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Co-designing tools and support for quality of life of people with disabilities and their families in times of Covid-19. A viable space for the disability case manager (DCM)?

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Abstract

The COVID-19 syndemic experience exacerbated the urgency of finding innovative solutions to support the autonomy, integration and care of people with disabilities in our country. Specifically, the fragility of the protection measures for the disabled and their families emerged forcefully, and they were all too often abandoned in residences -and in their own homes- as a result of dedicated service closures, leading to the loss of flexible or adequate alternatives and to an often unsustainable burden of care for families. The article first discusses the experimentation of introducing a disability case manager (DCM) in a local context, starting from an interesting drive for innovation exercised by a banking foundation that promoted a participatory process with public and private stakeholders. The second part explores the salient features of the DCM profile in relation to the needs that emerged from listening to local stakeholders, particularly care workers and disabled people and their families. In the last part, the experimentation is presented as a possible innovative path towards improving the quality of life and well-being of disabled people. Finally, several key recommendations are provided for urgent interventions to support disabled people and their families both during and after the syndemic crisis.

Keywords: *Disability; Social work; Syndemia COVID-19; Co-design; Disability case manage.*

1. Introduction

The health emergency linked to the rapid spread of the SARS-CoV-2 virus has been disrupting the landscape of economic and social relations in Italy since February 2020. In the context of great uncertainty about the characteristics and dangerousness of the virus, scholars around the world are almost embarrassed to draw a picture of the collective experience of disabled people (Brennan et al. 2020).

Recently, the term syndemic, a concept of anthropological derivation, was introduced and relaunched by the editor of The Lancet in September 2020 (Horton 2020). This term refers to the meeting of two pathological conditions that enhance each other with

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nefarious outcomes. However, it is not a matter of co-morbidity, as Maturo (2021) clarifies: "the novelty of the concept lies in the importance given to the social conditions that cause one of the two pathologies, indeed one can even consider syndemic as the encounter of a pathology with difficult social conditions (or with risk factors related to social conditions)" (p. 14). Although some international scholars have argued that the COVID-related crisis does not differentiate among social classes or genders when it impacts people who were already poor, had work problems, had high levels of existing debt, were homeless or had problems accessing health benefits (Friel and Demaio, 2020; Bambra et al. 2021), the most fragile people—those experiencing hardship—are often the most affected by factors that "syn-act", that is, that act together to make infection not only more likely but also more lethal (Favretto et al. 2021).

Experts indicated early on that disabled people were at higher risk of morbidity and mortality following COVID-19 infection. Moreover, many disabled people live in congregate settings, exposing them to a higher risk of transmission (Daly 2020; Dickinson et al. 2020). Disabled people who rely on home care provided by support workers and personal assistants have also been considered at risk, as many workers visit large numbers of disabled people regularly (Glynn et al. 2020). Undoubtedly because of these complexities, governments around the world were slow to react and respond to the needs of disabled people during the early pandemic (Pearson et al. 2022; Jalali et al. 2020; Kavanagh et al. 2020; International Disability Alliance 2021; Shakespeare et al. 2021).

At the national level, the health emergency has required urgent regulations to protect the health of the population and, at the same time, address the economic and social problems that accompanied (and in some way derived from) the lockdown. All initiatives aimed to combat the virus spread, as well as interventions to support work, the economy and social policies.

The COVID-19 syndemic experience was an exogenous shock that struck the social–health infrastructure with greater pressure at the local level and that exacerbated the urgency to find innovative solutions to support the autonomy, integration and assistance of people with chronic pathologies and disabilities in Italy (CNEL 2021). Specifically, the fragility of protective measures for chronic conditions, for the elderly population, for disabled people and for their families was exposed forcefully. During the syndemic, these populations were often abandoned in residences -and in their own homes- often as a result of dedicated service closures without flexible or adequate alternatives and with an often unsustainable burden of care for families (Mladenov 2015; Mladenov and Brennan 2021).

The paper positions itself within the international debate by proposing a strategy to support the wellbeing of disabled people and their families by introducing, starting with a multi-year experimentation, a professional figure who would function as a mediator between local social services and families of disabled people. The disability case manager (DCM) can be a resource to deal with the serious situation exacerbated by the COVID-19 syndemic. By first offering activities and interventions available in the territory, the DMC proposes to overcome the traditional boundaries among services and to valorise the individual professional figures already operating in local realities to favour accessibility, coordination, family assistance, school integration, work inclusion, tourism, etc. The case study raises significant questions concerning the role of new professional figures able to systemise the tacit knowledge of families and of people with disabilities themselves concerning the co-production of services and the territorial animation necessary to activate community resources, as well as the knowledge and skills needed to improve the quality of life of people with disabilities and their families.

The article first discusses the experimentation of introducing a DCM to the local context, starting from an interesting drive for innovation exercised by a banking foundation that promoted a participatory process with public and private stakeholders. The second part delves into the salient characteristics of the DCM profile in relation to the needs that emerged from listening to the stakeholders of the territory, particularly care workers and disabled people and their families. In the last part, the experimentation is presented as a possible innovation path towards improving the quality of life and well-being of disabled people. From the case study, we recommend some key interventions for the urgent support of disabled people and their families, both during and after the syndemic crisis.

2. Case study: the "Today is Tomorrow" experimental project

The overall project started at the end of 2015 when, in the face of the voiced needs of the territory, the theme 'After Us' was incorporated into the strategic plan of the MPS Foundation. It should be emphasised that the project was borne in a highly particular context in a circumscribed territory, the province of Siena, which for decades was accustomed to benefiting from substantial economic disbursements used to support a wide range of social services and which suddenly found itself deprived of these substantial resources that guaranteed widespread well-being and support for the start-up of new projects. The illusory belief of being able to obtain seemingly unlimited economic resources 'at the counter' had, moreover, contributed to consolidating a tendency to concentrate efforts on social and welfare services, effectively compressing intangible investments in social and relational capital and discouraging innovation and participation in supra-regional competitive funding programmes. In this scenario, following the end of easy disbursements (and above all to public bodies in the Sienese territory, as well as to the third sector for institutional activities and investments in varied sectors), many opportunities and even some consolidated services were closed, collapsing the expectations of families and individuals who for years were able to benefit from high-quality interventions and services. Today, individual risk, thanks to the profound systemic crisis we are experiencing, is overwhelming services, which are faced with increasingly complex needs and a substantial absence in the territory (except for a few "happy islands") of sustainable solutions and territorial infrastructure for during and after us.

The MPS Foundation's impulse to initiate participatory reflection on this issue and to explore possible lines of action has been raised in a scenario that, from a certain viewpoint, is entirely new. That is, with public services that are unaccustomed to working in a network, with third-sector organisations that are increasingly fragmented and tried by the economic crisis first and the syndemic crisis now (Scalvini 2020; Borzaga 2020) and with people with disabilities and their families who are increasingly angry or discouraged. Those that participated in the working group include ASL Toscana Sud-Est, which responds to the health and social needs of 841,208 citizens with its local socio-sanitary articulations; the Laboratory on Inequalities of the University of Siena; and a second-level foundation that gathers all the associations of disabled people in the area.

The working table, coordinated by an MPS Foundation official and a senior researcher from the University of Siena, characterised by a variable geometry in terms of the functions present at the meetings, was dedicated to a preliminary phase of analysis, purposed also to activate the relational dynamics and build a (albeit embryonic) group identity. First, a mapping of services and associations operating in the area of disability and the main initiatives conducted or in progress was carried out. The mapping gave a

picture of a rather uneven geographical distribution, with a strong concentration in the city of Siena and a progressive rarefaction in the rest of the provincial territory. The working group then carried out a survey of the good practices promoted outside the provincial territory, concentrating on activities and projects aimed at experimenting with experiences of residential autonomy using alternative solutions to institutionalisation, characterised by assistance levels of varying intensity and a tendency to be aimed at users in the light-medium range of disability. Concerning the national context, the main operations of the Foundations of Banking Origin have been reconstructed; therefore, the investigation was extended to some other important experiences identified through an open web search. The outcome of this first phase was the mapping of about 50 relevant experiences, later reduced to 12 projects, which were then examined in depth through telephone interviews or individual meetings, aimed at bringing out the most characteristic elements. This long and articulate preliminary phase of analysis created a shared awareness of the priorities for intervention within the working group, which have been implemented by a Memorandum of Understanding signed in late 2016 by the institutions and organisations involved; this agreement sanctioned the will to proceed towards common planning using the guidelines outlined.

Based on the evidence gathered in the analysis phase, the initiation to formulate a project was commenced at the beginning of 2017, at the end of which an intervention programme was created called 'Today is Tomorrow: During/after us in the Land of Siena'. This programme spread across the district areas of the provincial territory and focused on three specific objectives (referring to differentiated targets) that are still operational today:

(1) To increase the level of capability of families with disabilities to create family environments that are ready to support pathways to independence;

(2) To raise the skillset of professionals involved in various capacities of pathways to autonomy;

(3) To increase opportunities for the social lives of young people with disabilities, with specific attention to the transition from school age to adulthood.

In relation to these objectives, the following actions have been planned:

(a) A course of capacitation for families with disabled people, including young children (targeting 0–14 years), was activated through the establishment of four experimental groups led by a multidisciplinary team composed of psychologists and social workers of territorial services who have previous ad-hoc training.

(b) Three co-planning workshops were activated in collaboration with local services and third-sector entities (identified through appropriate notices) of interventions aimed at encouraging and accompanying the transition from school age to adulthood (so-called, After Us-School) in the three district areas.

(c) A training course was designed for volunteers and professionals (from voluntary organisations, social cooperatives, social services or civil society) involved or interested in acquiring skills that can be used in projects for the promotion of autonomy and independent living.

The interventions were incorporated into an implementation agreement between the partners involved (which also governed the related economic commitments), and they were started in January 2018 to last three years, thanks to a total funding of € 300,000.00 by the MPS Foundation.

The last of the experimental action points identified by the project group is at the heart of our analysis. The identification of a new professional profile is not extemporaneous but strongly rooted in the reality and needs of disabled people. The DCM

was in fact borne of the work of co-designing and co-producing services with the families of disabled people and with disabled people themselves, and it has undergone a significant acceleration following the advent of the COVID crisis.

3. The disability case manager and building responsible welfare in the syndemic era

The project evaluated the urgency of establishing training and a capacity-building path addressed to the various operators of autonomy in the area to promote and consolidate new knowledge, skills and attitudes to respond to the old and new needs of people with disabilities and their families from a promotional and activated perspective. In fact, the university, through the Laboratory on Inequalities (LSD), took on this initiative.

A 'professional refresher training' course was designed for volunteers and professional operators (from voluntary organisations, social cooperatives, social services or civil society) involved or interested in acquiring skills that can be used in projects for the promotion of autonomy and independent living. The course for 'DCM' (https://www.unisi.it/corso-disability-case-manager), starting from the assessment of the needs of people with disabilities, has provided participants with the knowledge and cultural tools to activate networking and work plans for people with disabilities. The ICF classification and the person-centred bio-psycho-social model represent the theoretical and conceptual basis on which the work of the new professional is centred. In the training course, which ended in June 2021, skills equivalent to an advanced course on ICF and related tools were provided, which are now essential for those working in public and private social institutions. The disability manager, starting from the range of activities and interventions available in the area, aims to overcome the traditional boundaries between services and to enhance the individual skills that already work in local realities to promote accessibility, coordination, family assistance, school integration, job inclusion, tourism, etc. The course is designed to provide participants with the tools to achieve a unified and coordinated vision of the skills needed to improve the quality of life of people with disabilities and the effectiveness of policies to ensure the participation of all people, with or without disabilities.

The experience proposed by the LSD in collaboration with the hybrid network created by the project "Today is Tomorrow", financed by the MPS Foundation, leads to significant questions regarding the new professional role, capable of putting into a system the tacit knowledge of people with disabilities and their families, as well as the set of knowledge and skills necessary to improve the quality of life of people with disabilities and their families.

To address the urgency linked to the advent of the COVID-19 syndemic and, particularly, the difficulty of responding adequately to the needs of persons with disabilities and their families, the MPS Foundation decided to include in its 2021 plan the possibility of launching a new networking project to promote the autonomy of persons with disabilities.

Alongside the efforts of the local network of public and private services, the investment of the MPS Foundation is positioned as a longer-term continuation of what has been given in the recent past, in favour of local welfare and with a certain propensity for investment sustainability. For this reason, in February 2021, the working table for project development was once again convened, with a view towards the co-production of local welfare services, to examine together the needs of the territory and opportunities for

development. From this first phase -including six meetings, three of which were focus groups- emerged the need to work on two thematic axes: the first dedicated to residential housing and the second to system solutions that insist on more intangible areas (e.g. awareness of families and the time of transition from school to adulthood). Therefore, at the end of July 2021, a meeting was held to return the work done by two social workers from the area, identified as spokespersons for the two working groups.

Among the results of this first phase of participatory planning, which at times was challenged to overcome the conflict between knowledge and the need to recompose a unified view that considers the original perspective of people with disabilities and their families, as well as the vision of the so-called "world of services", both public and private (Bilotti and Genova, 2021), it is worth noting the group that worked on the delicate moment of leaving the school world and entering the world of work, which for many means a difficult transition and for many others means facing the impact of the responsibilities of adult life, as well as the social stigma and the fragility of the caregiving system.

Uniting the main criticalities highlighted (inadequacy of taking on responsibility and lack of an overall vision capable of creating connections and enhancing latent resources) with the strengths, the working group has adopted an experimental approach oriented towards community management. The basic idea is to create a territorial task force articulated on two levels:

(1) A macro level of political–institutional coordination with adequate professionalism and seniority, to legitimise interlocutions at the top institutional and administrative levels;

(2) A more operational level with 2/3 junior profiles with the necessary skills and attitudes that would ensure work in the field, to be identified from the pool of graduates from the University of Siena's course for DCMs.

In terms of project development, once the senior coordinating resource has been identified, it would only be a matter of instituting an action plan over a three-year period, with the precise declination of objective and measurable expected results. A prerequisite for this approach must be an inter-institutional pact among the various systems involved (schools, services, productive sector, third sector) to obtain prior legitimacy in the territory. At the same time, thanks to the public–private co-design process underway, there should be a continuous improvement of the existing structures for taking care at the social-health level.

The creation of pathways linked to community management is particularly interesting. It seems to respond coherently to the urgency of proposing concrete practices to the suffering that has particularly interrupted the autonomy and inclusion of children and young people with disabilities, due mainly, but not exclusively, to the closure of schools and use of distance learning methods. Moreover, provisions to enhance the profiles of disability managers newly trained in the field means further investing in sustainable solutions that recirculate the local energies and resources in favor of the disabled people of the territory.

4. Outcomes from the case study: a possible innovation

In recent years, social and health policies protecting the rights of persons with disabilities have promoted the principles of autonomy, self-determination, personalisation, dignity and quality of life, despite a generalised climate of public spending cuts. As international studies have demonstrated, the response to the COVID-19 syndemic has led

to a sudden and more acute wave of cuts in services, overshadowing the needs of disabled people and even limiting their essential rights to focus all attention on health (Gulati 2021; Glasby and Needham 2020). As Shakespeare and colleagues conceptualised, disabled people faced a 'triple jeopardy' of higher risk from death, reduced accessibility to health and social care services and the additional impact of social barriers during the pandemic (2021). Furthermore, COVID-19 highlighted and amplified the existing fragilities in social and health care for disabled people, generating an impact on both those who received and those who provided care. The gap between the individual and collective needs of disabled people and their families on the one hand and the provision of services on the other is well documented by international studies (Flynn and Hatton 2021; Pearson et al. 2022; Shakespeare et al. 2021).

From the experience observed in the case study presented here, the DCM is a candidate for bridging this gap in the syndemic era. Indeed, some emblematic elements emerge that may be useful to achieve high standards for autonomy and independent living among persons with disabilities.

A first significant element concerns the very process of responding to the individual and collective needs of the actors involved. Activating public–private processes of co-design and the co-design of services oriented to the identification of the social needs of persons with disabilities and their families means making -at least in the national context- a concrete proposal of social innovation (Cajaiba and Santana 2014; Mingione and Vicari Haddock 2015; Cesareo 2017). The alliance between associations with a strong presence of parents of disabled people and the public sector likely represents a new relational paradigm in Italy based on cooperation and the convergence of basic objectives. The value generated by this renewed relationship between the public and private sectors should not be taken for granted. To grasp and exploit fully this new alliance of knowledge, it has been necessary to build a meeting space between the two worlds, close in mission, goals and desires, but often quite distant in practices and languages (Bilotti and Genova, 2021). The foundations of banking origin and, above all, universities can play an important role as bridge-builders between these two worlds, both through the promotion and management of similar projects and through using co-design as a method to negotiate new spaces of intervention, but also through specific training measures.

The second element of interest concerns the professional profile of the figure identified in the co-design process, whose actions ensure to equal respect for all citizens based on human dignity (Nussbaum, 2006). It refers to the well-known socio-relational model oriented towards finding strategies and methodologies to contribute to the full development of personal autonomy and the activation of the right to self-determination enshrined in the UN Convention on the Rights of Persons with Disabilities (2006). The disability manager, in this case, is capable of being a transmission belt, a mediator, between the complex system of public and private services (and/or of the private social sector) and the person with disabilities and their family. They know how to welcome and read the experiential experiences of people who are faced with life problems together with other subjects, including social workers, psychologists and other professionals involved in taking charge and supporting the processes of defining and implementing the life projects of disabled people through the most effective relational strategies. The DCM knows how to move within the theoretical framework centred on capabilities to find concrete strategies and tools of individual and collective co-responsibility to support persons with disabilities in realising specific objectives related to their desires and expectations. If we consider that too often public services have difficulty identifying and then applying tailor-made, non-

standardised tools, designed based on the person and not from the resources available for the implementation of interventions and services, it is easy to imagine how complex the work of DCMs can be.

The third element concerns the effectiveness and impact of introducing a DCM at the local level. It concerns the concrete possibility of applying a community welfare model (Allegri, 2017) that struggles to find concreteness, at least in the Italian context. As we have observed, DCMs have been involved in the promotion of concrete actions related to the development of the freedoms of individuals and local communities (Nussbaum, 2006, 2009; Sen, 1994). The DCMs worked to reactivate the sometimes-dormant resources of the territory through participatory processes, and they worked to arrive at a convergence of viewpoints (of parents and professionals) to achieve a shared responsibility for boys and girls with disabilities in the implementation of the personalised project and the "life project", in accordance with Law 112/2016 "Provisions on assistance in favour of persons with severe disabilities deprived of family support".

In the face of such "strengths", we cannot overlook possible "weaknesses" that need further development through participatory impact assessments. Among them, we would like to clarify the complexity linked to the heterogeneous composition of the working table. By core of territorial social services and representatives of families and disabled people was then joined by third-sector subjects and university participation. The risk is that the increase in complexity does not make the process more efficient and effective. In the experience recounted, the close connection between territorial services and the third sector (strongly emphasised during the planning phase and maintained during the planning and implementation of activities) increased complexity and the consequent expenditure of energy for the necessary alignments in terms of procedures, communication registers, negotiation of a new vocabulary, etc. In the short term, the DCM will be able to make a difference if supported by institutional pacts that involve sharing responsibility for the co-designed processes and if there is real involvement of disabled people and their families.

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