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»Coordinating Care«

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RADICAL HEALTH

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COORDINATING CARE Radically?

In *The Birth of the Clinic*, Michel Foucault proposed the term "clinical gaze" as a description for the dominant epistemological framework of clinical medicine.[1] He traced this framework's origin to the large teaching hospitals of the 19th century. It was here that the doctors' focus shifted from asking patients 'What is the matter with you?' to 'Where does it hurt?'.

"The clinical gaze effects a nominalist reduction on the essence of the disease."

Michel Foucault: *The Birth of the Clinic: An Archaeology of Medical Perception,* New York: Vintage Books (1994), p. 118.

Foucault noted that this narrower focus on measurable signs of pathology came at the expense of other explanations for illness, chiefly those rooted in the patient's lifeworld. Other scholars have criticized that healthcare practitioners following a purely biomedical model often ignore the patients' social context. The dominance of this model is also reflected in the traditional split between healthcare and social services. This is despite the large body of epidemiological scholarship demonstrating a strong link between a patient's social position and a variety of health outcomes. The significance of these social determinants of health has led many scholars to advocate for more integrated forms of care.[2]

Tudor Hard already voiced the need for the integration of fragmented services in the 1970s. He found that there was an inverse relationship between the need for services and their actual provision. In practice, this "inverse care law" means the most disadvantaged, with the highest need for medical and social services have the lowest level of service provision. Conversely, it is known that e.g., privileged patient groups, disproportionally access preventive health care interventions, such as cancer screening, thereby further increasing underlying health inequalities. The fragmented nature of social and healthcare services furtherly exacerbate inequalities in health and healthcare.
Fragmented services require users to become "active". They need to find, appraise, and choose their way in the vast landscape of public service provision. The ability to navigate this public service landscape is equally dependent on education, time autonomy, and other social factors. Difficulties in navigating services regularly result in delays to requests for help or taking "the wrong path", i.e. approaching a service unable to meet a client's specific need. It can also lead to discontinued care or people not accessing services altogether.

Julian Tudor Hart: "The Inverse Care Law", in: *The Lancet* 297/7696 (1971), pp. 405–412.

The German public service provision is often described as particularly fragmented and provider-centered.[3] Services follow professional boundaries, mandates, and jurisdictions to the detriment of the coordination and cooperation between services. More recently, locally practiced forms of coordinated and integrated care move away from such provider-centeredness, toward more patient-centered services (an internationally formulated healthcare policy aim). However, this change is not straightforwardly implemented and 'up-scaled'. It encounters various challenges and resistance. Of crucial interest to researchers studying this emerging shift in healthcare provision thus is: What makes the current arrangement so inert?

Can breaking up jurisdictions and boundaries be radical?

In answering this question, we find inspiration in Pierre Bourdieu's challenge of orthodox institutional arrangements in fields such as public services.[4] Orthodoxy describes a dominant belief. Heterodox positions contradict and challenge these by questioning the legitimacy of the dominant. Healthcare and social service arrangements and jurisdictions are historically grown structures that manifest culturally ingrained classifications and social inequalities; they store and reproduce powerful positions of – and relations between institutional actors as well as professionals and clients. We postulate that challenging or changing these arrangements and classifications through heterodox positions – as illustrated by our case studies – can thus be deemed radical.

Patient-responsive forms of care go beyond the biomedical model and provide methods of coordinating services.

The two case studies presented illustrate the inertia of the institutional arrangements of the German healthcare and social service system. By referring to them, we want to highlight heterodox attempts to institutionalize coordinated and more patient-responsive forms of care. Research suggests that coordinated care may reduce the impact of social inequalities in health care access and improve health outcomes.[5]

COORDINATING CARE Two Case Studies

The first case study portrays a shift in the provision of emergency rescue services towards the coordinated provision of social and health services. This change was triggered by the emergency telephone service 112 regularly being utilized to request help for low-acute medical problems or lacking social provision. The increase in low-acute calls prompted the need for institutional change. Krüger used interviews and participant observation to conduct research on the rescue service of a German city. For this article, she draws on current debates about the organization of the rescue service as well as on an interview excerpt with Mr. Reimann (pseudonym), an employee of her case study's rescue service planning department. The second case study, describes the work of the *Gesundheitskollektiv Berlin (GeKo)*, a German community health center, which brings together activists, medical providers, and psychosocial service providers, thereby providing coordinated, holistic and patient-centered care under one roof. Schuster's description of a German community healthcare center in Berlin (*GeKo*) relies on her participation in *GeKo's* working group on research and evaluation since 2018. As a medical doctor and member of *GeKo*, Schuster takes a reflective position inspired by the approach of observant participation. She reflects on the work of *GeKo* both as an activist and healthcare practitioner, as well as a health service researcher. Schuster's positions do not necessarily reflect the positions of the Berlin Health Collective.

Both case studies demonstrate heterodox positions in relation to the existing public service provision.

Their quest to provide care differently follows different trajectories. The first relies on a more conventional approach, and the second is more 'political'. We postulate that they represent two poles of the continuum of radically responsive, patient-centered care. At first glance, both cases appear incompatible. The rescue service and community healthcare center represent two distinct medical organizations, employing providers with different professions, trainings, and foci. The rescue service provides first aid and, in part, first medical interventions in case of medical emergencies. The *GeKo* is a community health centre aiming at implementing integrated primary health care at the neighbourhood level (Berlin, Germany). Yet, both cases experience similar problems and struggles to address these. Rescue services document increases in their use as well as frequent encounters with patients who not only suffer ill health or injury but also (psycho)social needs that are involved or stipulate a 112 call and ambulance operation internationally.[6] Primary care providers similarly observe (psycho)social needs.[7] Providers in each sub-field agree that not-addressing (psycho)social needs deemed as a mismatch to the (bio)medical model of illness influences patients' health and well-being, as well as their work, resulting e.g., in unmet needs and frustration. This chapter shows how planners in rescue services and primary health providers start to complement the limited toolboxes to address varied needs by re-scaling their focus from specific organizational mandates to responsive, patient-centeredness, i.e., from fragmentation to integrated and coordinated care.

COORDINATING CARE The Rescue Service

The field of emergency (para)medicine has seen increases in client numbers in emergency rooms (ERs) and the rescue service (inter)nationally. These increases are not related to a rising number of medical emergencies alone, i.e., life-threatening conditions and those that risk harming the health of clients. Many of these operations concern low acute cases in which clients are vitally stable – mandatory transports to ERs appear not necessary and in which clients might benefit from ambulatory, nursing, or social care. Yet, ER transports are usually issued. They follow the institutionalized logic of the 'chain of rescue'. The chain of rescue is conceptualized and practiced as a form of care that involves support by laypeople or professionals on the ground and includes first aid, the issuing of a 112 call, and eventually medical intervention by an ambulance crew and transport to the emergency room of a hospital. First aid and transport have long been considered the working focus of the rescue service in Germany.[8] In this context, alternative care provision is not envisaged or conceptually and organizationally facilitated. Yet, rescue services face a historic challenge: an increase in operations (in Germany, annual increases of 5%) of which many clients mismatch the original mandate of life rescue.[9] Frontline workers and researchers identify particular client groups who might benefit from other forms of care (e.g. nursing care, social work, housing, psychosocial crises support, ambulatory healthcare, self-help groups, and community services).[10] Frontline workers are regularly confronted with needs outside their mandate, with partly impoverished, chronically ill, and helpless clients, and evaluate their time-sensitive but short-term interventions as "insufficient". Rescuing a client from suffering that is "distal" to urgent biomedical causes has not been part of the paramedical toolbox, nor of its agenda. The rescue service works according to a specific rhythm: it responds promptly, processes quickly, and addresses acute healthcare needs. This logic developed to - and succeeded in - rescuing many lives and preventing damage to health.

While designed to respond to the extremes of the body and psyche, it has difficulties addressing other temporalities or conditions like homelessness, long waiting times for ambulatory appointments, depression, loneliness, or elderly, homebound care issues.

Frontline workers see such conditions as partly responsible for an increase in operations. The low threshold access to the rescue service and its outreach work brings some clients with difficulties in accessing other services regularly in contact with emergency care. A 112 call can trigger an operation, and an operation usually triggers a hospital transport while providers cannot necessarily be responsive to the client's non-medical problems. The chain of rescue can turn some clients with mismatching needs into a cue ball in the system (Mr. Reimann; rescue service planning unit). However, health service researchers and providers themselves started to regularly express their heterodox demands of a paradigm shift in publications, reports, and conferences. In an interview, Mr. Reimann explained instead of giving a uniform response (along the chain of rescue) to a diverse range of operational situations, rescue services "need to start to give different answers" to rethink healthcare provision.

"As in other countries, emergency rescue and emergency rooms are showing rising utilization rates. A sensible approach to managing this situation is to break away from the (linear) logic of '112 – ambulance – transport to the emergency room'. Internationally, experts agree that emergency rescue must be expanded into an integrated assistance system. This includes alternative services such as acute services with social workers, special services for crises as well as acute treatment for psychosocial and psychiatric emergencies, case management of frequent users, and better care for institutionalized facilities such as special forms of housing. Only by investing in this area can unnecessary transports and admissions be avoided – but this is not very easy to implement with separate sectors and responsibilities."

Rajan Somasundaram, Denis Gümbel, Stefan Poloczek, Harald Hasselmann, Joachim Seybold, Axel Ekkernkamp: "Notfallversorgung in Berlin - heute und morgen: It takes a system to save a life.", in: *Beitrag zum Denkanstoß 8: Gesundheitsregion Berlin-Brandenburg,* https://edoc.bbaw.de/frontdoor/index/index/docId/3644 (2022).

Recent years brought about an increasing understanding among providers, researchers, and planners in emergency care to adapt the rescue service and establish an integrative and coordinated aid service. In that, planners and practitioners aim at both: networking outside their mandate and profession and cooperating with various professions that respond to needs within and beyond emergency medicine. Such a heterodox position attempts to break with the linearity of the chain of rescue. In that, actors suggest a move from an organization-

centeredness to a patient-centeredness understanding of the rescue service, coordinating and facilitating access to other local services. Such a form of navigation may mitigate the effects of social inequality in service access and might increase a sense of responsiveness for clients.





Photographs by Daniela Krüger (2023).

One of the authors saw the metaphor of flowers, separated and grouped in one image and mixed and intermingled in a second, in a presentation by an emergency care planner who used similar images to explain the difficulties and benefits of working across professions and sectors to mitigate current challenges in emergency care.

As some providers and authors suggest, the shift may include an integration of different providers and sectors, bridging and integrating institutional turfs and professional boundaries. The first attempts in this direction are already in the making. The German city of Oldenburg introduced a pilot project called *Der Gemeindenotfallsanitäter*.[11] Their task is to evaluate whether a client can be sorted into other institutional paths such as nursing care, general practitioner care, or psychosocial services on-site. In a similar vein, the city of Copenhagen introduced *Sociolance* in 2015 as a pilot study, catering to unhoused people who often lack access to regular healthcare and institutionalized psychosocial support. The Berlin fire brigade established a preventive rescue unit within its service, and case management for those clients who frequently call 112, often for psychosocial needs, and facilitates access to other (social) services.[12] These approaches represent niches of more coordinated and holistic care. However, scaling up these niches from pilot studies to regular care faces challenges. Integrating and fully coordinating care by a prehospital aid service encounters sectoral and professional boundaries imposed by different jurisdictions, and funding schemes as well as trainings and professional self-understandings between e.g., ambulatory and hospital care, rescue service, nursing or psychosocial care.[13]

COORDINATING CARE The Community Health Centre

The main goal of *GeKo* is to provide coordinated curative and preventive care, and health promotion while taking into consideration social determinants of health such as rent increases, low income, precarious employment, racism, or poverty. The *GeKo* was developed as an association between healthcare providers and political activists. One of the aims is to address a shortcoming of the healthcare system: its fragmentation and the professional dominance by physicians. In 2022, *GeKo* opened its doors to provide integrated and coordinated community care, but decentralised activities in the community have taken place since 2016. *GeKo* provides care in an interdisciplinary and interprofessional, patient-centred, easily accessible, and participatory manner. These core values of the center's care provision have been developed in a cocreation process among its members in close cooperation with local stakeholders in the community it serves. The complex interaction between physical, mental, and social conditions of health are addressed by four main pillars: primary medical and psychotherapeutic care, community organizing and projects in the neighbourhood, self-help, and counselling and research and evaluation. The community health centre works with a multi-professional team of psychotherapists, community health nurses, social workers, health and social scientists, doctors, and physiotherapists. Dominant hierarchies within and between occupational groups are challenged by promoting shared, equal decision-making, regular exchange in collective case discussions, and knowledge transfer. Hierarchies between providers and patients are also addressed. Participation plays a role in medical care as well as in the ongoing organization and development of the health centre. The development of the centre and the services it offers are directly aligned with the needs of the people in the neighbourhood and thrive on close, direct contact with them. To understand the local populations' comprehensive social space and needs, we performed a needs-based analysis between 2017 and 2020. Mapping of existing structures and actors in the neighbourhood and focus group discussions with local stakeholders provided information on health care needs, care gaps, resources, and wishes. The analysis further included an exhaustive survey of the neighborhood's residents. It showed a strong association between ill health and a low educational degree. Also, housing-related struggles due to fear of eviction, difficulties to cover the rent, and overcrowding were common. Impairment in mental health was highly prevalent.

Among the *GeKo* team an understanding prevailed that health care would require more than consulting and treating patients along the biomedical model of health and illness.

The team actively created networks and cooperation with local providers. Neighbourhood groups focussing on problems in the community such as housing our nursery search strengthen the existing local structures and allow for coordinated referrals to community services, ranging from youth centers and pupils support to social care counseling in older age. Mobile health counseling has been implemented. It aims to improve access to information, counseling, and care, and to encourage the exchange and support of self-help among residents. Activity programs on a local public square are used as a way for community organizing which allows people to get in contact with neighbours, hear their problems, needs, resources, and ideas, and potentially exchange social support. While *GeKo* increased its providers satisfaction with the care it can provide together, it had to overcome various hurdles to institutionalize it. Difficulties included overcoming classical hierarchies, integrating different professional cultures, and living with the constant need to do more while being underfunded.

COORDINATING CARE Actually Radical?

However sharp the senses of providers for the social hardship of their patients, other than biomedical needs usually remain 'distal' to their practice.[14] They are neither part of the medical curriculum nor of its tool box. Waitzkin describes this as the "irony" of medical practice.[15] Insufficient nutrition, precarious working, and living arrangements, lack of access to regular healthcare, domestic and neighborhood violence, and lack of social support and nursing care are among such aspects that may be observed and even documented in screenings but are rarely addressed.[16] Although healthcare workers increasingly assess patients' socio-medical history, a knowledge base for identifying selection criteria for such interventions is scarce. Moreover, available institutionalized solutions to address social risks to health are lacking.[17]

The (para)medical gaze regularly hampers a responsive approach to the distal factors that influence patients' health outcomes.

It is cast in a historically grown and orthodox set-up of the field of healthcare. Recent attempts by planners, practitioners, and political activists to create more responsive institutionalized care for patients with mismatching needs lead to radical shifts, changes, and challenges. Rescue services and community care centers like *GeKo* appear to represent two poles of a continuum aiming for radically responsive care. Yet, radicality is a question of perspective. Other healthcare systems show different institutional arrangements and degrees of professional cooperation. So that actors of heterodox positions formulate other demands than overcoming sectoral and professional boundaries. And radicality is ever-changing. The approaches presented here challenge the persistent institutional healthcare arrangement while, simultaneously, producing residues. In this sense, radicality may be understood as processual and dialectical. Institutional changes in certain arenas and on specific levels may be accompanied by unintended consequences that undermine well-intended aims. To address previously described challenges rescue service personnel suggests assuming the role of a navigator concerning social and healthcare services. In doing so, they challenge a deeply rooted, historically grown role, position, and mandate – and, at the same time, the understanding of their profession. It is a change stipulated by planners and decision-makers. Professionals at the frontlines may experience a sense of deprofessionalization, feeling out of place due to the widened focus of their organization. *GeKo* bases its work on lowered professional hierarchies and participative formulated goals. Their approach is based on collective decision-making. The center attempts to break with professional turfs and hierarchies, including those between medical experts and laypeople.

Persistent knowledge hierarchies in biomedicine and social welfare procedures require continuous individual and collective reflection to address persistent (hierarchical) patterns.

Another residue concerns the question if coordinated and integrated care can prevent or increase fragmentation? Who has oversight and will be responsible for the (whole) person? *GeKo* brings together different professions and shared case discussions under one roof. This is certainly more difficult to achieve for large providers like rescue services. Case management, as tried by the Berlin fire brigade, could be a viable solution, but responsibility and mandate must lie with one provider. Also, a distant service navigator like a rescue service

may not detect client needs based on participation. Can their suggested care arrangements be more responsive if they rely on healthcare planning from the top? *GeKo* uses participative methods to adjust its services and to pursue patient-centered care. Thereby, the determination and reflexivity about what kind of needs clients see as relevant have greater weight. Yet, the scalability of their methods needs to be evaluated. Finally, integrated and coordinated care may increase the degree of responsiveness to clients' needs, overcome professional boundaries, and address non-medical needs – but does this merely mean that illness and psychosocial needs are managed better or can their distal sources really be addressed?

Notes

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4 Pierre Bourdieu: *Outline of a Theory of Practice*, trans. by Richard Nice, Cambridge: Cambridge University Press (1977).
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7 Dietmar Jobst, Stefanie Joos: "Soziale Patientenanliegen: Eine Erhebung in Hausarztpraxen", in: *ZFA Zeitschrift für Allgemeinmedizin* 90/12 (2014), pp. 496–501; Howard Waitzkin: *The Politics of Medical Encounters: How Patients and Doctors Deal with Social Problems*. New Haven: Yale University Press (1993); Thomas Zimmermann, Claudia Mews, Thomas Kloppe, Britta Tetzlaff, Moritz Hadwiger, Olaf von dem Knesebeck, Martin Scherer: "Soziale Probleme in der hausärztlichen Versorgung: Häufigkeit, Reaktionen, Handlungsoptionen und erwünschter Unterstützungsbedarf aus der Sicht von Hausärztinnen und Hausärzten", in: *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen* 131 (2018), pp. 81–89.
8 Institutionally, the rescue service is not included in the German Social Security Code IV (§ 27) which regulates healthcare.
9 Fabian Sieber, R. Kotulla, Bernd Urban, Se Groß, Stephan Prückner: "Entwicklung der Frequenz und des Spektrums von Rettungsdiensteinsätzen in Deutschland", in: *Notfall & Rettungsmedizin* 23/7 (2020), pp. 490–496.
10 Thomas Schmitt, Thomas Luiz, Stefan Poloczek, Tobias Huber, Marc Kumpch, Christian Madler: "Sozialepidemiologie einer neuen Einsatzkategorie", in: *Notfall & Rettungsmedizin* 5/2 (2002), pp. 102–109.
11 The German city of Oldenburg introduced a pilot project called "Der Gemeindenotfallsanitäter" ("the emergency care paramedic"). Their task is to evaluate whether a client can be sorted into other institutional paths such as nursing care, GP care, or psychosocial services on-site. The goal of community paramedicine is to prevent unnecessary transports to the ER and facilitate clients' access to other services (see: Gemeindenotfallsanitäter/ Malteser Hilfsdienst gemeinnützige GmbH [2022]: *Der Gemeindenotfallsanitäter,* https://www.gemeindenotfallsanitaeter.de [8 January 2022]).
12 Berliner Feuerwehr: "Struktur 2020: Die Berliner Feuerwehr organisiert sich neu", www.berliner-feuerwehr.de/fileadmin/bfw/dokumente/Publikationen/FW_Struktur2020_Web-PDF.pdf (2020).
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