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Tandems of lay experts and academic experts: How new civil societal collaboration models enhance societal transformation

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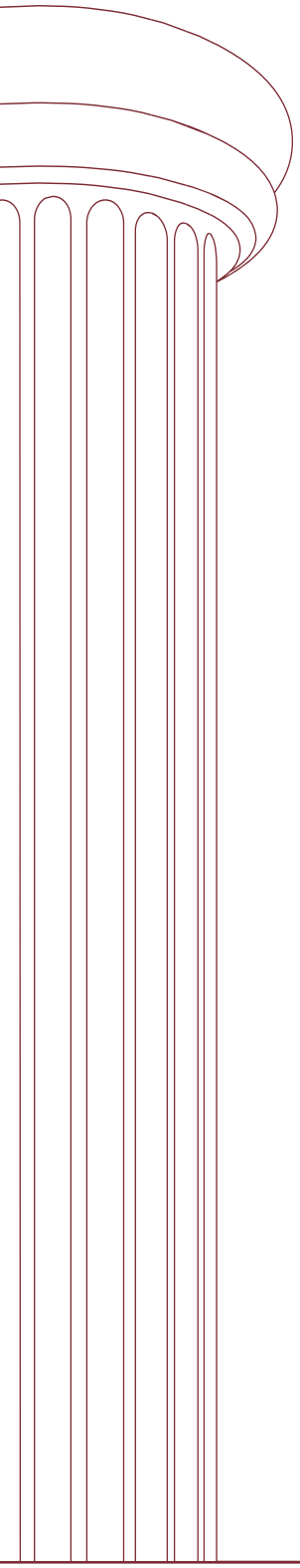

Wolfgang Chr. Goede

Tandems of lay experts and academic experts

How new civil societal collaboration models enhance societal transformation

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The Author

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Abstract

Late Munich sociologist Ulrich Beck (1944-2015) engaged in numerous public debates, among others on civil society. He considered it a "reform idea", a tool of democratization, even of "creative disobedience". Like many other academicians, he encountered difficulties though to properly define the term. At one point he compared civil society to a "pudding nailed to the wall". This distinctive image expressed his and others uneasiness with the inflationary usage of civil society and a sense of vagueness. This perception has not changed very much in recent years, especially in the general public. Therefore, more enlightenment, best practice and hands-on examples as well as in-depth perspectives on civil society and its modes of operation seem to be the command of the hour. This shall be undertaken and presented in this dossier within the field of self-organization, self-help and peer counseling, along the lines and frontiers of voluntary and professional engagement. One of the focuses is anxiety self-help and how it has evolved in a tandem partnership of lay experts and academic experts to a resourceful and valuable player in the realm of civil society. In view of the current corona uncertainties regarding our future in health-related aspects and, in general, post-corona societal modeling this type of twinning may become a shaping force and help civil society to win much more visibility and profile.

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Table of Content

1. Introduction 5
2. Reverse Bacon! 5
3. Patients can become their own therapists 6
4. Good-bye Hegel 7
5. Bottom-up versus top-down hierarchies 8
6. “Good moderators are like mid-wives” 9
7. Stand up for your anxiety! 10
8. “Self-help is the fourth column of the German health service system”.....11
9. Powerful defense against right-wing populism.....12
10. Health insurances – instigators of new business models 13
11. Roll-out of political coming-out 14
12. “Health system lacks speaking medicine – we fill the gap”.....15
13. Doctors can become patients and patients doctors 16
14. Accumulating technology in medicine increases patients’ fears 18
15. Brandt’s legacy: “To dare more democracy” 19
16. From “selpers” to “peer counselors”.....19
17. New frontiers: Integrate immigrants! 20
18. Challenges to meet: Catalytic Science and Enlightenment 2.0 21
19. Résumé.....22

1. Introduction

Approximately 20 million Germans, i.e. 25 percent of the population engage in volunteer work and social services for the good of the society. This figure correlates to similar proportions of volunteering in the European Union, the Global North and OECD countries.
In this dossier, we focus on the role of what has been known for a couple of decades in the volunteer segment as self-help, in recent years also as peer coaching and peer counseling. In Germany, self-help and peer coaching are particularly active in the field of health and, according to health officials, have become one of the columns of national health services. We'll look into the background of this, shed light on the genesis, follow strings and strands exemplified by the Munich and German anxiety self-help MASH and DASH as significant actors in the growing 3rd sector. Subsequently, the setup, role and function of tandems is examined, which is to say collaborative partnerships between concerned and afflicted citizens – so called every-day or experience experts – with learned, academic experts in the field of mental health, but also general health and beyond. This, in turn, will tap into the overlaying debate and question: Whether such tandems have potential to further inspire new academic spin-offs such as citizen science and catalytic science?

2. Reverse Bacon!

In November 2019, the German Science Writers TELI celebrated their 90th anniversary at the International Munich PressClub. When TELI was founded in 1929 in Berlin, science and technology were booming and nobody had any doubts that they were providing for the brightest conceivable future. Today, for some the promises of science and technology have become frail and are a matter of serious debate. No question that the world has progressed, but largely only materialistically, argue the skeptics. Climate change, severe environmental issues stemming from uncontrolled economic growth, wide-spread unhappiness and a deplorable mental health state of a large proportion of the populations, to name only a few drawbacks of modern science-based and technology-driven civilization have contributed to a sharp erosion of confidence of the general public in science as well as health. The TELI anniversary addressed this development with the question whether the competence of citizens could compensate for the loss of confidence in science[1]. The keynote was provided by Peter Finke[2], science theorist of the University of Bielefeld and a staunch critic of science. He is co-inventor of citizen science, author and editor of many publications which investigate the role of laypersons in science and research[3]. Finke established very clearly that amateurs

[1] Hanns-J. Neubert 2019: Wissen abgeschafft? Kann Bürgerkompetenz den Vertrauensverlust in Forscher und Ingenieure kompensieren? Available: https://www.teli.de/wissen-abgeschafft-kann-buergerkompetenz-den-vertrauensverlust-in-forscher-und-ingenieure-kompensieren/ (retrieving date 09.02.2020).
[2] Wikipedia, The Free Encyclopedia 2020: Peter Finke (Wissenschaftstheoretiker). Available: https://de.wikipedia.org/wiki/Peter_Finke_(Wissenschaftstheoretiker) (retrieving date10.02.2020).
[3] Peter Finke 2018: Lob der Laien. Eine Ermunterung zum Selberforschen, Oekom Publishing, Munich. With a summary of the author pertaining to the mentioned points on youtube (in German) https://www.youtube.com/watch?v=jeD-ZPsP2tM (retrieving date 26.05.2020).

and community-based research are of great value in science and constitute a highly needed corrective force.

In his TELI keynote address[4], Finke provided insights into his extensive research. He said that science had been ruled so far by Francis Bacon's 400 years old directive, namely to cut everything down into its smallest elements to thus gain understanding and happiness. "This has led in many ways to destruction and science needs to accept its responsibility for the state of planet earth", demanded Finke. As an alternative, he presented another model, in which he compared the scientific landscape to a mountainous area with peaks and valleys. The alpinists in this picture are the professional experts and hard-core scientists, who climb challenging peaks, whereas the hikers down in the valleys between the ridges are the lay scientists, citizen scientists, amateurs and everyday experts, whatever we shall call them. One depends on the other and, both alpinists and hikers, they complete each other and together make a winning team.

This topography is a well-chosen metaphor to explain the tandems between professional experts and lay experts, which are to be examined here. For Finke, the inclusion of the civil society in all science-related questions and research is a democratic must, in which Germany yet has a long way to go. The European Union, however, has been decisively more attentive to this agenda. The "EU Horizon 2020" framework, which shaped Europe's research in the past decade, was a large step towards inclusion. Many proposals and bids explicitly called for the dialogue with all stakeholders including civil society, citizen groups and 3rd sector organizations. To these ends, a comprehensive manual, "Promoting Societal Engagement in Research and Innovation", had been published under the lead of the Stuttgart university and distributed among universities, academic institutions and labs on the continent. The PROSO guide[5] digs deeply into the ins and outs of participation and contains a rich variety of state-of-the-art methods to promote engagement and inclusion. It is unquestionably a highlight of Horizon 2020 and a recommendable navigator in general all the way through participation.

3. Patients can become their own therapists

Coming back to Finke and the German context, he pinned down some fine examples of lay experts' involvement. Duisburg's neighborhood "Hochfeld" has been known for its social and urban deterioration. Professional social workers and neighborhood organizers banded together to give Hochfeld back its voice, across cultural borders and immigration, in an all-out

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[4] Peter L.W. Finke, 06.11.2019: Lecture on behalf of TELI 90th anniversary: Farewell to an era. Can science become a hope bearer again? (Munich, 06. 11. 2019: Vortrag aus Anlass des 90. Jubiläums der TELI Peter L. W. Finke (Bielefeld) Abschied von einem Zeitalter. Kann die Wissenschaft noch einmal zur Hoffnungsträgerin werden?). Available: https://teli.de/wp-content/uploads/2019/11/Vollversion_41.000Z_Vortrag-Mu%CC%88nchen-Vero%CC%88ffentlichungsfassung-TELI.pdf (retrieved 10.02.2020).

[5] The PROSO Consortium 2018: Promoting societal engagement in research and innovation: Moving towards Responsible Research and Innovation. Available: http://www.proso-project.eu/proso-support-tool-2018.pdf (retrieving date 10.02.2020).

effort to make it a flagship quarter. Community organizing[6] for example, a grassroots approach, which has come from the US to Europe and Germany, provides efficient tools to reinforce patchy neighborhood fabrics. Community Organizing, short CO, adopted confrontational and networking tactics from the labor movement to empower marginal populations. The German Forum Community Organizing foco[7] has introduced this method to the curriculum of social workers' education and training. While the traditional model of German social work has been to "feed the needy", with CO it's being reversed to "teach the needy how to feed themselves".

As another example of successful tandems between lay experts and professional experts, Finke pointed at "Stadtteilhistoriker"[8], neighborhood historians. Commons folks without an academic background in history reflect their own history and come to new conclusions, which professionals have overseen or ignored so far, also for political reasons or pressures. Our knowledge about the holocaust we largely owe to reports of victims. They triggered research, especially in the early years of the German Federal Republic, when in universities and administrations many Nazis held office and stonewalled investigation into their dark and so often bloody history. Just in parenthesis, the objectivity and neutrality of science has been debated for a long time and pops up as an almost inevitable topic at scientific and journalistic conferences. However, neighborhood and lay historians point out very clearly that research in general is biased and either driven or blocked by political agendas – another reason why citizen or lay science and the related applications are so valuable to make up for the deficits of academic science and its political and financial ties.

As a third case, Peter Finke pointed in his TELI address at the Munich and German Anxiety self-help and assistance MASH[9] and DASH[10]. "They are trying to solve one of the issues of today's live not with expensive health service, but through self-organization", Finke said and continued: "Also in this example, the heritage of a failing knowledge and scientific culture is countered with a new holistic approach, which gathers actively and passively concerned citizens and in which patients can become their own therapists."

4. Good-bye Hegel

In the ensuing discussion of the panel and the audience, the anniversary theme was reflected from different perspectives. Rupert von Strachwitz[11], political scientist and Maecenata Director, national platform of civil society research and debate, reminded of the

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[6] Wikipedia, The Free Encyclopedia 2020: Community organizing. Available: https://en.wikipedia.org/wiki/Community_organizing (retrieving date 10.02.2020).
[7] Forum Community Organizing e. V. Available: http://www.fo-co.info/ (retrieving date 10.02.2020).
[8] Projekt Stadtteilhistoriker. Available: https://www.sptg.de/projekte/unsere-themen/kunst-kultur-und-pflege-des-kulturellen-erbes/stadtteilhistoriker/ (retrieving date 10.02.2020).
[9] Münchner Angstselbsthilfe. Available: https://www.angstselbsthilfe-muenchen.de/ (retrieving date10.02.2020).
[10] Deutsche Angst-Hilfe e.V. Available: https://www.angstselbsthilfe.de/ (retrieving date 10.02.2020).
[11] More on Dr. Rupert Graf Strachwitz available: http://www.strachwitz.info/who-i-am (retrieving date 10.02.2020).

impact of civil society as part of the 3rd sector and non-government organizations. “It’s something very powerful. The East German civil society, for example, was the main force to topple the communist regime in 1989”, he said. In general, the civil society is made up of small entities, which by and large are more trustable than large and more anonymous organizations. “We have said good-bye to Georg Wilhelm Friedrich Hegel”, Strachwitz continued, the scholar, who had philosophized that our lives needed to be governed by an almighty powerful state. Nowadays we feel more at home with Karl Popper, who promoted the open society and the collaboration of many stakeholders. “This is also valid for science”, the Maecenata CEO stated: “Science is not only defined and directed by national science ministries.”

Martina Schraudner[12], board member of the German Academy of Science and Engineering acatech and panelist, pleaded for new models of transdisciplinary collaboration. As an example, she referred to newly implemented curricula at Munich’s Technical University TUM, which combine engineering with social sciences – as sort of academic tandems. This is an attempt to enlarge students’ horizons and create a new awareness that science is not being done for its own sake. A former TV science reporter in the audience approved of this newly evolving broad-based approach and specified that modern societies need to focus much more on philosophy, respective studies and disciplines, if they want to bridge the growing gap between natural sciences and social sciences including humanities. A blogger summarized the event: “Science conveys often the impression that it is detached from society and dedicated to its own needs. It’s about time that this attitude is being questioned by society. Only in dialogue over these deficits we’ll regain confidence in science.”

5. Bottom-up versus top-down hierarchies

This anniversary event and its critical assessment of modern science along with an array of options and solutions sets the tone and the stage for this dossier. In the 1920’s, science and society were completely distinct fields, divided by barriers in the magnitude of the “Berlin Wall”. In the 2020s, major walls have already fallen and are yet to fall. How do science and society meet and mingle, enter exchange and forge new types of collaboration and alliances? This shall be established and documented, among others, with the aforementioned organizations, MASH and DASH as well as related initiatives and networks.

Research on this topic and writing coincides with two other anniversaries. In 2020, MASH celebrates its 30th anniversary and DASH its 25th. In the 1980’s and 1990’s, the Bavarian capital Munich had been a hotbed of independent initiatives, which targeted largely health topics and issues. In 1985, the Munich Self-help Center SHZ[13] was founded and became the

[12] More on Prof. Dr. Martina Schraudner available: https://www.cerri.iao.fraunhofer.de/de/ueber-uns/leitung.html (retrieving date 10.02.2020).
[13] Selbsthilfezentrum München. Available: https://www.shz-muenchen.de/aktuelles/ (retrieving date 11.02.2020).

official umbrella of rapidly evolving several hundred self-help groups in the city. With the support of the ruling social democrats, but against the vote of the conservative and liberal party, the SHZ managed to get public funding for its operation and further growth. The founders remember how this grassroots approach to addressing health and, moreover, furnishing own services diametrically stood up against the top-down political and administrative thinking of, above all, the conservatives, many of whom perceived this as a rebellious act versus the established institutions. Notwithstanding this opposition, Munich went on historic track as one of the first cities in Germany to endorse self-organized self-help and bottom-up health care.

The controversial public debate and swiftly emerging success stories around the unfolding self-help movement encouraged a person by the name of Gerhard Schick. He had been ridden by anxiety issues and therapy had not led to the expected relief. So, frustrated and encouraged at the same time, he ventured into this unknown but so promising field. With SHZ support and guidance, Schick founded Munich Anxiety Self-help MASH[14]. It turned out that Munich just had been waiting for an opportunity to give vent to its anxiety concerns within the more informal settings of self-help. Clients poured in, the press discovered anxiety and reported in length and across the entire scope of disposable media channels about the unorthodox new mental health model[15]. Eventually, Munich City Hall couldn't help to pitch in to financially nourish its so overly well received health start-up.

6. "Good moderators are like mid-wives"

Indeed, MASH touched new ground and gave self-help another extra spin. It dared to step forward into the difficult field of psychiatry and applied an innovative method. Conversation groups were not chaired by professionals, but lay people who had experienced anxiety and come to grips with it. These lay experts were instructed and trained by professional experts such as social workers and supervised by doctors or therapists. What this tandem principle boils down to in practice is not therapy, as Finke named it, but a low-profile moderation of conversations around anxiety and panic, mixed many times with depression. The moderators follow a method, which is known as "Theme-centered Interaction" (TCI)[16] and which provides for intensive dialogues, all in all for laywomen and laymen easily to learn and to apply. Throughout the years, thousands of anxiety-afflicted persons have gone through MASH and found understanding, empathy, advice. Quite a few have managed to leave their symptoms behind, as evaluations show. There are many scientific, theoretical and practical explanations and arguments, why and how this methodology works.

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[14] Wolfgang Chr. Goede 2015: 25 Jahre Angstselbsthilfe: Wohin des Weges? daz Nr. 70, II/2015, p.19. Available: https://www.angstselbsthilfe.de/wp-content/uploads/2016/01/130.pdf (retrieving date 26.05.2020).

[15] Der Spiegel 46/1993: Angst vor der Angst. 15.11.1993. Available: https://www.spiegel.de/spiegel/print/d-13692866.html (retrieving date 11.02.2020).

[16] Wikipedia, The Free Encyclopedia 2019: Theme-centered interaction. Available: https://en.wikipedia.org/wiki/Theme-centered_interaction (retrieving date 11.02.2020).

To make a long story short, the underlying scientific documentation of this can be broken down into “talking to each other helps”. Sounds simple, but is in detail highly challenging in the anxiety framework. As one seasoned self-help practitioner once said, deadly serious: “Good conversation moderators are like mid-wives.”

MASH founder Gerhard Schick did not idle after his somewhat unexpected success, but went on organizing beyond Munich and Bavaria. He became a national, even trans-national, highly skillful networker for the good of anxiety self-help. With the knowledge he had gathered in Munich he reached out to local and regional groups throughout Germany, guided and assisted them in getting constituted and founding associations of their own. In 1995, Schick founded the German Anxiety Network DASH, a loose network of eventually approximately one hundred organizations, which worked similarly like MASH. Their means of communication became the journal “daz”[17], four times a year published with latest research on anxiety issues and the role of self-help groups. The current edition No. 89 deals with the question how anxiety affects people at work and how employers should deal with it.

7. Stand up for your anxiety!

In 2019, DASH was constituted as an independent body. It will tighten its bonds with groups throughout the country, many of which still go back to the 1990’s and are a result of Schick’s efforts. The relaunched DASH wants to step up its visibility throughout Germany, become a lobby organization on behalf of anxiety with the goal to destigmatize anxiety in society. This basically had already been envisioned by Schick 25 years ago and was quite far-sighted. With the modern means of communication this forward step has become more feasible now than then. Furthermore, the German anxiety pioneer went across national borders and collaborated with anxiety groups in Austria and in South-Tirol, Italy. Today, with this trans-national coalition, he could have zeroed in on Brussels and applied for lucrative EU funds.

The social pedagogue Christian Zottl was Schick’s successor as the MASH executive director. He instigated the re-organization of DASH from a loose network to a more closely knit lobby group and is its current executive director. After the coronavirus outbreak in Germany in March 2020 with an uprising concern of safety and noticeable fear throughout the society, Zottl became the voice of German anxiety with a very strong message: That fear and anxiety are normal, that the emotion protects us and we don’t have any reason to conceal it, feel bad about it, even consider it a dishonor or disgrace, like so many in an almost automatic reflex are inclined to do. In interviews in leading German media such as

[17] Die Angst-Zeitschrift available: https://www.angstselbsthilfe.de/daz/ (retrieving date 11.02.2020).

“Spiegel live”,[18] “Deutschlandfunk”[19], “ZEIT”[20] the DASH CEO encouraged viewers, listeners and readers to be upfront with their fears, to accept them as a natural response to corona threats of various sorts, not to sit on them, broodingly, but to share them with other people and thus reduce their emotional eminence.

This is common wisdom, developed during many years of self-help, which, in sum, have psychologists and psychiatrists reiterated in interviews during the corona crisis. Which means that science does not come to different recommendations than self-help. At this point, we are not reasoning about the question who is the leading force in this, but rather deposit a straight pleading that they both supplement each other and thus provide an argument for the tandem nature of both disciplines, as suggested by the title of this dossier. Moreover, Zottl was one of the driving forces behind establishing a regular news ticker under DASH auspices, which twice a day provides a digest of corona-relevant news, trends, backgrounds and also provides encouragement and enchantment during depressing times. “Angstfrei.news”[21] reached out to almost 10.000 people and after the UK Guardian picked up on it spilled over to the Anglo speaking world as an outstanding innovation[22]. Asked for a statement on behalf of DASH for this dossier, Zottl responded: “We need a powerful societal network for people with anxiety disorders. That goes hand in hand with a suitable societal climate, which promotes the open discourse of questions related to angst, fear, anxiety” along with a recognition of the advantages of a pro-active and transparent handling of this matter. DASH is supposed to be a platform for this.

8. “Self-help is the fourth column of the German health service system”

Christine Kirchner, national self-help expert and commissioned by German Social Health Insurances to promote self-help initiatives, moderated the founding process of DASH and coaches the current process of unfolding activities. With her experience and academic studies in the field, she tries to detect the rules behind self-organized processes. As to comments and a critical assessment of the tandem topic, she refers to her essay “Network Evaluation in Self-help Organizations”, which highlights the internal collaboration of partners and in-built challenges, as opposed to conventional networks with external partners and

[18] Stefan Kuzmany: Wie nützlich ist Corona-Angst? Spiegel Live. 07.04.2020. Available: https://www.spiegel.de/panorama/coronavirus-wie-gehe-ich-richtig-mit-meiner-angst-um-a-f4fad031-80ac-4472-bfc6-0e31b4c42eb0 (retrieving date 05.05.2020).
[19] Deutschlandfunk Nova: Coronavirus. Wenn Nachrichten Angst machen. 23. April 2020. Available: https://www.deutschlandfunknova.de/beitrag/coronavirus-wenn-nachrichten-angst-machen (retrieving date 05.05.2020).
[20] Stefanie Kara und Stefanie Lubahn: Psychisch krank in Quarantäne. ZEIT Online. 24. März 2020. Available: https://www.zeit.de/wissen/gesundheit/2020-03/psychotherapie-coronavirus-pandemie-psychologen-videochat-isolation-social-distancing/seite-2 (retrieving date 05.05.2020).
[21] Angstfrei.news available: https://www.angstselbsthilfe.de/angstfrei-news/ (retrieving date 05.05.2020).
[22] Jon Henley: Lockdown living: how Europeans are avoiding going stir crazy. The Guardian. 28.03.2020. Available: https://www.theguardian.com/world/2020/mar/28/lockdown-living-europe-activities-coronavirus-isolation (retrieving date 05.05.2020).

established hierarchies[23]. In summary, the paper published by Kirchner with the support of key self-help stakeholders comes to the following conclusions: Decision-finding processes in these somewhat informal settings are delicate and require diplomacy between two poles: conventional top-down hierarchal structures and self-steering bottom-up mechanisms. This constitutes a permanent field of tension which continuously needs to be balanced. “There is no formula” is one of the observations derived from many case studies. But if the adjustment process successfully succeeds, “self-help organizations with their central autonomy and flexibility are in their sustainability hard to beat”, concludes Kirchner. Paramount for reaching this quality are routines of self-observation and self-reflection and the evaluation of the state of the art of the self-help organization and its intern collaboration.

Her research is valuable not only for Germany, but the entire European Union EU, which Germany is a major representative of. Mental issues and anxiety are a health dilemma of all EU members. Roundabout 10 percent of the populations are affected, which are a burden on health systems and economic prosperity. Self-help and tandems of lay and professional experts could ease the problem, cut down on exceeding costs, generate more mental stability, improve life qualities.

Saving costs is a convincing argument for governmental and municipal agencies and a strong incentive to finance self-help organizations. They are mainly based on volunteering and work with low budgets. Already in the 1990’s, a study established that the tax money invested into MASH was well invested. Each German Mark which the city of Munich attributed to the organization resulted in a 15 times higher return rate. These figures have turned out valid and are still valid for many self-help organizations in the health sector and over the years and decades have contributed to their reputation and success. Insurances have started to appreciate the high efficiency and impressive economic performance of bottom-up health services. In 2019, they received 82 million Euros subsidies from the statuary health insurances in Germany. Long time ago, the conservatives gave up their initial opposition and became staunch supporters of self-help. Federal Health Minister Horst Seehofer (1992-1998, CSU, Bavarian conservative party) went on historic record with his remark that self-help is the “fourth column of the German health service system”[24].

9. Powerful defense against right-wing populism

Within only ten years’ time a previously perceived “underground movement” had won recognition and acceptance by highest political representatives. Empowerment had become mainstream in a society, which had been highly rigid till the 1970’s, the “post-Nazi era”, as

[23] Christine Kirchner 2020: Netzwerkevaluation in Selbsthilfeorganisationen (SHO). Available: https://www.socialnet.de/materialien/29017.php (retrieving date 05.05.2020).
[24] Jürgen Matzat 2002: Die Selbsthilfe als Korrektiv und ‚vierte Säule‘ im Gesundheitswesen. In: Forschungsjournal Neue Soziale Bewegungen, Vol. 15 No. 3. p.89. Available: http://forschungsjournal.de/sites/default/files/archiv/FJNSB_2002_3.pdf (retrieving date 26.05.2020).

Hildegard Hamm-Brücher, a political mentor of civil society had pronounced this period. Then, in the 1990's, Germany's reunification and the integration of the German Democratic (communist) Republic added new hurdles on the way to democracy. So, as a preliminary résumé, self-help has also been a very important tool to instigate self-organization and democracy in a country, which in its history had embraced dictatorial systems.

Almost needless to emphasize in this context that empowerment, self-organization and confidence in one's own and peer groups' resources is a powerful defense against seductive promises of populist political leaders, so much en vogue these days, especially in parliamentary and representative democracies of the traditionally liberal West. Now, that the democratic origins, property and quality of self-help have been established – what is the current state of self-help and tandem systems and what are the embedded challenges and risks?

In 1990, the founding year of MASH and fifth anniversary of SHZ, the Berlin Wall was still in the process of being demolished and Germany had barely entered its long-winding reunification process. The Euro was far from being on the horizon and not to be introduced in another twelve years' time. The Cold War slowly retreated and cleared the way for globalization, powered by emerging new information technologies. In Germany, the media was deregulated and private television and radio stations conquered the country with the erotic RTL Tutti Frutti show making waves. In offices, fax machines revolutionized communication. Almost stone age, compared to our means in 2020. Social media is omni-present, via youtube and podcast channels every individual can run her or his own tv, radio or erotic show, medical treatments and therapies are delivered via influencers and apps. Have these recent landslide transformations influenced or changed self-help?

10. Health insurances – instigators of new business models

Not too much, at least so far. Traditional chair circles with face to face conversation remain the main setup to deliver the service (at least till March 2020, when the coronavirus wave warranted virtual communication). Although NAKOS, the German self-help umbrella, observes new emerging formats, such as around Nordic walking, storytelling or taiji[25]. Even experimental and more artistic approaches such as impro and role playing have gone on record. They stimulate not only the cerebrum, but also other spheres of the human brain and thus diversify and deepen the impact of self-help practices. Besides, with the growing number of immigrants, new habits and customs access the German culture and transform it, which also counts for the arrival of new formats and gradually change or rewrite the self-help narrative – more details about this later.

[25] NAKOS.Info 120 2019: Selbsthilfe verändert sich. Neue Engagement- und Unterstützungsformen. Available: https://www.nakos.de/data/Fachpublikationen/2019/NAKOS-INFO-120.pdf (retrieving date 13.02.2020).

With a rapidly changing future panorama in recent years, along disruptive changes in our environmental, social and political perceptions, an uneasiness is taking possession of the self-help community with a somewhat growing preoccupation about how much longer the old principles may be applicable. This may also be triggered by health services and health insurances, which are quite upfront with their commitment to online services and treatments. BBK, the umbrella of 76 business health insurances in Germany, dedicated its self-help day 2019 in Düsseldorf entirely to the new online world. Experts in the field demonstrated to representatives of patient and self-help groups how they could make effective use of electronic devices and optimize their operations.

The message was clear: Be aware of the pitfalls, but don't wait for too long to modernize, and be smart enough to outwit the risks. Especially for elderly people, quite the majority in Düsseldorf, online is still a challenge and they need to be offered guidance and overall encouragement. For many difficult to grasp, but for younger members of self-help organizations absolutely feasible and increasingly implemented: to develop an app around your field of expertise, which draws on the exclusive experience and which arguably may be even superior to medical and clinical knowledge. Not only that it could be extremely useful for clients, but it may turn out as a business model and produce revenue for the usually underfinanced, not to say self-exploiting self-help sector.

11. Roll-out of political coming-out

As indicated by this dossier, which switches between the traditional "self-help" and new terms like "peer counseling" and "peer coaching", there is also some insecurity about the traditional branding. That the term "self-help" might become outdated had been raised and addressed for example already in 2014[26] at the annual convention of the German consortium self-help groups (DAG SHG). SHZ Deputy Director Erich Eisenstecken went more into analysis in a recent publication of NAKOS, the German national umbrella of self-help groups. Self-help implies "a deficit", he states in his essay with the title "Self-help and Self-organization"[27]. It insinuates "neediness" and thus "stigmatizes". "The critical-innovative, resource-oriented empowerment aspect is not sufficiently expressed by self-help", especially for outsiders, Eisenstecken objects. Principally, he continues, self-help or however it may be connotated, is being surmounted by "self-organization". Since antiquity, this has been an object of intense reflection and investigation, in philosophy by Platon and Kant, in social scientific system theory by Niclas Luhmann, in natural sciences and cybernetics by Heinz von Förster. "Self-

[26] Wolfgang C. Goede: Den Selbsthilfe – Wurzeln wachsen Flügel. In: daz Nr. 67, III/2014. Available: http://selbsthilfe-kontaktstellen.de/data/Dokumentationen/2014/DAGSHG-Jahrestagung-14-Goede-DAZ.pdf (retrieving date 12.02.2020).
[27] NAKOS.Info 121 2019: Selbsthilfe bildet: Erfahrungskompetenz trifft Berufs- und Fachwelt. Available at: https://www.nakos.de/data/Fachpublikationen/2019/NAKOS-INFO-121.pdf (retrieving date 12.02.2020).

organization is a universal concept", concludes Eisenstecken. But, obviously, also too general and not expressive enough, would object many self-helpers.

There is also a debate among self-helpers and self-organizers about prospective schemes of engagement. Notable is that self-helpers and, in general, patient groups become more self-confident and want to be recognized as stakeholders in health policy, research and drug development. Interestingly, the pharmaceutical industry is teaming up with them to articulate their concerns. In this constellation another work tandem of professional and lay experts may be seen. Of course, this partnership is driven by a massive self-interest on behalf of the industry, which in the past has been struggling with its ailing reputation. Self-help organizations had been targeted by big pharma's marketing strategists. In this relationship some self-helpers got too close to pharma, in the jargon "had gone to bed with their sponsors". NAKOS warns from ethical issues involved in these relations. It recommends to steer clear from entanglement and any conflict of interest.

At the vfa (Verband forschender Arzneimittelhersteller – pharma umbrella's PR arm) patient day 2018 in Berlin, the industry surprised with a highly participative and patient-driven moderation design[28]. In a world café, attendees divided into small groups and discussed a variety of themes around their future profile and activities. They unanimously agreed to become an active part of the interaction between doctors and research. "Don't talk about us, talk with us", urged patient group representatives from throughout Germany. They want to be accepted as self-responsible health citizens ("mündige Gesundheitsbürger*innen") and become part of the decision-making processes, not only pertaining to health policy, but equally important, get a voice in funding, budgets, and money flows.

As one speaker phrased this, the history of patient organizing and self-help encompasses almost 50 years in Germany. Now the groups move into their "political coming out" with equal rights and representation on all levels of the health system. The results of this world café went on the vfa patient portal and remained there for some time, despite or because of its strong political message.

12. "Health system lacks speaking medicine – we fill the gap"

Let's change the focus, from mental to cancer health. Women suffering from breast cancer and who were discontent with official health services actually laid the foundation for self-help long before the SHZ was founded. Already in the 1960s and 1970s breast cancer women turned into self-organizers around this disease, counseled each other, scrutinized and exchanged information and recommendations on doctors and treatments, encouraged and

[28] vfa. Patientenportal: Eine Selbsthilfegruppe finden. Available at: https://www.vfa-patientenportal.de/selbsthilfe/selbsthilfegruppen-stellen-sich-vor (retrieving date 13.02.2020).

supported one another. By doing so, they substantially contributed to overcome, also in the general public, the fear of cancer as a deadly disease and provided psychological relief. The pioneer role of women needs to be clearly understood and appreciated, when we talk about the roots of self-help and self-organization and how medical helpers, health services and self-helpers got to be valuable and self-reinforcing tandems. Since this early female engagement, cancer has become much more accepted and due to medical progress less lethal, while in some areas more frequent. For example, prostate cancer, which more than 60,000 males fall sick with annually in Germany.

Ortwin Thiel, affected and a patient himself, has been the long-time chairman of Munich Prostate Cancer Self-help. It is affiliated with the Bavarian Cancer Society and with the national umbrella. At the aforementioned self-help national convention in 2014, Thiel addressed the work of his group with the following words: “We define us as an extended arm of medical doctors and to compensate certain deficits in our health service system.”[29] The goal is intensive enlightenment about this type of cancer, introduction to treatments, counseling and encouragement. The prostate self-help chairman emphasizes, as did women before, that “there is substantial ignorance about cancer and that it is not a death sentence”. Thiel recognizes that doctors don’t find the time for long dialogues with their patients about the character of their sickness. “Here our health system reveals a lack of respect for speaking medicine”, he points out and adds: “Our job is, among others, to fill this gap.”

Thiel also dives into the importance of solidarity, which self-help and his group offer to boost the psychological stability and general well-being of patients. He, finally, stresses the political relevance of self-help as a stakeholder on the political agenda. Regional groups have joined to form a national umbrella, which engages along with other self-help entities to determine performance and services, which health insurances deliver to their members. “If the support of self-help were to be omitted, we would certainly face problems in our society”, concluded Thiel his lecture at the national convention of 2014. Everything he said is still valid in 2020.

13. Doctors can become patients and patients doctors

This is just another, quite prominent example of how self-help in Germany operates and impacts health services. According to NAKOS estimations, there are between 70,000 and 100,000 self-help units in operation throughout the country with some 3.5 million active members[30], roundabout four percent of the population. All in all, they have contributed to the fact that patients have become more self-confident about themselves; that they don’t feel like supplicants anymore, and that doctors and health personal engage more into dialogue; in

[29] Ortwin Thiel 2014: Selbsthilfegruppe Prostatakrebs München. Available: https://www.dag-shg.de/data/Dokumentationen/2014/DAGSHG-Jahrestagung-14-AG1-Thiel.pdf (retrieving date 13.02.2020).
[30] NAKOS: Selbsthilfe in Deutschland. Available: https://www.nakos.de/informationen/fachwissen/deutschland/ (retrieving date 15.02.2020).

short that both manage to meet more at eye level and consider themselves partners, the doctor as a counselor and guide, the patient as an intrinsic person, who wishfully accepts responsibility for her and his own well-being. The former barriers in doctor-patient relations have significantly been lowered, and sometimes roles between doctors and patients are even swapped, at least theoretically. This reversal describes the Berlin psychiatrist Jan Kalbitzer in his book “The Gift of Mortality” (Das Geschenk der Sterblichkeit). The distinction between therapist and patient is a mistake in his opinion: “Every human at some point of his live is in either one of these roles. It makes more sense to come to a professional agreement as to who has to help whom – based on who has more knowledge at the time or a temporarily greater psychological stability.”[31] This convertibility is a well-suited example to underline the tandem relationship and how intimately both parts are being intertwined and ideally, form a unique unit.

The bottom line of these two case studies may be read: Mental health has come out of the closet, so to speak. Disorders of any kind are no longer perceived as “craziness”. Psychiatry, therapy, and the clinical treatment of mental disorders, although yet stigmatized, enjoy increasing acceptance in our society. Cancer, after cardiovascular diseases the most frequent disease, is not getting demonized any more. Surgery and prostate removal, which until not too long ago had been an almost automatic reaction by doctors as well as patients upon a positive diagnosis, is making room for less invasive clinical options. This all has been also a result of self-help and self-organizing in the past 50 years and a more cooperative relationship of professional experts and lay experts.

However, there might have occurred implications or even unpleasant side-effects on the way, at least in the view of some of the traditional stakeholders. While medical students nowadays are trained, even by actors, how to skillfully engage in dialogue with patients, some of the older doctors are rather discontent and reject this new partnership. Not only because they regret to have lost authority, but newly empowered patients are sometimes hard to deal with. It will take time for all involved parties to balance the new hierarchies. The following is only a one-man sample, which was relayed to the author. It may show some of the irritations. During a cancer self-help social gathering, a natural scientist and retired chemist started to talk shop and demonstrated his understanding of self-help. Due to his profession he had gained deep insights into cancer treatments. As it was related, he was very conversational about the subject and shared with the listeners, triumphantly, that he knew much more about cancer than any doctor he had seen. It almost seemed like his hobby to visit doctors with his cancer disease and challenge them on proper treatment strategies. “I always come out as the winner”, he finished, as witnesses recall. Medical doctors’ response to patients like him are not documented, but can be easily predicted.

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[31] Jan Kalbitzer 2018: Das Geschenk der Sterblichkeit. Wie die Angst vor dem Tod zum Sinn des Lebens führen kann, Random House Publishing, Munich. p.90.

14. Accumulating technology in medicine increases patients' fears

How do health care workers view their relationship with their patients? Christian Leistner commented on this. He is looking back on almost half a century of experience as an emergency doctor, clinician, general practitioner and university lecturer. In his response, Leistner takes a critical stock of increasingly impersonal treatment, which promote more doubts and fears. Leistner remembers the beginning of his professional career, when patients in hospitals were treated rather holistically, with plenty of dialogue, involving the nurses, in communication in front of and with the patient: "It was teamwork, which saved a lot of time. The patient was always viewed as a whole, physically and psycho-socially. We had time for it."

And the times were different, recalls Leistner. "The patient in the early 1980s was between 50 and 85 years old, had been involved in one or two world wars, two currency reforms, all in all a lot of personal suffering! Most of the time patients in the 1980s had a basic trust in the doctor, without great fears, with great gratitude, partially uncritical, little questioning. The work may have been easier for the doctor at the time, he needed less time to inform relatives and discuss with them." Then, as more and more technical devices moved into clinics and medical practices at the end of the century, anonymization set in. "The thorough physical examination, the detailed medical history and the medical consultation were neglected," says Leistner. Many colleagues believed that technology would diminish patients' anxiety – today one should say customers, he notes –, for example in cancer diagnosis.

"No, on the contrary, fear is intensified", Leistner counters this approach. "Especially the so-called mature, sometimes too critical a patient, who is overwhelmed by the Internet and the media, requires a lot of conversation in addressing fears and doubts and to eventually dispel them", states the doctor. He suggests a less technically sophisticated medical operation that "promotes speaking medicine" – as Thiel also pointed out in his 2014 address – and relies on strong basic medicine around the traditional family doctor. "He examines, advises, clarifies, clears up doubts and fears, transfers patients if necessary and thus prevents unnecessary examinations."

In summary, Leistner's balance sheet would result in a relationship based on partnership and equal footing. The tandem team of a self-reliant and informed patient as well as an advising doctor would find its place in Leistner's scheme. For both parties it could provide more satisfaction, in general terms higher health quality and most importantly, almost guaranteed, significantly lower costs for the health system and the general public.

15. Brandt's legacy: "To dare more democracy"

The main focus of this close collaboration, reiterates and reinforces Markus Hendel, must be the patient. He is the chairman of a MASH conversation group and knows the concerns and needs of persons with anxiety disorders first hand. "All too often", he comments, "valuable perspectives from basic research seep away on their way into practice". With regard to the large field of affective disorders, Hendel adds, the findings of the newer cognitive science of the embodiment in particular would have led to expectations of a paradigm shift towards a holistic approach. But this is not so, he cautions: "In the institutionalized treatment and therapy of anxiety disorders, however, the division of soma and soul is often still determining, as participants from self-help groups repeatedly report." The increased exchange between the two sectors therefore holds great potential for anxiety research, as well as for the further development of anxiety assistance and anxiety self-help, and the prospect of a substantial gain for those affected, Hendel concludes.

Altogether, these statements of both, academic experts and lay experts point at a triple-win option, for patients, doctors, and the public. However, the medical and scientific community remains largely conservative and relies on operating top-down and within well-defined hierarchies. A cycle which started with the students' protests in the 1960s, climaxed politically in 1969 with Willy Brandt's winning campaign slogan "To dare more democracy" and led eventually to the alternative and green movement, in the wake of which the self-help movement prospered: Ever since, participation is still in the making and probably never will be finished, but continuously needs to be redefined and refocused. And, above all, it needs time, patience, empathy and a high dose of professional coaching.

16. From "selpers" to "peer counselors"

In the political field, many mayors for example are struggling with the public demand and an increasing number of stakeholders to have their voice heard and particular interests dealt with.
As a result, many villages and small towns encounter problems to find mayors. Indeed, governing like in the old days has become impossible nowadays, say some communication specialists and trainers, who try to address the problem. These professionals don't perceive the emergence of a multipolar democracy as an issue, but quite normal for a society in transformation. Political leaders, especially those with administrative responsibility, need to learn to moderate these processes, which these trainers have set out to teach them.

The Self-help Center Munich SHZ recognizes that especially elderly doctors and psychotherapists remain skeptical about participation and self-help, while this does not affect SHZ strategy to closely collaborate with the therapeutic sector. For example with the

promotion of patient seminars, during which therapeutic groups are being transformed into self-help groups. To make them more attractive, new terms and notions arise. Self-helpers merge to “selpers”. selpers.com is a new German platform around health competence and patient empowerment with the focus on cancerous diseases.

In its current directory[32], SHZ lists 1300 groups in Munich and vicinity, which mostly deal with health themes and which Munich’s mayor appreciates in his welcome address as “an important supplementation of the professional social and health services”. Acceptance of self-help is further rising in the view of health experts, adds a health insurance representative, and affirms: “Self-help groups act as experts in their own field and experience.”

So here we find again the ascent of self-help-”selpers” and aforementioned peer counselors onto the plateau of widely acknowledged experts. But one big challenge remains. How to open self-help to the increasing numbers of Non-Germans? The population of some metropolitan areas like for example Munich consists of 45 percent of immigrants (Berlin 34,5 percent, Germany-wide 25 percent) with different traditions, languages, religions, gender rules. This is being addressed by the SHZ Journal 1/2020[33], the content of which demonstrates that the institution, self-help pioneer of the first hours, tries to remain on top of the national self-help reflection and reform debate.

17. New frontiers: Integrate immigrants!

The SHZ Journal 2020 spring edition title reads “Intercultural Opening, Diversity, Social Justice” and principally deals with the question how to become sensitive for the customs and values of other cultures. It recognizes that due to language and cultural barriers information and flyers need to be written in “light German”, which means short, simple sentences. Not only communication barriers need to be lowered, the publication states, but also “one’s own handling of migration, culture, diversity on different organizational levels such as quality management, networking and public outreach need to be reconsidered”. What kind of training is needed to provide “intercultural fitness” for self-help institutions? How to encounter members of different cultures? And, above all, how to cope with culturally specific concepts of illness and health, also along with religious practices and, none the least, taboos around disease, moreover accept and understand without judging them right away? German self-help needs to discuss these questions and find answers and along the way normal German cultural standards can become relative. “Who is opening his culture to whom”, asks the SHZ

[32] Selbsthilfezentrum München 2018: Selbsthilfeverzeichnis. Available: https://www.shz-muenchen.de/fileadmin/shz/downloads/Broschüren/Selbsthilfeverzeichnis-2018-web.pdf (retriening date 26.05.2020).
[33] Einblick. Münchner Selbsthilfejournal 2020. Available: https://www.shz-muenchen.de/fileadmin/shz/downloads/einBlick/Einblick_0320_screen.pdf (retrieving date 03.03.2020).

journal, if in Munich almost half of the metropolitan population comes from beyond the German borderline.

The publication recommends a self-reflective attitude towards “invisible privileges and marginalization” in the everyday reality. It goes on to define diversity as a “radical disparity and plurality” related to “age, handicaps, appearance, language, social origin, gender/queer, sexual preferences, religion or secularity/denominational free”. Workshops around race theory, racism, colonialism shall enhance this debate. They include “structural discrimination” of immigrants and minorities in the public sector such as education, housing and real estate, politics and media, to name only a few[34]. To probe this, the SHZ staff underwent such a seminar and questioned its own values. It included role plays, which changed the perspective and provided the experience of how a native German feels in an unfamiliar cultural setting and is being exposed to it. The article stresses that there is a great need for intercultural opening. Especially in self-help groups around health themes immigrants are notably underrepresented, which needs to be brought into balance.

In a nutshell: Tandem building goes much further than previously described and established. Due to Germany’s rapidly changing demographic landscape, it also entails a cross-cultural approach to bridge the gap between German self-help experts and immigrants, who are experts of their own culture. Close collaboration and tandem building would be beneficial for both parts and could strengthen self-help and self-organizing. What the SHZ presents with this plea for intercultural openness is perhaps as spirited as when it went out in 1985 to establish a metropolitan self-help umbrella and thus setting an example throughout Germany. In light of the also changing political landscape, the above agenda might come in handy to cope with both, the mounting immigration pressure from crisis-ridden regions in the Global South and to respond adequately to growing nationalism and racism in the Global North.

18. Challenges to meet: Catalytic Science and Enlightenment 2.0

Towards the end, this dossier shall return to the meta level and finish up with some additional outlooks and closing thoughts on the topic. The sociologist Ortwin Renn has been one of the think tanks on participatory research in science. He currently heads the Institute of Transformative Sustainability Research IASS, Potsdam. In his most recent publication, “Felt Truths” (“Gefühlte Wahrheiten”[35]), he addresses increasing collective fears and distrust in politics, economy and also science. What he recommends, as a sort of relief valve as well as

[34] Covid-19 deaths in the United States were unproportionately higher in the African-American and Hispano communities, due to less access to health services and at the same time being on the front line of maintaining services during the peak of the pandemic. Shelby Lin Erdman: Black communities account for disproportionate number of Covid-19 deaths in the US, study finds. CNN. 06.05.2020. Available: https://edition.cnn.com/2020/05/05/health/coronavirus-african-americans-study/index.html (retrieving date 08.05.2020).
[35] Ortwin Renn 2019: Gefühlte Wahrheiten. Orientierung in Zeiten postfaktischer Verunsicherung. Barbara Budrich Publishing, Leverkusen. Available: https://shop.budrich-academic.de/produkt/gefuehlte-wahrheiten/ (retrieving date 11.03.2020).

trust-building measure, is “a deliberative participation culture”. Deliberate means decision making by public discourse and consultation, which patient and self-help groups, for example, demanded at the vfa patient day 2018 Berlin. “Transdisciplinarity” is in Renn’s view the way to go. It bridges the scientific disciplines, brings them together again, and important for our tandem question, with the inclusion of “knowledge bearers outside of science”, as the scholar writes, in close conjunction to Finke’s previous “alpine mountain-valley” metaphor. In this manner, knowledge is being “co-created”, Renn explains, with “the early involvement of all relevant knowledge bearers in the research process”, lay experts from all walks of live included. This is what he has defined a “catalytic process and catalytic science”, which to promote is the goal of IASS, with all stakeholders in one pool.

A comprehensive synopsis of newly developing methodological and transformational approaches delivers the catholic ethicist Markus Vogt, LMU University Munich, in his also recently published perspective “Ethic of Knowledge” (“Ethik des Wissens”[36]). He got them all, among many others: Finke, Renn, also physicist Ernst Ulrich von Weizsäcker, vice-president Club of Rome and his quest for a “new enlightenment” or “Enlightenment 2.0”[37]. In the 18th century, the enlightenment period laid the intellectual foundation of our modern civilization. It led to the democratic upraise of the occident and provided the womb of current scientific reasoning and its technological offshoots. Weizsäcker criticizes “reductionism” (Bacon: “Take the world apart into its smallest parts!”) and suggests, as a profound paradigm shift, a new holistic scientific thinking, which reconciles the old, outdated icons of European enlightenment (i.e. Adam Smith) with 21st century thinking. “There is not one dogmatic truth, but various truths”, Weizsäcker stated at a 2019 Berlin symposium[38].

The scientific and societal job is to get them into a new balance. Which, ideally, the described tandems contribute to in their own and genuine ways.

19. Résumé

This dossier tried to demonstrate that civil society is a vital force in shaping our lives, in the concert with established institutions such as political parties, business world, research and technology. As some of the examples showed, civil society has corrective and reformative effects. Self-help as part of self-organizing has changed health services by turning around its delivery from top-down to bottom-up. Along these transformation lines, new viable partnerships have arisen between lay experts and professional-academic experts. These

[36] Markus Vogt 2019: Ethik des Wissens. Freiheit und Verantwortung der Wissenschaft in Zeiten des Klimawandels. Oekom Publishing, Munich.
[37] Deutsche Gesellschaft Club of Rome. Available: https://www.clubofrome.de/neue-aufklaerung (retrieving date11.03.2020).
[38] Eckart von Hirschhausen: "Beim Klimawandel führt unsere Jetzt-Besoffenheit in die Katastrophe“. Stern. 16.08.2018. Available: https://www.stern.de/gesundheit/gesund-leben/ernst-ulrich-von-weizsaecker-im-interview---beim-klimawandel-fuehrt-unsere-jetzt-besoffenheit-in-die-katastrophe--8211664.html (retrieving date11.03.2020).

tandems possess not only a unique democratic quality, but they reach deeply into the foundations of scientific thinking and contribute to paradigm shifts expressed for example by “Catalytic Science” or “Enlightenment 2.0”.

Whether the “pudding nailed to the wall”, as Ulrich Beck once pronounced the civil society, has become firmer and more robust remains to be seen. Its loose structure, though, might be of great advantage. Different to political parties, for example, civil society is much more flexible and can easily adjust. After all, its pudding contexture may be its USP, unique selling point – its outstanding and many other institutions and societal bodies superseding quality.

To this closing paragraph, as it originally had been planned in the structure of this dossier, an additional remark, added shortly before the publication deadline and due to the current turbulences inflicted by the coronavirus to our health system as much as political and economic system. From the beginning on, the voices of the civil society made themselves heard and offered valuable resources to find strategies and solutions for the crisis[39]. As Joris Steg, Bergische University Wuppertal phrased it: „The current crisis can indeed contribute to strengthening democracy by empowering people and shifting the fight against crises from the state to civil society.”[40] It has very much indeed brought about historical achievements in Germany such as the fall of the Berlin Wall 1989 and the successful handling of the refugee crisis in 2015. The German civil society has sufficiently demonstrated its civil power and, needless to say, in tandems it could even go further.

[39] Rupert Graf Strachwitz: Zur Corona Krise: Eine Stimme aus der Zivilgesellschaft. 27.03.2020. Available: http://www.strachwitz.info/resources/Stimme_27_III_2020.pdf and b-b-e: Coronavirus in Demokratie- und Engagementpolitik. Available: https://www.b-b-e.de/corona (retrieving date 14.05.2020).
[40] Joris Steg: Krisenzeit. Die Corona-Pandemie wird unsere Welt nachhaltig verändern. Krisen aber sind eine Konstante der Gegenwart. IPG. 30.03.2020. Available: https://www.ipg-journal.de/regionen/global/artikel/detail/krisenzeit-4201/ (retrieving date 07.05.2020).

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	Nr. 126	**En quoi se constitute le pouvoir de la société civile?** Une analyse sur la base de l´exemple de l´économie collaborative *Julia Dreher*
	Nr. 127	**Stiftungen als Schulträger** *Rupert Graf Strachwitz*
	Nr. 128	**Shrinking Space of Civil Society** *Karen Ayvazyan*
	Nr. 129	**Where does German Humanitarian Assistance stand?** **Wo steht die deutsche humanitäre Hilfe?** *Ralf Südhoff & Sonja Hövelmann - Centre for Humanitarian Action*
	Nr. 130	**Colombia's Negative Peace. A Challenge for Civil Society?** *Wolfgang Chr. Goede*
	Nr. 131	**Die Kirche auf dem Weg in die Zivilgesellschaft Teil 1: Text** *Henning von Vieregge*
	Nr. 132	**Die Kirche auf dem Weg in die Zivilgesellschaft Teil 2: Materialien** *Henning von Vieregge*
2020	**Nr. 133**	**The King, Religion, the State, and Civil Society in Morocco: Can Think Tanks Help?** *Hind Arroub*
	Nr. 134	**Civil Society and Democratisation in the Eastern Partnership Countries: A Shrinking Space** *Karen Ayvazyan*
	Nr. 135	**Der Kampf gegen Geldwäsche, Steuerhinterziehung und Terrorismus. Was haben Stiftungen damit zu tun?** *Rupert Graf Strachwitz*

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