Health is Wealth and Documents are the Currency

Exploring the Role of NGOs in Facilitating Healthcare Access for Undocumented Migrants in the Netherlands

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Abstract

Undocumented migrants (UMs) in the Netherlands face significant barriers to accessing healthcare despite legal entitlements to 'necessary medical care.' Non-governmental organisations (NGOs) play a critical role in facilitating healthcare access for UMs, yet empirical research on their specific contributions remains limited. This study aims to explore how NGOs perceive their role in facilitating healthcare access for UMs in the Netherlands and how these perceptions align with their actual practices. The research employs a qualitative exploratory design, conducting twelve semi-structured interviews with professionals from various NGOs supporting UMs. Thematic analysis was used to identify key roles and strategies employed by these organisations. The data revealed four main roles: 1) mediating, 2) educating, 3) advocating, and 4) delivering services. The findings suggest that while Dutch NGOs appear to share a common goal of facilitating healthcare access for UMs within the existing Dutch healthcare system, some of their strategies happen outside of the regular system, thereby creating a parallel system. Consequently, there seems to be a discrepancy between how NGOs perceive themselves (i.e., the role they *think* they should take) and the role they play in practice. The Dutch NGOs in this study face a humanitarian-equity dilemma, where limited resources and high pressure from UMs' immediate needs, lead them to prioritize direct assistance over addressing systemic issues. Consequently, many NGO strategies offer temporary solutions that help individual cases but fail to sustainably integrate UMs into the regular healthcare system. To increase lasting change, NGOs should focus more on educational and advocacy roles and collaborate to reduce costs and enhance effectiveness. This strategic shift is essential for creating sustainable solutions that ensure UMs are included in the regular healthcare system and uphold the principles of equity and justice.

Keywords: Undocumented migrants, Nongovernmental Organisations (NGOs), healthcare access, Netherlands

Introduction

According to the latest estimation, the range of undocumented migrants (UMs) residing in the Netherlands during the period from mid-2017 to mid-2018 was between 23,000 and 58,000 (Heijden et al., 2020). Researchers expect the number of UMs to be much higher, however, precise estimations are challenging due to the inherent invisibility of this group to institutions, due to their undocumented status (Ombudsman Metropool Amsterdam, 2021). Since the early 1990s, the Dutch government has taken more restrictive measures to control migration. In 1998, the Linking Act (Koppelingswet) came into practice to discourage illegal residency in the Netherlands by linking the legal status of a migrant to the benefits of the welfare state, thereby excluding UMs from many public services like the national healthcare insurance system. In the Netherlands, having health insurance is mandatory to access healthcare services. While individuals without insurance can still register with a general practitioner, they must pay for the care themselves, which is especially challenging for many undocumented and uninsured individuals (Goorts & Smal, 2022).

However, there is an exception to the Linking Act, that allows UMs to access "necessary medical care", which includes all services covered under basic health insurance. This exception is due to the European Convention on Human Rights, which obliges member states like the Netherlands to uphold various fundamental rights, including the right to "medical care and necessary social service" (United Nations, 1948). Since 2009, healthcare providers can claim reimbursement, through the CAK, for medical costs incurred from treating "uninsurable" patients and those unable to pay, often including UMs (Hintjens et al., 2020; Karl-Trummer et al., 2010). This reimbursement arrangement ensures that undocumented and uninsured individuals do not have to bear the costs of care if they can demonstrate their inability to pay.

Consequently, under this exception in the Linking Act and the reimbursement arrangement, UMs are legally entitled to access healthcare services without incurring any costs themselves. However, a crucial consideration is that even if entitlements are established, it does not guarantee access in practice. Estimations are that almost one-third (29%) of UMs in the Netherlands, did not receive the necessary medical care to which they were entitled (Biswas et al., 2012). Moreover, many UMs exclude themselves from healthcare services due to shame, lack of information, or fear of being deported (Hintjens et al., 2020; Schoevers et al., 2010). Across Europe, many of the same barriers impact access to healthcare services for UMs: legislative, financial, and administrative hurdles; absence of interpretation and cultural mediation services; unreliable information regarding the health conditions and histories of migrant patients; limited awareness of entitlements and accessible services; and inadequate organisation and coordination among healthcare services (Chiarenza et al., 2019; Priebe et al., 2011; Van Ginneken, 2014). Thus, even though the state of the Netherlands has ensured legal entitlements for UMs to access healthcare services, the health needs of UMs are unmet due to the many barriers in practice.

In many European countries, nongovernmental organisations (NGOs; i.e., self-governing and not-for-profit entities geared towards improving the quality of life for disadvantaged individuals, that are often philanthropic and humanitarian in nature; (Anheier & Daly, 2006; Vakil, 1997)) have emerged to help UMs overcome these barriers and fill gaps in healthcare provision by the state. They function as “right intermediaries”, offering guidance and practical support in accessing healthcare services (Bruzelius, 2020, p.601-604). Some organisations also provide medical services themselves (Ambrosini, 2015; Ambrosini & Van der Leun, 2015). In one way or another NGOs have had a longstanding role in welfare systems, however, in recent debates the role of NGOs as welfare service providers has been contested. A concern is that portraying NGOs as solutions to welfare provision problems might obscure the issues linked to their involvement in this provision (Piccoli & Perna, 2024). They risk creating parallel and potentially inequitable healthcare structures, thereby legitimizing the state's retreat from its welfare responsibilities and other unintended consequences may occur when NGOs serve as welfare service providers alongside the state (Gottlieb et al., 2012; Piccoli & Perna, 2024).

Limited access to healthcare for UMs is a cause for concern. UMs should be regarded as a vulnerable group compared to the general population due to their lack of legal residence status and precarious living conditions (Kvamme & Ytrehus, 2015). Their poor quality of life increases their susceptibility to health problems, exacerbated by barriers to healthcare access (De Vito et al., 2016; Myhrvold & Småstuen, 2019). Consequently, UMs tend to disregard minor health issues, potentially resulting in more severe complications (Kvamme & Ytrehus, 2015). Ensuring healthcare access for these migrants is essential for community health and prevention efforts. Untreated health issues can increase marginalization, hinder integration, and exacerbate illnesses, whereas healthy migrants are better equipped to integrate and contribute to society (Norredam, 2011). Additionally, considering the lack of visibility of UMs and their resultant heightened vulnerability (Ombudsman Metropool Amsterdam, 2021), this study aims to raise awareness of the precarious living situations of UMs and of the efforts of NGOs to improve these situations.

This study contributes to the debate on NGOs' role as welfare service providers by investigating their role in facilitating access to healthcare services for UMs in the Netherlands. Despite the recognition that NGOs frequently fill gaps left by the state's reluctance or inability to provide welfare services, there has been limited empirical study on the specific types of services these NGOs offer to immigrants ineligible for (certain) state-funded services, and how they deliver these services across various settings (Ambrosini & Van der Leun, 2015). Previous studies in the Netherlands have addressed the health status and barriers to healthcare utilization among UMs, mainly focusing on the formal healthcare system (Biswas et al., 2012; Hintjens et al., 2020; Schoevers et al., 2010). However, there is a notable gap in understanding the informal mechanisms through which UMs access healthcare services facilitated by NGOs. This study aims to fill this gap by exploring the roles and services provided by NGOs in the Netherlands, providing insights into the role NGOs play in the welfare landscape.

Background

The Dutch government introduced the Linking Act in 1998 to exclude UMs from the labour market and welfare facilities (Kos et al., 2016). Despite being a national-level law, there is no corresponding national-level strategy for its implementation. The Netherlands has a long history of being a unitary yet decentralized state, however, the decentralization of policymaking has accelerated in the last decade (Groenleer & Hendriks, 2020). Dutch municipalities now bear the primary responsibility for critical sectors such as housing, healthcare, and social services. However, this increased policy responsibility is coupled with, on average, reduced national funding and limited ability for municipalities to raise taxes (Groenleer & Hendriks, 2020). The rationale for decentralization has been accompanied by the introduction of the *participation society*, aimed at bringing policy closer to the people and justifying budget cuts. This approach posits that municipalities, with their intimate knowledge of local conditions and collaboration with civil society, can deliver services more efficiently and affordably (Hoekman et al., 2018). Despite this justification, many municipalities have approached these significant decentralizations with apprehension and most municipalities are still grappling with its implications (Groenleer & Hendriks, 2020).

As local governments now bear not only responsibility for the well-being of their local populace but also for UMs, they often work together with NGOs and faith-based organisations, a so-called "shadow-network", to provide services for UMs (Pluymen, 2008, p.314). Thus, in this space of splintered responsibility for the distribution of public goods, NGOs have sought to support municipalities to "fill service gaps left vacant by the rollback of welfare provisions" (Siruno, 2021; Woolford & Curran, 2013, p.45). With success, UMs who are socially embedded in support networks or NGOs are more likely to claim their health rights in practice (Hintjens et al., 2020). Considering this complex shadow network of service provision for UMs in the Netherlands and the debate brought forth by literature discussing the risks of NGOs serving as welfare service providers alongside the state, this qualitative study was designed to empirically investigate the role of NGOs in an intricate healthcare system and the governance of irregular migration.

Theoretical Framework

To explore the role of NGOs in helping UMs exercise their right to health and access healthcare services, it is essential to understand the broader role of NGOs in Dutch civil society. Additionally, evidence indicates that legal guarantees of healthcare access do not ensure equal access across populations, necessitating a clear understanding of what "access" to healthcare entails (Mudd et al., 2022).

NGOs in Dutch Civil Society

Civil society encompasses a web of organisations, collectives, and informal activities that operate besides the state and the market. It represents the domain of voluntary private initiatives and active civic participation (Foley & Edwards, 1996). NGOs within civil society are considered "the embodiment of certain values that are crucial to democracy and good government" (Smith & Grønbjerg, 2006, p.229). Similarly, Berger & Neuhaus (1996) explain that NGOs serve as crucial mediating institutions between the government and its citizens, to protect individual freedom and enhance community accountability for addressing social issues. Alternatively, Weisbrod (1988) emphasizes a different role for NGOs, arguing that they primarily emerge to fill the gaps of unmet needs, particularly for minorities or marginalized groups within society.

The history of the non-profit sector and civil society in the Netherlands is extensive and one of the crucial points for understanding the role of NGOs in Dutch society is the process of pillarization in the 20th century, which refers to the vertical segregation of different population groups and the educational, healthcare, and social agencies serving them, based on religious or political affiliations (Burger et al., 2001). One of the important consequences of the pillarization has been the collective financing of private agencies, starting with state support for denominational schools and expanding to other services. Consequently, private nonprofit organisations deliver many services in education, healthcare, and welfare, funded by taxes, compulsory insurance, and other collective means (Burger & Veldheer, 2001). To date, the NGO sector plays a significant role in the delivery of public services (Brandsen & Pape, 2015).

In addition to service delivery, NGOs in the Netherlands fulfill a role more commonly associated with civil society. They function as membership and advocacy organisations, empowering citizens to respond to the state's retreat from its welfare obligations (Dekker, 2013). In this role, NGOs contribute to community building and the development of social capital (Habraken et al., 2013). Furthermore, similar to many welfare states, the decentralization of social service delivery coupled with significant budget reductions, has prompted local governments to explore alternative modes of service provision, increasingly turning to NGOs and other so-called third-sector organisations. This trend underscores the growing significance of NGOs in local governance (Reijnders et al., 2018).

Understanding Healthcare Access

Access to healthcare has been conceptualized in various ways. While “access” is most often used to denote the factors that influence the initial contact or utilization of services, opinions vary on which aspects should be considered part of access and whether the focus should prioritize describing provider characteristics or the care process itself (Frenk, 1992). Authors that focus on the care process consider access as a characteristic of health services, highlighting the ability of services to be accessed or utilized by those in need of care (Salkever, 1976).

While acknowledging the influence of user and provider characteristics on access, many authors place more emphasis on the role of healthcare resources’ characteristics that might influence the utilization of services (Levesque et al., 2013). However, one of the most extensively used access frameworks is Andersens’ behavioral model for health services utilization, which predicts that a sequence of predisposing, enabling, and need factors influence an individual’s utilization of healthcare services (Andersen, 1995).

Where Andersen focuses primarily on the behaviour of care seekers, Penchansky & Thomas' (1981) framework conceptualizes access in terms of the fit between patient needs and the capacity of the healthcare system to meet those. This model integrates both attributes of service providers and service users. Similarly, Mooney (1983) posits that access to healthcare depends on supply factors such as service location, availability, cost, and appropriateness, as well as demand factors like knowledge, attitudes, skills, and self-care practices.

These demand and supply side factors can also be understood as enablers or barriers to access. Identifying the potential barriers and enabling factors that influence access to services may prove useful for promoting healthcare access for UMs in the Netherlands and ultimately to better address their health needs (Appoh et al., 2020; Boateng et al., 2012). This is crucial because it is these barriers and enablers that determine access in practice.

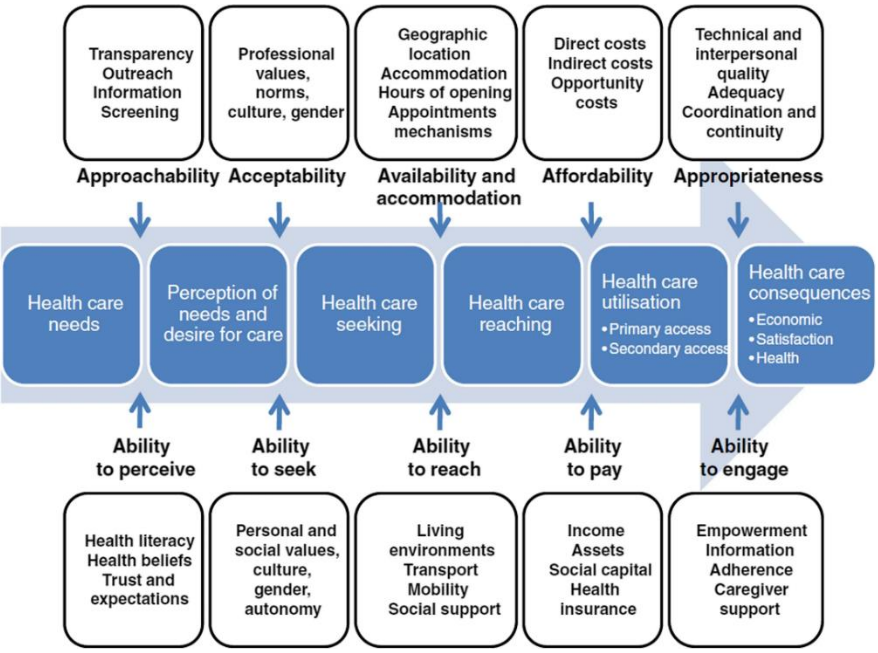
Given that migrant and ethnic minority populations often report poorer health compared to the majority host populations, considerable research has been devoted to examining the barriers to healthcare access (Nielsen & Krasnik, 2010). Several studies conducted in the Nordic welfare states have identified factors such as lower economic status, cultural differences, language proficiency, lack of education or knowledge of the system, and lack of culturally sensitive healthcare services as barriers to accessing healthcare among immigrant populations (Akhavan, 2012; Alzubaidi et al., 2015; Sandvik et al., 2012). An additional barrier arising from a lack of education and knowledge of the system is the difficulty migrants face in navigating the healthcare system (Grant et al., 2015). Related to linguistic and cultural barriers, many studies emphasize that a lack of interpreting services constitutes a significant barrier, often leading to suboptimal communication and consequently potentially inadequate care provision for immigrant populations (Bischoff & Denhaerynck, 2010; Chiarenza et al., 2019; Wollscheid et al., 2015).

Hacker et al. (2015) conducted a comprehensive literature review on the barriers to healthcare experienced by UMs specifically, further studies supporting the evidence of these barriers are available in their review. In addition to the barriers faced by documented migrants, UMs encounter challenges related to their undocumented status. Fear is a major barrier to healthcare access for UMs and includes fear of deportation, and stigma, and are often mentioned together with distrust in authorities (Hintjens et al., 2020; Marshall et al., 2005; Schoevers et al., 2010; Whyte et al., 2015). Another significant barrier unique to UMs is related to the reimbursement arrangements intended to enhance healthcare accessibility. In practice, these arrangements often increase administrative complexity, which has been demonstrated to hinder healthcare providers from delivering care (Goossens & Depoorter, 2011; Hacker et al., 2015).

Understanding “healthcare access” in relation to these barriers is crucial for identifying ways to improve it. While previous conceptualizations of access often focus on either the supply or demand side, Levesque et al. (2013) developed a multidimensional framework, illustrated in Figure 1, that allows researchers to look into barriers at the patient and health system level (Cu et al., 2021). The supply side includes dimensions such as approachability, acceptability, availability/accommodation, affordability, and appropriateness of the healthcare system. The demand side encompasses individuals' abilities to identify healthcare needs, seek services, to reach healthcare resources, obtain or use services, and receive care appropriate to their needs (Levesque et al., 2013). Considering the comprehensiveness of the framework in identifying potential barriers to access, it is valuable for understanding which of these barriers NGOs address to improve healthcare access for UMs.

Figure 1

Levesque conceptual framework for healthcare access



Note. From Levesque, J.-F., Harris, M. F., & Russell, G. (2013). Patient-centred access to healthcare: Conceptualising access at the interface of health systems and populations. *International Journal for Equity in Health*, *12*(1), 18.

Initially, this exploratory study was focused primarily on how NGOs perceived their role, yet data gathered already in the first interviews (discussed below) suggested the need to focus on how NGOs perceive their role as well as how these perceptions compare with what happens in practice. Therefore, the research question answered in this exploratory thesis is:

"*How do NGOs working with undocumented migrants in the Netherlands perceive their role in facilitating access to healthcare services, and how does this compare with their actual practices?*"

Methodology

Study Design

This study employs a qualitative research design to explore the role of NGOs in facilitating access to healthcare services for UMs, through semi-structured interviews with professionals working at Dutch NGOs working for and with UMs. With limited existing research on this topic, the study adopts an exploratory approach to gather insights into the perceptions and practices of these NGOs. Semi-structured interviews are chosen for their suitability in exploring complex social issues and to yield rich information on perceptions of NGOs on their role and practices (Matthews & Ross, 2010). This method allows flexibility for themes to emerge while maintaining the same structure across the interviews (Braun & Clarke, 2013).Given ethical considerations related to interviewing UMs directly, interviews were conducted exclusively with NGO professionals representing their organisations. This project was submitted for ethical approval and was waived by the Ethical Committee of Utrecht University.

Participant Sample and Recruitment

The final sample consists of 12 semi-structured interviews with 11 different NGOs. Participants held roles such as social workers, lobby specialists, and volunteers. Foundation LOS, a national organisation facilitating exchange and collaboration among NGOs supporting UMs, maintains a list of these NGOs on their website, which served as the initial source for potential participants in this study. Additionally, *De Sociale Kaart*, a website listing organisation assisting homeless and undocumented individuals, was also consulted for potential participants. By reviewing their websites, only NGOs explicitly mentioning they addressed healthcare access for UMs were selected for inclusion in the study.

After identifying suitable organisations, purposive sampling ensured a diverse group from various parts of the Netherlands. All NGOs were contacted via email and asked to distribute an information letter about the study, including the request for their members to volunteer, thus relying on the organisation to facilitate this communication. When a personal email address was available on the NGO’s website, it was utilized instead of the general email address, aiming to enhance response rate (Ritchie & Lewis, 2003). Moreover, snowball sampling was used, utilising the network of already participating NGOs (Braun & Clarke, 2013).

The initial recruitment response rate from purposive sampling was 47% (8/17). Two NGOs declined due to capacity issues, six provided no explanation and one responded after the recruitment phase of the research had been passed. Additionally, three organisations were recruited through snowball sampling. While the small sample in this study might be a limitation, this can be mitigated if rigorous purposive sampling has taken place that ensures a diverse group of participants (Ritchie & Lewis, 2003). In the case of this study, the sample includes a variety of organisations differing in size and scope, encompassing both regional and nationally active NGOs from various locations across the Netherlands.

Data collection

Five face-to-face and seven Microsoft Teams interviews were conducted, averaging 40 to 60 minutes each. Based on a preliminary theoretical framework and literature, a semi-structured interview guideline was developed, initially focusing on the activities, strategies, and operational challenges encountered by NGOs. Activities and strategies are understood as all actions undertaken by NGOs to facilitate access. For instance, participants were asked: "What does the organisation do to help overcome the barriers to accessing healthcare? Could you provide examples?". Additional questions regarding collaboration with other NGOs and stakeholders within the healthcare system, including local governments and healthcare professionals, were incorporated after the first interview. For instance: "To what extent do you collaborate with other NGOs? Or other civil society organisations? Do you collaborate with the government? What does that collaboration look like? Could you provide an example?" (See Appendix A for the full interview guide).

The breadth and depth of responses varied depending on participants' roles, experiences, and expertise. Interviews continued until no additional information was provided, indicating that theoretical saturation was achieved (Guest et al., 2006). Interviews were audio-recorded and transcribed verbatim using GoodTape software, and personal identifiers were removed during pseudonymisation.

Data Analysis

Thematic analysis was chosen for its ability to systematically identify and interpret patterns within qualitative data suitable for this exploratory research (Matthews & Ross, 2010). This approach, which focuses on identifying and describing themes across the dataset, was preferred over other possible approaches, like grounded theory, as the goal was to gain a comprehensive understanding of participants' views rather than to develop new theories grounded in the data.

The first phase consisted of familiarisation with the data. Some expected categories, regarding for example barriers experienced by UMs, were based on themes derived from the theoretical framework and literature that also informed the interview guide. During the second phase, a number of themes worthy of further exploration were identified. For instance, all interviewees talked about building a parallel system, however, they did so in distinct ways in relation to their views on the role of NGOs. Other key themes were related to the activities and strategies NGOs used and collaboration. These initial themes were further explored by defining and progressively updating sub-themes, and interpreting the data contained within each sub-theme. Lastly, key themes were inductively refined by going back to the raw data and finalizing overarching themes. Coding and analysis were performed with NVivo. Table 1 presents examples of how data excerpts were assigned specific codes and the overarching themes into which they were inductively categorized. The full codebook can be found in Appendix B.

Table 1: Coding Process: Excerpts, Codes, and Emerging Themes

Data excerpts	Codes	Themes
"And therein [week], workshops are offered that also improve their access to healthcare. So, there are six different workshops, of which one is specifically focused on how to access healthcare. These workshops provide practical tips on this topic." (p.04) "And we also provide information through educational sessions (voorlichting). So once a month, we have a themed evening." (p.11)	Goal of work to improve agency Course to improve knowledge on rights	Education Role
"But the knowledge does trickle down. Even among general practitioners, through practices. Of course, more and more doctors are collaborating within practices, which also makes a difference. They also know how to reach out to us; if someone doesn't know something, they call or email us regularly." (p.10) “When we say someone has no income, they truly have no income. I believe we have achieved that over time.” (p.05)	Brand awareness (naamsbekendheid) NGO believed by authorities	Status

Positionality

My interest in this study stems from my public health background and my belief that the right to health is fundamental and should be protected. This intrinsic motivation brought me to do this research but my personal views on this topic inevitably shape this research process. One potential bias could be my personal critical opinion on how the Dutch government deals with the right to health for UMs, as I believe more should be done to protect UMs' rights. This perspective might align closely with the views of the NGOs participating in this study, leading to a risk of biased interpretation favoring these organisations when they criticize the government's role in this issue. Moreover, NGOs were also critical of each other's work in the interviews, and this could influence my perceptions of NGOs I would interview later in the process. To mitigate these biases, I have employed several strategies throughout the research process. During the interview process, I followed the interview guide and focused on keeping my responses neutral to their answers, to ensure that participants' views were their own and to avoid my views influencing the responses of participants. For the data analysis, the findings and interpretation of the findings were verified as much as possible with other sources of data.

Results

Dutch NGOs appear to share a common goal of facilitating healthcare access for UMs living in the Netherlands. Generally, the preference is to do this by facilitating 'regular' access, that is, access within the existing Dutch healthcare system, as this respondent noted:

> *"Of course, it is always preferable for someone to be part of the regular system. For someone to have a general practitioner in the neighborhood where they live. Where they can build a kind of trust relationship. Where they don't have to explain everything about their legal situation every time. And where a general practitioner thinks along with them or refers them when necessary." (p.01)*

However, acknowledging the shortcomings of the Dutch system, several respondents also mention strategies for facilitating healthcare for UMs that happens outside of the regular system, thereby creating a parallel system. This was viewed as unsustainable in the long term. Consequently, there seems to be a discrepancy between how NGOs perceive themselves (i.e., the role they *think* they should take) and the role they play in practice. Four different roles emerged through the interviews: 1) the mediating role; 2) the educating role; 3) the advocacy role; and 4) the service delivery role. Note that while this section analytically distinguishes four separate roles, in reality, these categories are less neat and overlap.

The Mediating Role

The first prominent role identified is the role of NGOs in mediating between UMs and relevant organisations or individuals to facilitate healthcare access. Interviewees highlighted the networking strength of NGOs through various activities. These include referring UMs to GPs they know are open to working with UMs, facilitating conversations with less willing GPs, and connecting with other NGOs to exchange knowledge on best practices. Additionally, NGOs assist UMs in securing funding for more complex and expensive care. Below is a quote that illustrates that NGOs play an important role in mediating communication between care professionals and UMs:

> *"We often spend the whole day working on clarifying things for our own clients. Clients often don't understand that they have been referred. So, we frequently have to talk with all those general practitioners to figure out what was actually said." (p.02)*

NGOs' mediation role addresses the primary concern highlighted by all participants: the difficulty in finding healthcare providers willing to manage the additional administrative challenges of treating UMs. To fulfill this role, NGOs rely on a network of care professionals willing to assist UMs. This strategy is crucial for integrating UMs into the regular healthcare system. This can involve formal collaborations, such as the networks of dentists in Amsterdam and The Hague who volunteer their services. A less formal strategy involves maintaining strong relationships with local GPs and NGOs emphasize the importance of sustaining these relationships, noting that having GPs or retired GPs as staff enhances communication with other healthcare providers about UMs' needs. This participant's account illustrates the robust networking capabilities and sensitivity of NGOs in maintaining strong connections with care professionals who are willing to care for UMs:

> *"But a healthcare provider, like our dentist or optician, shouldn't have everyone from all over [city] sent their way. That would be too much for anyone. We're not a very large organisation, so we generally don't rely on them excessively. We also try not to send too many cases at once. Otherwise, you overwhelm them. If they're doing it for free, you have to be considerate". (p.03)*

It is important to note that this network and connection with care professionals extends both within and outside the regular health system. Some professionals assist UMs in their practices but do not officially register them as patients, thereby still excluding them from the regular health system.

The Educating Role

The educating role can be divided into education by NGOs directed at UMs or education and knowledge sharing with other organisations or healthcare professionals. The educational activities directed at UMs consist of; a WhatsApp helpdesk, informative websites and walk-in hours where people can ask questions or get guidance in navigating the Dutch healthcare system. Workshops and courses related to disease prevention were also mentioned. NGOs active in the same region mentioned collaborative efforts to educate undocumented women on sexual and reproductive health. Additionally, NGOs organize workshops to educate people on their rights and how to claim them. The effort underlying most educational activities is to empower UMs by equipping them with information to assert their rights effectively as illustrated by this quote:

> *"And then there is a ten-week course, with one of those days really focused on access to medical care. We also do a sort of role play, like if you're at a doctor's office and they say no, I'm not going to help you, you're not entitled to this. Then we really practice standing up for yourself." (p.04)*

Education activities targeting care professionals and other stakeholders aim to inform them about the rights of UMs and the potential roles they can play in supporting them. There are variations in the extent of focus and structure among NGOs in these efforts. One NGO provides structured education through accredited e-learning modules on care provision for UMs. In most cases, NGOs adopt less formalized approaches, like explaining the reimbursement arrangement to care professionals. This occurs when professionals either refuse to help UMs due to payment concerns or when they independently seek clarification from NGOs.

The Advocacy Role

In their advocacy role, NGOs aim to signal the issues faced by UMs in accessing healthcare, employing indirect strategies to inform public opinion and influence local and national policy on the topic. NGOs perceive advocacy as integral to their mission, as articulated by one participant: "*Our approach has always been both individual support and collective struggle to improve the lives of undocumented people." (p.05)*

Participants mentioned engagement in advocacy activities, but approaches varied among NGOs. These activities include publishing reports, organizing conferences, campaigning, and engaging in media outreach to raise awareness about pressing issues concerning UMs. Some NGOs also engage in lobbying efforts, such as sending complaints to the National Ombudsman. At the local level, some NGOs have regular meetings with the municipality to discuss issues and initiatives related to UMs' healthcare access.

NGOs vary in their experiences of lobbying effectiveness, for example, one participant expressed frustration over perceived ineffectiveness in lobbying, mentioning uncooperative municipal officials. An NGO working throughout the Netherlands mentions that local lobbying effectiveness depends on the specific context and "*sometimes municipalities are quite willing to set up various initiatives or designate their own subsidy funds specifically for access to care for this group. Because of this, we see that local lobbying can be very effective." (p.06.1)*

Service delivery Role

This role covers the direct provision of healthcare services by NGOs to UMs. One NGO operates its own GP practice and has mobile healthcare units that visit various cities. These services often involve collaboration with other NGOs at their facilities. It is important to note that distinctions between NGO volunteers and staff working in public health services are blurred. In many cases, the doctors at NGOs are volunteers who devote part of their time to NGOs or are retired doctors and GPs. The distinction between this approach and that used in the mediating role lies in the fact that in this case, healthcare is delivered outside of the regular care system.

Some NGOs opt to not provide direct care but instead refer UMs to other NGOs that do. They emphasize the ease of access for minor health issues but express concerns about the quality of care for more serious health issues compared to the regular healthcare system. Additionally, they mention that these service NGOs face high demand and are frequently overwhelmed with activity. It is important to note that for most NGOs this is the workstream they prioritize the least and some even explicitly avoid it due to concerns about perpetuating a parallel healthcare system for UMs. An NGO that is against this mentions that by providing care *“you end up only taking care of the people who come to you, and you shouldn't want to build a parallel system to relieve the other system”. (p.07)*

Factors influencing the role of NGOs

The findings suggest NGOs experience multiple barriers and enablers to fulfilling these roles as mediators, educators, advocates, and service providers. A recurring theme in the interviews was the lack of resources, including time, money, and (volunteer) staff, which hindered NGOs from taking on certain roles. Due to these constraints, NGOs prioritize direct assistance to UMs. NGOs experience the needs of UMs as overwhelming and immediate, leading them to opt for direct assistance through education and services over indirect methods such as lobbying or campaigning. Additionally, justification of how resources are used towards funders and donors plays a role in what NGOs can do:

> *“I once suggested to a fund that [...] there should be something to help professionals easily understand all the rights. She responded, 'You don't need to educate professionals, do you?' So, it's harder to get support for that than if you say, 'I am literally helping someone.'” (p.08)*

Secondly, collaboration came forward as an important enabler for the four roles. NGOs highlighted the importance of working with various actors within the health system, including other NGOs within their region, but also to collaborate across regions to share successful strategies and address common challenges. Collaboration also enables smaller NGOs to take on roles they would otherwise be unable to take. The larger organisations, often with more resources, support smaller NGOs by assisting in the development and maintenance of their programs. This was also noted regarding the advocacy role, where larger NGOs set up lobbies or campaigns and smaller NGOs join to support.

However, collaboration also requires effort and time. The following quote illustrates how NGOs have to balance their resources concerning a monthly national meeting among NGOs:

> *“X organizes a meeting once a month, I think. We always get an invitation, but we don't attend very often because we're quite busy. However, I still believe we should focus on it a bit more.” (p.01)*

Status emerged as another theme in the interviews, indicating that NGOs with higher status have more influence in fulfilling certain roles. This influence is evident in the experience shared by participants that when NGO representatives call professionals who initially refuse to assist someone, they find that the cases of UMs are taken more seriously. Some NGOs even provide booklets or stamps for UMs to show they have been in contact with the NGO, facilitating easier access to care.

However, one participant's account suggests that the ability of NGOs to secure care for UMs may be less about the NGO's status and more about the privilege of Dutch workers within the NGOs or the presence of discrimination and racism among care professionals:

> *"A while ago, for example, a woman at a midwife's office was approached by the assistant three times during her appointment about not having health insurance and needing to pay. [...] So, I said, you can just point out the CAK agreement. But if they keep saying that three times, it helps to call the healthcare provider. And it's really unfortunate, but then I, as a white Dutch person, say, there is a CAK arrangement. And she has probably already told you about it. Midwifery care is covered, so please help her. […] and then it's settled, and no more questions or complaints are raised" (p.01)*

Additionally, NGOs experience they have developed a trusted status among UMs, who often refer each other to these organisations. NGOs mention that UMs frequently find it more comfortable to seek assistance from them rather than from GPs or other official institutions. One participant mentioned that *"[...], there's a bit more trust in organisations that operate outside the system because they think, yes, we remain a bit more out of sight, and that might be safer for us since we are undocumented." (p.06.1)*

Lastly, it was theoretically expected that UMs would experience barriers related to fear, lack of knowledge, and language, which were confirmed by the interviewees. Additionally, the findings highlight factors less discussed in the literature, revealing systemic issues within the Dutch healthcare system affecting both UMs and documented individuals. Examples include the lack of available GPs and healthcare costs that exceed basic insurance coverage. One participant mentions that:

> *"These are problems that affect the entire society. You often notice that people in vulnerable positions, such as undocumented migrants, are the hardest hit by the*

> *immense pressure on healthcare. So, I think it's primarily the overall understaffing in healthcare that trickles down to the rest of society." (p.09)*

These structural issues in the Dutch healthcare system are difficult for NGOs to address. As one participant explains:

> *"[...] and that is very clear, for example, in GGZ (mental healthcare). We also receive a lot of questions and requests for help regarding that. But the waiting list is ridiculously long for everyone. So, we won't be able to change anything for an undocumented person. No matter how dire the situation sometimes is." (p.06.2)*

Some NGOs view these systemic issues in healthcare as both challenges and opportunities for advocacy. They highlight those issues such as dental care not being covered by basic insurance and the lack of language interpretation in medical settings, which also affect other marginalized groups in society. Consequently, these NGOs strategically align their lobbying and campaigning efforts around barriers shared by other socioeconomically disadvantaged or migrant communities, aiming to receive broader societal support for improving healthcare access.

Discussion

Although UMs in the Netherlands are legally entitled to access healthcare, formal rights mean little unless they can be effectively realized. Access is a multifaceted concept, as illustrated by Levesque et al. (2013), who highlight the numerous potential barriers to access on both the supply and demand side of healthcare. Research indicates that UMs encounter significant barriers to healthcare access, exacerbating their vulnerability to health issues (De Vito et al., 2016; Myhrvold & Småstuen, 2019). In many European countries, NGOs have emerged to help UMs overcome these barriers and fill gaps in healthcare provision by the state, however, little information is available on their role in the Netherlands.

To address this knowledge gap, this research aimed to explore how NGOs working with UMs in the Netherlands perceive their role in facilitating access to healthcare services, and how this compares with their actual practices. The findings in this study suggest that while Dutch NGOs appear to share a common goal of facilitating healthcare access for UMs within the existing Dutch healthcare system, some of their strategies happen outside of the regular system, thereby creating a parallel system. Consequently, there seems to be a discrepancy between how NGOs perceive themselves (i.e., the role they *think* they should take) and the role they play in practice.

This discrepancy appears to stem from systemic issues within the healthcare system that are challenging for NGOs to address. The shortage and overburdening of GPs are well-documented problems in the Dutch healthcare system. Due to cutbacks in healthcare and social services, GPs have been tasked with additional responsibilities that were previously managed by other entities (Linssen, 2022). This issue itself serves as a barrier to healthcare access for both documented and undocumented individuals. Moreover, participants experienced difficulties in finding care professionals willing to assist UMs, citing administrative hurdles and discrimination as contributing factors. Racism is widely discussed in the literature on social determinants of migrants' health and as a barrier to accessing health services. A scoping review on racism in the European context highlights how racism reinforces inequities in healthcare access and quality for racialized migrants (Pattillo et al., 2023). Further research into racism within the Dutch health system, specifically concerning UMs, would be crucial for NGOs. Such information could enhance their advocacy efforts, as NGOs have indicated that addressing broader societal issues affecting UMs is more effective.

While the interviews identified four roles —mediating, educating, advocating, and service delivery— the findings highlight how these differ in priority. The prioritization of these roles by NGOs reflects their perception of the high and urgent needs of UMs, underscoring their belief they play a critical role in addressing these immediate care needs. NGOs struggle to decide whether to invest in education and advocacy with the aim for long-term systemic improvement or direct assistance to individuals in urgent need of care. Given their experience of the overwhelming immediate needs of UMs, NGOs often opt for the latter, focusing on direct aid and services rather than long-term systemic change.

Moreover, the complexity of needs among UMs significantly challenges NGOs in their efforts to assist, which in turn can heighten the perceived urgency of these needs. The high care needs experienced by NGOs can be attributed to the multifaceted nature of the issues faced by UMs. Participants noted that many UMs often deal with multiple, interconnected problems, not limited to health. UMs can be classified as clients with multiple problems "who have multiple, interconnected needs that span health and social issues and require different healthcare (e.g., mental healthcare or addiction care), social care (e.g., social benefits) and welfare services at the same time" (Reinhoudt-den Boer et al., 2022, p.268). While this complexity heightens the urgency for NGOs to provide care, it also presents a more challenging task for them to assist.

Additionally, participant accounts indicate a shift towards increased direct aid and service delivery by NGOs. In addition to concerns about establishing a parallel system, participants expressed concern about the quality of NGO care. This concern is justified, as evidence from multiple countries indicates that NGOs primarily reliant on volunteers are unable to provide the same quality of care as the regular system (Castañeda, 2013; Eick et al., 2022).

Thus, although NGOs generally agree that they should not exacerbate the exclusion of UMs from the regular care system, they do contribute to this parallel system by directly providing care or by facilitating connections to healthcare professionals outside the regular system. This discrepancy between what NGOs think they should do and their practical actions can be understood through Piccoli & Perna's (2024) argument that in contexts where the universal right to healthcare is legally established but not enforced by public authorities, civil society organisations (CSOs) encounter a fundamental dilemma between humanitarianism and equity. CSOs are driven by the humanitarian belief in alleviating human suffering, which means that CSOs provide emergency care but also non-emergency care to maintain overall well-being. However, in countries where healthcare is a universal right, they claim that governments might use CSO efforts as a way to shirk their responsibility for achieving health equity (Piccoli & Perna, 2024).

NGOs in the Netherlands operate in a similar context where UMs have the right to medically necessary care, but where the government does not take responsibility for ensuring this. The findings of this study illustrate that the NGOs are dealing with this humanitarian-equity dilemma in their work as well.

Strengths and Limitations

This study is set in the field of public health, which is an inherently interdisciplinary field (Dhakal, 2019). By studying the roles of NGOs in facilitating healthcare access for UMs, this study combined sociological aspects like the social determinants of health but also incorporated political science to understand the background of migration policies and how this influences healthcare accessibility. Lastly, the humanities give insights into the notions of health equity and related policy development. The incorporation of these disciplines allows for a comprehensive analysis that addresses the complex interplay of social, political, and health factors.

Some important limitations apply, first, qualitative research can never claim to be representative in a statistical sense, as samples are small and, in this case, purposive (Guest et al., 2006). However, since it aims to explore rather than quantify, it is an appropriate method for examining the role of NGOs which is often overlooked in health system research, especially because NGOs are part of the “shadow network” for UMs and are not part of the regular healthcare system. Nonetheless, the representativeness of the field may be limited as not all organisations approached agreed to participate in this study. Moreover, there might also be NGOs that have not been approached at all as they were not identified, which is a possibility as many organisations exist that work with UMs and are more difficult to find as they are not part of an official system.

Even though most NGOs are active in cities in the urban agglomeration in the Netherlands (the Randstad), this study still includes a meaningful sample of NGOs that are active at the national level and that vary in size. Moreover, the richness of their information and the fact that theoretical saturation was obtained suggest robust analysis of the question in this study (Guest et al., 2006).

This study exclusively interviewed professionals working at NGOs, and therefore, the perspective from UMs on the role of NGOs is only reflected by second-hand accounts, and their views would be important to explore in future studies. While many barriers to healthcare access have been identified, more research into enabling factors could contribute to NGOs improving their approaches to facilitating access. The article of van den Muijsenbergh et al. (2016) provides practical advice on performing research ethically with UM.

Transferability of the findings to other countries might be an issue, however, many other countries have similar or even more strict policies regarding the right of access to healthcare for UMs (Cuadra, 2012), and therefore NGOs in these settings are likely to also play an important role and to likewise struggle with the humanitarian-equity dilemma (Ambrosini, 2015; Piccoli & Perna, 2024).

Implications and Recommendations

Current strategies employed by NGOs often serve as temporary solutions, addressing individual cases rather than sustainably integrating UMs into the regular healthcare system. Piccoli & Perna argue that NGOs have an inherently political role when they help UMs as they “become part of political processes that draw the boundaries of who is included in, and who is excluded from, public services” (2024, p.13). This political role, while present in some NGO strategies is often implicit. Therefore, NGOs should explicitly consider and evaluate their political impact in this field.

Moreover, the authors argue that NGOs, by focusing on advocacy, can avoid contributing to the creation of a parallel system (Piccoli & Perna, 2024). They assert that the primary objective of advocacy should be to convince public agencies to take over the tasks currently managed by NGOs, which can be achieved through lobbying, campaigning, or litigation. While many papers recommend advocacy for legal changes to grant UMs better access (Hacker et al., 2015), this thesis has shown that legal access alone is insufficient. Instead, advocacy should address the practical barriers to healthcare access. However, it is important to acknowledge that advocacy efforts can be time-consuming and expensive, posing challenges for NGOs with limited resources to take on these activities.

Therefore, it is recommended that NGOs increase collaboration among each other. By working together, NGOs can reduce costs and make advocacy efforts more attainable, particularly for smaller organisations. Successful examples of collaboration among NGOs demonstrate that such partnership can enhance the impact and sustainability of their efforts (Larruina et al., 2019).

Moreover, two recommendations by Siegmann et al. (2017) are relevant. Firstly, they suggest that providing UMs with a CAK card to inform healthcare providers of their entitlement to medically necessary care and the reimbursement arrangements, could address the barrier of being declined care due to payment concerns. I recommend that NGOs target their advocacy towards realizing this card as it targets an important barrier. Secondly, Siegmann et al. (2017) suggest focusing on addressing GPs' lack of knowledge about UMs' entitlement to healthcare. Participants mentioned that they already educate care professionals informally, however, NGOs could enhance these efforts by collaborating. For instance, they could pool resources to promote the e-learning for care professionals developed by one of the participating NGOs.

Piccoli & Perna (2024) mention that while service delivery contributes to a parallel system for UMs, it can also serve as an opportunity for advocacy by highlighting the lack of healthcare access for UMs. NGOs in this study have adopted this strategy, but face challenges in ceasing direct care provision due to high demand among UMs. Although the initial goal was to combine the service provision with lobbying and advocacy, the persistent high demand has made it difficult to discontinue services. This ongoing provision risks establishing a parallel system, contradicting their advocacy objective. Therefore, the main recommendation is for NGOs to focus on advocacy addressing practical barriers to healthcare access rather than legal entitlements. Additionally, increased collaboration among NGOs will be necessary to overcome resource limitations, enabling more effective and sustainable advocacy efforts.

A final recommendation arises from a novel finding in this research, not directly linked to the primary research question but significant in its implications. It became evident that a significant barrier is the digitalization of healthcare processes, a topic that has not yet been addressed in the literature on barriers to access for UMs. For example, many GPs require online forms for registration creating two issues. First, UMs able to access these forms often cannot complete them due to the requirement of an address. Second, digital forms presume access to the internet, electronic devices, and the necessary digital skills. Research on the digitalization of welfare services highlights the inequalities in access to electronic devices and digital skills, which could lead to unequal access to services (Baay et al., 2015; Hummel et al., 2023). Further research into digitalization barriers for UMs is crucial. It would provide essential evidence for NGOs to effectively strategize and advocate for inclusive healthcare policies and practices, ensuring equitable access for UMs.

Conclusion

Undocumented migrants in the Netherlands face significant barriers to accessing healthcare despite their legal entitlements to “necessary medical care”. This research demonstrates that NGOs play a critical role in facilitating healthcare access for UMs. Despite their invaluable efforts in addressing immediate needs, NGOs risk legitimizing a parallel system that allows the state to retreat from its welfare duties. Thus, NGOs must critically reflect on their roles to effectively integrate UMs into the regular healthcare system and hold the government accountable for its welfare responsibilities. The Dutch NGOs in this study face a humanitarian-equity dilemma, where limited resources and high pressure from UMs’ immediate needs, lead them to prioritize direct assistance over addressing systemic issues. Consequently, many NGO strategies offer temporary solutions that help individual cases but fail to sustainably integrate UMs into the regular healthcare system. To increase lasting change, NGOs should focus more on educational and advocacy roles and collaborate to reduce costs and enhance effectiveness. This strategic shift is essential for creating sustainable solutions that ensure UMs are included in the regular healthcare system and uphold the principles of equity and justice.

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Appendix A - Interview guide

Over de organisatie (als weinig informatie beschikbaar op website)

- Kunt u mij vertellen wat **X** doet en is?
- Wanneer is het opgericht? En waarom?
- Waarom wilt u UMs helpen met betrekking tot gezondheidszorg?
- Wat is het doel van het werk met ongedocumenteerde migranten?

Obstakels voor Ongedocumenteerde Migranten:

- Welke obstakels ziet de organisatie die ongedocumenteerde mensen ervaren bij het verkrijgen van toegang tot gezondheidszorg?

De Werkzaamheden van de organisatie:

- Wat zijn uw activiteiten met betrekking tot gezondheidszorg specifiek voor ongedocumenteerde mensen in Nederland, dus hoe helpt u hen? Kunt u enkele voorbeelden geven?
- Wat doet de organisatie om te helpen bij het overwinnen van de eerder genoemde obstakels bij het verkrijgen van toegang tot gezondheidszorg? Zou u voorbeelden kunnen geven?
- Welke strategieën heeft de organisatie om UMs te helpen bij het verkrijgen van toegang tot gezondheidszorg?
- Op welke stakeholders in dit veld richt het werk van de organisatie zich?
- Kiest u projecten of werk op basis van behoeften die u ziet die nog niet worden vervuld door uw organisatie of andere organisaties/ instanties?

De rol van de organisatie/ NGOs?

- Kunt u de rol van de organisatie beschrijven bij het helpen van ongedocumenteerde mensen bij het verkrijgen van toegang tot gezondheidszorg?
- Hoe ziet u de rol van uw organisatie tov andere NGO's in NL?
- Hoe zou u de rol van de organisatie omschrijven ten opzichte van andere actoren die actief werken voor en met ongedocumenteerde migranten?
- In hoeverre werkt u samen met andere NGO's? Of andere maatschappelijke organisaties? Werkt u samen met de overheid? Hoe ziet dat eruit? /kunt u daar een voorbeeld van geven?
- Zou u kunnen uitleggen waarom u denkt dat NGO initiatieven ontstaan in de gezondheidszorgsector voor ongedocumenteerde mensen?
- Kunt u uitleggen waarom u denkt dat andere actoren deze activiteiten/ diensten die jullie uitvoeren niet uitvoeren/ verlenen?

Obstakels voor de Organisatie

- Wat zijn enkele uitdagingen waar de organisatie mee te maken heeft in haar werk om ongedocumenteerde migranten toegang te geven tot gezondheidszorg?
- Hoe gaat uw organisatie om met deze uitdagingen?

Toekomst

- Kunt u beschrijven hoe u de rol van de organisatie ziet in de toekomst?

Appendix B - Code Book

Barrieres

- Barrieres bij Care Proffesionals voor toegang geven
    - CAK teveel administatie
    - Grijsgebied CAK betalingsonmacht
    - Huisartsen zetten geen tolken in
    - Kent CAK niet
    - Minder huisartsen welwillend
    - Overvolle huisartspraktijken
    - professionals geen kennis over UMs zorg rechten
    - Slecht handelen van zorgprofessionals
    - Taal
    - UMs kosten teveel tijd

- Barrieres voor UMs toegang zorg
    - BSN zorgt voor problemen toegang zorg
    - Culturele verschillen zorgsysteem
    - Digitalisering
    - Gebrek zelfredzaamheid
    - Geen adres
    - Geen geld voor zorg
    - Geen zorgverzekering
    - Kennen systeem niet
    - Multiproblematiek bij UMs
    - Ouder worden verergert problematiek
    - Nodige zorg valt buiten basispakket
    - Racisme
    - Taal
    - UM gebrek kennis rechten
    - UM komen niet bij NGOs
    - wonen buiten de stad

- Barrieres bestaande problemen in zorgsysteem
    - Druk op systeem
    - Dure zorg buiten basispakket
    - NGOs moeten zorgdruk over huisartsen verdelen
    - Volle overbelaste huisartsen
    - Communicatie problemen tussen UM en zorgproffesionals

- Barriers voor werk NGOs
    - Geen cijfers over UMs
    - NGO moeten UMs zelf opzoeken
    - Niet willen houden aan landelijke criteria
    - Politiek
        - NGO wil niet transparant te zijn naar Overheid

        - Overlog met gemeente heeft weinig zin
    - Resources
        - Kleine capaciteit om alle rollen te nemen
        - Kunnen zorgverleners niet accountable houden
        - NGO kleine capaciteit
        - Problematiek financiering NGO initatieven
        - Verantwoording naar fondsen
        - Vrijwilligers tekort
    - Te grote problematiek bij UM
    - Trage burocratie overheid
    - Weten wat UMs nodig hebben
    - Zelfde problemen als UM zelf

Doelgroep

- Doelgroep die valt buiten de LVV
- UM belang bij onzichtbaarheid
- UM gewend aan uitsluiting
- UM onzichtbare groep
- UM vergeten doelgroep
- UMs afgebakende groep voor NGOs
- UMs gelijk aan andere vulnerable groepen
- Doelgroep breder dan alleen UMs

Expertise

- Andere organisaties weten niet hoe UM te helpen
- Betere cultuur sensitiviteit
- Iedere NGO eigen specialiteit
- NGO heeft expertise werk met UMs

Netwerk

- Bekent zijn met welwillende zorgverleners
- Meer bekendheid regelingen voor UM bij Proffesionals

Parallel systeem

- Argument VOOR parallel systeem
- Evalutatie van parellele systmen
- Geen uitvoerende zorg willen leveren
- Kritiek bouwen parallel systeem
- Nood is hoog
- UM kwetsbaarder als uit reguler systeem

Politiek

- Invloed politiek op beleid
- Invloed politiekekleur op beleid gemeente
- onwetendheid bij politiek over UM
- Politiekbeleid is anti UM
- Politieke kleur beinvloed handelen van zorgproff
- Regionale politieke climaat beinvloed rol van NGOs
- Zorgrecht UM alleen door internationale druk

Public Health

- Public Health versterken
- UMs als Publlic Health Risico

Regio Impact

- Regiobinding bij hulp kunnen verlenen

Rol

- Dubbele rol; individueel hulp en pleitbezorger
- Rol NGOs samenbrengen
  - Rol Eerste Aanspreekpunt
  - Rol NGO als tussenpersoon met andere zorgpartijen
  - Rol van Kennis deling
- Rol NGOs van Pleitbezorger
  - Rol van Signaleren Problematiek
  - Signaleren Mentale Promblematiek
- Rol NGOs vullen gat zorgverlening UMs

Samenwerken

- Doel van Samenwerking
  - Leren van NGOs andere stad
  - meer impact
  - Overleg Kennis delen
- Op EU niveau met partnerorganisaties
- Op stad niveau
- Overleg
  - Landelijk overleg betrokken partijen
  - Regionaal overleg betrokken partijen
- Samenweking met zorgprofessionals is goed
- Samenwerken is lastig
- Verminderd over de jaren
- Samenwerken om Politiek te beinvloeden
  - NGOs moeten samenwerken met overheid
- Samenwerking is essentieel

- Niet willen concureren met anderen
- Samenwerking met GGD
    - UMs niet bekend bij GGD
- Met andere NGOs
    - Complexe zorg via andere zorgverlenende NGO
    - Om te regelen zorg
    - Ondersteunende rol voor andere organisatie
    - Aanvullend aan NGOs die meer directe interactie met UM hebben
    - Samenwerken met lopende initiatieven NGOs

Status

- Betalen met fondsen makkelijker geaccepteerd
- Kunnen uitleggen van UM regelingen
- Macht
- Naamsbekendheid
- NGO heeft netwerk zorgproff
- NGO heeft veel kennis over UMs
- NGO vertrouwensrelatie met UMs
- NGOs gelooft bij uitleg over situatie van UMs,
    - Door het zijn van Nederlands
- Stempel NGO helpt bij toegang zorg

Toekomst

- Bang voor nieuwe politiek
- Herstellen van publieke sector
- Meer activisme tegen politiek
- Meer signalren en stem versterken
- NGOs moeten meer focus op UM in reguliere zorg
- Nodig samenwerking maatschappelijk werk
- Toekomst meer activisme werk
- UM problematiek word groter
- Willen groeien met bestaande programmas

Verantwoordelijkheid

- Beleid zorg individuele verantwoordelijkheid
- Gemeente neemt verantwoordelijkheid
- Gemeente voelt niet verantwoordelijk voor UMs
- GGD moet grotere rol en verantwoordelijkheid
- GGD Neemt verantwoordelijkheid
- Meer maatschappelijke verantwoordelijkheid nodig
- Overheid neemt geen verantwoordelijheid
- vakvereniging verantwoordelijkheid kennis

Werk NGOs doen

- Advocacy
    - Doel om politiek te beinvloeden
        - Campange voeren
        - Demonstreren
        - Lobby
        - Lobby bij gemeente
        - Lobby voor problemen groter dan alleen UMs
        - lobby werk met andere NGOS
        - Signaleren bij Ombudsman
    - Doel Zichtbaarheid UMs vergroten
        - Delen van verhalen UMs
    - Werkgroepen voor onderzoek
- Als NGO de steun zijn voor UMs
- Education
    - Doel Voor zelfredzaamheid
        - Cursus voor jezelf opkomen
        - Cursus voor UM rechten kennis vergroten
        - Geven rechten boekje UMs
        - Spreekuur
        - Willen dat mensen zelfredzaam zijn
    - Drempel tot zorg zoeken verlagen
    - Educatie ziekte
    - Preventie van UM zorg nodig hebben
    - Werkzaamheden gericht op zorgprofessionals
        - CAK uitleg
        - Informatie sessies voor zorgprof door NGOs
        - Maken van e-learning voororg professionals
        - Niet gestructureed
- Mediation
    - Doel om UM in reguliere systeem te krijgen
        - Netwerk opzetten ZorgProff
    - Doel UM direct helpen aan zorg
        - Als NGO meegaan naar arts
        - Liever niet met mensen mee
        - Doorverwijzen naar huisarts
        - Financiering zorg individuen regelen
        - Helpdesk vragen
        - Noodoplossingen
        - Postadres voorziening
        - Spreekuur zorgvragen
- Werk focus op mensenrechten
- zorgverlening

    - Zorgverlenende NGOs zijn druk
    - Zorgverlening door NGO
        - Directe zorgverlening door NGOs
        - Incidenteel zorg verlenen
        - Niet de beste zorg

Werk NGOs willen doen

- barrieres alternative workstreams
    - Te weinig tijd voor alternatieve werkzaamheden
- Mentale gezondheid zorg opzetten
- Voorlichting aan UM
- Zorgprofessionals educatie