the social security of children and pensioners (LRA Görlitz

11 Görlitz is a regional authority operator according to the principles of local self-government.

12 Oberlausitz is a geographic region including parts of Saxony, Poland and Brandenburg.

2017: 28). In the district of Görlitz the ratio is 100:74, i.e. that almost three employees pay for the social security of four children and/or pensioners (for comparison: the ratio in Leipzig, Saxony's most populous city, is 100:56)<sup>13</sup> (LRA Görlitz 2017: 28).

The general economic situation in the district of Görlitz is rather weak. The net household income did not grow between 2012 and 2015 and amounted to 1,628 € which is the lowest household budget in Germany, while the average per capita net income amounted to 1,094 € (LRA Görlitz 2017: 32 f.). One explanation for these below-average incomes are the high shares of persons receiving either pensions (34.2 %) or unemployment benefits (7.4 %) (LRA Görlitz 2017: 33, Tab. 2.2), which again is interrelated with the high social-charges quotient in the region. Although the incomes did not increase between 2012 and 2015, the district was able to generate over 1,200 new jobs in the time span (LRA Görlitz 2017: 38).

11.4 % of the district's population are severely disabled (i.e. they suffer from a disability that impairs at least 50 % of their cognitive or physical ability) (LRA Görlitz 2017: 50). The statistics show that especially persons older than 65 are increasingly affected by disabilities. Persons over the age of 85 face an even greater risk of becoming severely disabled (65.3 % of this population share are affected) (LRA Görlitz 2017: 52, Tab 6.2). Persons with disabilities have the possibility to live in a home for the disabled where they receive full or partially in-patient care. The district of Görlitz offers 1,275 of those care places to mentally and multiple disabled persons, to the chronically mental ill as well as to multiply substance addicted persons (LRA Görlitz 2017: 52, Tab 6.2). To persons with disabilities who can do specific types of work despite their suffering are jobs in sheltered workshops available (LRA Görlitz 2017: 54 f.).

In 2015, 14,522 persons were in need of nursing care, while 42.5 % of them were nursed privately at home by either family members or other affiliates (LRA Görlitz 2017: 56, Tab. 7.1). The number of dependent persons increases continuously since 2011. The financing of the "help for care" is an important factor for the district's public authorities, especially since the number of persons receiving nursing allowance is continuously increasing and is already far above the average of Saxony (LRA Görlitz 2017: 57), which is interrelated with the low household incomes in the region. Another factor of the high rates of need of professional or private care providers is that traditional social help systems like family based care provision become rarer as the younger generations tend to leave the rural region and move to more attractive and lively urban areas of the country, while the partners (usually women) of dependents are often neither able nor capable of taking thoroughly care for them (LRA Görlitz 2010: 8).

The above reported descriptive statistics just confirm what the county council has already recognised in 2010 (LRA 2010): The district of Görlitz is a region with significant infrastructural weakness, additionally with a low standard of SG[e]I provision in terms of health care and mobility. Its social structure is strangled by the highest unemployment and child poverty rates as well as the lowest purchase power nationwide, which leads to high social expenditure on one side and low tax revenue on the other, thus the financial possibilities and the control capabilities of the public authorities become increasingly limited (LRA 2010: 5). This challenge of demographic change, not only the nationwide change of the ageing society but also the region-specific

13 Please note that these numbers are relatively crude indicators and fulfil primarily the function of descriptive statistics that give a general overview of the social structure.

ic circumstances, need to be faced with optimism, commitment and serious engagement, but also an open-minded attitude towards new creative concepts and innovative approaches of social space-oriented provision of SG[e]Is and caring community building.

To guarantee the regional provision of public services and welfare production in the future, the authorities of the district of Görlitz have conceptualized a reference framework for integrated social planning which set goals that clearly correspond to the guidelines discussed in the previous chapters (LRA 2010). The provision of primary care, social security and SG[e]Is in the framework of social space generation shall be based on the principles of tolerance for different life plan developments in terms of recognizing the freedom of choice, the equality of life chances despite regional/local disparities, the inclusion of outsiders and the homo patiens into society, improvement of life quality (and well-being) through increasing autonomy, self-determination and self-responsibility, equal access to SG[e]Is, redistribution of various resources, the need-based offer of public services and social benefits in a nearby and sustainable social infrastructure and the continuous empowerment of civic involvement and volunteer engagement (LRA Görlitz 2010: 12 f.).

While German citizens generally have the right and entitlement to the same and common non-discriminatory, equal, cost-effective and comprehensive primary care through SG[e]I provision, there are undeniable differences in regional and local demographics and social and material infrastructures and their respective developmental possibilities. The political strategy of the adaptation of living standards and the demand for social justice evokes the question of its feasibility without offering viable solutions (LRA Görlitz 2010: 23). A unified strategy of primary care and SG[e]I provision for every rural and urban district in Germany is unjustifiable against the background of differentiated living conditions, life forms and communities' capabilities (LRA Görlitz 2010: 23). Especially infrastructurally weak rural regions like the district of Görlitz need to rethink their social welfare management and replace commonly used public service provision methods with flexible, holistic, innovative "tailor-made" approaches of caring community building that enables and promotes the creation of social capital, inclusion, social participation, autonomy and self-responsibility, meaningful role offers, mutual-aid and care as well as social embeddedness, thus improving personal and collective well-being and quality of life with human dignity. Therefore, the Social Network Lausitz as well as the attached KISS and their activities in cooperation with NAKOS<sup>14</sup> (national contact office for incitement and support of mutual-aid groups), the public authorities, medical service provider and insurances as financial sponsors play a highly significant role in this context (SNL 2012: 5).

### 5.1.2 General Presentation of the Network

The "Social Network Lausitz" is a project of caring community building situated in Weißwasser, a municipality with about 40,000 inhabitants located in the northern district of Görlitz/Oberlausitz, Germany, which is operated by eight employees. This project, in the legal form of a non-profit limited company (gemeinnützige Gesellschaft mit beschränkter Haftung: gGmbH)

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14 <https://www.nakos.de>.

was founded and is operated by a local private family business that shows exceptional social engagement in the region: the nursing company Kunze. Attached to the network is a contact and information office for mutual-aid groups (Kontakt- und Informationstelle für Selbsthilfe-Gruppen: KISS) which used to be funded by the Diakonie, but is financially supported by the health insurance program AOK Plus in Saxony in the course of mutual-aid funding in accordance with § 20h SGB V since 2011 (Schulz-Nieswandt 2018 a: 62). The network offers a variety of social assistance services of general interest for different target and age groups as well as problematic living situations and indication groups but also connects various partner companies and institutions which are, not only, but mostly related to mutual aid. The services are *inter alia* executed by so called “Lotsen” who are former or active members of local mutual-aid groups that cooperate with various institutions like schools and the local hospital in Weißwasser together with the KISS (mainly responsible for the discharge management)<sup>15</sup> to assist and support discharged patients in their everyday life by introducing the patients to suitable MAGs that are located nearby their place of residence.

Other social initiatives organized and offered by the network are a travel club for senior citizens, a tuition program for students and neighbourhood assistance, often realized through volunteers and with support of partner institutions like the town of Weißwasser, district of Görlitz, the state chancellery of Saxony and other local institutions like sport clubs, social and health associations, mutual aid groups, and regional businesses (SNL 2018 a: 11 & 48 f.). The network connects 143 mutual-aid groups supported by the KISS, over 60 financial supporters and cooperative partners who raised over 350,000 € of funds together and over 400 volunteers, in various projects related to mutual-aid and civil involvement (SNL 2018 a: 6 f.). The services of general interest that are provided by the network evolve around four priorities: mutual aid & consultation, neighbourhood assistance & civic engagement, the travel club & leisure activities and prevention & events (SNL 2018 a: 14 f.). The KISS (the contact and information office for mutual-aid groups) is the main responsible institution for mutual-aid affairs. The office puts people in need in contact with the relevant mutual-aid groups directly, works in coproduction with the local mutual-aid groups and the hospital of Weißwasser on patient discharge management, helps interested individuals to found their own groups and encourages already active members to engage in further social activities of public welfare (SNL 2018 a: 18). The KISS is operated by three employees and is, just like the SNL, supported by different partners like health care institutions such as insurers and hospitals, public authorities such as the city and district councils and the regional social planner as well as private companies and credit institutions ([kiss-weisswasser.de](http://kiss-weisswasser.de)). While the KISS takes care of the day-to-day operations that are typical for contact offices, i.e. supporting mutual-aid activity in the region (see chapter 3 for an overview), the SNL is primarily engaged in projects and initiatives of civic involvement and volunteering. The projects supported by the SNL evolve mostly around neighbourhood assistance/neighbourly help situated directly in the living environment of those in need, which is realized through volunteers. According to the SNL the potential of welfare production through neighbourly help remains too often untapped, as it is the ideal social space for donating and sharing,

15 For a detailed description of the cooperation between hospitals, mutual-aid groups and contact offices in the discharge management read Trojan et al. 2012.

not only material goods, but also life experience and general knowledge (SNL 2018a: 23). Also, there is often a stronger social cohesion in rural municipalities which manifests in an unconscious neighbourly help and this great potential, which has been somehow neglected by the mutual-aid organisation so far, can be fostered and realigned towards a strengthening of mutual-aid activity (SNL 2017a: 3). Therefore, the network brings together engaged every-day companions with senior citizens and others in need, who receive hourly aid and support in house-keeping, doctor appointments or even simple walks through the park (SNL 2017a: 3). The following section will discuss all other activities of the SNL in depth.

## **5.2 The Integration of MAGs and Their Members in Caring Community Building in the District of Lausitz**

This section will give a detailed insight into the work and the implemented projects that have been supported by the KISS Weißwasser over the last decade. These projects will be analysed in terms of their effects and social benefits for the local and regional population of the district of Görlitz and how far the Social Network Lausitz as well as the attached KISS Weißwasser could effectively foster local caring community building and social welfare production.

Since September 2011 the KISS Weißwasser is sponsored by the Social Network Lausitz gGmbH and over the last eight years the KISS as well as the SNL have managed to develop themselves into the driving force of mutual-aid activity and civic involvement in the district of Görlitz, thus fostering local caring community building. Over the course of this development much has changed: the KISS started with only one part-time employee with nine hours of opening per week and is nowadays operated by three full-time employees offering 35 hours of consultation per week, it became member of the mutual-aid umbrella organisation Paritätischer Wohlfahrtsverband, set up a website and other presences on online platforms which provide news and information on mutual-aid activities, groups, events and specific health and psychosocial health issues and connected persons in need, MAGs, socially engaged individuals and initiatives, public authorities and economic businesses as well as (health care) professionals for cooperation and partnerships (SNL 2012: 2, 2018b: 6).

In the year 2012 the KISS officially supported 136 MAGs single-handedly as the only mutual-aid support institution in the district (SNL 2012: 5). The number of supported groups did not fluctuate substantially over the course of time, on one hand because some groups eventually disband due to member inactivity, either by mortality and lack of new members or, much more positively connotated, because all members overcome their personal problems and are no longer dependent on the group activities, but on the other hand new MAGs are founded under the guidance of the KISS. In 2018 the contact office actively supported 141 groups that are funded in accordance with § 20h SGB V, thus independent of the specific health issue, out of which twelve were founded in the same year (SNL 2018b: 5). In fact, many more groups are active in the district of Görlitz but as they remain unregistered their actual number cannot be stated here (SNL 2012: 5).

The core business of the KISS Weißwasser corresponds to the usual tasks fulfilled by contact offices already described in section 3.1 of this thesis. Its activities focus on supporting MAGs,

providing information on mutual-aid activities and events, networking and cooperating with local and regional health care or social initiatives and persons interested in civic involvement with the aim to improve the SG[e]II provision of the chronically or mental ill, persons with disability, substance addicted persons as well as their relatives (SNL 2018 b: 4f.). In cooperation with NAKOS, the regional public authorities, health insurance funds like the AOK Plus and professional health care institutions the contact office strives for the consultation of persons who are looking for a suitable MAG or help to found it, support and give advice to MAGs regarding subject-specific, organisational or financial questions, coordinating and networking MAGs, offering knowledge transfer and training in mutual-aid organisation, improving and deepening the cooperation of various socio-infrastructure institutions and further developing the mutual-aid landscape in the district of Görlitz (SNL 2018 b: 4f.). Besides the consultation during the office hours in Weißwasser, the employees visit the municipalities Zittau, Löbau, Niesky, Görlitz and Rothenburg every two month to offer their services and give advice on specific mutual-aid related topics face-to-face (SNL 2018 b: 7ff.). In 2018, the KISS gave advice to, informed and connected over 420 persons with MAGs either telephonic, written or personally, while the most provided service was the consultation on psychological problems (SNL 2018 b: 14). E.g. during a town meeting the municipality of Rietschen was introduced to possibilities how to improve social help infrastructures through mutual-aid activity, volunteering and neighbourly help, specialized on reducing stigmatising the elderly citizens in the context of rural social space development (SNL 2018 a: 24). Persons who were seeking help needed information on MAGs, services provided by the KISS, voluntary services, psychological first aid and funding applications (SNL 2018 b: 18). Since August 2015 the KISS is in larger premises which include two meeting rooms that are barrier free and designed to fit the needs of the disabled (SNL 2015: 2). The MAGs can use both rooms for their group meetings for a fee of 10€ per meeting. In the case of an acute problem the contact office set up an emergency hotline that is available after the opening hours, offering first aid for psychological stress and the possibility to get in contact with social psychiatric (as well as integrational) services that cooperate with the KISS and were able to reduce scepticism towards health care professionals (especially on the part of MAG members) (SNL 2013: 13).

Another important task of the contact office evolves around fostering public relations in the name of mutual-aid activity in the region. Being present on self-organised or public events, in the regional newspapers and radio program or by founding projects that reveal the beneficial effects of mutual-aid activity, the KISS was able to show the regional community how important well-organised alternative and community based SG[e]I provision can be. Since 2014 the KISS as well as the SNL have websites that are barrier free in terms of an option to display all texts in simplified language, realized by a specialized agency, to adapt the letter size for better readability and are fairly easy to navigate (SNL 2014: 6). Further digital services that have been added over time and are still in development are a YouTube channel,<sup>16</sup> a Facebook page,<sup>17</sup> consultation hours via the instant messaging service Skype twice a week and the smartphone application MAMMUT (<https://kiss-weisswasser.de/kontakt/>). The digitalisation of mutual-aid orga-

16 [https://www.youtube.com/channel/UCOxLCjzwg458GJ\\_1m7e3ThQ](https://www.youtube.com/channel/UCOxLCjzwg458GJ_1m7e3ThQ).

17 <https://www.facebook.com/KissLandkreisGR/>.

nisation in Germany will be discussed in an upcoming subsection of this chapter more detailed as it has some rather decisive implications for the further development of the whole landscape. Ultimately, most of the KISS' activities are related to public relations as they are announced on the websites and often accessible by the public, in the context of living inclusion and raising awareness to social problems, thus fostering empathy through understanding alternative living situations.

In the course of caring community building and SG[e]I provision the contact office planned, initiated and established a long list of events described in the following. As the KISS is mainly concerned with mutual-aid affairs most of the events evolved around the improvement and development of the network and infrastructure for MAGs, e.g. the annual network conference for mental health which is a training session, funded by the health insurer IKK Classic, where at MAG members and moderators exchange their personal experiences and sensitivities on group dynamic issues and learn from expert moderator presentations (SNL 2015: 21). Specialist lectures regarding certain health or psychosocial issues and organisational topics relevant for MAGs are held regularly e.g. on ADHD, funding in accordance to § 20h SGB V, filing subsidy applications for funding, depression, substance addiction and abuse, hearing-impairment, dementia, Parkinson's disease, mental illness, different forms of cancer, sexual abuse and many more. The lectures are held by professionals and provide enough time to discuss the topic with the audience, which is constituted by self-affected persons, relatives and interested persons alike, so different opinions and viewpoints are revealed, needs and social grievances are articulated and if further debated in public can be responded to in the context of social caring community building.

Similarly, the KISS regularly participates in the regional self-help days and organises events to raise more awareness to mutual-aid activity and volunteering in the context of mutual-aid. Target-group oriented workshops offered affected persons to articulate their needs for an improved regional health care provision. Further, the events aimed for informing the interested community on local and regional MAGs and other services provided by the KISS (SNL 2016 a: 23). Also, the contact office presents itself on its own account to other regional socially involved associations and to the public authorities to facilitate cooperation between these potential partners, the office and the local MAGs. For example, a trip was organised for over 100 mutual-aid active persons to the third patient congress for depression in Leipzig, funded by the AOK Plus (SNL 2015: 24). The participants could listen to readings and presentations as well as attend various workshops. In cooperation with the East German chamber of psychotherapists and the contact office of the district of Bautzen, the KISS Weißwasser organised a symposium where at local and regional therapists and MAGs could get to know each other, discuss the potentials and limits of non-professional group therapy as well as plan future collaborations (SNL 2018 a: 25 f.). Members of MAGs, relatives of care dependents and socially engaged persons could learn practically and theoretically how to treat and handle persons in need of nursing care in a workshop (SNL 2018 a: 25 f.). Under professional guidance the participants learned how to move somebody from a bed into a wheelchair, how to pick up a person who fell and which techniques are the best for both sides in the context of domestic care (SNL 2018 a: 25 f.). "Am I different because...?" is a regular series of events organised by the KISS together with the community psychiatric centre Weißwasser, a social team and the town association to give a platform

to persons who suffer from social exclusion (SNL 2015: 22ff.). Usually, an expert starts by giving a professional point of view on the taboo topic and afterwards an affected person reports on personal experiences, problems and fears that often remain hidden to society. Ideally, both presentations complement each other so the audience receives a comprehensive understanding for the discussed health issues, fostering the sensitivity and empathy which might lead to less exclusion or even increased inclusion of the homo patiens (SNL 2015: 22ff.). Thus, the KISS in cooperation with its partners carries out much needed public relations educational work by raising awareness to social and health related issues.

As the KISS is responsible for all mutual-aid affairs in the region and supports MAGs in the whole district of Görlitz, it has established the tradition of corporate meetings of the groups in their respective local municipalities of Bad Muskau, Niesky, Görlitz city, Löbau, Weißwasser, Rothenburg, Großschweidnitz and Zittau, where at the MAGs can come together, get to know each other and learn about the different groups in a framework of social exchange between persons who are differently limited in their social participation but share the commonality of relying on mutual-aid activity (SNL 2018 a: 2). Thus, the groups inform and educate each other, foster the local mutual-aid organisation and stay embedded in social local communities reducing exclusive mechanisms. Noteworthy is the local mutual-aid organisation in Niesky which managed to achieve a high level of autonomy and self-organisation and responsibility, leading to a well-connected local mutual-aid landscape that is less reliant on external support (SNL 2013: 2).

Aside of its generally mutual-aid oriented events the contact office hosts events that aim at strengthening the social exchange, inclusion, embeddedness and cohesion of the local community e.g. annual neighbourhood festivals (SNL 2016 a: 25), a senior dance with more than 250 participants, theatre plays on social taboos like drug abuse and movie nights specifically showing films that are concerned with mental illnesses (SNL 2016 a: 25ff.). Although not all the listed are about pure entertainment but have serious topics, they all focus on a get together of committed citizens who foster an active community and vivid living environment while reducing social isolation and anonymity.

### 5.3 Permanent Projects and Initiatives initiated and supported by the KISS

Alongside the implemented and successfully hosted events which are usually very limited in time, organised only onetime, annually, or in a few cases more than once a year, the KISS started and supported various permanent projects during the last eight years of activity. The challenge is to find a balance between creating reliable established infrastructures of SG[e]I provision and a flexible spontaneous reaction to newly arising needs and requirements in the population. By increasing the effort of networking with regional institutions to improve the various branches and activities the SNL is engaged in, it could continuously improve the local and regional social infrastructure, generate social capital and foster growing local caring communities in cooperation with powerful partners<sup>18</sup> like public authorities, social and health care profes-

18 <https://www.soziales-netzwerk-lausitz.de/unsere-projekte-partner/>.

sional institutions and economic businesses of different types. Many projects are still active as of October 2019, others have been successfully finalized, and still others had to be shut down due to lack of funds, support and involvement. Not all initiatives are directly related to mutual-aid activity and organisation, but are concerned with community well-being, evolving around the needs of the homo patiens, either senior citizens, children or those who are otherwise impaired and limited in social participation. In the following some of these projects will be presented to give an overview of the variety, focal points and the scope of effects in terms of societal and personal benefits regarding well-being, quality of life and participation in the light of human dignity.

A topic that has already been addressed here is the introduction of self-help friendly health care institutions which evolves around integrating MAG members into the discharge management. In 2014 the KISS made the first step towards patient orientation and self-help friendly health care institutions by planning a permanent cooperation with the district hospital in Weißwasser (SNL 2014: 6). The concept, when successfully implemented through cooperation of MAGs, health care professionals at eye level and a contact office acting as a mediator, helps newly discharged patients to receive almost immediate support when they return home, as MAGs can introduce themselves to diseased persons who might be overstrained by their sudden change of living conditions (e.g. in the case of chronic illness) (Trojan et al. 2012). Self-help friendliness also prevents the so called “revolving door effect”<sup>19</sup> that possibly occurs after discharge. The KISS initiated the structured and systematic cooperation of local/regional MAGs and the district hospital in Weißwasser to become a self-help friendly institution (SNL 2015: 9). This project also serves as a pilot project that is planned to be implemented in all hospitals in the district of Görlitz, if the cooperation is successful and financial funds are approved (SNL 2015: 9). A successful cooperation benefits all involved actors and parties: the patients receive access to alternative health care structures which the hospital is not able to provide anyways, the MAGs can strengthen their groups through new members and the hospital offers more successful discharge management and can receive a certificate for self-help friendliness that promotes the institution’s quality management which again fosters the economic competitiveness.<sup>20</sup> But the whole process takes much time, willpower, good communication and engagement of all involved actors to become a generator of qualitative health care provision.

Another meaningful project initiated by the KISS was the targeted promotion of MAG funding in accordance to § 20 h SGB V in the rural areas of the district of Görlitz, as the offer was clearly more often accepted by MAGs in the regional cities (SNL 2015: 8). Fears of contact with mutual-aid activity are to be reduced by awareness training, information and voluntary experienced mutual-aid actors who encourage interested persons in need to participate in or found new MAGs. Further important steps in this project are preventive educational work about vari-

19 While the term in English language areas refers to economic and political actors switching roles, the revolving door effect in the health care context describes the phenomenon that occurs when patients are discharged unprepared from hospitals, rehab clinics, etc. If the patient is overstrained with the diseases, disability or simply everyday life, he/she is more likely to need treatment again, thus returning to the health care institution shortly after discharge. The revolving door is an exaggerating metaphor for leaving and re-entering the health care institution in a short period of time. It is not only a preventable misery for the patient but is an unnecessary burden for the professionals and additional expense for the institution.

20 <https://www.selbsthilfefreundlichkeit.de/>.

ous health issues, embedding mutual-aid organisation into local political processes as well as generally fostering the establishment and sustainable maintenance of a regional mutual-aid landscape (SNL 2015: 8). As the financial funding of MAGs concerned with dementia is not possible in accordance with § 20h SGB V, the KISS in cooperation with the social federation Saxony enabled the foundation of a contact office especially for persons with dementia and their relatives (SNL 2015: 9). Besides giving respective persons a place to go for consultation and information, the contact office places socially engaged persons to accompany dementia patients to foster familial and neighbourly care arrangements, continuous development of low-threshold care structures, extensive care provision for persons with a substantial limitation of every-day life capabilities and to develop voluntary support structures of mutual-aid for relatives (in form of MAGs) (SNL 2015: 10).

The project “Lausitzer Sterne” (Lausitz’ Stars), started in 2017 and still active, evolves around strengthening the social cohesion and improving the quality of life in Weißwasser. Local inhabitants, associations and companies can articulate suggestions on how to achieve a better social environment or infrastructure, which will be published on the specially created website,<sup>21</sup> as well as on the SNL homepage, their Facebook site and sometimes even in the local newspaper and socially involved citizens can help to realize suggested projects and receive in return small benefits like vouchers for a zoo visits, tickets for a city festival, crafts courses, etc. (SNL 2016 b; 2018: 23 f.). This project thus resembles an artificially created social exchange platform based on need-oriented civic involvement where performed effort and received compensation are not necessarily equalized and at the same time have charitable benefits for the local community. The “rewards” in form of vouchers or other personal benefits are sponsored by local businesses and social initiatives, giving an incentive to participate in the program in a framework of resource redistribution through the mechanism of indirect reciprocity. As persons who become a “Star” and engage in realizing suggestions are listed publicly on the website one could argue that another incentive to actively participate and contribute to society is the improvement of personal social prestige. But Burns/Williams/Windebank (2004: 146) have presented notable considerations that one-sided social support relations (i.e. receiving some kind of support through others) without having the option, opportunity or capability of donating back (whether directly or indirectly) is often rejected by the receiving persons as they might feel bad for “exploiting”, are ashamed of being in need or feel useless. I.e. that mutuality and reciprocity in communities might be more successful as a method of caring community building than a one-way support system based on voluntary work and civic involvement.

Since 2015 there is a ceremony for the regional mutual-aid award, which is funded by the AOK Plus that awards annually three MAGs and their members who performed outstandingly (SNL 2015: 25ff.). The award shows the SNL’s appreciation and honours the group members’ engagement and efforts. In the course of the ceremony representatives of the district of Görlitz have underlined their willingness to support future regional mutual-aid initiatives as the health care provision in the region will become increasingly challenging in the next years (SNL 2016 a: 28 f.). The public authorities of the district of Görlitz recognize the partially precarious status of regional health care and therefore signed a cooperation agreement with the SNL and

<sup>21</sup> <https://www.lausitzer-sterne.de/>.

the health insurer AOK to foster mutual-aid activity in rural areas (SNL 2016 a: 28 f.). Outcomes of this agreement are e.g. the consultation and information of persons interested in mutual-aid via Skype, the popular video chat program, through the KISS as well as the implementation of mutual-aid guides (Lotsen) in rural municipalities who help affected persons to orientate themselves in the local mutual-aid landscape (SNL 2016 a: 28 f.). Thus, especially affected persons limited in mobility have improved access to the contact office's services. Another successful initiative was the cooperation with the hospital of Großschweidnitz to become more self-help friendly and offer consultation hours regarding mutual aid at least once a month (SNL 2016 b).

Besides the above presented most important and meaningful projects the KISS implemented and supported several smaller, but also mention worthy projects that are introduced shortly in the following. The contact office offers preventive and educational projects for students at the school of Boxberg. The class teachers are supported by the KISS during the projects which aim to improve social competences and health protection abilities (SNL 2017 b). Further a consultation hour is offered to students, parents and teachers at the school. Another student related initiative is a mentoring program in the context of neighbourly social exchange that brings retired teachers in touch with students in need of tutoring (SNL 2017 b). The committed seniors experience self-empowerment and responsibility through new meaningful social roles, get in contact with children and young adults and reduce their own social isolation, while the students get the opportunity to improve school grades. Further, the senior-citizen delegation of Saxony invited the KISS to a conference where an employee could give a lecture on mutual-aid for the elderly in connection with training sessions (SNL 2018 a: 19). The KISS presented its own projects specialized for the elderly, which range from MAGs, over mentoring services, to generation meetings that foster self-healing powers, inclusion and social participation (SNL 2018 a: 19). In 2016 the SNL and contact office published an extensive action guideline for self-help,<sup>22</sup> financially funded by the provincial headquarters of Saxony, that is specifically addressed to persons with disabilities and aims at informing them about possibilities to receive consulting services and support, find employment and sheltered or alternative housing that is suitable for specific impairments, find accompaniment for daily life, leisure time and nursing care as well as their entitlement to benefits (SNL 2016 c: 11). With the action guideline on their hands, persons with disability have the opportunity to help themselves (less in the sense of reciprocal mutual-aid but by self-empowerment) in specific living situations and to find the right persons and institutions to address, thus improving their personal independence and inclusion. The guidelines support the addressees to come to the decision to take life into their own hands and overcome passiveness by finding assistance. Additional projects that are still active and supported by the SNL as well as the KISS according to the website<sup>23</sup> are: voluntary companions for the psychologically handicapped (also SNL 2018 a: 23), a psychiatric municipality centre of Weißwasser, a structuring and coordinating health care related mutual-aid promotion in rural areas, voluntary accompaniment and consultation for impaired persons, a coordination unit for neighbourly help in

22 <https://kiss-weisswasser.de/selbsthilfe-angebote/handlungsleitfaden-hilfe-zur-selbsthilfe-fuer-menschen-mit-behinderung/>.

23 <https://www.soziales-netzwerk-lausitz.de/unsere-projekte-partner/>.

Weißwasser in accordance with § 45 d SGB XI<sup>24</sup> for care dependent persons and their relatives (everyone who is of legal age, does not live with the care dependent and is not a nursing professional can become a companion (SNL 2018 a: 23)), the social sponsors of Lausitz (Lausitzer Sozialpaten) who are regional businesses or private persons that are willing to provide either valuable knowledge or financial resources to local social initiatives (SNL 2018 a: 23), the network programme “engaged town Weißwasser”,<sup>25</sup> funded by the BMFSFJ, which establishes a sustainable landscape of civic involvement and aims at developing institutional cooperation rather than single projects, a travel club for seniors as well as a contact point for persons with addictions informing on MAGs and offering an emergency hotline.

In the context of community psychiatric care provision, the KISS managed to establish networks in the fields of addiction, disability and nursing care (SNL 2014: 20). The respective networks meet regularly and discuss relevant topics, institutional changes, exchange news and personal experiences. Self-affected persons as well as professionals of help systems participate alike, while an employee of the KISS acts as a moderator. The nursing care networks aims at improving the interaction of local and regional care services and their cohesion, while the professional network for work with the disabled was concerned with the accessibility of the district hospital and a better comprehension of the work in sheltered workshops (SNL 2014: 20). Further topics discussed by the networks were: new care support act, addiction prevention, de-escalation management for drug addicts, guardianship for dementia patients and harm to the well-being of children.

#### **5.4 The Use of Digital Services in Mutual-aid Activities – A Challenge for the Provision of Services of General Interest**

Digitalisation has already influenced and sustainably and multidimensionally impacted most of the areas of the human daily life: work, housing, consumption and especially communication (Schulz-Nieswandt 2018 b: 280). After decades of existence it has nowadays also reached all three system-levels (see subsection 3.1) of the mutual-aid organisational structure, especially the more professionalised macro-level where the members of patient associations are mostly organized online. Digitalisation is assumed to have an inevitable significant influence on the organisation and practice of the mutual-aid movement. What are the implications for the morphologic transformation, the originality in the sense of authentic face-to-face interaction among group members? Which are the positive opportunities digitalisation can bring into solidary corporative organised mutual aid? And what are the potential risks and maybe even dangerous aspects digitalisation might add to the transformation of mutual-aid activities (Schulz-Nieswandt 2018 b: 280ff.)?

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<sup>24</sup> Nursing care dependents situated in domestic care are entitled to a relief amount of 125 € per month. The amount is earmarked for the purpose to grant quality assured services, such as day and night care, short-term care, ambulatory care and practical support in everyday life to relief nursing relatives and other nursing affiliates.

<sup>25</sup> <https://www.engagiertestadt.de/weisswasser/>.

Internet-based mutual-aid activity is based on its real-life model and corresponds to the common definitions, but there are structural differences in terms of forms of communication and reciprocity due to anonymity (Köstler 2013: 287f.). More and more mutual-aid active persons use the Internet for group work and health related research, as 99 % of all German mutual-aid initiatives on the national level already set-up homepages that provide information on specific goals, contact addresses of various MAGs, health care professionals and other institutions and membership advantages, while 60 % also offer forums and chatrooms where registered members can get in contact with other affected persons (Walther 2015: 8). Additionally, there are numerous forums founded by pro-active self-affected persons, that reach thousands of likewise affected individuals (Walther 2015: 8). Other forms of Internet-based, digitalised mutual-aid activity incorporate informational video clips, self-written indication-specific encyclopaedias (so called Wikis), Facebook pages as well as other social media presences (Walther 2015: 9). As there are forums operated by (pharmaceutical) companies that try to make financial profit from theirs users, the NAKOS defined characteristics of purely user-oriented mutual-aid forums: the purpose is experience exchange of (self-)affected persons who want to improve their limited quality of life, registration is unconditional (free of charge, no membership elsewhere is required) and the providers do not seek to generate commercial profit (Walther 2015: 11). Certain benefits of Internet-based mutual-aid activity<sup>26</sup> are the independence of time and space, as especially mobile devices allow to connect to forums and chatrooms almost anywhere and anytime bridging long distances instantly, thus advantaging especially persons heavily limited in mobility. Further, as written exchanges and discussions remain accessible over very long periods they function as collective archives for succeeding affected persons and digital services fill in gaps of missing mutual-aid infrastructures, e.g. in very rural regions or affectedness by rare diseases without related MAGs on the local level (Walther 2015: 11) The anonymity on the Internet provided by identity unrelated user names and profile pictures enables low-threshold accessibility even for persons with low socio-economic status, also as access to the Internet is generally affordable in Germany and forum/chatroom registrations are often free of charges (Köstler 2013: 291). Further, the user autonomy is higher in digital mutual-aid activities as the anonymous users can decide how much they want to reveal of their personality and identity. Anonymity also benefits those too shy or ashamed to step into face-to-face interaction or talk about taboo subjects openly (Köstler 2013: 291). Persons who started being active in mutual-aid on the Internet might learn about face-to-face MAGs in their surroundings and shift, parallel to their online activity, to participate in said groups, thus internet-based mutual-aid activity can function as a “door opener” to further alternatives of health care provision (Köstler 2013: 290).

Due to the large number of users, widespread anonymity and high fluctuation among discussion participants, the development of cohesion, solidarity and group affiliation among mutual-aid active Internet users is more tedious and difficult compared to its real-life counterpart (Köstler 2013: 289). An imaginable counterproductive development of the mutual-aid movement on the micro-level through increasing digitalisation, regarding the use of websites and internet forums, is that persons who are interested in MAGs and need further support with their health related struggles possibly tend to search for help exclusively on the internet, receiving their informa-

26 See also Schulz-Nieswandt (2018 b: 288 f.).

tion and indication-specific advice by empathic self-affected persons on a digital basis (Schulz-Nieswandt 2018 b: 284 f). I.e. mutual-aid and its advantages are then consumed passively, time-shifted and in absence of physical direct face-to-face interaction with group members that can show visible and interpretable emotions, gestures and facial expressions, human beings that are touchable and able to give a hug, show a smile or share a laugh, are empathic and understanding: short, all types of physical interactions that cannot be transferred in a digital substitute. Eventually, the preference of Internet-based mutual-aid activity over face-to-face group interaction (or vice versa) might remain a matter of personal preference and social as well as technical capabilities, availability of local MAGs and online supplements and the quality of all listed factors. The extent of personal (parallel) use of said offers can settle anywhere between the two poles of real and digital social environments. Further, the extensive informational materials on health issues found on the Internet seems to be generally accepted by the population without questioning its validity, suggesting this source of knowledge is rather sufficient to overcome personal health or psychosocial problems, besides using professional services. Thus, MAGs become increasingly unattractive to potentially affected persons which results in a decline of group members and volunteers acting in mutual-aid initiatives nationwide, along with a pressure to further professionalise offered information materials and services. But the Internet is undoubtedly significantly useful for the organisation of MAGs and institutions on the other levels of analyses: for communication between umbrella and patient associations, contact offices and mutual-aid groups, general information on groups and their meeting dates, information on current events, conferences, funding etc, all of it in an easy, digitalised form thus free of post deliveries, paper waste and the costs involved. This online offer may lead to an active participation in mutual-aid activities on a non-digital but physical level, although it is assumable that there will be crowding out effects by an ongoing digitalisation (Schulz-Nieswandt 2018 b: 285).

In line with these expectations, Schick (2019: 4 f.) sees a positive aspect in the simplified and efficient way of data transfer between hospitals, physicians and pharmacies, thus leading to improved therapies as every health professional has the same information, can see what medical examinations have already been executed and what might need to be done yet. Of course, the patient should have the same access to their own health related data. The newly passed appointment service and care provision law<sup>27</sup> that comes into force on 1st January 2021 asks the health insurances to provide access to a digital patient file which is accessible by mobile devices also (Schick 2019: 4 f.). The law improves the appointment allocation through a centralized service facility and increases the amount of consultation hours physicians need to offer, along with an improvement of the health care provision in rural areas.<sup>28</sup> That is especially useful for the chronically ill as they have always access to their health related information and data, thus making it easier to find information on assistance programs more quickly and barrier free, enabling them to participate in their social environment/community autonomously (Schick 2019: 4 f.). But the digital data and privacy protection of the patient's health related information always needs to be guaranteed.

27 Terminservice- und Versorgungsgesetz: TSVG.

28 <https://www.bundesgesundheitsministerium.de/terminservice-und-versorgungsgesetz.html>.

Digitalisation is omnipresent in our civil society and already pressures non-profit organisations to adapt their administrative processes, structures and content services to contemporary standards (Rasmussen 2019: 5). As it is a continuous, initially not ending process the civil society has the collective task and obligation to learn how to handle digitalisation properly and eventually use as well as shape the possibilities provided by it to generate and improve public welfare in the third sector (Rasmussen 2019: 5). The shaping aspect includes enabling access to digital services and its technologies, promoting user competences,<sup>29</sup> enabling data-based innovations<sup>30</sup> for society, protecting personal data in the digital space and creating the digital future through innovative visions, societal concepts and positions (Rasmussen 2019: 6). Goal of the whole process is a civil society that is comprehensively sensitised, competent and able to express itself regarding digital contents and services (Rasmussen 2019: 7). Non-profit organisations nowadays need a concept how to build a secondary digital environment focused on the civil society (Rasmussen 2019: 10), thus they are challenged to offer and make use of digital services that benefit society and social welfare as well as possibly shape these services innovatively.

On the one hand the digital mutual-aid services have positive impacts on patient empowerment through low-threshold accessibility as well as an increased autonomy, which leads to a more democratised health care provision, but on the other hand the services require to fulfil certain quality standards and users who are willing to learn related abilities to make use of them properly (Köstler 2013: 287). Services should offer easily accessible and operable platforms of knowledge and experience exchange that allow gathering information and knowledge as well as activate coping abilities of their users (Köstler 2013: 294). Qualitative standards of digital mutual-aid services should include independence, user-friendliness data protection and privacy, non-commerciality and transparency in terms of purpose and financing (Köstler 2013: 295). In line with the above stated considerations the SNL has also recognized that digitalisation offers interesting potentials and opportunities for rural mutual-aid organisation in terms of bridging long distances and mobility issues as well as new possibilities to get in touch with young adults, but at the same time leads to an increasing population share of especially young persons who are Internet addicted (SNL 2019 a: 2). Therefore, the network developed a conception called “AnDi”<sup>31</sup> that shapes the potentials of digitalisation and benefits from it, while also improving user competences enabling profound media capabilities in the context of rural mutual-aid organisation that balances digital and analogue face-to-face services (SNL 2019 a: 3). Based on experiences with mutual-aid active persons and network partners as well as in the light of above mentioned structural and societal changes the SNL plans to develop and implement new innovative models of mutual-aid organisation in rural areas that aim at improving first contact options for (esp. young) persons initially unrelated to mutual-aid, connecting digital and analogue services meaningfully to further develop the target group-specific access to relevant topics, improve the digital media competences and capabilities of mutual-aid active persons and create MAGs concerned with internet addiction and lastly initiating the generation change in mutual-aid structure, i.e. introducing young adults to MAGs who then fill in gaps left by former group/

29 Digital competences include frequency, implicitness and consciousness when using the Internet.

30 Data-based innovations generate practical insights and solutions through digital structures and data.

31 “AnDi” stands for *Analogue and Digital* resources in the context of rural mutual aid.

initiative members (SNL 2019 a: 4). The main target group is the population of the district of Görlitz which is looking for social exchange, support of mutual-aid activity with a special focus on young persons aged 14 to 27 (SNL 2019 a: 4). The target group will be addressed either through the common ways of communication or through digital services, i.e. social media, the mutual-aid app MAM[MUT], hyperlinks, etc. To realize the concept's main goals, multiple steps are required (SNL 2019 a: 4ff.): first, educating and informing young adults in their digital living environment on the various benefits of mutual-aid activities by contacting youth groups and associations, including young persons' ideas into development processes of digital service, founding MAGs for young people and cross medial provision of information, contact points and initial counselling. Second, finishing the development of the mutual-aid app MAM[MUT] including an improved search function for MAGs throughout Saxony and barrier free access to the app itself. Third, creating a YouTube channel for the KISS<sup>32</sup> together with informational and instruction videos on mutual-aid related topics incorporating group members, social institutions, and health care professionals. Fourth, shaping and further developing the political framework for the financial funding of mutual-aid engagement in accordance to § 20 h SGB V. The concept includes an intern quality management to ensure the quality of results during the process, while additionally being scientifically supported by the University of Applied Sciences Görlitz and the University of Cologne (SNL 2019 a: 8).

The above mentioned mutual-aid application for mobile devices, called "MAM[MUT] – Digital Mutual-Aid in Saxony", is the newest implementation in the course of digitalising mutual-aid organisation in the federal state and attracting young adults to mutual-aid activities. After passing the closed beta status in 2018 the app is currently (autumn 2019) running in an open beta version (SNL 2018 a: 28). MAM[MUT] is available for iOS and Android mobile devices and downloadable free of charge from the system intern app-stores. The application's purpose is, similar to mutual-aid forums and chats, to give mutual-aid active and/or interested persons an online platform where they have the possibility to communicate with likewise affected persons and exchange information, knowledge and experiences. Further app functions include a search tool for MAGs throughout Saxony either by entering the postal code of personal residence to look for all MAGs located nearby or by entering individual medical indications to show relevant groups in the region. The app also offers a news feed operated by various contact offices of Saxony informing users on events or specific request of MAGs ([time4innovation.de/mammut](http://time4innovation.de/mammut)). Personal tools such as a diary, a mediation planner that reminds users to take a certain medication at a customized time via push notification as well as a simple appointment calendar (e.g. to organise doctoral appointments), while a separated SOS-section provides direct contact to rescue services, contact offices/KISS', pastoral care hotlines and an emergency chat in case of severe psychosocial issues. Similar to online social networks, users have the possibility to post anonymously and publicly on a digital notice board links, audio and video files or simply any other mutual-aid related contents that might be interesting for all other users. The app does not require users to register to use its functions with the exception of private chat-rooms which requires creating an account (also free of charge) that allows users to invite others

<sup>32</sup> The YouTube channel of the SNL and its KISS can be found under: [https://www.youtube.com/channel/UCOxLCjzwg458GJ\\_1m7e3ThQ](https://www.youtube.com/channel/UCOxLCjzwg458GJ_1m7e3ThQ).

to private group chats, thus MAGs can expand their work into the digital space in private and protected atmosphere under Data Protection Directive.

## 5.5 The Effects and Social Benefits of the Social Network Lausitz in a Social-Political Perspective

The Social Network Lausitz has successfully developed a sustainable concept of (cooperative) generation of public services of general interest, nursing and health care, civic involvement and voluntary engagement, thus maintaining its role as a driving force of public welfare production in the district of Görlitz, Saxony. Without doubt, the network and its cooperation partners managed to significantly contribute to the provision of SG[e]Is and the establishment of social care networks that produce social capital, especially through targeted support of local mutual-aid activities and an innovative development of said activities by fostering inherent untapped potentials. Supporting mutual-aid activities and groups enhances the socio-cultural embeddedness and inclusion of the involved actors. MAG members reciprocally learn coping strategies, gain access to comprehensive knowledge and information, become layperson experts on living daily with mental or physical health problems or psychosocial issues, while experiencing new meaningful roles, identification and personalisation mechanisms by participating in social environments constituted by other self-affected members and groups dynamics in the modes of self-empowerment, -responsibility and -efficacy, thus improving personal well-being and quality of life. As a reminder: although individuals directly benefit personally from mutual-aid activity, it is not comparable to (health/social) insurance benefits. Mutual-aid benefits emerge from the cooperative activities that aim at collectively improving living situations, based on participative, inclusive reciprocity and the concept of self-affectedness, i.e. members alternate in their roles of homo patiens and homo donans. Another positive side effect is the relieve experienced by the affected person's social environment like family, friends and colleagues. The established mutual-aid structures are therefore a significant factor of social welfare production as they foster social networks (with active actors in all sectors), offer a substantial supplement to the professional health care system maintained by the third sector, while further developing innovative approaches of civic involvement based on these existing structures were made possible by the SNL. The mutual-aid activity in the district of Görlitz supported by the Social Network and its related KISS, thus, can be considered to be a means of social inclusion, embeddedness and networking of alternative health and nursing care provision that is, to a large extent, maintained by the caring community as well as the existent regional mutual-aid landscape constitutes a preferable starting point to transfer mutual-aid activity into civic involvement.

As the SNL recognised that successful local caring community building requires social space as well as need oriented innovations, it adapted its actions and services continuously to regional and local infrastructural conditions and the requirements of persons in need, in the context of capability development, empowerment and personalisation for those embedded in this specific environment. Thus, the Social Network Lausitz is an institution that aims at the provision of SG[e]Is that fulfil the standards of equal availability, accessibility, awareness and quality related acceptability. This is of especially great importance regarding the general infrastructural

weakness, the continuously demographic ageing and the considerable extent of social precarity and isolation in the district of Görlitz.

While the previous subsection listed and described numerous activities executed by the SNL as well as the KISS, this very subsection will discuss and analyse the effects and benefits that emerged through said activities. The analysis is based on the documents that were already presented in this chapter. I.e. there were no data analysed with statistical quantitative methods, but rather are offered services, implemented projects and innovative developments set in the context of the theoretical considerations, the examination of the German mutual-aid organisation as well as the legal background presented in the previous chapters. For a comprehensively science-based evaluation of the Social Network Lausitz one will need to wait for the results of the scientific monitoring carried out at the Chair of Social Policy and Methods of qualitative Social Research, University of Cologne. The now following analysis will only touch certain aspects of the caring community efforts in the district of Görlitz and will only superficially investigate its efficacy and reveal common welfare benefits. This said, the following statements on the provision of SG[e]Is and welfare production mechanisms through the SNL and the KISS Weißwasser do not contain any scientifically valid results on the extent of quality or range of said services and mechanisms. Although, cautious tendencies in this regard will be discussed.

As the majority of activities executed by the SNL as well as the KISS are related to mutual-aid organisation on the meso and micro level and support of MAGs, both institutions offer services that aim at “help to self-help”. Not only do the institutions generally promote mutual-aid activity by consulting MAGs, offer barrier-free meeting rooms, organize financial funding in accordance with § 20 h SGB V and § 45 d SBG XI etc, but also help founding new MAGs or get interested persons in touch with already existing groups. Thus, the local and regional mutual-aid landscape is kept alive while the established infrastructures of mutual-aid activity can be further developed. As already mentioned, one specific challenge of social space oriented social support is to find a balance to establish a permanent infrastructure of social support and inclusion in the light of human dignity, while also reacting to newly emerging needs in the population with innovative solutions that, on the one hand help individuals to cope with personal existential problems and, on the other hand fosters public welfare. Civic involvement (of the elderly people) leads to new chances of intergenerational empowerment structures that promote active contributions to a participative society. On the one hand, this leads to an activation of capabilities and competences of the homo patiens, is, on the other hands connected to a societal and welfare state related interest in the benefits of the human and social capital that emerges from that activation (Klie 2011: 394). The diversity and variety of social networks in which civic involvement is accessible, optional, possible and transparent are important conditional principles of successfully providing SG[e]Is, inclusion and generation of social capital in caring communities (Klie 2011: 395 f.). Considering the wide range of services and projects the SNL and the KISS offer and support, especially by actively participating in the conceptualisation of mutual-aid organisation in rural areas, both social non-profit institutions seem to be well aware of social problems and needs. With the introduction of various online presences, digital forms of communication (e-mail, Skype, emergency hotline for psychological distress) and features that enhance their user friendliness (simplified language, adaptable letter size on websites) the KISS made an important step towards barrier-free access to its services, especially advantageous for

persons strongly limited in their mobility (e.g. severely disabled, critically ill persons). Additionally, the Kiss offers face-to-face consultation in five other municipalities in the district of Görlitz for those unable to travel to the social institution's premises in Weißwasser. Eventually, one could argue that the KISS Weißwasser (and of course every mutual-aid contact office) functions as an inclusive gate opener for mutual-aid organisation as continuously and, hopefully, increasingly more persons in need receive access to the benefits of mutual-aid activity that have been described in subsection 3.2, or at least learn about it and spread information on it in their social environment. As the contact office as well as the SNL are both operated by qualified full-time employees with several years of job experience, who constantly cooperate with other experts and professionals from the health care system, e.g. in the context of lectures and long-term projects, the provided services of (non-economic) interest can be expected to generally meet the standards of quality related acceptability. Another important priority of SNL and KISS is the promotion of public relations by informing the regional population (in need of cure and care) on mutual-aid related services at various events, on the Internet and traditional media. But the extent of the range of the public relation efforts as well as their acceptance among the local population remains unclear at this point, as only quantitative empirical surveys can reveal in how far the regional population is aware of the SG[e]Is provided by the SNL. The contact office reports 420 consultations via phone, email or face-to-face, but this number explicitly excludes counselling during the events the KISS was part of (SNL 2018: 14). A high level of public relation activities will certainly increase the SNL's range or at least help to maintain the status quo. Finding cooperation partners that are willing to financially fund promotional activities will also benefit this project.

Many events, activities and projects executed have already been described in subsection 5.2 but their effects and social benefits have only partially discussed. Therefore, the most important projects will be summarizing analysed in terms of their contributions to regional SG[e]I provision and local caring community building. Additional to the SG[e]Is that are provided by mutual-aid activity and promoting it, the KISS organises regularly lectures on health and psychosocial issues that are held by professionals and affected persons equally. These lectures primarily educate and inform participants but also give affected persons a voice to articulate their needs to the public, thus raising awareness to specify supply gaps and improve the communities understanding and personal empathy, which potentially results in a reduction of alienating or stigmatising outsiders and fostering their social inclusion. The workshops organised can convey practical skills and capabilities to participants who are e.g. concerned with domestic care thus improving well-being and quality of life of the care dependents and the nursing relatives also. Hosting festive events like neighbourhood festivals, the senior dance or cultural activities strengthen the community's cohesion, inclusion and personal social embeddedness, thus fostering local networks that generate social capital. Based on social engagement potentials inherent in mutual-aid activity the SNL introduced a few initiatives that aim at motivating local citizens to become civically involved e.g. in social cohesion and public infrastructure related support (Lausitzer Sterne), tutoring for students, every-day accompaniment and support for impaired persons and dementia patients as well as neighbourly help in accordance with § 45 d SGB XI. On one hand these initiatives provide meaningful roles to those voluntarily offering their support, on the other hand persons in need receive support in their daily life, are empowered and

encouraged to be more confident and autonomous, improve their mobility, reduce their social isolation by increasing social participation, activity and self-responsibility. These services of general interest can foster public health and nursing care as well as the embeddedness into local caring communities of socially isolated and excluded persons who are otherwise limited in their capabilities to participate and interact with society. A cooperation with local health care institutions in the context of self-help friendliness and patient orientation enhances the discharge management processes for all actors involved. Patients are introduced to MAGs when still in stationary therapy, know where to go when overstrained with disease related problems after being discharged, have access to a wide range of expert knowledge from self-affected persons and are encouraged to be more self-responsible and autonomous in further therapy and decision making processes. This form of cooperation between MAGs, the KISS and health care institutions improves health care provision and patient empowerment in the region. Lastly, (semi-)professional networks concerned with substance addiction and disability offer a platform for thematic relevant discussions on institutional change, the current status indication related support systems and grievances that need to be overcome in the region. If these networks can articulate topic related recommendations for action towards public authorities, they might become a serious representation of interests of affected persons.

The above presented micro-level analysis of SG[e]I provision executed and supported by SNL and KISS in the framework of caring community building is an innovative approach that develops welfare production structures on the local and regional level. The national government and its institutional authorities as well as the federal states and municipalities have the primary responsibility for social security, but local communities need to be given more autonomy and a larger scope of action to establish and maintain a social space to enable a need-oriented provision of public services of general interest, even if financial resources are short. As in chapter 4 sufficiently presented, there is legal certainty that German municipalities have the obligation to guarantee a permanent provision of services of public interest. A central problem here is that many municipalities are deeply in debt and are not able to manage their budget consolidation, as they are situated in structurally weak regions that are additionally burdened with a weak economy and high unemployment (as is also the case for Weißwasser) (BMFSFJ 2017a: 24). However, the government and the federal state authorities are in charge to enable the municipalities to fulfil their obligations. Regarding the §§ 20 h SGB V, 45 d SGB XI and 45 b SGB XI (from the 26<sup>th</sup> of May 1994 (BGBI. I, p. 1014), last amended by Article 10 from 22<sup>nd</sup> of March 2020 (BGBI. I, p. 604) which stipulate how health and nursing care related mutual-aid activity and support can be financially funded, there is solid foundation to foster caring community building. But what if these financial resources are not sufficient to guarantee a municipal provision of SG[e]Is? Schulz-Nieswandt (2018 a: 58 f.) suggests an approach that includes mixed financing accomplished by partnerships between municipalities and social insurances, while the process management would be under control of local public authorities. A quality case and care management that enables structures of consultation and social networking promoting institutions included in the above-mentioned paragraphs to optimise interface connections with health care, nursing care and help for the disabled would thus be guaranteed through those partnerships (Schulz-Nieswandt 2018 a: 58 f.). Therefore, the social insurances need to reconsider their role and become an active player in the municipal provision of SG[e]Is as they are self-gov-

erned institutions of the public sector and share its responsibilities in terms of social security (Schulz-Nieswandt 2018 a: 60). According to the Commission of the seventh Report on the Elderly a social policy approach based on modern fundamental rights and anthropological findings is necessary to conceptualise local political innovations of sustainable social caring communities, while moving further away from economising, bureaucratising and centralizing the provision of health care and nursing (BMFSFJ 2017 a: 44). But there is no fully developed concept of a reorganised and restructured principle of subsidiarity (in the framework of a welfare-mix approach) that offers a well-balanced interaction between the welfare state, the welfare market and societal engagement/civic involvement, which is necessary in the light of an imminent overburden of the state and the NGO welfare organisations like Caritas, Diakonie, Rotes Kreuz, der Paritätische and Arbeiter Wohlfahrt (BMFSFJ 2017 a: 47). This redevelopment considers the promotion and funding of civic involvement as a key feature in the production of social capital through provision of SG[e]Is in caring communities that foster cooperation, networking and participation of all relevant actors (BMFSFJ 2017 a: 47) and is part of the social learning process that aims at the inclusion of the homo patiens in the light of human dignity. The principle of subsidiarity explicitly includes the social voluntary engagement of the homo patiens, e.g. in mutual-aid structures. The opportunity to participate meaningfully in reciprocal care and social support structures is essential for the quality of life of those who are in need of help, especially for senior citizens. Therefore, it is necessary to establish a local infrastructural framework of social security that provides relevant public services of general interest (i.e. caring community building). Social institutions like the Social Network Lausitz and its integrated contact office can play decisive roles in this form of caring community building, when including local citizens and the homo patiens as well as their living environment and the social space they are embedded in, in shaping and development processes. The seventh report on the Elderly attaches particular value to social networks like that established in Weißwasser. Great potential comes from the mutual-aid activity, especially in the context of an autonomously independent supplement to professional health care. As Klie (2011: 401) states: “The actual vitality of civic involvement in the care context is based on mutual-aid activity and various local initiatives”. In this context civic involvement can prove itself as dignity securing participation, as solidarity among “distant” relatives, under no circumstances as a substitute for professional nursing care, but as a new culture and structure of a local caring community (Klie 2011: 404).

One can argue that the SNL has achieved to improve the provision of municipal services of general interest, but the local public authorities have to recognise their duty to fund and promote the established infrastructures and further focus more on improving the regional health care provision and public transport for persons challenged in their mobility. The SNL made an important step towards social change and progress by initiating social inclusion of the homo patiens through mutual-aid activity and civic involvement that is autonomously operated by local citizens. Based on the universal values (freedom, equality, solidarity) inherent in the Charter of Fundamental Rights of the European Union, the UN Convention on the Rights of Persons with Disabilities, the UN Universal Declaration of Human Rights and other German legal regulations, the innovative development of the third sector in Weißwasser, embedded in a welfare-mix approach based on the principle of subsidiarity, assumingly resulted in increased social participation, embeddedness and cohesion of the homo patiens, thus enabling a daily living with

greater personal and collective well-being and quality of life with dignity. The SNL and the KISS take care of maintaining the interaction in the dialogue of reciprocity between homo doans and homo patiens by constituting a platform of social exchange.

## 6 Conclusion

This thesis has discussed and analysed the possibilities and limitations of an innovative approach of municipal provision of services of general [economic or non-economic] interest in the framework of social space oriented local caring community building with focus on the options of financial funding of mutual-aid activity in accordance with § 20 h SGB V and § 45 d SGB XI. It turned out that the KISS Weißwasser, supported by the Social Network Lausitz, established significant infrastructures that generate social capital through networking, based on the promotion of corporative mutual-aid activity, its support and a further development of civic involvement of health and nursing care supplements and every-day accompaniment for the homo patiens who then experience genuine social participation in the mode of personalisation, (self-)empowerment and responsibility and meaningful role taking in the context of social embeddedness and reciprocity. Maintaining these infrastructures of social capital generation and networking them to the professional health and nursing care service providers, health and nursing care insurances and municipal public authorities in the sense of subsidiarity and a welfare-mix approach ideally results in a successful provision of SG[e]Is situated in a solidly built caring community. A corporative organisation of SG[e]I provision activates local citizens<sup>33</sup> and is therefore a viable option to realize subsidiarity in communities (BMFSFJ 2017a: 51). This form of collectively provided cure and care is expected to significantly improve the well-being and quality of life of the homo patiens and their social environment constituted by direct relatives, friends, colleagues and neighbours. Therefore, these means of welfare production on the local level are considered as eligible as they will gain increasingly importance, regarding the further evolving social change (BMFSFJ 2017a; Schulz-Nieswandt 2018a). German municipalities are legally bound to guarantee the provision of SG[e]Is but are, probably often, limited in their financial resources and scope of action in these terms. Although, §§ 20h SGB V and 45 d SGB XI provide a legal basis to financially fund MAGs and their relevant support institutions (mutual-aid contact offices), these funds may be insufficient to maintain SG[e]Is in a long-term perspective. With both, the public authorities and the social insurances unwilling or unable to bear responsibility, the statutory social insurances are expected to reconsider their roles as simple providers of individual health and nursing care benefits, towards active support-

<sup>33</sup> Kluth (2018) discussed the possibilities of infrastructural corporations for municipal services of general economic interest. Infrastructural corporations generate economic as well as social capital in a region, not only among corporation members but also for the community, through networking. This form of solidary cooperation is largely independent from state interference, thus engaged citizens can shape social infrastructures to their own requirements. An advantage is that the legal form allows legal persons to become members, i.e. that municipal authorities can be permanent reliant partners. Examples for infrastructural corporation activity areas are: education, culture, health care and social services, energy and communication. The provision of SG[e]Is through infrastructural corporations could be combined brilliantly with the concept of caring community building.

ers of local and regional solidary care networks by providing financial resources, expert knowledge and, if needed, care and case management, without taking too much control over developing processes in individual municipalities and districts (Schulz-Nieswandt 2018 a: 72). In turn, municipalities must be given a larger scope of action to successfully coordinate and regulate local generic caring community building. A control function of the national government in caring community building would be defective as it is contradictory to the concept of social space-oriented infrastructure management of care provision. Burns/Williams/Windebank (2004: 128) are convinced that direct state involvement into community development and building may have disadvantageous impacts on the solidary growth of the community as well as the individual and collective responsibility that is fostered through community activities. Therefore, direct influence and community regulations through municipalities and other authorities should be limited or even completely avoided wherever possible for the sake of the communities' organisational autonomy and to counter undermining people's trust. Eventually, there is a comprehensive legal foundation that is capable of enabling caring community building lawfully in the sense of the above mentioned considerations, the most basic and relevant laws and acts are presented in chapter 4 of this thesis, but the German Social Code offers even more opportunities in form of laws that must be innovatively interpreted to make use of (e.g. § 7 c SGB XI for nursing facilities and § 71 SGB XII for work with the elderly) (Schulz-Nieswandt 2018 a: 66 f). Even more when considering the small probability of new draft laws in the near future. That means not only are citizens required to become socially engaged in their direct living environments, but public authorities and social insurers are even more obliged to enable civic involvement on the local and regional level by playing an active role and strike out in a new direction. The KISS as well as the SNL as "local agencies of social capital generation" are required to be included and invited to regional conferences of participation, health or nursing care (depending on the established institutions in the respective federal state), as they are intermediate structures on the meso-level that are in direct touch with MAGs and citizens on the micro level, thus bringing knowledge and expertise linked to the homo patiens real-life contexts to the table (Schulz-Nieswandt 2018 a: 66 f.). This would be a form of patient representation on the regional level, subordinated to the patient representation in accordance with § 140 f SGB V from the 20<sup>th</sup> of December 1988 (BGBI. I, p. 2477), last amended by Article 5 from the 22<sup>nd</sup> of March 2020 (BGBI. I, p. 604).

Due to the large heterogeneity between and within municipalities and neighbourhoods, e.g. regarding the unequal distribution of personal capabilities and living conditions, every municipality is required to develop their own concepts of social networking according to the principles of need and social space orientated social policy making (BMFSFJ 2017 a: 26). When analysing necessary care structures, it is important to focus on this heterogeneity and take into consideration to what extent different life situations influence social inclusion and receiving and providing care as well as to what extent they enable and limit civic involvement (BMFSFJ 2017 a: 26). Although the principle of subsidiarity is supposed to be the general regulatory framework for caring community building and need as well as social space oriented provision of SG[e]Is, that does not imply that different municipalities are meant to focus on fostering totally different capabilities and living conditions (BMFSFJ 2017 a: 52). A high standard of equivalence and equality of well-being and quality of life across the nation is the goal, without disregarding cer-

tain needs of various demographic groups. Social policies, therefore, need to guarantee design freedom when shaping and developing social space. Communities need their freedom and self-responsibility to develop themselves into appropriate solidary social structures in which inclusion is actively lived, social cohesion is the foundation of togetherness and reciprocal care for each other is available when needed. But without being abandoned by the public authorities on all administrative levels.

The case example of caring community building in Weißwasser and the district of Görlitz supported by the local KISS and the Social Network Lausitz has demonstrated that the concepts of inclusion, social participation and provision of SG[e]Is to foster existential coping strategies and self-empowerment of the homo patiens as discussed in the previous chapters of this thesis are practically feasible and eligible, at least to a certain extent. Embedding the process of caring community building in a subsidiary welfare-mix approach could not be fully implemented, as the responsible public authorities are very limited in their financial resources due to the region's weak socio-demographic infrastructure, although they recognise the importance of the Social Network's activities. But a strong and vital local community offers incentives for people to stay in and for others to join them, which could decrease the socio-structural degeneration of municipalities and regions (Burns/Williams/Windebank 2004: 32). The AOK Plus in Saxony is an important partner of the SNL as the health insurance financially funds the Network and supports events and projects in the municipality of Weißwasser. The role of the AOK Plus thus corresponds to the role of an active player in caring community building and recognises its opportunities to foster public welfare based on their obligations as self-governed institutions of the public sector. And eventually all other social insurances are required to recognise this role, otherwise achieving social change and maintaining social security become increasingly difficult for society. The demographic change of an older growing society will cause an imbalance between the population share that makes use of insurance benefits and the share that must pay for it, leading to a growth of social inequality. Further, a growing population share that needs social embeddedness, participation, inclusion, caring love and every-day accompaniment in the light of human dignity requires the support of their direct social environment as well as the more distant local community. And lastly, the municipalities must guarantee the provision of SG[e]Is to improve communal and personal well-being and quality of life as well as create infrastructures that are able to provide, organise and develop means of social capital production through the modes of social space oriented mutual-aid activity and civic involvement. If this is successfully achieved by all actors involved our solidary society proceeds further towards a much-needed social change.

## Kurzfassung

*Wie die Förderung kommunaler fürsorgender Gemeinschaften durch Selbsthilfe-Finanzierung im Sinne der §§ 20 h SGB V und 45 d SGB XI gelingen kann, dargestellt am Beispiel des „Sozialen Netzwerk Lausitz“*

*Anthropologie der Gabe und Soziologie der Reziprozität; Daseinsfürsorge; Förderung fürsorglicher Gemeinschaften; Inklusion; intersektorale Netzwerkarbeit; Management sozialen Wandels, Selbsthilfe/Gegenseitigkeitshilfe; Sozialraumkoordination*

*Der von der Wissenschaft prognostizierte sozialstrukturelle Wandel, hin zu einer immer älter werdenden (deutschen) Gesellschaft impliziert einen wachsenden Bedarf in der Daseinsvorsorge hilfebedürftiger Menschen, vor allem im Bereich der Gesundheits- und Pflegeversorgung. Vor dem Hintergrund eines kontinuierlichen Fachkräftemangels in diesen Bereichen laufen Sozialversicherungen und Staat Gefahr ihrer Pflicht die soziale Sicherheit zu gewährleisten nicht mehr in vollem Umfang nachkommen zu können. Innovative und alternative Herangehensweisen der lokalen Daseinsvorsorge, besonders im ländlichen Raum, nutzen wirkungsvolle Resourcen der Selbsthilfeorganisation, die sich effizient mit weiteren sozialen Institutionen, NGOs, örtlichen Unternehmen und den Bürgern vernetzt. Fachliche und finanzielle Unterstützung leisten im Idealfall die Kommunen, sowie die Sozialversicherungen im Rahmen der §§ 20 h SGB V und 45 d SGB XI. Dieser Beitrag präsentiert und analysiert eine erfolgreich gelingende Koordination der Daseinsvorsorge durch eine Kontakt- und Informationsstelle für Selbsthilfegruppen in der Oberlausitz/Sachsen, die vorwiegend im Dritten Sektor agiert.*

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