



After-hours primary care for people with intellectual disabilities in The Netherlands—Current arrangements and challenges



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ABSTRACT

Background: Little is known about the organisation of after-hours primary care for people with intellectual disabilities (ID), and mainstream care is not self-evidently accessible or fit for this group. A first step towards improvement is a greater understanding of current after-hours primary ID care.

Aims: This study explores the organisation of and experiences with after-hours primary care provided for people with ID in The Netherlands.

Methods and procedures: A telephone survey amongst 68 care provider services including questions on organisational characteristics, problem areas, facilitators, and inhibitors.

Outcomes and results: A multitude of different after-hours primary care arrangements were found. Primary care physicians (PCPs) were involved in almost all care provider services, often in alliance with PCP cooperatives. Specialised ID physicians had differing roles as gatekeeper, primary caregiver, or consultant. Most problems during the after-hours arose regarding daily care professionals' competences. Facilitators and inhibitors of after-hours primary care were themed around complexity of, and need for, specialised care, multidisciplinary team of professionals, communication and information, and prerequisites at organisational level.

Conclusions and implications: Evidence on specific after-hours health needs of people with ID is needed to strengthen collaboration between specialist ID care services and mainstream healthcare services to adequately provide care.

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1. Introduction

After-hours primary care for people with intellectual disabilities (ID) concerns a vulnerable group in a fragile situation. After-hours care is provided outside the regular opening hours of daytime primary care practices and typically has a more urgent and ad-hoc character (Giesen, Smits, Huibers, Grol, & Wensing, 2011). Appropriate after-hours primary care for people with ID is important for their health, safety, and access to hospital care. However, little is known about the current provision of after-hours primary care to this group, and a plea has been made for high quality health-services research (Balogh, Ouellette-Kuntz, Bourne, Lunsky, & Colantonio, 2008).

In general, healthcare for people with ID is challenging. Firstly, compared to the general population, people with ID have greater health needs and disparities, and they experience barriers when seeking access to healthcare services, acute or otherwise (Hayden, Kim, & DePaepe, 2005; Krahm, Hammond, & Turner, 2006; Perry et al., 2014; van Schrojenstein Lantman-de Valk & Walsh, 2008). Secondly, primary care physicians (PCPs) experience challenges in relation to communicating with people with ID and to knowledge about special health needs (Hogg, 2001; Iacono, Davis, Humphreys, & Chandler, 2003; Mastebroek, Naaldenberg, Lagro-Janssen, & van Schrojenstein Lantman de Valk, 2014). Thirdly, mainstream health systems often lack the required knowledge, experience, and accessibility to provide quality healthcare for people with ID (Bradbury-Jones, Rattray, Jones, & MacGillivray, 2013). These issues pose potential risks to good quality after-hours ID care and demonstrate the necessity to evaluate its current state.

In The Netherlands, mainstream after-hours primary care is not self-evidently accessible or fit for people with ID. Many different actors are involved in Dutch after-hours primary care. Table 1 provides a quick overview of these actors. For the general population, after-hours primary care is provided by PCP cooperatives: regional large-scale care organisations where PCPs are supported by additional staff. Evaluation of these cooperatives shows they are accessible, efficient, safe, well-organised, and of high quality (Giesen et al., 2011). People with ID living in residential settings or community houses receive primary care facilitated by specialised care provider services, where either PCPs or ID physicians provide primary care during office hours. This depends on the care provider services' vision on medical care and on their collaboration with local healthcare services like PCP practices and cooperatives. As a result, each care provider service has its own after-hours arrangements with PCPs, specialised ID physicians, and additional staff like residential nurse gatekeepers who manage access to further care.

There is little insight into the organisation and efficacy of after-hours primary care for people with ID in residential setting. Furthermore, experiences suggest that after-hours primary care within care provider services in The Netherlands is sometimes of poor quality and constrained by financial restraints. A greater understanding of current after-hours primary ID care will provide insight into opportunities for improvement. The aim of this study is to explore the after-hours primary care provided by care provider services for people with ID in terms of organisational characteristics, problem areas, facilitators, and inhibitors.

2. Methods

This study employed an explorative telephone survey among Dutch care provider services for people with ID, focusing on their provision of after-hours primary care.

Table 1

Key professions and organisation in Dutch after-hours care for people with ID.

Primary care physician (PCP)	Provides the first contact for a person with a health concern and the treatment of varied medical conditions, not limited by diagnosis, cause, or organ system, and serves as a gatekeeper to secondary hospital care.
PCP cooperative	Regional large-scale non-profit organisation of after-hours primary care where PCPs are supported by nurses, management staff, and chauffeurs, and take turns being on duty for the patient population of all participating PCPs.
ID physician	Medical specialist, unique to The Netherlands, who is trained postgraduate to provide medical care for people with ID and commonly is employed by care provider services.
Care provider service	Non-profit organisation providing both residential and community living arrangements for people with ID. Arrangements can be continuous or with visiting support of multidisciplinary nature, including daily care professionals, nurses, management staff, behavioural therapists and ID physicians.
Behavioural therapist	Therapist with an academic degree in pedagogy sciences or psychology employed by care provider services.
Nurse gatekeeper	Vocational nurse trained at Community College or registered nurse trained at University of Professional Education, who serves as a gatekeeper employed by care provider services.
Daily care professional	Support staff trained in assistant nursing or pedagogic at vocational education in Community College and employed by care provider services. Tasks include assisting people with ID in personal, daily, and social care and home health aides.
Management	Management of teams of daily care professionals, medical staff (e.g., physician, behavioural therapist, nurse and daily care professional), and finances employed by care provider services.

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