

# BMJ Open Does risk and urgency of requested out-of-hours general practitioners care differ for people with intellectual disabilities in residential settings compared with the general population in the Netherlands? A cross-sectional routine data-based study

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#### ABSTRACT

**Objectives** To investigate whether people with intellectual disabilities (ID) in residential setting were more likely than people from the general population to request out-of-hours general practitioner (GP) care and whether these requests had a similar level of urgency.

**Design** Cross-sectional routine data-based study.

**Setting** Two GP cooperatives providing out-of-hours primary care in an area in the Netherlands.

**Population** 432 582 persons living in the out-of-hours service areas, of which 1448 could be identified as having an ID.

**Main outcome measures** GP cooperative records of all contacts in 2014 for people with and without ID were used to calculate the relative risk of requesting care and the associated level of urgency.

**Results** Of the people with ID (448/1448), 30.9% requested out-of-hours GP care, whereas for the general population this was 18.4% (79 206/431 134), resulting in a relative risk of 1.7 (95% CI 1.6 to 1.8). We found a different distribution of urgency level for people with and without ID. Generally, requests for people with ID were rated as less urgent.

**Conclusion** People with ID in residential setting were more likely to request out-of-hours GP care than the general population. The distribution of the urgency level of requests differed between the two groups. The high percentage of demands relating to people with ID requesting counselling and advice suggests that some out-of-hours GP care may be avoidable. However, more insight is needed into the nature of out-of-hours primary care requests of people with ID to direct structural and reasonable adjustments towards the improvement of health information exchange in and around-the-clock access to primary care for people with ID.

#### Strengths and limitations of this study

- This is the first study to date to compare out-of-hours primary care use and the urgency of requests of people with intellectual disabilities (ID) with the general population.
- All care provider services in the out-of-hours service area cooperated to enable identification of people with ID in the administration system, meaning that the study population was limited to their residents.
- Awareness of underestimation of the urgency of requests of people with ID in out-of-hours general care is timely and internationally relevant.

#### INTRODUCTION

Many challenges persist in the provision of primary care for people with intellectual disabilities (ID) during daytime as well as out of hours.<sup>1 2</sup> As a result, equity in healthcare access as defined in the United Nations' Convention on the Rights of People with Disabilities is at stake.<sup>3-5</sup> The confidential inquiry into the premature deaths of people with ID in the UK reported an elevated mortality and indicated that a better quality of healthcare for people with ID could reduce excess mortality.<sup>6</sup> This reinforced the need for routinely available data to provide evidence on, and monitoring of, health inequities of people with ID.<sup>7 8</sup> In primary care, lots of data are generated routinely.<sup>9</sup> Most studies on primary care for people with ID focused on daytime care, indicating that people with ID have higher healthcare demands<sup>4 10</sup> and

different health needs than the general population.<sup>11</sup> The demand of people with ID for out-of-hours GP care, however, is unknown.

Out-of-hours primary care is provided outside physicians' regular practice schedule and can lower costs by reducing avoidable and expensive emergency department visits.<sup>12</sup> In Western countries, out-of-hours primary care is organised in several forms and is increasingly provided in large-scale GP-based organisational models with integrated care.<sup>13,14</sup> The Dutch model of GP cooperatives is an example of a regional large-scale out-of-hours organisation where GPs are supported by additional personnel like nurses and chauffeurs.<sup>15</sup> Out-of-hours GP care is typically targeted at health issues that cannot wait until the next working day, thus having an urgent and ad hoc character.<sup>13</sup> Furthermore, out-of-hours primary care is the gatekeeper to out-of-hours hospital care, which in addition is internationally of growing research interest with high found overall hospitalisation rates and associated costs.<sup>16–20</sup> GP cooperative care for people with ID in residential setting is an untapped area and forms an important link in their health and safety. One might expect the out-of-hours GP care for people with ID to be similar to that for people in the general population: care in response to requests characterised by an urgent character.

This study aims to compare out-of-hours GP care for people with ID in residential setting with out-of-hours GP care for the general population, based on routine data. The objective of this study is to investigate whether people with ID in residential setting are as likely as people from the general population to request out-of-hours general practitioner care and whether the requests are similar with respect to their level of urgency.

## METHODS

### Design and setting

This population-based cross-sectional study used routine data for the full year of 2014 of two out-of-hours GP cooperatives, serving 432 582 persons living in the service areas of Nijmegen and Boxmeer in the Netherlands. The Dutch model of GP cooperatives is in place since the year 2000, and evaluation of these cooperatives show they are accessible, efficient, safe, well-organised and of high quality.<sup>13</sup> Depending on their residential status and the local out-of-hours care arrangements, people with ID in the Netherlands either receive out-of-hours primary care from GP cooperatives or from care provider services, the latter involves different actors such as specialised ID physicians, nurse gatekeepers and GPs.<sup>21</sup> In the area under study, out-of-hours primary care for all persons with or without ID is exclusively and routinely provided by the GP cooperatives.

### Study population

In total, 1448 people with ID were identified based on addresses available for both residential and community

**Table 1** Urgency levels of the national triage system of the Dutch College of General Practitioners<sup>22</sup>

Life threatening	Immediate action required, the vital functions are threatened or delaying treatment will cause serious and irreparable damage to the patient's health.
Acute	Vital functions are not (yet) in danger, but there is a fair chance that the patient's condition will soon deteriorate or delaying treatment will cause serious and irreparable damage to the patient's health. Take action as soon as possible.
Urgent	Do not postpone too long. Treat within a few hours because of medical or humane reasons.
Routine	There is no pressure resulting from medical or other grounds. Time and place of treatment should be discussed with the patient.
Counselling and advice	A physical examination can wait until the next day.

living arrangements derived from all care provider services for people with ID in the out-of-hours service areas of the GP cooperatives of Nijmegen en Boxmeer, the Netherlands. The study population lived at community housing or residential campuses of long-term care provision, where they receive continuous or visiting 24 hours support.

### Measurements

The administration system with the routine data of the GP cooperatives was queried for all contacts on weekdays between 17:00 and 08:00 and during weekends and holidays. The administration system contained all individuals who made one or more request(s) for out-of-hours primary care. The degree of urgency of every request was rated on a 5-point scale (table 1) by telephone nurses conform the validated classification method: National Triage System of the Dutch College of General Practitioners.<sup>22</sup>

### Statistical methods

The number of people for whom requests for out-of-hours GP care were made was used to estimate the relative risk (RR) with 95% CI.<sup>23</sup> The 95% CIs for proportions per urgency level were calculated using the score method with continuity correction while this is more informative than a point estimate.<sup>24</sup> Contacts for which the level of urgency was missing (n=9) were excluded.

## RESULTS

About a third (30.9%) of the people with ID (448/1448) requested out-of-hours GP care compared with 18.4% (79 206/431 134) in the general population (RR 1.7; 95% CI 1.6 to 1.8), making people with ID more likely to request out-of-hours GP care compared with the general population. The sex and age distribution of people with

**Table 2** Sex and age distribution of people with ID and the general population who requested out-of-hours GP care

	People with ID (n=448)		People from the remaining general population (n=79 206)	
	n	%	n	%
<b>Sex</b>				
Female	204	45.5	42 099	53.2
Male	244	54.5	37 107	46.8
<b>Age category</b>				
0–19	70	15.6	22 989	29.0
20–39	171	38.2	19 331	24.4
40–59	119	26.6	17 766	22.4
60–79	80	17.9	13 404	16.9
≥80	8	1.8	5 716	7.2

GP, general practitioner; ID, intellectual disability.

ID and the general population who requested out-of-hours GP care differed with more males in the ID group and less minors and elderly (table 2).

Requests relating to people with ID were rated as less urgent than requests relating to the general population. The different distribution of urgency level entailed more than 60% of requests made by people with ID categorised as counselling and advice and did not reflect on life threatening requests (table 3).

## DISCUSSION

People with ID in residential setting were more likely to request out-of-hours GP care compared with the general population. This aligns with the higher health requirements of people with ID in daytime GP care.<sup>4 10</sup> Requests of people with ID in residential setting were more often classified at the lowest level of urgency, requesting counselling and advice.

For this first study on out-of-hours primary care requests of people with ID living in residential setting, all care provider services in the out-of-hours service area provided address data to enable the identification in the routine

data system. Consequently, children and adults with ID who live in other housing arrangements, for example, with relatives or with outreach disability support, have been falsely categorised as members of the general population which would be expected to have influenced the pattern of requested care. Literature on ID study populations demonstrate prevalence of 0.6–0.7%.<sup>16 25</sup> In this study, a prevalence of 0.3% (1448/432 582) was found. This misclassification may have had a minor impact in the direction of overestimation of the out-of-hours care for the general population compared with the ID group. Results are generalisable to people with ID living at care provider services for people with ID.

A structural limitation in health and healthcare services research is the absence of registration of ID in databases and the absence of national baseline information on the health of people with ID.<sup>26</sup> Equality and equity of access to healthcare,<sup>3 5</sup> means that there ought to be adequate information about the health of, and healthcare for, people with and without ID. Research using routine data and administration databases is generally less demanding, has fewer ethical constraints and is less costly and time consuming than most other types of research. Routine data research has the potential to both provide insight and drive quality improvement.<sup>27</sup> Currently, routine data research does not benefit people with ID to its full potential. In addition, meaningful collaboration with people with ID in conducting routine data research could further improve its quality, though methods to do so are yet to be specified.<sup>28</sup> This study confirms, in yet another national context, the importance of questions about knowledge on, and awareness of, care being offered to people with ID, as raised by Lennox *et al*, Heslop *et al* and McCallion and McCarron.<sup>1 6 8</sup>

People with ID were more likely than those without to request out-of-hours primary care, which suggests that they use healthcare services differently. Accessibility of daytime primary care, which is commonly used in less urgent situations, could play a role in this. The National Triage System is developed based on the general population. Its (lack of) sensitivity to the specific health needs, different presentations and predictors of early morbidity

**Table 3** Level of urgency of out-of-hours GP care demands for people with ID and the general population

	Demands related to 448 out of 1448 people with ID		Demands related to 79 206 out of 431 134 from the remaining general population	
	n	% (CI)	n	% (CI)
Overall demands	1318		125 439	
<b>Urgency</b>				
Life threatening	27	2.0 (1.4 to 3.0)	3332	2.7 (2.6 to 2.7)
Acute	120	9.1 (7.6 to 10.8)	16 090	12.8 (12.6 to 13.0)
Urgent	286	21.7 (19.5 to 24.0)	42 729	34.1 (33.8 to 34.3)
Routine	90	6.8 (5.6 to 8.4)	19 432	15.5 (15.3 to 15.7)
Counselling and advice	795	60.3 (57.6 to 63.0)	43 856	35.0 (34.7 to 35.2)

GP, general practitioner; ID, intellectual disability.



in people with ID needs to be reviewed in this, as it could potentially influence healthcare access. Addressing challenges in the interface between daytime and out of hours may improve access to around-the-clock primary care by providing better information on self-care and when to seek help.<sup>9</sup>

The high percentage of counselling and advice requests suggests that some out-of-hours GP care may be avoidable. While the ID group has been selected from residential care provider services, their carers were most likely the ones making the requests. People with ID and their carers may more frequently request out-of-hours GP care because they feel uncertain when facing health problems.<sup>9</sup> These uncertainties may be adding to difficulties in the exchange of health information between carers and GPs and GP practices not being fit to the consultation and communication needs of people with ID.<sup>29 30</sup> Good practice depends on the knowledge, and flexibility of individual carers and healthcare professionals, which has been shown to lead to reasonable adjustments being initiated random throughout organisations.<sup>31</sup> More insight into the nature of out-of-hours primary care requests will help to appoint reasonable adjustments that are structural to address avoidable care, make out-of-hours primary care better accessible and effectively manage needs of people with ID at GP cooperatives.

Differences in care requests and healthcare needs of people with ID in residential setting and the general population are present in out-of-hours GP care. This stresses the need for directing interventions towards improvement of health information exchange and more attention for the interface between in-hours and out-of-hours care. In addition, challenges in around-the-clock access to primary care for persons with ID in residential setting need to be addressed. Further steps have to be made regarding safety of primary care to get insight into why out-of-hours care is requested and to help understand factors related to the large numbers of out-of-hours primary care requests made concerning people with ID.

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